

**Healthcare professionals' perspectives on breaking bad  
news for motor neurodegenerative conditions: a mixed-  
methods thesis**

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for the degree of Doctor of Philosophy

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# Declaration

I declare that this thesis is my own work, and has not been submitted in substantially the same form for the award of a higher degree at this institution or elsewhere.

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# Acknowledgments

Exactly four years ago I embarked on this journey that is called a PhD in Health Research, not expecting the how much it would change me as a person. Four years and a global pandemic later, I feel stronger, more sensitive and more curious about the world around me. Growing up in a small family from a low socio-economic background and in a country that was facing a tremendous crisis both in terms of its economy and its morals, it was difficult for me to have dreams. Education has always been a shelter for me, and I have been lucky and honoured to have met teachers who believed in me, inspired me to and have guided me along the way. On this note, I would like to thank Sofia Triliva and Georgios Panagis for being the great people they are and for encouraging me to pursue a career in research.

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## **Rationale for the Alternative Format**

This thesis is presented in the Alternative Format, following Lancaster University's Manual of Academic Regulations and Procedures (MARP). It consists of four empirical papers suitable for publication, one of which is a literature review. The publishable papers are interconnected and follow a logical sequence. The choice of an Alternative Format for the current thesis was made in agreement with the candidate's academic supervisors and the director of PhD studies in the Division of Health Research. An Alternative Format was considered appropriate for the mixed methods approach of the thesis and aimed at improving the dissemination of findings.

# Thesis Abstract

Breaking bad news in a medical context, such as the delivery of a diagnosis, is usually a distressing experience both for the bearer and the receiver. Although this experience can sometimes take only few minutes, research has shown that how a diagnosis is communicated can have a long-term impact on individuals' understanding and management of their condition. Most studies on this topic have been conducted from the patients' perspective and in the field of oncology, where bad news is often associated with a life-threatening disease and intensive treatments. However, how bad news is broken can be a critical issue for other conditions that are not curable and for which treatment options are limited, such as motor neurodegenerative diseases (MNDDs). Although these conditions are relatively common and can affect individuals' physical and cognitive functioning, studies regarding delivering such diagnoses especially from the professionals' perspectives are limited.

The aim of the present alternative format PhD thesis was to investigate professionals' practice and experiences of communicating the diagnosis for four MNDDs: Parkinson's disease, motor neurone disease, Huntington's disease and multiple sclerosis. For this purpose, a mixed-methods approach was employed, and a series of interconnected studies was conducted. Initially, a scoping review of quantitative and qualitative studies of patients' and doctors' perspectives on breaking bad news for MNDDs was completed in order to establish pre-existing knowledge and research gaps on the topic. A survey study then assessed UK

neurologists' practice in breaking bad news for these conditions and identified important aspects of the consultation that required further research. Two qualitative studies were then conducted. A thematic analysis study was completed to establish non-medical healthcare professionals' involvement in breaking bad news to newly diagnosed patients with MNDDs and an interpretative phenomenological analysis study aimed at exploring neurologists' lived experiences of delivering these diagnoses was then conducted.

Findings from the scoping review indicated that a significant proportion of patients were dissatisfied with aspects of their diagnosis delivery consultation, mainly the time dedicated for these appointments, the amount of information that was provided and doctors' manner which was often characterised by a lack of empathy. The review also revealed a research gap on studies on doctors' views, especially from a qualitative perspective. The empirical studies of the thesis that focussed on neurologists' perspectives showed that, overall, professionals achieved high standards of practice, especially in terms of acknowledging the critical importance of the task and providing an appropriate environment for these consultations. However, professionals' intention to provide a patient-centred consultation was often compromised by organisational restrictions such as a heavy workload and limited time slots. Participants discussed the challenges of providing tailored information, attempting to minimise patients' distress and discuss the uncertainties surrounding the course and prognosis of MNDDs. Neurologists were also challenged by the emotional impact of delivering these diagnoses and witnessing patients' often intense emotional reactions. Being the bearer of bad news often elicited feelings of guilt, sorrow and powerlessness due

to the incurable nature of MNDDs as well as fears regarding participants' own mortality and the unpredictability of life. The thematic analysis study highlighted non-medical healthcare professionals' significant involvement in breaking bad news to newly diagnosed patients with MNDDs. Participants reported having a significant role in helping patients understand their diagnosis and its impact on different aspects of their lives but also in providing emotional support and helping patients regain a sense of control and maintain a positive outlook. The findings of the thesis suggest that professionals in the UK did not follow any specific guidelines for breaking bad news, did not receive any formal source of support despite the emotional burden associated with the task, and had often received little to no training focussing on breaking bad news for these conditions. The implications of these findings for clinical practice and organisational change are discussed and suggestions for future research on the topic are provided.



# Chapter One

## General Introduction

### Breaking Bad News

Communication is a core part of medical practice mainly aimed at the effective exchange of information and the creation of an interpersonal relationship which will facilitate an accurate diagnosis and treatment plan (Ong, De Haes et al., 1995). Effective doctor-patient communication is therefore a critical component of high-quality healthcare, associated with increased patient satisfaction, self-management and positive health outcomes (Matusitz & Spear, 2014) and considered a prerequisite for patient-centred care (Bauman et al., 2003) and shared decision-making (Charles et al., 1997). However, studies on the topic often indicate patients' discontent with their communication with doctors, while the latter tend to overestimate their communication abilities (Ha & Longnecker, 2010).

A particularly challenging aspect of this type of communication is the delivery of a serious diagnosis, a process commonly referred to as 'breaking bad news' (BBN). Bad news is usually described as '*any information likely to alter*

*drastically a patient's view of his or her future'* (Buckman, 1984, p.1597). Since such medical information may also be perceived differently, for example as a relief, the term 'significant news' has also been suggested (Mishelmovich et al., 2016). Apart from the delivery of a diagnosis, BBN can also refer to the communication of a poor prognosis or the announcement of the death of a loved one or the transition to palliative care. For ease of reference, 'breaking bad news' will be used in this thesis to reflect the communication of a serious diagnosis and other, often difficult, conversations healthcare professionals (HCPs) have with newly diagnosed patients (e.g., about the impact of a condition on patients' lives).

In the previous century, based on a paternalistic approach to providing care, doctors would often conceal the true diagnosis to 'protect' the patient from harm. This was known as the non-disclosure model of BBN which was based on the assumption that doctors should decide what is best for the patient, patients do not want to know their diagnosis and they need to be protected from bad news (Girgis & Sanson-Fisher, 1995). Today, however, ethical and even legal considerations related to patient autonomy and a patient's 'right to know' have pushed modern medicine towards a more patient-centred model of care that respects individuals' own preferences and decisions regarding their healthcare (Chin, 2002). In this context, most patients particularly in western countries are now informed about their diagnosis, especially since they are required to provide informed consent and make decisions regarding their care (Keating et al., 2005). Patients who are well-informed about their condition can participate in shared decision-making by considering different treatment options and associated risks, expressing their values and preferences, and making joint decisions about their

care plan with HCPs (Elwyn et al., 2012; Kon, 2010). Shared decision making has been considered an important aspect of BBN (Rat et al., 2018), associated with a variety of positive patient outcomes (Shay & Lafata, 2015) and is also considered an ethical imperative, respecting patients' autonomy (Elwyn et al., 2012).

This shift to more patient-centred communication seems to have stressed the importance of investigating the process and consequences of BBN. The majority of research on the topic has been conducted from the patient's perspective and within the field of oncology, where bad news is associated with life-threatening conditions and thus requires careful consideration. Studies of cancer patients' communication preferences regarding the delivery of their diagnosis have indicated that although doctors' expertise and the content of the conversation are the most important factors, emotional support and setting-related factors are also important in influencing the perceived 'success' of such a consultation (Aminiahidashti, et al., 2016; Brown, et al., 2011; Parker et al., 2001). Additionally, the perceived quality of the diagnosis delivery has been associated with enhanced patient satisfaction (Schofield et al., 2013), understanding of the disease (Kaplowitz et al., 1999), involvement in decision making, and better psychological adjustment (Roberts et al., 1994) but also, when conducted poorly, with prolonged patient distress, confusion and poor treatment adherence (Fallowfield & Jenkins, 2004). These findings are significant in that they should inform health care professionals' practice, whose task is even more challenging as it needs to take into account the differences in communication preferences among patients and the need to be sensitive to the demographic, psychological and cultural variables that shape them (Fujimori & Uchitomi, 2009).

Nevertheless, the process of BBN is not only difficult for the receiver but can be arguably considered one of the most challenging and emotionally draining tasks faced by health care professionals (Espinosa et al., 1996; Zielińska et al., 2017). However, the volume of research on professionals' perspectives with diagnosis delivery is limited and it mostly focuses on in-training doctors and oncologists' experiences and practice. A critical literature review of studies using self-report and psychophysiological measures of stress showed that, during the communication of bad news, doctors can experience moderate levels of stress, with stress reactions lasting for hours or even days after the consultation (Studer et al., 2017). This is particularly important for oncologists who consider this aspect of their job as a contributing factor to burnout (Armstrong & Holland, 2004). Moreover, a metasynthesis of qualitative studies of oncologists' experiences in BBN highlighted doctors' difficulty in finding the balance between providing adequate information and sustaining patients' hope for a successful recovery (Bousquet et al., 2015). Doctors also reported other factors that affected their practice and the quality of the consultations they provided such as time constraints, lack of private space and their own emotions of anger, guilt, powerlessness to make a positive difference and personal fear of death.

The recognition of the difficulty and the impact of BBN for both for the deliverer and the receiver has led to the development of recommendations and guidelines to aid professionals carry out this challenging task. The SPIKES (Setting up, Perception, Invitation, Knowledge, Emotions) protocol (Baile et al., 2000) has been one of the most widely used set of guidelines for disclosing bad news,

especially in cancer care. The protocol approaches BBN in a stepwise manner and suggests six steps and techniques which include setting up and preparing for the consultation, assessing patients' perceptions of their medical situation, obtaining patients' invitation for information, providing information while checking patients' understanding, addressing and empathically responding to patients' emotions and, finally, summarising and presenting treatment options to be discussed with the patient. Although such strategies seem sensible and have contributed to the development of practice and research on the topic, they have not been adequately supported by evidence (Fallowfield & Jenkins, 2004; Dean & Willis, 2016). For example, although some empirical studies have shown that professionals following specific guidelines for BBN feel more confident about their practice (Baer et al., 2008; Baile et al., 2000) and experience less stress (Hammond et al., 1999), there is not enough evidence linking following guidelines - or receiving training on BBN (Fallowfield & Jenkins, 2004) - with patient outcomes (Dean & Willis, 2016; Paul et al., 2009;). Furthermore, a concern regarding the use of protocols, such as SPIKES, for BBN relates to a possible increased detachment from the patient due to an overemphasis on the process and the steps involved, rather than the interaction and the shared human experience between the professional and the patient (Dean & Willis, 2016).

Besides oncology, research on BBN has also been conducted occasionally within obstetrics, paediatrics and accident and emergency medicine (Fallowfield & Jenkins, 2004). Nevertheless, the delivery of bad news can be a critical issue in other medical specialties as well, such as neurology. Neurological conditions can be life-limiting, life-altering and/or life-threatening and neurological bad news at

diagnosis can include conversations about disability, chronic conditions, prognostic uncertainty and even advance care planning and end-of-life care (Lemmon & Strowd, 2016). However, a large neurological patient experience survey of more than 10,000 participants in the UK showed that diagnosis communication was an aspect of their healthcare with which patients were not always satisfied (The Neurological Alliance, 2019). Patients reported experiencing severe diagnostic delay as 39% of respondents had to see their general practitioner (GP) five or more times before being referred to a neurologist and 28% waited more than 12 months to see a neurologist after a referral had been made. In addition, 23% of respondents reported not receiving an intelligible explanation of their diagnosis when they were first told they had a neurological condition and 43% were not provided with written information at diagnosis. The survey included patients with a variety of neurological diagnoses, from migraine, functional neurological disorder and epilepsy to neurodegenerative conditions and brain tumour. However, investigating the communication of bad news for specific neurological conditions could lead to a more in-depth understanding of the current practice and challenges surrounding it.

## **Motor Neurodegenerative Diseases**

The current thesis will focus on the four most common motor neurodegenerative conditions (MNDDs): Parkinson's disease (PD), multiple sclerosis (MS), Huntington's disease (HD) and motor neurone disease (MND). Neurodegenerative conditions are characterised by a progressive deterioration and loss of neuronal structures and functions in the nervous system (Burli,

Thomas, Beaumont, 2010) which can affect patients' physical, cognitive and psychological functioning (Abdo et al., 2010). Neurodegenerative conditions share some common features such as a clinical course that is constantly progressive until death, presenting phenotypic variability, being more common in advancing age and being mostly incurable with therapies usually yielding slight or temporary improvements (Lynch et al., 2016). As such, neurodegenerative conditions are associated with a high burden of illness in terms of their impact on patients' functioning and quality of life, but also their impact on a family, social and economic level (Hirtz et al., 2007). Research on healthcare issues in MNDDs specifically is critical as MNDDs such as PD and MS are quite common and less common ones such as MND and HD are associated with a poor prognosis (Beart et al., 2017). Additionally, despite being considered primarily disorders of movement, their impact on cognitive, psychological and social functioning is increasingly recognised (Beart et al., 2017; Simpson, McMillan & Reeve, 2013). In this section, the epidemiological and clinical background of the aforementioned MNDDs is presented in order to provide context for the subsequent studies of the thesis.

### **Parkinson's Disease**

Parkinson's disease is a progressive neurodegenerative condition named after James Parkinson who first described it in 1817 (Noyce & Bandopadhyay, 2017). It is the second most common neurodegenerative condition (after Alzheimer's disease) and the most common MNDD, affecting 1-2 people per 1000, with its prevalence rising to 1% in people above the age of 60 (Tysnes & Storstein,

2017). Although less common, PD can also affect younger people, with cases of young onset PD (occurring before the age of 40 or 50) constituting about 5-10% of total cases of PD (Golbe, 1991). PD is mainly caused by an increasing loss of dopaminergic neurons in the substantia nigra pars compacta of the basal ganglia which eventually leads to disorders of movement such as tremor, bradykinesia, rigidity and postural instability (Kouli et al., 2018). PD is diagnosed clinically based on established diagnostic criteria, however the misdiagnosis of PD is not uncommon, and several follow-up appointments might be needed for an accurate diagnosis (Marsili et al., 2018).

Despite PD historically being viewed as a movement disorder, the prevalence and importance of other physical, psychological and cognitive difficulties have been increasingly recognised (Chauduri et al., 2006; Gallagher et al., 2010). These difficulties can include fatigue, olfactory and sleep disturbances, bladder and bowel problems, speech impairments, problems with memory, dementia, depression and anxiety (Noyce & Bandopadhyay, 2017). Some of these can predate diagnosis by several years, can be as disabling as the motor manifestations of the condition (Goldman & Holden, 2014; Truong et al., 2008) and their severity is a critical determinant of health-related quality of life (Soh et al., 2011). Anxiety and depression can be experienced by 25-35% of patients with PD (Dissanayaka et al., 2010; Reijnders et al., 2008;), and they can have knock-on effects on, for example, sleep and cognitive performance, anxiety can worsen tremor, dyskinesia and speech, and depression can contribute to slowness of movement and apathy (Noyce & Bandopadhyay, 2017). Although these difficulties may be partially attributed to neurobiological changes due to PD, social and



psychological factors also contribute to their development (Garlovsky et al., 2016; Simpson et al., 2013).

PD is currently incurable with therapeutic strategies focussing on the management of symptoms. Motor features of PD can only be observed once 30-50% of dopaminergic neurons in the substantia nigra have been lost which is believed to be too advanced for neuroprotective treatments to have an effect (Sieber et al., 2014). The management of PD therefore mainly focusses on the alleviation of motor symptoms through either dopamine replacement therapy (l-dopa) or the use of dopamine agonists which directly stimulate dopamine receptors. However, due to inevitable disease progression, patients can experience severe physical and often cognitive decline at later stages of the condition (Noyce & Bandopadhyay, 2017). Symptoms eventually become increasingly non-responsive to treatment and the long-term use of symptomatic treatment can contribute to motor fluctuations, dyskinesia, psychosis and impulse control behaviours (Franke & Storch, 2017; Lizzaraga et al., 2020). At these stages, options such as deep brain stimulation can be considered, although it is not appropriate for all patients and only helps with the management of some motor symptoms (Noyce & Bandopadhyay, 2017). Finally, because of PD's vast heterogeneity in terms of its clinical course and the varied symptomatology, patients can benefit from multidisciplinary patient-centred care which recognises all aspects of the condition and the usefulness of non-pharmacological interventions which aim at increasing or maintaining independence and quality of life (Van der Marck, 2009).

## **Multiple Sclerosis**

Multiple sclerosis is a chronic inflammatory, demyelinating and neurodegenerative disease of the central nervous system and the most common MNDD affecting young adults (Filippi et al., 2018). Although there has been some controversy regarding the neurological nature of MS, it has been suggested that neurodegeneration is the major cause of irreversible neurological damage (Trapp & Nave, 2008). MS has a prevalence of 150 to 200 per 100,000 population (Mackenzie et al., 2014) and is more common in women, who are up to three times more likely to be diagnosed with MS than men (Orton et al., 2006). Disease prevalence for MS is on the rise with a total of 2.8 million people estimated to live with MS worldwide and the mean age of diagnosis is 32 years (Walton et al., 2020). The pathology of MS is mainly characterised by the accumulation of demyelinating plaques and axonal loss in both the white and grey matter of the brain and spinal cord (Filippi et al., 2018). Although the aetiology of MS is still poorly understood, epidemiology studies suggest that both genetic and environmental factors (e.g., smoking status, diet, geographical latitude, vitamin D levels and exposure to the Epstein-Barr virus) can increase the risk of developing MS (Buzzard et al., 2017; Olsson et al., 2017). Because of the often-young onset of MS and the long survival rates, the burden of MS can be particularly high both in terms of disability and healthcare costs (Stenager, 2019).

Both the clinical presentation and clinical course of MS are heterogeneous and fairly unpredictable (Filippi et al., 2018; Goldenberg, 2012). MS symptoms can

include motor, visual and somatosensory disturbances, cognitive impairments, fatigue and psychological difficulties such as depression (Filippi et al., 2018). MS can present in different phenotypes with different clinical courses, with relapsing-remitting MS (RRMS) being the most common, affecting 85-90% of patients. Patients with RRMS experience periods of remission and unpredictable relapses characterised by neurological dysfunction. Most patients with RRMS will eventually develop secondary progressive MS which leads to increased difficulties as the disease progresses. Only a small proportion of patients are diagnosed with primary progressive MS where the disease progresses from the onset. Although MRI can be used to confirm a diagnosis, MS is primarily diagnosed using clinical criteria, for example the occurrence of two or more episodes of central nervous system dysfunction followed by at least partial recovery is sufficient for the diagnosis of RRMS (Filippi et al., 2016).

The management of MS is variable and depends on the disease phenotype, the clinical manifestations of the condition and the patient's circumstances. Although MS is still considered incurable, RRMS is treatable thanks to advances in the effectiveness and availability of a variety of disease-modifying treatments (DMTs) (Costelloe et al., 2016). DMTs can help prevent relapses and the development of new lesions and slow or reduce disease progression. The more effective therapies are, however, associated with considerable risks and the selection of treatment depends on several variables such as a patient's comorbidities and family planning concerns. Relapses can also be acutely managed with the use of corticosteroids to aid faster recovery (Filippi et al., 2016). However, there are still no effective treatments for progressive MS, where

alleviating symptoms is the main form of disease management. The symptoms of MS can be managed with pharmacological therapies, though their clinical efficacy is not always backed up by strong evidence (Filippi et al., 2016). Poorly managed difficulties such as psychological problems and fatigue can severely affect patients' quality of life and contribute to decreased social participation and loss of the ability to work (Marrie et al., 2015). Beyond pharmacological treatments, other approaches which involve a variety of HCPs have shown promising results in helping patients with the psychological, cognitive and physical difficulties associated with the condition. Such approaches include cognitive behavioural therapy (CBT) (British Psychological Society, 2021), fatigue management courses (Asano & Finlayson, 2014), cognitive rehabilitation (Amato et al., 2013), physiotherapy (Learmonth et al., 2016) and physical exercise (Motl et al., 2017).

### **Huntington's disease**

First described by George Huntington in 1872 (Huntington, 1872), HD is a genetic neurodegenerative condition caused by a mutation of the HTT gene on the short arm of chromosome 4 (Huntington's Disease Collaborative Research Group, 1993). Medium spiny neurons of the corpus striatum of the basal ganglia are particularly affected by this mutation, but HD is increasingly recognised as a disease of the whole brain and body (Bates et al., 2015). The prevalence of HD exhibits significant geographical differences, it is, however, estimated that about 10.6–13.7 people per 100,000 in western populations live with HD (Bates et al., 2015), with UK showing an increased prevalence of 12.3 per 100,000 people (Evans et al., 2013). Because of its hereditary nature, the often-young onset, its

progressive course and the multi-faceted impact on movement, cognition, behaviour and affect, HD is considered one of the most debilitating conditions for both patients and their families (Bates et al., 2015).

The inheritance of HD is autosomal-dominant, meaning that affected individuals have a 50% probability of passing the mutated gene on to their children, regardless of the condition of the other parent. HD is also fully penetrant: the disease will manifest in all individuals who carry the mutation (Mahalingam & Levy, 2014). Predictive gene testing is available for individuals with a family history of HD, however the percentage of people at-risk who choose to undertake the test can be as low as 3% (Tibben, 2007), with the UK presenting a higher percentage of 15% to 26% (Quarrell & Rosser, 2014). Gene testing allows people to know whether they carry the expanded gene even decades before the onset of symptoms, however, the diagnosis of HD for individuals with a family history is clinical and is conventionally made when chorea (involuntary, irregular and unpredictable movements) manifests (Burke et al., 2016). The exact disease onset is, however, often difficult to identify and patients usually experience changes in their behaviour, mood or cognition that predate the clinical diagnosis (Walker, 2007).

The course and symptomatology of the disease can be variable. The average age of motor onset is 42 years, but juvenile onset (onset before the age of 20) makes up for 5-15% of HD cases (Burke et al., 2016). Because of the progressive, neurodegenerative nature of HD, the, sometimes subtle, changes experienced during the presymptomatic phase of the disease will eventually lead

to the development of severe movement disorders and cognitive and psychological difficulties. Besides chorea, whose severity can reach a plateau or even decrease as the disease progresses, patients with HD also experience impairments of voluntary movements which eventually lead to progressively severe disruption to their ability to perform daily activities (Bates et al., 2015). Disorders of voluntary movements include impaired gait, posture and fine motor skills, dystonia, dysarthria and dysphagia and, as the disease progresses, patients exhibit rigidity, dyskinesia, akinesia, becoming slower and experiencing difficulties in initiating movement (Roos, 2010). Cognitive dysfunction in HD is usually characterised by general cognitive slowness, impaired executive functions, such as organising, impaired emotion recognition, speech and learning ability, impulsivity and disinhibition (Dumas et al., 2013; Wright et al., 2017). Although not as consistent as the motor and cognitive manifestations of the disease, psychological difficulties such as depression, apathy, irritability, anxiety and, less commonly, delusional depression and psychotic symptoms, can present early in the disease course and can be a source of severe disability (Bates et al., 2015; Burke et al., 2016). The mean life expectancy is 20 years post diagnosis with patients typically dying from falls, dysphagia, aspiration pneumonia and inanition (Walker, 2007).

There are currently no effective DMTs for HD and the management of the disease is therefore confined to symptomatic treatment. Only one drug has been approved specifically for HD which targets chorea, but medication commonly used for other movement and psychological difficulties can help alleviate patients' symptoms (Bates et al., 2015). Aside from pharmacotherapies, patients may

benefit from a multidisciplinary approach that includes physiotherapists, occupational therapists, speech and language therapists and dietitians. These professionals can help patients practically through suggesting home adaptations and the use of supportive equipment (e.g., communication devices or walking aids) and can also help patients with managing their symptoms and activities of daily living (Bilney et al., 2003; Nance, 2012). Although very little research has addressed the use of psychological interventions to manage psychological difficulties commonly experienced by HD patients (Zarotti et al., 2020), international guidelines suggest the use of CBT approaches (Bachoud-Lévi et al., 2019). As the disease progresses, specialised care facilities, hospice care and specific programmes developed for the management of late-stage HD may be required to support patients (Bates et al., 2015).

## **Motor Neuron Disease**

Motor neuron disease, also known as Amyotrophic Lateral Sclerosis (ALS)<sup>1</sup> and Lou Gehrig's disease, is a neurological condition characterised by the degeneration of motor neurons (Ilieva & Maragakis, 2017). The condition affects both upper motor neurons (neurons that project from the cerebral cortex to the brain stem and the spinal cord) and lower motor neurons (that project from the brain stem or spinal cord to muscles), causing a variety of motor and other symptoms (Hardiman et al., 2017). Although 10-15% of all MND cases are classified as familial and are associated with gene mutations, most MND cases are sporadic with causal factors still remaining unknown (Ilieva & Maragakis, 2017). The incidence of MND in Europe ranges from 2 to 3 cases per 100,000 individuals

<sup>1</sup> Although MND and ALS are used interchangeably in the literature, in the UK, ALS is recognised as the most common form of MND and is the form of MND we focus on in this thesis.

(Logroscino et al., 2010) and it is estimated that 5000 people in the UK are affected by MND at any one time (Motor Neurone Disease Association, 2017). Incidence is higher in men, with a male to female ratio 1.5 to 1.2 and the disease usually affects people between the ages of 50 and 70. There are currently no diagnostic tests for sporadic MND which is diagnosed through an often-lengthy process of multiple medical examinations that can last from 10 to 18 months on average (Andersen et al., 2012). As there is currently no cure for MND, life expectancy ranges from 3 to 5 years from symptoms onset, although slower and more rapid rates of progression are recognised (Ilieva & Maragakis, 2017).

The clinical manifestation of MND can also be significantly variable. Most patients, around 60% of cases, present with limb-onset, experiencing weakness in the upper or lower limbs initially, with other functions being affected as the disease progresses (Hardiman et al., 2017). About one third of patients exhibit bulbar-onset which is characterised by speech and swallowing difficulties and is associated with a poorer prognosis (Chio et al., 2009) and increased psychological distress (Goldstein et al., 2006). Respiratory-onset accounts for 5% of cases and is also associated with a poorer prognosis (Hardiman et al., 2017). The condition eventually leads to severe deterioration of muscle, loss of movement, impaired speech and swallowing and respiratory insufficiency. Besides the impact on physical functioning, MND causes some form of cognitive impairment in 40-50% of patients (Abrahams, 2013; Niven et al., 2015), while 10-15% of patients with MND fulfil the criteria for the diagnosis of frontotemporal dementia (Phukan et al., 2012) which progressively affects behaviour, personality and language (Seltman & Matthews, 2012). Moreover, individuals with MND usually have poorer



psychological health compared to the general population (Montel et al., 2012) and up to 50% of patients might experience depression (Hardiman et al., 2017). The severity of the physical and cognitive symptoms of the disease can be a source of psychological and social difficulties for patients, such as identity disruption, loss of social roles, loss of independence, fear of choking and limited emotional coping abilities (British Psychological Society, 2021).

There are currently two DMTs for MND; riluzole and edaravone. In the original trial (Lacomblez et al., 1996), 18 months of riluzole treatment led to 3-month survival increase compared with placebo, and edaravone has been proven to slow disease progression. However, edaravone is not currently approved in Europe and, in other countries, it is only administered to patients with early onset and rapid disease progression (Hardiman et al., 2017). Given the unavailability of curative treatments for MND, management mainly focusses on maintaining and improving quality of life through symptomatic and palliative care. Symptoms are usually managed with medication used in the management of other diseases, but non-pharmacological approaches are essential in managing certain aspects of the condition. Speech therapy, for example, can help delay the progression of dysarthria and improve communication through the prescription of communication aids. Additionally, nutrition through a gastrostomy tube might be needed for patients with severe dysphagia and non-invasive ventilation, which can be used to treat respiratory failure, has been found to prolong survival and improve quality of life. Psychological interventions have also shown promising results in improving patients' wellbeing, but further research is needed (Zarotti, et al., 2021). Finally, early integration of palliative care and timely transition to

end-of-life care is critical in symptom management, helping patients retain a sense of control and reducing patient fears and preventing a distressing death (Oliver et al., 2016).

## **Research Aim and Objectives**

Given the impact of these MNDDs on all aspects of patients' lives, their progressive nature and the variability and uncertainty in terms of their clinical course, BBN for these conditions can be a critical process for patients and a challenging task for professionals. In addition, since these conditions are currently incurable, emphasis should be given to the effective management of the disease and the provision of optimal healthcare.

The aim of this thesis is to develop an understanding of HCPs' perspectives on BBN for MNDDs in the UK by investigating their current practice and exploring their experiences in engaging with this task. The idea/need for thesis emerged from a study conducted by two members of the supervisory team about the experience of being diagnosed with PD (Warren, Eccles, Travers & Simpson, 2016). In this study, patients described their negative experiences with diagnosis delivery, explaining that there was a lack of compassion and sensitivity from the diagnosing doctor and a sense that doctors did not have sufficient time for the consultation. A provisional literature search revealed that similar experiences had been documented by patients with other MNDDs, yet empirical studies on

neurologists, the primary doctors diagnosing these conditions, or other professionals working with newly diagnosed patients were lacking.

The research objectives specified below will facilitate the process of achieving the research aim described above.

- Research Objective 1: Establish pre-existing knowledge and identify potential research gaps on patients' with MNDDs and doctors' perspectives on diagnosis communication.
- Research Objective 2: Investigate neurologists' current practice, attitudes and lived experiences of communicating an MNDD diagnosis in the UK.
- Research Objective 3: Explore non-medical professionals' range of involvement in breaking bad news to newly diagnosed patients with MNDDs in the UK.

## **Chapter Two**

### **Overview of Methods**

#### **Philosophical Considerations in Mixed Methods Research**

Mixed methods research (MMR) refers to the use of both qualitative and quantitative methodologies in a study or a series of connected studies usually in order to answer complex research questions (Creswell & Clark, 2007). Although research in the fields of psychology and health had been historically dominated by quantitative approaches, the recognition of the importance of qualitative inquiry in the past two decades has led to an increased interest in combining quantitative and qualitative methods (Tariq & Woodman, 2013). Mixed methods research is now a prominent approach, especially in applied health research in the UK, following the recommendations of the Medical Research Council (MRC, 2000) and the National Institute for Health and Care Excellence (Kelly et al., 2009) on the usefulness of combining qualitative and quantitative methodologies.

However, MMR was not always viewed positively by the research community. A few decades ago, and especially during the 1980s, mixing

qualitative and quantitative methodologies was not considered good practice due to the perceived incompatibility of the paradigms underlying qualitative and quantitative research (Alise & Teddlie, 2010; Hall & Preissle, 2015). Research paradigms have different ontological (the nature of reality), epistemological (the nature of knowledge) and methodological (how can knowledge be acquired) assumptions. On the one hand, the ontological assumption in positivism suggests that an objective reality outside of human perception exists. In terms of epistemology, positivism supports the idea that reality can be measured objectively via scientific measures, usually via quantitative, often experimental methodologies (Bishop, 2015). On the other hand, constructivism, for example, has often been the underlying paradigm of qualitative research. Constructivism's ontological and epistemological assumptions suggest that there are multiple, socially constructed and ever changing realities and that knowledge is time and context dependent, acquired through the interaction of the researcher with study subjects and the study of meanings attached to phenomena (Krauss, 2005). These seemingly diametrically opposite philosophical underpinnings of the two paradigms led researchers to an intellectual debate, the so-called 'paradigm wars' (Gage, 1989). The incompatibility thesis was supported by both qualitative and quantitative purists who were sceptical about mixing methods derived from different paradigms and thought such attempts were difficult or impossible and lacked a strong epistemological perspective (Hesse-Biber, 2015).

Drawing from the principles of the philosophy of pragmatism (Maxcy, 2003), advocates and theorists of MMR proposed the 'compatibility thesis', supporting the idea that philosophical debates are only secondary to the

production of useful and impactful knowledge (Freshwater & Fisher, 2015). Pragmatism focuses on efficiently answering research questions and '*solving practical problems in the real world*' (Feilzer, 2010, p. 8), appropriately drawing on both qualitative and quantitative methods to meet these goals. A pragmatic approach advocates that both qualitative and quantitative methods are important and useful, and their combination can gain from their strengths and minimise their weaknesses (Johnson & Onwuegbuzie, 2004). Pragmatism has been therefore considered the 'third paradigm' and the 'philosophical partner' of MMR (Johnson & Onwuegbuzie, 2004). However, pragmatism has been criticised for its ontological and epistemological agnosticism. Having no set positions on this metaphysical dialogue, pragmatists have been accused of undermining the influence of researchers' beliefs on the research processes, the research findings and their interpretation (Maxwell & Mittapalli, 2010). Critics of pragmatism's focus on practical implications of research have noted that pragmatism has not provided an explanatory foundation for its aspiration for the 'transferability' of functional knowledge and that its notion that the truth of knowledge lies in its practical usefulness provides a shallow and fragile basis for truth (Heeks et al., 2019). Moreover, pragmatism's emphasis on formulating contextual and problem-centred research questions can hinder its ability to identify and explore structural social and political problems (Thompson, 1996).

## **Research Design in MMR**

The main rationale for the adoption of a mixed methods approach is the assumption that it can address complex research questions in a more nuanced and

comprehensive way than quantitative or qualitative approaches alone (O'Cathain et al., 2008). In one of the most widely cited papers on MMR, Greene and colleagues (1989) identified five purposes for MMR: a) *triangulation* (testing corroboration and convergence among data and findings from different methods), b) *complementarity* (enhancing the elaboration of findings), c) *development* (using findings from one method to develop or inform the design of the other method), d) *initiation* (specifically aiming to uncover contradictions and discrepancies between findings from different methods in order to develop new perspectives) and, e) *expansion* (extending the breadth and scope of inquiry, using different methods to explore different aspects of a research question). Besides the different purposes of MMR, Greene (2007) has also suggested another four aspects of MMR design within which different studies can differ. These are: a) *timing*, the sequence of studies, b) *status*, whether different methods are of equal importance or not, c) *development*, whether findings from one method inform any others and, d) the actual measures and *methods* used. Another critical dimension of MMR design is how and when the integration of quantitative and qualitative methods and data will be achieved. Integration is concerned with the relationship between research methods in achieving the research aims and how qualitative and quantitative data and findings are combined and mutually utilised to address the research question (Bazeley, 2017). Integration can happen at different stages of the research process, for example during the study design process (e.g., establishing that qualitative data will lead to the construction of a quantitative measure) or during the interpretation and reporting stage (e.g., combining qualitative and quantitative data in a narrative) (Fetters, Curry & Creswell, 2013).

## **Philosophical Stance of the Thesis**

A pragmatic mixed methods approach was deemed appropriate for the current thesis. Pragmatism and MMR have been embraced within health research, focussing on the impact of research and providing a methodological flexibility (Frost & Shaw, 2015) which would allow for a more nuanced exploration of a multi-faceted healthcare communication research topic such as BBN. The need for this thesis was pragmatic itself as it arose from individuals with MNDDs' data indicating dissatisfaction with how they received their diagnosis and the absence of data on professionals' perspectives, especially in the UK. It was, therefore, a pragmatic decision to design this project to enhance our understanding on professionals' perspectives on BBN for MNDDs. Personally, I feel that pragmatism's practical orientation and its commitment to answering questions and solving real-world problems kept me focussed on designing studies, collecting data and interpreting findings in a manner that would yield helpful implications and conclusions.

However, reflecting on the limitations and criticisms of pragmatism, a metaphysical position was also deemed essential in defining the thesis' (and my own) ontological and epistemological positioning. As a philosophical stance, critical realism does not only reflect my beliefs about the nature of the world and the nature of knowledge but can also be combined with pragmatism to develop a pragmatist-critical realist stance. On an imaginary continuum of research paradigms with positivism at one end and constructivism on the other end, critical realism sits somewhere in the middle. Although it retains an ontologically realist



perspective, supporting the idea that there is a 'real world' irrespective of human perception, it argues for an epistemological relativism, acknowledging that there is also an 'observable' world constructed from human perspectives and experiences (Bhaskar, 2008). Offering a middle ground for researchers, critical realism's worldview *'does not reduce the world to unknowable chaos or a positivistic universal order, nor does it place objective truth value on the perspectives of human beings or remove the influence and importance of human perspectives'* (Clark et al., 2008, p. 68). Heeks and his colleagues (2009) have explained the reasons why an intersection of pragmatism and critical realism would be possible and appropriate. Firstly, because of pragmatism's ontological and epistemological agnosticism, there are no conflicts between the two paradigms' metaphysical positionings. Secondly, both paradigms are considered a third paradigm between positivism and interpretivism, pragmatism in a methodological and critical realism in an ontological and epistemological sense. Thirdly, responding to criticisms of pragmatism, contemporary pragmatism theorists (DeForge & Shaw, 2012) have started to explore and support this potential fusion of pragmatism and critical realism. In particular, pragmatism can benefit from drawing on the axiology of critical realism which acknowledges that social structures in the 'real world' can produce observable oppression and unequal outcomes.

The adoption of a pragmatist-critical realist philosophical stance for this thesis would therefore serve the purpose of maintaining a focus on responding to the 'real world' problems and aiming for practical implications, while being reflective on the influence of subjectivity in the entire research process and sensitive to the axiology of critical realism and its emphasis on emancipation and

social structural influences (DeForge & Shaw, 2012). Methodologically, this philosophical stance is compatible with both quantitative and qualitative methods as it recognises methods as a toolkit to reach functional knowledge but also promotes methodological eclecticism based on the nature of the research question and the phenomena under study (Sayer, 2000). A pragmatist-critical realism stance therefore influenced the selection of mixed methods that explored professionals' perspectives on BBN on different levels (their practice, attitudes, lived experiences), with an emphasis on qualitative methods (thematic analysis and interpretative phenomenological analysis) that acknowledge the subjective and active role of the researcher in interpreting qualitative accounts.

## **Research Design and Methods of the Thesis**

The research design of the current thesis is based on Greene's (1989, 2007) classifications of MMR designs. Adopting mixed methods in this case mainly serves the purpose of *complementarity*, addressing '*overlapping but also different facets of a phenomenon, yielding an enriched, elaborated understanding of that phenomenon*' (Greene, et al., 1989, p. 258). Professionals' perspectives were explored through both quantitative and qualitative methods in order to capture professionals' reported practice and capture the current state of practice in the UK (mostly quantitatively) but also their subjective experience of delivering an often-devastating diagnosis (mostly qualitatively). Mixed methods were also employed for the purpose of *development*, as the first two studies (a scoping review and a quantitative survey on neurologists' practice and perspectives) were used for the development of the next two qualitative studies. The first point of integration was

therefore achieved at a study design level. In terms of timing, the design was explanatory sequential as studies with different methods were conducted in different time points, with the quantitative study informing the consequent qualitative study (Kajamaa et al., 2020). Regarding the status of the different methods, the thesis is predominantly qualitative both in terms of research volume (two qualitative studies and one quantitative study) and in terms of how the richness of qualitative data facilitated the process of reaching the research aim. Although the quantitative survey was important in providing context and informing the development of one of the qualitative studies through descriptive statistics, pragmatic limitations in terms of the number of participants did not allow for advanced statistical analyses to test specific hypotheses and draw statistically significant findings. Using the typology of MMR designs by Johnson and Onwuegbuzie (2004), a sequential unequal mixed methods design (quan → QUAL) was employed. Finally, qualitative and quantitative findings were also integrated at the interpretation stage (Chapter 7, General Discussion) (Fetters et al., 2013) of the thesis using the technique of ‘weaving’, presenting the findings from all studies in a narrative, on a theme-by-theme basis (Fetters, Curry & Creswell, 2013; Othman et al., 2021). Integration at this level aimed to explore convergence, complementarity, silence or discrepancies between findings from different methods.

## **Theoretical Considerations and Perspectives**

The acknowledgement of communication as a core issue in healthcare has led to an increased volume of research in the field. However, this research has often been practical and empirically driven, lacking a theoretical basis. Although

this could be partially due to the applied nature of the field, it has been argued that the use of theories in health communication research can improve the understanding and application of research's findings (Cameron et al., 2009). In addition, the use of theoretical frameworks and concepts has been particularly recommended for mixed methods studies in order to act as a map to guide research, explore causal mechanisms, establish clinical significance of results, increase credibility and, overall, aid the researcher in managing the variety of concepts and techniques used in mixed methods research (Evans et al., 2011). Indeed, *"a theory is a set of interrelated constructs (concepts), definitions, and propositions that present a systematic view of phenomena by specifying relations among variables, with the purpose of explaining and predicting the phenomena"* (Kerlinger, 1986, p. 9). As such, theory can lead to the prediction of future behaviours, emotions and cognitions and to a better explanation of the underlying mechanisms of the subject matter (Cameron et al., 2009). In this section, I will provide an overview of theories and theoretical concepts that will guide this thesis, contributing to the design of the proposed studies and the interpretation of the findings.

Bylund, Peterson and Cameron (2012) argued that being interpersonal communication by nature, research on health communication would benefit from the use of interpersonal communication theories. The researchers made a distinction between individually-centred, interaction-centred and relationship-centred interpersonal communication theories that could be of use -and have been used in some cases- in health communication studies. Since this thesis is

empirically studying solely professionals' perspectives on BBN, individually-centred theories will mostly be used.

Individually-centred theories are in nature psychological theories attempting to explain human communication using several constructs that represent cognitive functions and behaviours involved in communication. Like most, if not all, social interactions, communication is a goal-oriented, problem-solving behaviour, therefore it can be argued that the ultimate goal of communication between healthcare providers and patients is the receipt and delivery of high-quality care (Hulsman, 2009). The Goals-Plans-Action Theory (GPA) explains the process of message production intended to influence others as a 3-step sequence; **goals** – what people are trying to achieve, the desired outcome, which then activates **plans** – mental representations of verbal and non-verbal strategies to attain the goal and **action** – the implementation of the plans (Dillard, 2015; Bylund, Peterson & Cameron, 2012). Goals can be either primary or secondary. Primary goals are essentially the purpose of the interaction, while secondary goals relate to other considerations that shape or limit the interaction. which in our case could be the establishment/maintenance of a good relationship between the health professional and the patient. Goals in a BBN consultation can be multiple: explaining the nature, causes and symptoms of the condition to the patient, discussing treatment options, but also maintaining/establishing a relationship with them, checking their understanding, and attending to their emotion. However, it is often that primary and secondary communication goals are relatively incompatible (Dillard, 2015) making the interaction particularly

challenging – e.g., informing a patient about a serious diagnosis and maintaining their hope.

Based on communication theories and medical communication research, Hulsman (2015) suggested a goals-based model of determinants that explain physicians' communication behaviour in medical consultations. According to this model, within one consultation, physicians are dealing with multiple goals, which they identify and assess according to several goals' properties such as importance, difficulty and complexity. Physicians have constantly to monitor and shift through goals, while being sensitive to patient cues – which are often under-detected – and respond accordingly. Cognitive scripts (plans in the GPA theory) that professionals develop through experience and education are activated via goal-detection and guide the formation of effective responses and behaviours. However, this model acknowledges that communication is not only regulated by goals, but also by internal and external constraints such as knowledge, skills, attitudes, patient characteristics, stress and time.

The topic of this thesis is to explore professionals' perspectives on BBN news for MNDDs. 'Perspectives' can be considered a broad or too abstract term so these theoretical concepts and processes presented above can provide both a context and several areas of focus which constitute professionals' perspectives on BBN. However, limiting our theoretical lenses to just these theories above would raise the risk of developing a microscopic and reductionist view of the process of BBN which would not align with our pragmatist-critical realism stance. Instead throughout the design, data collection, data analysis and interpretation of findings,

a systems theory-informed approach was also adopted. Systems theory suggests that complex systems (e.g., the healthcare system) consist of not only several individual parts with distinct properties but also the relationship and interdependence between these parts. Such systems affect and are affected by their environments and are dynamic in that they are adaptable and can learn from experience (Johnson et al., 2018). In contrast with reductionism which intends to solve problems within systems by 'fixing the broken part', systems theory suggests that problems can be attributed to deficiencies in individual parts but also to dysfunctional relationships between parts or unhelpful interactions with the environment (Johnson et al., 2018). The medical culture is known for looking at individual responsibility to explain negative outcomes (Jackson & Sambo, 2020) and this can be reflected in the discourse used in health research which often implies an accusation of doctors for not being sensitive or patient-centred enough when communicating with patients. Maintaining a systems theory-informed thinking throughout the research process helped me abstain from such practices and develop a genuinely curious attitude towards exploring and understanding HCPs' perspectives on BBN. A systems-informed approach also ensured a sensitivity to the identification of different, often wider, factors surrounding the actual healthcare-provider communication that could influence both the quality of this interaction but also the professionals' practice and experiences of BBN (e.g., organisational factors).

Finally, it is important to note that the exploration of professionals' perspectives and the interpretation of findings were inevitably influenced by the findings of numerous empirical patient studies (mostly the studies included in the

scoping review conducted as part of this thesis, Anestis et al., 2020) and guidelines (e.g., Baile et al., 2000), which have provided information on what is important when BBN. Breaking bad news was also approached as a critical process for the establishment and maintenance of the professional-patient relationship, which is considered vital for an accurate diagnosis and an effective treatment plan (Hellin, 2002). Additionally, professionals' experiences and practice were explored in relation to recognised dimensions of the patient-centred model of care, such as respect for patient's autonomy and needs, patient education and emotional support to relieve fear and anxiety (Davis et al., 2005). My intention was to explore how professionals' practice in BBN to patients with MNDDs reflected such pillars of patient-centred care and how their perspectives and experiences compared to and could potentially explain the sub-optimal experiences reported by patient studies.

## **Synopsis of Individual Studies and Methods**

This section provides an overview of the sequence and methods of the studies that were conducted in order to achieve the research aim. As this is an alternative format thesis, each study will be referred to as publishable paper (PP) followed by a number, indicating the sequence of the studies. The methods used for each study are only discussed briefly and more details in terms of the rationale for each method can be found in each individual PP. Figure 1, at the end of this section, illustrates the sequence and logic of the studies.



In order to build a strong rationale for the empirical studies of the thesis and detect pre-existing empirical research on professionals' perspectives on BBN to patients with MND, PD or MS<sup>1</sup>, a scoping review of the literature was conducted (PP1). As the main purpose of the review was to map and summarise empirical research on this topic, a scoping approach was chosen, which allowed for a rigorous search strategy but required less specificity than a systematic review, so studies of different designs could be included (Arksey & O'Malley, 2005; Levac, et al., 2010). Both patients' and doctors' perspectives were included in this review since our hypothesis from other domains of medicine was that studies on patients' perspectives would stress the need for improvements in the process of BBN which, along with the limited number of studies on the doctors' perspectives, would stress the importance of further investigation of HCPs' perspectives, which is the aim of this thesis. By including both patient and doctor perspectives in this review we also hoped to achieve an understanding on the neurologist-patient interaction at such a critical moment, highlight any potential communication mismatch, and identify areas of improvement and gaps in the literature that the rest of the thesis would attempt to cover. Indeed, the scoping review revealed a significant research gap on professionals' perspectives on BBN, especially from a qualitative perspective. The review also highlighted several important aspects of the patient experience such as inadequate information provision, limited consultation times and lack of empathy by doctors at diagnosis. These findings informed the development of interview guides for the qualitative studies (PP3 & PP4) which allowed participants to elaborate on their practice and experiences with these aspects of the consultation.

<sup>1</sup> HD was excluded from the search as no studies on the topic were found.

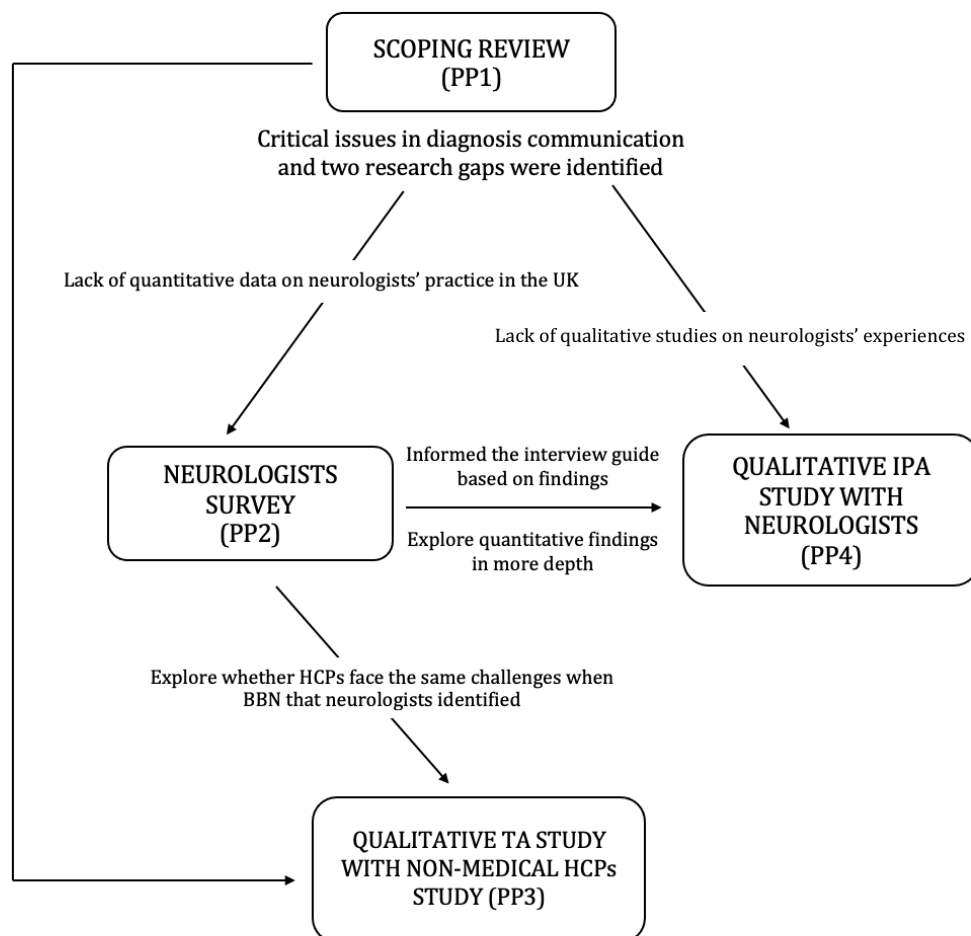
The scoping review also found no studies on neurologists' practice in the UK, so it strengthened the rationale for a quantitative survey (PP2) which aimed at assessing neurologists' current practice and perspectives on breaking the diagnosis of an MNDD. The survey was based on one study (Aoun et al., 2016) about the communication of an MND diagnosis which was included in the scoping review and was adapted to address the different MNDDs of interest. The survey highlighted several key aspects of neurologists' diagnosis communication practice such as short consultation times, tendency to not convey a sense of optimism to patients with MND and HD and lack of training. Such findings were used to inform the design of the consequent qualitative studies where these issues could be explored in-depth. In addition, quantitative data from PP2 provided a general context (complementarity) for the interpretation and integration of findings in the General Discussion chapter of the thesis.

The two qualitative studies were then conducted simultaneously; however, we refer to the study of non-medical HCPs as PP3 as it was completed first. The decision to conduct a qualitative study to explore non-medical HCPs' range of involvement in BBN was based on three factors. Firstly, while conducting the scoping review, findings from some studies indicated that patients were satisfied with the support they received at diagnosis by specialist nurses who had a crucial role in educating and supporting the patient and their families. Secondly, becoming increasingly familiar with the scientific literature on BBN, I started viewing it as a more dynamic and long-term process which involved other HCPs apart from doctors. Thirdly, staying true to a systems approach, I believed that the inclusion of a variety of HCPs who provided care to newly diagnosed patients with

MNDDs would help create a more holistic understanding of the actual process of BBN for MNDDs. For this study which was mainly exploratory and aimed at investigating HCPs' range of involvement, a thematic analysis (TA) approach was chosen. This approach is in line with our pragmatist-critical realist stance as it acknowledges researchers' active role in developing themes from qualitative data and allows for both inductive and deductive analysis (Braun & Clarke, 2019).

The second qualitative study (PP4) employed an interpretative phenomenological analysis (IPA) framework as it aimed to explore neurologists' lived experiences of BBN for MNDDs. The need for PP4 emerged from the significant research gap on qualitative explorations of neurologists' experiences of BBN for MNDDs identified by PP1. Interpretative phenomenological analysis was the method chosen for this study as it is established for the study of lived experience in health research (Smith, 2017) and because of its emphasis on how people make meaning out of their experiences, aiming to draw out the psychological concomitants of those (Murray & Wilde, 2020). Besides focussing on how neurologists experience navigating such difficult conversations from a communication point of view (assessing information preferences, tailoring information giving, being empathic), this study also focussed on the emotional experience of being the bearer of bad news for these conditions. The findings helped develop a more comprehensive understanding of neurologists' experiences of BBN and were used to attempt an explanation of why patient studies often report negative experiences with diagnosis communication. Finally, based on the study's findings and in line with our systems-informed approach,

organisational changes to support professionals manage the emotional demands of BBN and offer genuine patient-centred care at diagnosis was emphasised.



**Figure 1:** Thesis studies' sequence and logic flowchart.

## Chapter Three

### Publishable Paper One (PP1)

*Giving and receiving a diagnosis of a progressive neurological condition: A scoping review of doctors' and patients' perspectives*

**Status:** Published in Patient Education and Counseling journal (see Appendix 2)

#### Statement of authorship:

Mr Eleftherios Anestis: 80%      Signed:.....

Prof Jane Simpson: 5%      Signed:.....

Dr Ian Fletcher: 5%      Signed:.....

Dr Fiona Eccles: 5%      Signed:.....

Dr Maddy French: 5%      Signed:.....

**Giving and receiving a diagnosis of a progressive neurological condition: A  
scoping review of doctors' and patients' perspectives**

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## **Abstract**

**Objective:** Delivering a life changing diagnosis can be a distressing experience for patients and a challenging task for professionals. Diagnosis delivery can be especially difficult for individuals with neurodegenerative diseases such as motor neurone disease (MND), multiple sclerosis (MS) and Parkinson's disease (PD). This review aims to scope the literature on doctors' and patients' perspectives on diagnosis delivery for these conditions in order to enhance our understanding in this area and identify potential research gaps.

**Methods:** A scoping review methodology was used, and data were summarised using content analysis.

**Results:** 47 studies fulfilled the inclusion criteria. Studies showed that although patients were generally satisfied with diagnosis delivery, a considerable proportion was still dissatisfied with aspects of the consultation, especially the information and time provided and the doctor's approach. Only six studies addressed doctors' perspectives, which focused more on doctors' practice.

**Conclusion:** There was a significant research gap in professionals' perspectives. The review also found that although basic standards of good practice were being met, a significant proportion of patients were dissatisfied with diagnosis communication. Practice implications: Professionals delivering such diagnoses need to assess and respond to patients' information needs, provide time for questions and maintain an empathic attitude.

**Keywords:** breaking bad news, diagnosis communication, neurodegenerative conditions, motor neurone disease, multiple sclerosis, Parkinson's disease, scoping review

## **Introduction**

Diagnosis delivery for a significant health condition is a particularly challenging aspect of doctor-patient communication and most commonly described as 'breaking bad news' (Harman & Arnold, 2017). Bad news is usually described as 'any information likely to drastically alter a patient's view of his or her future' (Buckman, 1984, p. 1597). How such news is delivered can have a long-term impact on the patient's satisfaction with care (Schofield et al., 2003), understanding of the disease (Kaplowitz et al., 1999), involvement in decision-making, psychological adjustment (Roberts et al., 1994), prolonged distress, confusion and treatment adherence (Fallowfield & Jenkins, 2004). At the same time, delivering a serious diagnosis can also be an emotionally challenging task for healthcare professionals. This aspect of their clinical work can induce moderate but lasting stress reactions (Studer et al., 2017) and emotions of anger and guilt, and distressing thoughts around their powerlessness to make a positive difference and their own personal fear of death (Bousquet et al., 2015).

Studies in this area have been conducted predominantly within fields such as oncology, obstetrics and emergency medicine (Fallowfield & Jenkins, 2004), however bad news delivery can be a critical issue in other medical specialties such



as neurology. Progressive neurological conditions such as Parkinson's disease (PD), multiple sclerosis (MS) and motor neurone disease (MND) are incurable and result in a gradual decline in physical and cognitive functioning, restricting individuals' daily activities and affecting their quality of life and psychological functioning (Batista & Pereira, 2016). Before receiving their diagnosis, patients often experience a stressful pre-diagnostic period (Mitchell et al., 2010), are often misdiagnosed and may experience significant diagnostic delay (Adamec et al., 2013; Aires et al., 2019; Kelly et al., 2011). Reaching a diagnosis for such motor neurodegenerative diseases (MNDDs) can be a demanding task for health professionals due to the similarities in and overlap between symptoms of different conditions (Abdo et al., 2010; Galvin et al., 2017) and the need for specialised testing. Communicating the diagnosis can also be challenging for doctors since such 'bad news' might elicit reactions of different types of distress from the patients (Storstein, 2011).

Given the progressive, often life-threatening nature of these conditions and the likely stressful pre-diagnostic experience, receiving the diagnosis will be a critical time for patients. A PD patient survey reported that 'satisfaction with the explanation of the condition at diagnosis' had a significant effect on future quality of life (Global Parkinson's Disease Survey Steering Committee, 2002). This review will focus on three neurological conditions which all include forms of neurodegeneration (i). Neurologists commonly deliver these diagnoses which primarily affect movement and have a high 'burden of illness' i.e. impact on both human and economic dimensions (Hirtz et al., 2007). A scoping review was undertaken to identify and summarise existing empirical studies which addressed

doctors' current practice and perspectives on breaking bad news, and patients' experiences and perspectives on the process of diagnosis delivery. Other reviews in this area have not focused solely on receiving the diagnosis but more on the experience of services (Foley et al., 2012a; Foley et al., 2012b, Methley et al., 2015) or doctor-patient interactions in general (Soundy et al., 2016) and have excluded studies on professionals' perspectives. Including both patient and doctor perspectives will achieve a better understanding on the neurologist-patient interaction at this critical timepoint and will help identify areas of miscommunication, and gaps in the literature.

## **Method**

A scoping review was adopted to incorporate patients' and doctors' perspectives that have been reported in qualitative and quantitative studies. Scoping reviews focus on mapping and summarising key concepts from a range of research activities and identifying potential gaps in a broad research topic (Arksey & O'Malley, 2005). They offer similar rigour to reviews using a systematic review methodology, and aim to understand complex topics and not simply summarise the best available evidence. Heterogeneous designs can be included and quality assessments are not usually conducted (Levac et al., 2010). This review followed the 6-step framework developed by Arksey and O'Malley (2005) and further recommendations by Levac and colleagues (2010). Five of six steps were completed, while the sixth optional step, consultation, was omitted. These steps are briefly outlined below:

i. Identifying the research question

The research question was: What are patients' and doctors' perspectives on the delivery of the diagnosis for MND, MS and PD? The term 'perspectives' was intentionally broad in order to capture both a priori themes such as patient satisfaction and doctors' practice and to identify and map other key concepts addressed by the literature.

ii. Identifying relevant studies

PubMed, CINAHL, PsycINFO and Scopus were accessed, using subject terms where available. The search strategies were developed with the help of a subject specialist librarian (see Table 1). The citation lists of all the included papers were hand searched for additional studies, Google Scholar's 'cited by' service was also accessed.

iii. Study selection

Table 2 summarises inclusion and exclusion criteria. Empirical studies of any design were included in the review if they were published in a peer-reviewed journal and addressed patients' or doctors' perspectives on the delivery of diagnosis for MNDDs focusing on the consultation when the diagnosis was delivered. As a first step, titles were screened and all irrelevant papers were excluded. Then abstracts were screened, irrelevant studies were excluded, relevant studies were included and potentially relevant studies were read in full. The main reasons for excluding articles included: no data on diagnosis delivery, a focus on the pre-diagnosis journey, and only addressing patients' emotional reactions to diagnosis. The first author screened all retrieved citations and consulted the rest of the research team to resolve any ambiguity. Additionally, a

random 10% of all retrieved citations were reviewed by another author (MF) and any discrepancies were resolved. Figure 1 at the end of this chapter features a PRISMA diagram which illustrates the study selection process.

iv. Charting the data

Study information and results which addressed the research question were extracted (see Table 4).

v. Collating, summarising and reporting the results

Except for a few cases of basic numerical analysis of percentages, data answering our research question were analysed qualitatively through a conventional content analysis approach (Hsieh & Shannon, 2005). The content codes were organised into meaningful categories which summarised available evidence. Results regarding patients' perspectives were analysed and reported independently for each neurological condition, and doctors' perspectives were analysed together due to the limited number of relevant studies.

## **Results**

### *Overview of studies included in the scoping review*

In total, 47 studies were included in the review. Table 3 summarises basic study characteristics and Table 4 presents characteristics for every study included in the review. The majority of studies ( $n = 22$ ) focused on MS; studies on doctors' perspectives were severely underrepresented in the literature with only six studies included in this review. Qualitative and quantitative methodologies were equally represented in the patient studies and all study designs were

retrospective. Studies represented a range of countries, mainly from a western perspective, however the similarity of themes across studies indicated that patients' experience of receiving a diagnosis shared common features.

### **Receiving the diagnosis of MND**

#### *Satisfaction with diagnosis delivery*

In general, patients with MND were satisfied with the way neurologists delivered the diagnosis, but this was not always the case. Patients in an Italian survey gave high ratings of satisfaction with bad news communication and felt that the doctors were encouraging and understood their feelings during the diagnosis (Chiò et al., 2008). Other quantitative studies (Abdulla et al., 2014; Aoun et al., 2016a) reported mixed results; although the majority of patients were satisfied with how the diagnosis was delivered, 32%–35% of patients felt dissatisfied. In particular, patients were mostly satisfied with the privacy provided and the absence of interruptions during the consultation, with only a few exceptions reported. Satisfaction was also positively associated with patients' perceived ability of their neurologist, although it is unclear whether the term ability specifically referred to their communication skills or their general medical competence (Aoun et al., 2016a). However, 36%–56% of patients rated their doctor's ability as average or below average (Aoun et al., 2016a; McCluskey et al., 2004). Similarly, qualitative studies also revealed mixed results with patients sharing both positive and negative experiences (Aoun et al., 2018a; O'Brien et al., 2011) although a study of a single centre which was following international guidelines for MND care received only positive feedback (Hugel et al., 2006).

### *Information provision*

Given the rarity and life-threatening nature of MND, patients often required detailed information about their diagnosis. Patients wanted to know about current research on MND, disease-modifying therapies, their prognosis (Chiò et al., 2008), their entitlements to services (Hugel et al., 2006), the treatment plan and information sources (Aoun et al., 2016a; O'Brien et al., 2011). However, it was sometimes felt that the doctor shared insufficient information about these topics (McCluskey et al., 2004; O'Brien et al., 2011). Patients also reported their dissatisfaction with doctors, indicating that the information given was not always adequate and that the doctors did not always check they had clearly understood the information (Pavey et al., 2013) or provide the opportunity for questions (Johnston et al., 1996). This elicited a 'feeling of abandonment' with patients feeling responsible for seeking information about their condition themselves. However, some patients felt that there was limited potential for further information due to the poor prognosis (Seeber et al., 2016) and a qualitative study highlighted that patients' receptivity to information differed dramatically (Callagher et al., 2009).

### *Consultation duration*

Survey studies reported a mean consultation of approximately half an hour (Aoun et al., 2016a; McCluskey et al., 2004). Patients who had received longer consultations were more satisfied and considered their doctor more skilled (Aoun et al., 2016a). On the contrary, doctors who were judged to possess poor skills only spent an average of 13.4 min on the consultation (McCluskey et al., 2004). Patients

were often frustrated with a very short consultation as they did not have the opportunity for discussion (Aoun et al., 2018a). At the same time, they knew the clinicians were in high demand and it could take months for the next appointment (Pavey et al., 2013). Receiving such a complex diagnosis required time for them to digest the information provided, express their feelings and ask questions. The evaluation of a fast-track diagnostic service based on principles of good practice in breaking bad news showed positive patient satisfaction regarding the communication of the diagnosis and the time taken (Callagher et al., 2009). Similarly, a qualitative study which assessed patients' perspectives on diagnosis delivery in a 2-tiered approach reported positive outcomes. Patients viewed the second appointment - which they received only 10–14 days after the first - as an opportunity to prepare questions, clear misunderstandings and make informed decisions regarding their treatment (Seeber et al., 2016).

#### *Doctors' empathy*

Qualitative studies and qualitative comments in quantitative studies sometimes highlighted the need for doctors to show more empathy. Patients often felt that their doctors did not approach such a serious diagnosis in a caring and sensitive way and were described as 'detached', 'very clinical' and 'insensitive' (Aoun et al., 2018a; Hogden & Cook, 2017). Similarly, Pavey et al. (2013) described that patients considered that doctors were unwilling to be personally involved and offer emotional support; a participant in the Hughes et al. (2005) study also reported feeling 'dehumanised'. However, most studies that addressed the issue reported mixed experiences (Aoun et al., 2018a; Hughes et al., 2005; Johnston et al., 1996; O'Brien et al., 2011; Remm et al., 2019) or even exclusively positive

experiences (Callagher et al., 2009). Patients valued being listened to when they expressed their anxieties and fears regarding the future (Seeber et al., 2016) and those who were satisfied with their doctor's approach (Aoun et al., 2018a) described them as a 'fantastic, caring person' and 'kind and empathetic'. Interestingly, the older study reported that patients often found a straightforward and even blunt disclosure style acceptable (Beisecker et al., 1988).

### **Receiving the diagnosis of MS**

#### *Satisfaction with diagnosis delivery*

Regarding general satisfaction with the way doctors broke the bad news for a MS diagnosis, studies presented mixed results. A quantitative survey showed that 67% of patients were completely and 24% were partially satisfied with the diagnosis delivery, 64% thought the medical staff were kind, 30% thought they were attentive and only 6% thought they were unfriendly or hasty (Lorefice et al., 2013). It is noteworthy though, that this survey was conducted in a single MS centre. Additionally, two studies from Norway which used the same questionnaire found that there was definitely room for improvement as only 33%–55% of patients were satisfied with the circumstances in which their diagnosis was communicated (Gottberg et al., 2008; Ytterberg et al., 2008). Qualitative studies, on the other hand, indicated that although some positive experiences were reported by patients, these were the exceptions (Johnson, 2003; Malcomson et al., 2008).



### *Information provision*

Beyond sharing their preference to be told their diagnosis in an honest and clear way, patients in most studies also shared their views on the amount and nature of the information they received during the diagnostic consultation. A survey showed that although 90% of MS diagnoses were given by neurologists, only 50% of patients considered them their major support regarding the meaning of the diagnosis (Heesen et al., 2003). In general, data from both quantitative and qualitative studies showed that patients felt they were not provided with adequate information about their condition (Edwards et al., 2008; Heesen et al., 2003; Hepworth & Harrison, 2004; Johnson, 2003; Malcomson et al., 2008; Pretorius & Joubert, 2014; Solari et al., 2007; Thorne et al., 2004; Thornton & Lea, 1992; Yazdannik et al., 2015) or they had to push to receive the information they wanted (Pretorius & Joubert, 2014).

At the time of diagnosis patients seemed to need general information about MS, information on treatment options and managing their symptoms (Heesen et al., 2003; Thorne et al., 2004; Thornton & Lea, 1992), information on counselling services (Hepworth & Harrison, 2004; Wollin et al., 2000) and lifestyle changes (Malcomson et al., 2008; Pretorius & Joubert, 2014). A survey (Heesen et al., 2003) showed that 52% of patients were not informed about MS therapies when the diagnosis was made, however in a more recent study (Lorefice et al., 2013), 79% of patients considered their doctor's information on treatment choices to be exhaustive. Patients preferred information to be communicated in a simple and direct way (Solari et al., 2007; Thorne et al., 2004), without the use of medical jargon (Solari et al., 2007) and reference to worst case scenarios (Thorne et al., 2004). However, a few studies made it clear that the type of information provided

at diagnosis should be tailored to the individual (Solari et al., 2007) and some patients might not want any additional information at that point when the diagnosis itself is 'enough to handle' (Thornton & Lea, 1992). In addition, patients often felt that accessing reliable information sources was not facilitated by healthcare professionals (Johnson, 2003) who sometimes failed to signpost patients to organisations or specialised MS centres which could have been useful (Edwards et al., 2008; Lode et al., 2007; Malcomson et al., 2008).

Patients explained that effective information provision at the time of the diagnosis would help mitigate the fear elicited by the diagnosis (Malcomson et al., 2008; Thorne et al., 2004). Moreover, in a study in which 43.2% of patients were dissatisfied or very dissatisfied with the information they received at diagnosis, satisfaction with information was associated with more adaptive coping with the condition (Lode et al., 2007). Nonetheless, some patients expressed the view that even though the doctor might have provided them with information about their diagnosis, their state of shock might have not allowed them to assimilate it (Barker-Collo & Cartwright, 2006; Edwards et al., 2008).

#### *Consultation duration*

Time dedicated to the consultation was an important variable which shaped patients' experiences of diagnosis delivery. A survey showed that 50% of patients thought that time taken by the doctor to deliver the diagnosis was too short (Edwards et al., 2008) and patients in qualitative studies (Ceuninck van Capelle et al., 2006; Pretorius & Joubert, 2014; Solari et al., 2007) also reported that their appointment felt 'rushed'. Doctors were perceived to be in a hurry to see the next patient, with not enough time to ask questions and receive answers.

### *Doctors' empathy*

Patients in several studies reported that sometimes their doctors did not show any empathy, did not provide emotional support and delivered the diagnosis in a casual and overly medical way (Barker-Collo & Cartwright, 2006; Ceuninck van Capelle et al., 2006; Edwards et al., 2008; Hepworth & Harrison, 2004; Malcomson et al., 2008; Pretorius & Joubert, 2014). In a UK study with focus groups, out of 103 patients with MS, only 8 reported being happy with the communication of their diagnosis (Hepworth & Harrison, 2004). Some qualitative studies captured some extreme scenarios, for example, patients who were told their diagnosis over the telephone (Edwards et al., 2008; Isaksson & Ahlström, 2006), on Christmas Eve (Edwards et al., 2008) or via mail (Solari et al., 2007). Neurologists were sometimes viewed as 'diagnosers' with little or no interest in the patients (Dennison et al., 2016; Johnson, 2003), unable to understand fully the patients' perspective (Malcomson et al., 2008). Patients who had negative experiences reported anger, disappointment and bitterness towards the medical profession (Dennison et al., 2016; Edwards et al., 2008). Furthermore, a quantitative study associated discussion of patients' emotional well-being with the professional at the time of diagnosis with positive post-diagnostic outcomes (White et al., 2007). In this study, 44% of patients reported having such a discussion with their doctor which was associated with significantly higher levels of acceptance of their condition as well as other benefits.

## **Receiving the diagnosis of PD**

### *Satisfaction with diagnosis delivery*

Data on overall satisfaction with the delivery of PD diagnosis indicated that there was room for improvement with 49% of patients being satisfied with their consultation, 29% being neutral and 22% being dissatisfied (Schrag et al., 2018). A more negative image was drawn in another study where 52.5% of patients rated their experience with the diagnosis delivery as good or very good and 45.3% as poor or very poor (Bloem & Stocchi, 2012). However, this difference can potentially be explained by differences in culture and healthcare systems since, although both were European surveys, the second study gathered data from 35 countries whereas the first one did so from 11.

### *Information provision*

In Bloem's and Stocchi's (2012) European survey, 62.2% of patients reported having received general information about their condition and although less than 1% reported not having received any information, only 22.1% said they received detailed information. Around 14% received information about medication at diagnosis and less than 2.8% received information regarding PD support organisations. In the same study, the information provided at diagnosis was considered helpful or very helpful by 64% of respondents, with a more recent European survey reporting the same percentage (64%) (Schrag et al., 2018). In this survey, although respondents reported having received general information about the causes, symptoms and medication, nearly half stated they had not received any information on non-drug treatments at diagnosis. Qualitative studies

often reported patients' negative experiences with information provision at diagnosis. Patients often felt that they left the consulting room with very little information about their condition (Habermann, 1996; Macht et al., 2003; Peek, 2017). There were instances when patients' questions were not answered in a satisfactory manner (Macht et al., 2003) or patients reported receiving no information at all from their doctors but were encouraged to buy a book about PD or search information on the internet instead (Peek, 2017).

#### *Consultation duration*

Inadequate information provision could be associated with limited consultation duration since only 38% of patients in the most recent European patient survey reported being given enough time to ask questions, while 17% would have liked more than the time they were given and 12% were not given any time at all (Schrag et al., 2018). Other studies also reported short consultation times (even 5-10 minutes in extreme cases, Macht et al., 2003) which did not allow time for a detailed explanation of the diagnosis (Habermann, 1996; Peek, 2017; Warren et al., 2016). On the other hand, some patients were satisfied with the information they were provided (Macht et al., 2003) and it should be noted that being given too much information was also at times considered problematic (Shaw & Vivekananda-Schmidt, 2017).

#### *Doctors' empathy*

European surveys presented mixed patient experiences regarding the doctor's approach to delivering the diagnosis. Bloem and Stocchi (2012) used a 10-point Likert scale to measure clinicians' attitude, ranging from abrupt to kind,

in which 58.9% of patients gave positive scores (6–10) and 36.4% gave negative scores (1–5) with 16.9% choosing the best possible and 11.3% the worst possible score. Percentages differed in a more recent survey where 50% of patients reported that their PD diagnosis was communicated quite or very sensitively and 50% felt it was given not very or not at all sensitively (Schrage et al., 2018). Qualitative studies were consistent with these findings and provided vivid accounts of patients who felt that receiving the diagnosis was an important moment for them which was not always handled appropriately by the doctors. The diagnosis was often communicated abruptly, in a casual way, without any sensitivity or compassion (Shaw & Vivekananda-Schmidt, 2017; Peek, 2017; Warren et al., 2016). Patients often shared similar stories in which their diagnosis was handled ‘routinely’ in a ‘business-like’ way, in an appointment so ‘swift’ that they did not have space to consider their reaction (Peek, 2017). On the contrary, an account from a patient who had a positive experience with her doctor indicated that patients value doctors who show an understanding of the emotional impact of the diagnosis, adopt a positive attitude and provide reassurance that their condition can be managed with professional help. Indeed, a more sensitive delivery of the diagnosis was associated with higher patient satisfaction, having a stronger relationship with satisfaction than the helpfulness of the information provided, and the time provided to ask questions (Schrage et al., 2018).

### **Doctors’ perspectives on communicating the diagnosis for MNDDs**

Studies on doctors’ perspectives on communicating a diagnosis for MNDDs were limited and reported little data on the actual consultation. Instead, these

studies focused on other issues such as when the diagnosis should be disclosed. Data relevant to our review question were mostly associated with neurologists' practice.

For the case of MS, doctors often (Heesen et al., 2003; Papathanasopoulos et al., 2008) (28%–58.3%) avoided using the term 'multiple sclerosis' when communicating the diagnosis or did so only at the end of the consultation or in subsequent visits (57%) (Martinelli et al., 2012). Instead, other terms such as 'demyelination' or 'nervous system infection' were used (Papathanasopoulos et al., 2008), possibly because they were considered less 'negatively charged' and less associated with the stigma associated with the term MS. Overall, neurologists in these surveys seemed to be sensitive to the emotional impact of the diagnostic process and reported being willing to support patients through information provision. The vast majority reported delivering the diagnosis of MS in a private setting (Papathanasopoulos et al., 2008), involving patients' relatives (Martinelli et al., 2012; Papathanasopoulos et al., 2008) and approximately 50% took more than half an hour (and sometimes more than an hour) for the consultation (Heesen et al., 2003; Martinelli et al., 2012). Most neurologists felt emotionally involved in the relationship with the patient (64%) and used the shared decision-making model (87%). They aimed to initiate bidirectional communication, answered patients' questions (61%) and tried to 'offer comfort and support suggesting a disease-modifying therapy' (Martinelli et al., 2012). Around 77% believed the way they communicated the diagnosis assisted the patient in understanding the meaning of the diagnosis (Papathanasopoulos et al., 2008) and although 79% considered their communication practice as competent, only 14% believed they had managed all patient needs and expectations (Martinelli et al., 2012).

Apart from a survey assessing MND care in Italy, which found that the time taken to explain the diagnosis was around 30 min (Chiò et al., 2001), the only survey focusing solely on the communication of MND diagnosis was conducted in Australia and assessed neurologists' current practice and experiences of breaking bad news (Aoun et al., 2016b). Most neurologists (68%) used two consultations to deliver the diagnosis with the mean duration of each consultation being 23 min. The duration was double (45 min) for neurologists who practised in multidisciplinary MND clinics. Almost all (98%) of neurologists reported having a patient's relative involved in the consultation, 73% referred to an MND association and 78% gave the diagnosis in a private space but only 41% were always able to avoid interruptions. Regarding the content of the consultation, the degree of certainty, how the diagnosis was reached and the course of the disease were the most discussed aspects, while being honest without taking away hope, dealing with a patient's emotions and spending enough time were the most challenging aspects. About 70% of neurologists reported that delivering the diagnosis was a 'very to somewhat difficult' task and believed that difficulties were due to the lack of effective treatment for MND, the fear of causing distress or not having all the answers. Moreover, communicating the diagnosis induced 'high to moderate' stress and anxiety for 65% of neurologists.

Finally, Pinder's study conducted in the UK (Pinder, 1992) explored general practitioners' (GPs') perspectives on the diagnosis of PD. This qualitative study focused on professionals' experience of reaching the diagnosis and the beliefs that informed their practice. Diagnosing was often a 'eureka moment', a moment of theoretical 'coherence' that gave satisfaction to the doctors. The diagnosis was viewed positively since it did not only validate their role as



‘diagnosticians’ but also enabled them to initiate treatment, help patients manage their condition and prove their symptoms credible. A PD diagnosis was not viewed as so ‘emotionally loaded’ by GPs especially when it was diagnosed in older people and it was often compared with other ‘more serious’ conditions. Doctors tried to incorporate these views into the communication of the diagnosis to help patients come to terms with the disease. In addition, several doctors were more empathetic and tried to deliver the diagnosis in a way which showed consideration for how PD might affect patients’ relationship with their bodies and their daily lives.

## **Discussion and conclusion**

### **Discussion**

Although the topic of breaking bad news has been studied more extensively within other fields of medicine (Fallowfield & Jenkins, 2004), a considerable number of studies were identified that addressed this issue for MNDDs. This scoping review revealed a significant research gap in doctors’ perspectives of delivering a MNDD diagnosis. Moreover, the small number of doctor-studies included in this review made it difficult to compare and contrast patients’ and professionals’ views on the delivery of the diagnosis of an MNDD. Overall, patients across conditions were fairly satisfied with the way they were told their diagnosis and more recent papers drew a more positive image than older ones, potentially due to the growing emphasis on the importance of communication in healthcare and the patient-centred care ‘movement’ (Cameron et al., 2009; De Haes & Bensing, 2009). Most doctors also reported relatively high standards of practice

in delivering this task. However, survey studies reported considerable percentages of patients who were dissatisfied with the process and, with the qualitative studies, illustrated several aspects of the diagnosis delivery consultation which could be improved.

Effective information provision and patient education are considered two of the pillars of patient-centred care, a model of care considered appropriate for individuals with chronic conditions and complex health care needs such as MND (Hogden & Crook, 2017), MS (Charlesworth & McManus, 2017) and PD (van der Eijk et al., 2013). However, patients in the studies included in this review often expressed their dissatisfaction with both the amount and nature of information they received (or did not receive) during the delivery of their diagnosis. Studies with newly diagnosed cancer patients have shown that information provision can lead to several positive outcomes such as gaining a sense of control, reducing anxiety, promoting compliance, realistic expectations, self-care and feelings of safety (Mills & Sullivan, 1999). Increasing patients' knowledge of their condition can tackle stereotypical disease representations that do not apply for all cases (e.g., equating having MS with being wheelchair-bound and dependent). Providing adequate and timely information at diagnosis is also vital for shared-decision making, especially for conditions such as multiple sclerosis when longterm treatment decisions have to be taken early on (Colligan et al., 2017; Heesen et al., 2011). Additionally, some patients reported that their doctor did not signpost them to relevant organisations or reliable information sources which raised feelings of abandonment. This was a missed opportunity to connect with community-based organisations which have been shown to generate a feeling of

relief while offering a holistic approach to supporting patients and their carers (Aoun et al., 2018b). Being left alone to seek information for their condition themselves, patients often turned to the internet, where information sources varied in reliability and could be misleading, especially regarding treatment options (Hallingbye & Serafini, 2011; Kothari et al., 2015).

On the other hand, studies on neurologists' practice illustrated a willingness to support patients via information provision. Although, as stated above, the limited volume of data on doctors' perspectives does not allow for robust comparisons, this discrepancy between patients' experiences and doctors' reported practice could be attributed to doctors' often not assessing accurately patients' information needs (Colligan et al., 2017). The preferred amount of information differed significantly among patients, but in general it seemed that doctors tended to underestimate patients' information needs (Clayton et al., 2007).

Whether health care professionals showed compassion while delivering the diagnosis was another major topic addressed. Patient studies across conditions reported mixed results regarding the doctor's manner of managing the consultation. While this was not the case for everyone, it was often felt that they did not receive emotional support at the time of diagnosis and described unsympathetic, detached, insensitive professionals with an overly medical and casual approach. In other words, as Habermann (1996) noted: 'The human significance was passed over and objectified by what is known about the disease and treatment'. (p.404). Patients' negative experiences highlighted a contrast

between their strong emotional reaction to the news of the diagnosis and the often-emotionless practice of their doctors, which left them feeling angry, disappointed, bitter or even dehumanised. A factor that could partially explain why individuals felt they did not receive adequate information and emotional support from their doctors were time constraints. Individuals across conditions often reported receiving short consultations, which caused frustration and a sense of being 'rushed' (Macht et al., 2003).

### **Practice and research implications**

This scoping review showed that several aspects of the diagnosis delivery process could be improved. Although the difficulties inherent in effective doctor-patient communication are significant, efforts must be made to promote a culture of continuous professional development and learning in this important area (Levinson, 2011). Adopting a truly patient-centred approach to communication needs to be the overarching framework for development and improvement. As part of this, healthcare professionals delivering such diagnoses need to assess patients' information needs by being sensitive to patient cues, checking their understanding of the information provided and providing time for questions. However, given that many professionals are restricted by time, it is suggested that they at least provide basic information about the condition, an overview of treatment options and effects of the condition on daily life and then signpost patients to reliable information sources such as specialist nurses and disease associations which will further support them. Delivering the diagnosis in two consultations has also been found to be beneficial to patients. Moreover,

professionals need to maintain a caring and empathic attitude, avoid an overly medical and detached approach and provide support especially to patients who show the need to share their concerns and emotions.

Beyond practice implications, future research should incorporate doctors' views, encourage experiential and emotional explorations and, therefore, create a deeper and more holistic understanding of the doctor-patient communication at the time of diagnosis. The aim of this would be to shed light on the challenges and facilitators of effective communication at this time, inform best practice guidelines and appropriately support professionals.

### **Limitations**

This scoping review's main limitations are the inclusion of only studies written in English due to funding and time constraints, and the potential inclusion of low-quality studies due to the absence of a quality appraisal tool. However, this is usual practice in scoping reviews (Pham et al., 2014). In addition, the screening of the titles/abstracts and the eligibility assessment of the papers were made by only one person and only 10 % of the citations were reviewed by a second person.

### **Conclusion**

This scoping review found that diagnosis communication is a crucial moment for patients with MNDDs which requires a careful approach from doctors. Although some basic standards of good practice were being met and patients were

generally satisfied, a significant proportion of patients were dissatisfied with the way they were given their diagnosis and reported issues related to inadequate information provision, lack of empathy and insufficient consultation duration. The review also found an important research gap on professionals' perspectives of giving bad news to individuals with these conditions. More research involving both the bearer and the receiver of bad news for MNDDs is needed for the development of evidence-based training programmes and guidelines for diagnosis communication, all informed by a patient-centred approach.

Endnote (i): MS's neurological nature has been a matter of controversy in medicine. We signpost to this review of data that supports neurodegeneration as the major cause of irreversible neurological damage: Trapp, B. D., & Nave, K. A. (2008). Multiple sclerosis: an immune or neurodegenerative disorder?. *Annu. Rev. Neurosci.*, 31, 247–269.

## Tables and Figures

**Table 1.** Search Strategy (Databases searched on July 29<sup>th</sup> 2019)

Database	Search Terms
<b>Pubmed</b>	<p>(((((("Multiple Sclerosis/diagnosis"[Mesh] OR "Multiple Sclerosis/physiology"[Mesh]) OR ("Motor Neuron Disease/diagnosis"[- Mesh] OR "Motor Neuron Disease/physiology"[Mesh])) OR ("Amyotrophic Lateral Sclerosis/diagnosis"[Mesh] OR "Amyotrophic Lateral Sclerosis/psychology"[Mesh])) OR ("ParkinsonDisease/diagnosis"[Mesh] OR "Parkinson Disease/psychology"[Mesh])))</p> <p>AND</p> <p>(((((((((("Patient Satisfaction"[Mesh] OR "Referral and Consultation"[Mesh]) OR ("Physicians/ethics"[Mesh] OR "Physicians/psychology"[Mesh])) OR "Communication"[Mesh]) OR "Truth Disclosure"[Mesh]) OR "Attitude to Health"[Mesh]) OR "Physician-Patient Relations"[Mesh]) OR "Attitude of Health Personnel"[Mesh]) OR "Professional-Patient Relations"[Mesh]) OR "Health Personnel/psychology"[Mesh])</p>
<b>Scopus</b>	<p>(TITLE-ABS-KEY("parkinson* disease" OR "motor neuron* disease" OR "amyotrophic lateral sclerosis" OR "Lou Gehrig" OR "multiple sclerosis"))</p> <p>AND</p> <p>(TITLE-ABS-KEY("bad news" OR (communicat* W/4 diagnos*) OR (deliver* W/4 diagnos*) OR "being diagnos* OR (receiv* W/4 diagnos*) OR (giv* W/4 diagnos*)))</p>
<b>CINAHL</b>	<p>(MH "Parkinson Disease/DI/ED/EI/NU/PF") OR (MH "Amyo- trophic Lateral Sclerosis/DI/ED/EI/NU/PF") OR (MH "Multiple Sclerosis/DI/ED/EI/NU/PF") OR (MH "Motor Neuron Diseases/DI/ED/EI/PF/NU")</p> <p>AND</p> <p>(MH "Parkinson Disease/DI/ED/EI/NU/PF") OR (MH "Amyotrophic Lateral Sclerosis/DI/ED/EI/NU/PF") OR (MH "Multiple Sclerosis/DI/ED/EI/NU/PF") OR (MH "Motor Neuron Diseases/DI/ED/EI/PF/NU") PsycINFO (DE "Parkinson's Disease") OR (DE "Amyotrophic Lateral Sclerosis")) OR (DE "Multiple Sclerosis") OR (DE "Neurodegenerative Diseases")</p> <p>AND</p> <p>(DE "Diagnosis") OR (DE "Medical Diagnosis") OR (DE "Preferences") OR (DE "Information Seeking") OR (DE "Health Personnel Attitudes") OR (DE "Therapeutic Processes") OR (DE "Neurologists") OR (DE "Client Satisfaction") OR (DE "Health Service Needs") OR (DE "Neurodegeneration") (DE "Quality of Care") OR (DE "Quality of Services") OR (DE "Client Attitudes").</p>

**Table 2.** Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Empirical studies	Reviews, guidelines or opinion papers
Written in English	Written in any other language
Published in peer-reviewed journals	Published in non-peer-reviewed journals
Adult patients' and doctors' perspectives	Child or adolescent patients, patients' families, carers or healthcare professionals' other than doctors' perspectives
Studies focusing on people with MND, PD or MS	Studies focusing on other conditions or studies which include MND, PD or MS but do not report separate data for these conditions
Studies reporting data on doctors' and patients' perspectives on the diagnostic delivery consultation (e.g., patients' information needs and satisfaction with the consultation, doctors' practice and attitudes towards breaking the bad news and doctor-patient communication at the point of diagnosis in general)	Studies who focus on other aspects of diagnosis delivery such as the timing of the diagnosis, the pre-diagnostic period, or the long-term impact of diagnosis delivery. Also, studies which only report data on patients' emotional reactions or coping with the diagnosis.



**Table 3.** Characteristics of included studies

Total number of studies included	47
Studies on patients' perspective	42 (MND= 15, MS=20*, PD=7)
Studies on doctors' perspectives	6 (MND=2, MS=3 PD=1)
Quantitative studies	19
Qualitative studies	25
Mixed-methods studies	3
Countries	UK= 15, Australia= 6, USA= 4, Italy= 5, Germany= 3, Sweden= 3, Netherlands= 2, South Africa= 2, Canada= 1, Greece= 1, Iran= 1, New Zealand= 1, Norway= 1, 2 European, multi-country surveys

\*One study (Heesen et al., 2003) addressed both patient and professionals' perspectives.

**Table 4.** Characteristics of studies included in the review

No.	Paper	Was diagnosis delivery the main focus of the study?	Methodology	Participants*	Country	Main results*
1	Abdulla et al., 2014	No	Quantitative	106 people with MND	Germany	68% were satisfied with how the diagnosis was delivered, 69% were satisfied with the amount and 77% with the comprehensibility of information provision.  Qualitative comments about impersonal/too short consultation.
2	Aoun et al., 2016b	Yes	Quantitative	248 people with MND	Australia	65% were satisfied with diagnosis delivery and 35% were not satisfied.  Higher satisfaction was associated with longer consultation times.
3	Aoun et al., 2018	Yes	Qualitative	248 people with MND	Australia	Mixed results regarding neurologist's empathy and emotional support provision as well as time provided for the consultation.  Information preferences differed among participants but signposting to the MND Association was viewed positively.
4	Aoun et al., 2016a	Yes	Quantitative	73 neurologists	Australia	68% reported requiring two consultations to convey the diagnosis.  Mean consultation time was 23 minutes and 45 minutes for neurologists practicing in MND multidisciplinary clinics.  70% found delivering the diagnosis "very to somewhat difficult", 43% found responding to patient/family emotional reactions to be difficult and 65% experienced "high to moderate" stress and anxiety.  Being honest but not taking away hope (80%); dealing with the patient's emotion (38%) and spending the right amount of time (28%) were found to be the most challenging aspects of diagnosis delivery.  74% were 'somewhat to very interested' to receive training in responding to patient's emotions.

5	Barker-Collo & Read, 2006	No	Qualitative	16 people with MS	New Zealand	<p>Patients shared their experiences with doctors' 'overly medical or formal approach'.</p> <p>All participants wanted information about MS at the time of the diagnosis but were aware that shock at that point did not help assimilate it.</p>
6	Beisecker et al. 1988	No	Quantitative	41 people with MND, but only 35 were asked about diagnosis disclosure	United States	Of the 35 patients who responded to questions about diagnosis delivery, 24 described a straightforward or even blunt disclosure style. Out of these 24 patients, 19 found this an acceptable disclosure style but others thought the physician seemed upset for having to give such a diagnosis or talking about the fatality of the disease took away all hope.
7	Bloem & Stocchi, 2012	No	Quantitative	2068 people with PD	35 countries in Europe	<p>52.5% of patients rated their experience with the diagnosis delivery as 'good or very good' and 45.3% as 'poor or very poor'.</p> <p>62.2% of patients reported having received general information about their condition, 22.1% received detailed information, 14% received information about medication at diagnosis and less than 2.8% received information about PD support organisations.</p> <p>66% found information provided to be 'helpful or very helpful'</p>
8	Callagher et al., 2009	Yes	Quantitative (Clinical audit of patient satisfaction)	23 people with MND	United Kingdom	Patients receiving their diagnosis through a 'fast-track' service which utilised knowledge from the 'breaking bad news' literature and limited waiting times shared their positive experiences with the consultation they received at the time of diagnosis and were content with the privacy, time and sensitivity provided and having a relative present.
9	Ceuninck van Capelle et al., 2015	Yes	Qualitative	10 people with MS	Netherlands	Patients could vividly remember the physician delivering the diagnosis and reported mixed experiences. Some were satisfied with how the doctor handled the consultation and the way they explained the diagnosis, while some others reported receiving the diagnosis in an abrupt manner, not having their questions answered and their emotions attended.
10	Chio et al., 2001	No	Quantitative	36 centres with an interest in MND (questionnaires)	Italy	<p>Mean consultation time for diagnosis delivery was 32.7 minutes in large centres and 27 minutes in small centres.</p> <p>Written information at diagnosis was given by 8 (36%) small and 5 (36%) large centres.</p>

				filled by neurologists)		
11	Chiò et al., 2007	No	Quantitative	60 people with MND	Italy	<p>Patients gave high ratings about their overall satisfaction with diagnosis delivery and how encouraging and understanding of their emotions their physician was. Higher satisfaction was associated with the feeling that the physician has understood their feelings.</p> <p>Most patients wanted to receive information about current research on MND (65%), therapies that could slow disease progression (56.7%) and MND outcome (43.3%)</p>
12	Dennison et al., 2016	No	Qualitative	15 people with MS	United Kingdom	<p>Patients reported negative experiences about how their diagnosis was communicated and the lack of support they received at that time which left them feel distressed and upset. Neurologists were viewed as 'diagnosers' with no interest in patients' perspectives.</p> <p>All patients reported diagnosis as an unsuitable point for receiving prognostic information.</p>
13	Edwards et al., 2008	Yes	Qualitative	24 people with MS	United Kingdom	<p>Many participants were not satisfied with how they received their diagnosis, especially with physicians' often casual and unsympathetic approach. One participant reported being given the diagnosis over the phone and another one at Christmas Even. Such negative experiences elicited emotions of disappointment and anger</p> <p>The majority felt they had not received adequate amount of information (n=20)</p>
14	Gottberg et al., 2008	No	Quantitative	166 people with MS	Sweden	55% of patients were dissatisfied with the situation in which they first received the diagnosis
15	Habermann, 1996	No	Qualitative	16 people with PD	United States	<p>Reactions of shock when receiving the diagnosis did not allow some participants to process the information provided at that point, but others clearly recalled being given very little information about their diagnosis. A participant who received inadequate information at the point of the diagnosis shared his experience with an unsympathetic professional who only saw him for 12 minutes and did not give him any hope.</p>

						Living and coping with the disease were not discussed with their physician at the point of diagnosis.
16	Heesen et al., 2003	Yes	Quantitative	434 people with MS, 80 neurologists	Germany	<p>90% of patients reported receiving the diagnosis from a neurologist and 50% considered them the major aid helping to understand the disease and up to 50% reported that the time invested by the physician for the diagnosis delivery was too short. 30% reported that information was given too cautiously and 52% were not informed about available therapies at the point of diagnosis, 71% of those who received such information rated the extent as sufficient.</p> <p>28% of neurologists do not use the term multiple sclerosis when explaining the diagnosis, 84% try include patients' relatives to the consultation, most of them believe that 80%-100% of their patients are fully informed about their diagnosis but 70% thought their patients are well-informed about therapeutic options</p>
17	Hepworth & Harrison, 2004	No	Mixed (questionnaires and focus groups)	2030 questionnaire respondents and 103 participated in the focus groups (people with MS)	United Kingdom	<p>Out of the 103 patients who participated in the focus groups, 49% mentioned negative experiences they had when they received their diagnosis and only 8 participants were happy with how they were given the diagnosis. The most often negative experiences were related to the physicians' attitude and inadequate provision of information and support.</p> <p>Data from the questionnaires showed that at the point of diagnosis over 50% of participants would like to receive information on symptoms and management, drug treatments, disease course, exercise, diet and information for the family. The study also showed that whereas only 20% of patients diagnosed in 1980 received information about their diagnosis, the majority of patients (70%) diagnosed after 2000 had received information at diagnosis.</p>
18	Hogden et al., 2012	No	Qualitative	14 people with MND	Australia	Two participants reported having limited understanding of the implications of MND at the time of diagnosis which implied inadequate information provision, but also several participants were frustrated that professionals did not share information on survival times and disease trajectories.

						Patients considered insensitive communication of the diagnosis by neurologists as one of the negative experiences they had had with interacting with healthcare professionals.
19	Hugel et al., 2006	Yes	Qualitative	13 people with MND	United Kingdom	Patients in this single-centre study were satisfied with how their diagnosis was communicated and particularly valued being given the diagnosis in a private setting, with a relative or carer involved in the consultation, in an empathic way tailored to their needs.
20	Hughes et al., 2005	No	Qualitative	9 people with MND	United Kingdom	Patients needed information about their entitlements to services at the point of diagnosis.  Some patients felt that the physicians delivering the diagnosis were distant.
21	Isaksson & Ahlström, 2006	No	Qualitative	61 people with MS	Sweden	Some patients reported having received the diagnosis through the telephone and felt angry about the way they were informed.
22	Johnson, 2003	Yes	Qualitative	24 people with MS	United Kingdom	Patients shared a variety of experiences related to how they had received their diagnosis, but most of them shared their dissatisfaction with how this had been approached by the professionals. Some patients felt the neurologists were only concerned with reaching the diagnosis and had no further interest in them as patients, leaving them feeling 'cut-off' post diagnosis. More positive experiences were reported by a patient who was given the news by their GP and five participants who were told of an MS nurse.
23	Johnston et al., 1996	Yes	Quantitative	50 people with MND	United Kingdom	29 patients understood what they told at diagnosis, 15 did not and 5 were unsure. 24 patients asked the questions they wanted to ask but 22 did not and understanding was associated with being able to ask questions. Half of the patients were given the diagnosis with no one else included in the consultation and only 8 had been asked to bring someone. Four patients were given the diagnosis in a non-private setting. 23 patients reported some good points about how they received the diagnosis, such as the doctor telling the truth, being honest and direct and showing kindness/empathy. 26 patients reported some bad points such as being told the diagnosis in a vague or indirect way, not being able to ask questions or the lack of privacy.

						Patients suggested improvements for better diagnosis communication such as giving more information and providing clearer explanations.
24	Lode et al., 2007	No	Quantitative	86 people with MS	Norway	56.8% of patients were satisfied and 43.2% were dissatisfied or very dissatisfied with the information they received at diagnosis (satisfaction with information was associated with future coping with the condition and the employment of problem-solving strategies).
25	Lorefice et al., 2013	No	Quantitative	497 people with MS	Italy	<p>67% of patients were completely satisfied with their diagnosis, 24% thought the process to be lacking in some respects and 9% were dissatisfied, while 64% thought the medical staff were kind and 30% thought they were attentive.</p> <p>Information on MS therapies and therapeutic choice were considered exhaustive by the majority of patients (79% and 83%) and 53% of patients were satisfied with information about future therapy options.</p>
26	Macht et al., 2003	No	Qualitative	33 people with PD	Germany	<p>At diagnosis, patients needed information on the causes, symptoms and treatment choices.</p> <p>Patients shared a variety of experiences regarding the communication of their diagnosis. Those who shared positive experiences had been immediately given diagnosis and disease-related information tailored to their needs and felt they could cope with their condition. On the other hand, patients were not always provided with information or answers to their questions about their diagnosis in a timely manner. A patient also reported that they were given the diagnosis within 5-10 minutes without any further explanation.</p>
27	Malcomson et al., 2008	No	Qualitative	13 people with MS, 2 focus groups	United Kingdom	7 patients shared their experiences with the physicians' often abrupt and insensitive approach to diagnosis delivery, which lacked empathy and understanding. 10 participants also thought that professionals were vague when giving the diagnosis. 11 participants reported that they received no information about coping with the diagnosis and the symptoms and daily living with the condition. These negative experiences caused confusion and worry to these participants, whose questions about their condition remained unanswered and felt the physicians could not understand how they feel. In contrast, one participant shared a positive experience with how she received the

						diagnosis by a GP who provided her support and information and was also offered counselling and help from nurses.
28	Martinelli et al., 2012	Yes	Quantitative	172 neurologists	Italy	<p>96% of neurologists communicated the diagnosis in a private setting</p> <p>52% required less than half an hour, 38% require 30-60 minutes and 10% require more than an hour to deliver the diagnosis.</p> <p>61% answered patients' questions and doubts and try to offer comfort and support, suggesting a disease-modifying therapy</p> <p>26% provided written information</p> <p>88% preferred to involve patients' relatives in the consultation</p> <p>32% straightforwardly used the term multiple sclerosis from the beginning of the consultation, 11% avoided using it and 57% only used it at the end of the consultation or in subsequent visits.</p> <p>87% used language aimed at obtaining cooperation and bidirectional communication, 79% would like to tailor their communication on patient's psychological profile but only 3% thought this is possible, mostly because of limited time resources</p> <p>64% felt emotionally involved in the relationship with the patient</p> <p>79% rated their communication as adequate or competent, but only 14% thought they could manage all patients' needs and expectations</p>
29	McCluskey et al., 2004	Yes	Quantitative	144 people with MND	United States	<p>Patients reported that physicians spent an average of 32 minutes to deliver the diagnosis, 36% spend less than 20 minutes, 27% spent less than 15 minutes, 17% spend less than 10 minutes and 5% less than 5 minutes.</p> <p>Patients rated the physician's performance as poor (16.4%), below average (8.6%), average (31%), good (19%), or excellent (25%).</p> <p>Less than half of physicians informed patients about MND-related association and about half gave information on specialised centres. 65% of physicians identified MND as terminal, but according to patients only a few (11%) discussed end of life options, hospice (9%) and tracheostomy and ventilation (17%).</p> <p>Rating of physician's performance was associated with time spend to deliver the news.</p>
30	O'Brien et al., 2011	Yes	Qualitative	24 people with MND	United Kingdom	<p>Patients reported mixed experiences regarding diagnosis delivery. Some reported positive experiences, where bad news was adequately explained in a sensitive manner. Others had unsatisfactory experiences,</p>



						reporting blunt interactions with physicians with poor communication skills and empathy. Some patients also talked about the very short consultation that lacked privacy and information provision. Patients with such negative experiences felt anger but could also feel sympathy and understood the difficulty that physicians faced when breaking bad news.
31	Papathanasopoulos et al., 2008	Yes	Quantitative	217 neurologists	Greece	41.7% of neurologists used the term multiple sclerosis when delivering the diagnosis and preferred other terms such as demyelination or nervous system infection. 78.7% included patients' relatives in the consultation Most physicians felt that the information they provided helped the patient understand the meaning of the diagnosis. When a patient does not fully understand the meaning of the diagnosis, 72% of physicians thought this was mainly because of their education level and also their emotional response to the news (51.9%). 52% reported investing more than 30 minutes, 22% more than an hour and at least two sessions to deliver the diagnosis.
32	Pavey et al., 2013	Yes	Qualitative	41 people with MND	United Kingdom	It was common in participants' accounts to feel that diagnosis delivery was carried out in a way that avoided personal involvement and lacked emotional support and empathy. Limited consultation duration and inadequate information provision and explanation of the diagnosis was also a common issue for patients. Some reported being informed about the MND Association but this was not the case for everyone. Finally, some patients reported that they had not been asked to bring someone with them.
33	Peek, 2017	Yes	Qualitative	37 people with PD	United Kingdom	Most patients talked about their negative experiences of being diagnosed. They felt their interaction with the doctor was 'business-like' and 'swift', the physicians did not seem to understand the emotional impact of the diagnosis and often offered a very short appointment, providing little or no explanation of the diagnosis. On the contrary, patients appreciated an approach that showed that the significance of this moment was respected by the doctor, who provided reassurance and a sense of hope.
34	Pinder, 1992	Yes	Qualitative	15 people with PD, 18 GPs	United Kingdom	GPs approached diagnosis delivery based on their theoretical knowledge and felt content having 'solved the puzzle' and being able to manage the

						<p>condition via medication. Most of them felt the diagnosis of PD is not as emotionally loaded, comparing it to other more severe neurological conditions and considered it a somehow natural outcome of the ageing process, ideas which they try to incorporate in the diagnosis delivery consultation. However, some GPs also acknowledged the 'horrifying' impact the diagnosis might have on the patients and tailored their consultations accordingly.</p> <p>Although data on the patients' perspectives focused mostly on their emotional reaction and coping with the diagnosis, it is implied that patients at the point of diagnosis had unanswered questions regarding the nature of PD.</p>
35	Pretorius & Joubert, 2014	No	Qualitative	10 people with MS	South Africa	<p>Most participants were dissatisfied with their doctors' often unsympathetic or 'rushed' approach, reporting very short consultation times and little or no information provision about how to cope with MS and adjust their lifestyle.</p>
36	Remm, 2019.	Yes	Qualitative	6 people with MND	Australia	<p>Patients reported mixed experiences regarding the physician's approach to diagnosis delivery. Patients valued being cared for and treated as a person rather than a diagnosis and felt anger when this was not the case. Patients with positive experiences felt their physician was genuinely interested in them, someone who they could speak openly and trust.</p>
37	Schrag et al., 2018	Yes	Quantitative	1775 people with PD	11 European countries	<p>50% thought they were given the diagnosis quite or very sensitively and 50% felt they were told not very or not at all sensitively.</p> <p>38% reported being given enough time to ask questions and discuss concerns, while 17% would have liked more time to ask questions, 12% reported not having been given any time to ask questions and 28% felt they were not able to ask question at that time anyway.</p> <p>2% reported not being given any information at all, patients received mostly information on symptoms, diagnosis, causes and medication and almost half of the respondents did not receive information on non-drug treatments. Information was perceived as helpful by 64% of respondents, but 36% did not find the information helpful.</p> <p>49% were satisfied, 29% were neutral and 22% were dissatisfied with the consultation at diagnosis.</p>

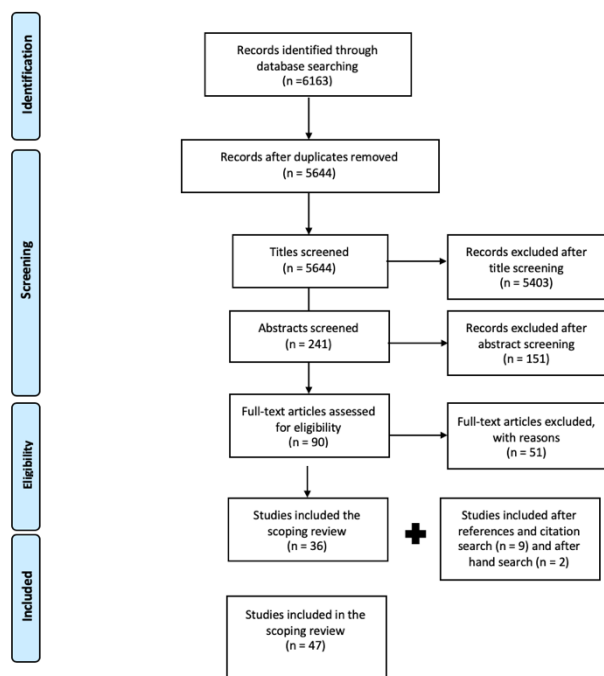
						Patient satisfaction was associated with more sensitively diagnosis delivery, time provided to ask questions and quantity of information provided.
38	Seeber et al., 2016	No	Qualitative	10 appointments observed, 21 people with MND were interviewed	Netherlands	Some patients wanted to obtain as much information as possible while others were more reserved at diagnosis, however everyone wanted to know about prognosis and available therapies. Patients valued when the physicians were straightforward and had asked them to bring someone with them and being offered a second appointment to further explain the diagnosis was generally viewed positively. Patients valued this quick follow-up appointment since it gave them the opportunity and time to ask questions, clear misunderstandings, but also express their stressed, wishes and expectations about the future.
39	Shaw et al., 2016	No	Qualitative	12 people with PD	United Kingdom	While some participants were satisfied with how they were given their diagnosis, others had negative experiences, such as being told in a non-private environment or being told in an abrupt, impersonal manner. Patients' information preferences at diagnosis also differed, with some patients wanting as much information possible, while others felt that too much information was not helpful for them.
40	Solari et al., 2007	Yes	Qualitative	23 people with MS in two focus groups	Italy	Patients reported mixed experiences regarding how they received their diagnosis, but it was generally agreed that patients diagnosed more recently had more positive experiences. All participants agreed that physicians should invest adequate time for diagnosis delivery, however not all had enough time to discuss the diagnosis in-depth and ask questions. Patients also required a private setting without interruptions when receiving the bad news and when this was not the case, they felt helplessness. Patients had different preferences regarding the presence of significant others or other healthcare professionals in the consultation at the point of diagnosis but agreed that the presence of staff not involved in the consultation impaired the confidentiality of the meeting. Regarding information provision, patients agreed that it should be tailored to the situation and the needs of the individual, but explanations should be kept simple, using direct language and avoiding medical jargon. Patients valued bilateral communication and being offered a quick follow-up appointment with the same physician to further discuss the diagnosis and ask questions.

41	Thorne et al., 2004	No	Qualitative	12 people with MS	Canada	Participants talked about the value of timely and direct information provision and their disapproval of being patronised by physicians who did not want to give too much information, avoided to talk about worst-case scenarios and were evasive and general rather than direct and specific. However, a participant felt disempowered by learning about the chronic and degenerative nature of MS.
42	Thornton & Lea, 1992	No	Mixed	40 people with MS	South Africa	70% felt they did not receive sufficient information at the time of diagnosis and out of 30% who did so, most believed it was because they had pushed for it and others felt they would not be able to cope with additional information. Although most participants felt their consultants would be able to answer their questions, some thought they were ignorant to know what questions to ask.
43	Warren et al., 2016	Yes	Qualitative	6 people with PD	United Kingdom	Patients shared negative experiences they had with diagnosis delivery, particularly a lack of compassion or sensitivity from the diagnosing physician. Patients also had the sense that professionals did not have sufficient time for the consultation.
44	White et al., 2007	No	Quantitative	145 people with MS	United States	44% of patients reported that a medical provider discussed their emotional well-being with them at the time of diagnosis Patients who reported talking about their emotional well-being at diagnosis had significant higher levels of acceptance and positive outcomes Illness Cognition Questionnaire.
45	Wollin et al., 2000	No	Mixed	34 people with MS completed the questionnaire and 7 were interviewed	Australia	73% of patients believed patients should be informed about how MS affect patients at diagnosis (the need for information on MS symptoms was also a common theme for the patients interviewed). Information on managing (57%) and treatment (50%) of MS was also favoured. Regarding information about services at the point of diagnosis, patients reported that information about counseling (62%), support groups (59%), and physiotherapy and exercise (58%) would have been useful. From the 29 patients who answered the open-ended questions of the survey, 20% had been advised to contact MS society and 17% indicated they had received no useful information at diagnosis.
46	Yazdannik et al., 2015	No	Qualitative	20 people with MS	Iran	Some patients were not satisfied with how the diagnosis was communicated, especially when they were only provided with a brief

						description of the diagnosis and the consultation was rushed or they felt the professional did not pay attention to their mental needs.
47	Ytterberg et al., 2008	No	Quantitative	219 people with MS	Sweden	57% of patient were satisfied with the circumstances under which the diagnosis was delivered

\*The table only addresses study participants and results that relate to the research question of this review.

**Figure 1.** PRISMA Diagram



## Chapter Four

### Publishable Paper Two (PP2)

*Neurologists' current practice and perspectives on communicating the diagnosis of a motor neurodegenerative condition: a UK survey*

**Status:** Published in BMC Neurology journal (see Appendix 2)

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**Neurologists' current practice and perspectives on communicating the  
diagnosis of a motor neurodegenerative condition: a UK survey**

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## **Abstract**

**Background:** The communication of a life-changing diagnosis can be a difficult task for doctors with potential long-term effects on patient outcomes. Although several studies have addressed the experiences of individuals with motor neurodegenerative diseases in receiving this diagnosis, a significant research gap exists regarding professionals' perspectives, especially in the UK. This study aimed to assess UK neurologists' current practice and perspectives on delivering the diagnosis of a motor neurodegenerative disease, explore different aspects of the process and detail the potential challenges professionals might face.

**Methods:** We conducted an anonymised online survey with 44 questions, grouped into four sections; basic demographic information, current practice, the experience of breaking bad news and education and training needs.

**Results:** Forty-nine professionals completed the survey. Overall, participants seemed to meet the setting-related standards of good practice; however, they also acknowledged the difficulty of this aspect of their clinical work, with about half of participants (46.5%) reporting moderate levels of stress while breaking bad news. Patients' relatives were not always included in diagnostic consultations and participants were more reluctant to promote a sense of optimism to patients with poorer prognosis. Although professionals reported spending a mean of around 30–40 min for the communication of these diagnoses, a significant proportion of participants (21–39%) reported significantly shorter consultation times, highlighting organisational issues related to lack of capacity. Finally, the majority of participants (75.5%) reported not following any specific guidelines or protocols



but indicated their interest in receiving further training in breaking bad news (78.5%).

**Conclusions:** This was the first UK survey to address neurologists' practice and experiences in communicating these diagnoses. Although meeting basic standards of good practice was reported by most professionals, we identified several areas of improvement. These included spending enough time to deliver the diagnosis appropriately, including patients' relatives as a standard, promoting a sense of hope and responding to professionals' training needs regarding breaking bad news.

**Keywords:** Breaking bad news, Diagnosis communication, Patient-provider communication, Neurodegenerative, Motor neurone disease, Multiple sclerosis, Parkinson's disease, Huntington's disease

## **Background**

Breaking bad news is a critical and distressing process for patients but also an often stressful and challenging task for clinicians (Fallowfield & Jenkins, 2004; Ptacek & McIntosh, 2009). Bad news in medicine refers to 'any information likely to alter drastically a patient's view of his or her future' (Buckman, 1984, p. 1597) such as the communication of the diagnosis of a potentially life-changing condition. How a diagnosis is delivered can have a long-term impact on patient outcomes such as treatment adherence (Fallowfield & Jenkins, 2004), psychological adjustment and involvement in treatment decision making (Roberts et al., 1994), understanding of the condition (Kaplowitz & Safron, 1999) and satisfaction with care (Schofield et al., 2003). From the doctor's perspective, breaking bad news can be an emotionally burdensome and intrinsically difficult task, with factors such as time constraints, intercultural differences in relation to diagnosis disclosure and lack of private space making it even more challenging (Bousquet et al., 2015).

Most studies on the delivery of bad news have been conducted within the field of oncology. However, the delivery of bad news can be a critical issue in other medical specialties such as neurology. Storstein (2011) argues that when breaking bad news, neurologists deal with specific challenges that relate to particular medical considerations and the emotional aspects of neurological diseases. In particular, several chronic neurological conditions, such as Parkinson's disease (PD), multiple sclerosis (MS) and Huntington's disease (HD), are incurable, have a progressive nature and impact both physical and cognitive functions [8], while

others, such as motor neurone disease (MND), can also be more immediately life threatening (Winhammar et al., 2005). A scoping review of doctors' and patients' perspectives on giving and receiving the diagnosis of MND, MS or PD (Anestis et al., 2020) revealed mixed results regarding patients' experiences and satisfaction with how diagnosis delivery was handled. The main factors which contributed to negative patient experiences were the often-limited duration of the consultation, inadequate information provision and a perceived insensitive approach by the professional breaking the news. Moreover, the review found a significant research gap on studies addressing the physicians' perspectives, which could offer a better understanding of the doctor-patient interactions at the time of the diagnosis.

The aim of this study was to assess UK neurologists' current practice when delivering the diagnosis of a motor neurodegenerative disease (MNDD), in particular PD, MS, HD and MND. Currently, there are no UK studies on this topic, the aim of the study was to explore different aspects of the process, such as the setting, duration and challenges of communicating a diagnosis of this nature. In addition, potential factors affecting practice and differences between delivering the diagnosis for different conditions were also explored. As the results are descriptive, no hypotheses were made.

## **Method**

The study was approved by both the authors' host institution's research ethics committee and the Health Research Authority, a unified system for the governance of health research in the UK.

The questionnaire used for this study was constructed after a comprehensive review of the relevant literature on breaking bad news and guidelines such as SPIKES, the Six-Step Protocol for Delivering Bad News (Baile et al., 2000) and the National Institute for Health and Care Excellence (NICE) guidelines for the management of MND (NICE, 2016), MS (NICE, 2014) and PD (NICE, 2017). It was also largely based on the questionnaire used by Aoun et al. (2016b) for a similar study on neurologists' experiences on delivering the diagnosis of MND in Australia. The first draft of the survey was reviewed by two practising neurologists for clarity and relevance and adjustments were made based on their comments.

The survey was hosted online on the Qualtrics platform and was open for 2 years (from September 2018 to September 2020). Eligible participants were medical professionals, including specialist registrars, practising in the UK who had experience in delivering the diagnosis for at least one of the conditions included in the survey. The survey comprised 44 questions grouped into four sections; demographic information, current practice, the experience of breaking bad news and education and training needs (see Appendix 3). It was completed anonymously, and questions were mainly closed with several open-ended questions where participants were asked to elaborate on their answers or provide any further comments. Participants were recruited through the Association of British Neurologists (ABN), other associations related to neurology or MNDDs and through collaborations with National Health Service (NHS) trusts.

Data from the closed questions were imported and analysed in IBM SPSS 26 software package (IBM, 2019), using descriptive statistics; means, standard deviations, range and frequencies. In addition, qualitative data from the open-ended questions of the survey were used to enhance, explain and expand the findings from the analysis of the quantitative data. Respondents who completed less than 50% of the survey ( $N < 5$ ) were excluded from the study.

## **Results**

### *Participants' profile*

Forty-nine professionals responded to the survey; 43 consultant neurologists, 4 neurology specialist registrars, one consultant neuropsychiatrist and one clinical fellow. Participants were mainly male (67%), almost half of them were in the 41–50 age group (48%) and had a mean of 10 years of experience (ranging from less than one to 23: SD = 6.8). Almost all participants mainly practised in England, 5 participants mainly practised in Wales and although all participants practised in the NHS, 12 participants were also practising privately. See Table 1 for a summary of participants' demographics.

### *Diagnosis disclosure*

Most participants had experience in communicating all four diagnoses under review; 90% of professionals had experience in breaking bad news for PD, 88% for MND, 84% for MS and 67% for HD. Most of the professionals who had

experience in delivering the diagnosis of HD (73%) had only communicated 1–20 diagnoses, which can be explained by the rarity of the condition and the diagnosis of onset<sup>1</sup> of HD potentially being given mostly in specialist clinics.

The vast majority of professionals (87%) reported always disclosing the diagnosis for these conditions to the patients. Text comments highlighted that it would be ‘fundamentally unethical’ not to inform a patient of their diagnosis. Participants believed that being honest and transparent about the diagnosis helped with the management of the condition and building a relationship with the patient. However, some comments indicated that professionals would not disclose the diagnosis only when patients had clearly stated that they did not wish to know or when the diagnosis was not definite and further investigation was required. Moreover, 30% of participants reported that they would sometimes refer patients to other medical professionals who would then deliver the diagnosis. Qualitative comments indicated that they would follow this approach when they were uncertain about a diagnosis or they could refer to a specialist clinic.

#### *Setting, time and people involved in the consultation*

When asked about the setting of the consultation, 74% of participants reported ‘always’ delivering the diagnosis in a private space and 96% stated that ‘most of the time’ or ‘always’ the diagnosis was communicated without any interruptions. In addition, 75% of professionals reported always maintaining eye contact with the patient and 75% arranged to have suitable seating at the same level as the patient without a desk or barrier.

On average, professionals reported investing around 30 min for the delivery of the diagnosis for PD ( $M = 30$ ,  $SD = 9.3$ ), MS ( $M = 28.7$ ,  $SD = 10.4$ ) and HD ( $M = 29.9$ ,  $SD = 16.5$ ) and 41 min ( $SD = 26$ ) for MND. However, a considerable proportion of participants (21% for PD, 32% for MS, 39% for HD and 20% for MND) reported spending 15 to 20 min for the diagnosis consultation and 30% of participants reported spending over an hour to communicate the diagnosis of MND. More than half of professionals (64%) believed patients were given enough time to ask questions and express their emotions. However, across conditions, 58–69% of professionals ‘sometimes’ needed more than one consultation to explain these diagnoses and 23–35% ‘always’ needed more consultations. One participant explained that diagnosis communication was a more dynamic process, beyond the diagnostic consultation:

*‘I do not think that breaking the diagnosis is really a one-off event (even if you had all the time in the world), but rather a process that continues throughout much of the time that you look after an individual as the disease and the patient’s relationship with it often change as time goes on.’*

Furthermore, 72% of professionals did not refrain from giving a diagnosis at any specific time or day, and those who did so explained that they avoided giving bad news at a late appointment or before the weekend if the patient was not accompanied by someone and also before patients’ birthdays or before holidays such as Christmas. Regarding the involvement of other people in the consultation, 60% of professionals stated that ‘most of the time’ or ‘always’, patients were asked to bring someone to the consultation, however 15% reported

that patients were not asked to bring someone. In addition, 53% of participants 'sometimes' included other healthcare professionals in the consultation and 19% 'never' did so.

### *Content of the consultation / information giving*

Almost all participants agreed that how the diagnosis was reached (96%), treatment options (96%), the degree of certainty of the diagnosis (92%) and the course/prognosis of the disease (90%) were topics that should be discussed with the patient at diagnosis. Causes of the disease (76%) and current research (63%) were also considered important topics to be covered. Additional comments showed that neurologists also chose to discuss other important topics, such as the family, hereditary and legal implications of the diagnosis (e.g. driving), information on the support plan and other healthcare professionals who would be involved in their care and signposting to related charities and reputable sources of information. In addition to oral information, 28% of professionals 'always' provided patient-tailored information in written form and 43% did so 'most of the time'. Information on local support groups and national charities was 'always' shared by about half of the participants for PD, MS and HD and by 67% of participants for MND. When asked whether they promoted a feeling of optimism when delivering a diagnosis, more respondents reported 'probably' or 'definitely' promoting hope in PD (91%) and MS (90%) than HD (39%) and MND (31%).

### *Personal experiences and challenges in breaking bad news for MNDDs*



Regarding the perceived difficulty of diagnosis communication for these conditions, 54% of participants believed that it was 'definitely' and 23% that it was 'probably' a difficult task for the physician. Most professionals (74%) agreed that being honest without taking away hope was the most challenging part of communicating the diagnosis of MNDDs, followed by spending the right amount of time (47%). Dealing with the patient's emotional reaction (25%), involving the family of the patient (14%) and involving the patient or family in decision making (12%) were considered difficult by fewer participants. When asked about how often they faced several potential barriers during a breaking bad news consultation, professionals reported that fear of causing distress (32.5%), excessive workload (32.5%) and perceived lack of time (30%), were among the most often experienced barriers, which they faced 'most of the time' or 'always'. Conversely, fear of the 'messenger getting blamed for bad news' and lack or sufficient training in breaking bad news were not often experienced as barriers. In addition, 46.5% of respondents reported experiencing moderate and 9% reported high to very high levels of feelings of stress and anxiety during the delivery of these diagnoses, while only 12% reported not experiencing such feelings at all.

Overall, most professionals (61%) believed they were 'good' at communicating the diagnosis of a MNDD, 23% assessed themselves as 'very good' and none thought they were 'poor' at it. For PD and MS, more than half of the respondents were confident to very confident (63%) that patients left the consultation having taken in all the information relevant to them at that point. However, for the case of HD and MND, 61 and 58% of professionals respectively

were 'not sure' to 'really not confident' that patients had taken in all the relevant information. In general, 81% believed patients were 'somewhat satisfied' to 'very satisfied' with how the diagnosis was delivered.

### *Strategies and training on breaking bad news*

In the last part of the survey, participants were asked to report on the strategies they employed and the training they had received in breaking bad news. Most professionals (75.5%) reported not following any specific strategy or best practice guidelines when delivering an MNDD diagnosis. Those who did explained that they followed NICE guidelines and were familiar with research on best practice and breaking bad news. Most professionals (83%) had received some kind of training on breaking bad news, either as a part of their formal education, clinical training or by sitting in with other clinicians who broke bad news. Qualitative comments also showed that respondents had learnt how to break bad news through experience, advanced communication skills training and generic training on breaking bad news, although the latter had focused on cancer. Around 31% had received no training in techniques of responding to patients' emotions and, for those who had, they reported having received such training as a part of their degree or developed these skills through experience and observing others breaking bad news. Finally, most participants (78.5%) were somewhat to very interested in receiving further education on breaking bad news and on techniques for how to respond best to patients' emotional needs.

### *Qualitative comments*

Most qualitative comments given by participants were related to the challenges of communicating the diagnosis of an MNDD. Two common issues for professionals were related to limited consultation times and the lack of capacity to schedule a follow-up with the patient soon after diagnosis with some follow-up appointments booked for even 15 months post-diagnosis. Therefore, especially in general neurology clinics, participants had to cover many different topics in one single consultation, although the official time slot allocated for the appointment was not long enough:

*'Given current waiting lists for some of my movement disorders clinics, it may be 9 months before I next see a newly diagnosed PD patient. I therefore not only have to explain the diagnosis, pathogenesis, and treatment options but also explain the treatment plan and contingencies for possible hiccups to cover a ridiculously large period of time in (officially) fifteen minutes. Is it any surprise my clinics (overruns) by several hours.'*

*'Insufficient time for vast amount of information to be usefully imparted. Pregnancy discussions alone merit a full consultation.'*

Conversely, a participant who was also practising privately reported that they could *'see patients again within a week to go over questions and discuss treatment plans once dust has settled'*.

Several professionals talked about this lack of capacity as '*a service delivery issue*', which, apart from limited consultation time, involved insufficient access to nurses and administrative staff who could coordinate these appointments: '*Someone (is needed) to coordinate (the) pathway so everything (is) available at consultation: relative, nurse, info etc.*'. Specialist clinics seemed to be able to offer a better service, however one participant commented that referrals were not always possible when there were no specialist services locally.

Apart from organisational factors which affected their practice, professionals addressed how various illness and patient-related factors could affect their diagnostic practice. Diagnostic and prognostic uncertainty were common issues for participants delivering MNDD diagnoses. One person highlighted feeling '*pressured*' by patients to give a diagnosis, even though they had not reached diagnostic certainty. Similarly, it was not always possible to share prognostic information, for example regarding the rate of progression and the potential level of future impairment. In addition, it was often commented that the lack of curative treatments made breaking bad news more difficult, especially when patients were initially unaware of the incurable nature of their condition. However, being able to offer symptom management for PD and disease modifying treatments for MS made the process of diagnosis delivery more positive.

On an emotional level, professionals reported several patient-related factors that made breaking bad news more challenging:

*'At times a patient's situation particularly resonates and this can be emotionally draining on the clinician.'*

Participants mentioned several cases that were particularly challenging, such as delivering a PD diagnosis to young people, delivering an MS diagnosis to young women who wanted to have children (*'shattering hopes'*), delivering an HD diagnosis to people with children or delivering the diagnosis of MND to a patient who was presenting rapid progression or with already advanced symptoms at diagnosis. One professional used the word *'despondency'* to describe how they felt when delivering such diagnoses.

## **Discussion**

This is the first UK survey study to address doctors' practice and experiences in communicating the diagnosis of an MNDD.

Generally, participants seemed to meet the setting-related standards of good practice (Baile et al., 2000) in breaking bad news by communicating the diagnosis in a private space, avoiding interruptions, arranging suitable seating and maintaining eye contact with patients. Regarding involving other people in the consultation, there was room for improvement since only 21.3% of professionals always asked patients to bring someone in consultation, 38.3% did so most of the time and 15% never did. One participant highlighted the fact that asking a patient to bring someone with them might act as a warning and could also increase their distress prior to the consultation and affect how much information they could

absorb. However, although involving patients' relatives in a diagnostic consultation can be a challenge for healthcare professionals, they can offer emotional support, serve as the patient's advocate and receive important information they will need if they act as the patient's primary caregivers (Delvaux et al., 2005; Merckaert et al., 2013). Moreover, several MNDDs guidelines specifically recommend or imply that, with the patient's agreement, their support network should be present at diagnosis (Andersen et al., 2012; NICE, 2014; NICE, 2016; NICE, 2017).

Consultation duration reported by professionals in this survey was not always optimal and qualitative comments showed that organisational factors affected how much time they could invest for diagnostic consultations. Participants reported spending a mean of around 30 min to deliver the diagnosis of PD, MS and HD and 41 min for MND, however there was a considerable percentage of professionals (20–39%) who reported spending 15–20 min. The latter falls short compared to the European Federation of Neurological Societies (EFNS) recommended guideline of 45 to 60 min for the diagnosis of MND (Andersen et al., 2012), however there are no published guidelines on consultation times for the other MNDDs. These findings correspond with both UK (Habermann, 1996; Peek, 2017; Warren et al., 2016) and international (Aoun et al., 2018a; Edwards et al., 2008; McCluskey et al., 2004; Macht et al., 2003; Solari et al., 2007) MNDD patient studies which have reported short consultation times that often led to patient dissatisfaction. Even though participants in this study reported sharing information on how the diagnosis was reached, the impact of the condition on patients' lives and their care plan, they still believed patients left the consultation not having taken in all information relevant to them at the point of

diagnosis, especially for the case of MND and HD. This is possibly linked to limited consultation times or, as one participant noted, due to patients' state of shock which affects how much information they can absorb. Professionals reported that they would often need more than one consultation to fully deliver the diagnosis. However, this is challenging since, particularly for PD, qualitative comments highlighted issues related to lack of capacity to book early follow-ups with some consultations being booked even 15 months post-diagnosis.

Most professionals agreed that diagnosis communication for MNDDs was a difficult task and being honest without taking away hope was the most challenging aspect of the consultation, a challenge which has also been reported by Aoun's survey of neurologists in Australia (2016b) and professionals working in other medical specialties such as oncology (Bousquet et al., 2015). Participants in this study reported being particularly reluctant to promote a feeling of optimism when delivering the diagnosis of HD and MND. As some qualitative comments suggest, this could be associated with the poor prognosis for these conditions, however EFNS guidelines for MND (Andersen et al., 2012) encourage professionals to discuss reasons for hope, such as ongoing research, drug trials and the variability of the disease and specifically advise against not providing hope during diagnosis. It should also be noted that providing hope is not always analogous to indicating the possibility of a cure. Hope can be generated for the optimal management of the condition, in whatever form that has to take. Instilling hope therefore can take many forms and is an important aspect of the patient's rehabilitation (Soundy et al., 2015). Feelings of hopelessness in people with MND have been reported to be more strongly correlated to quality of life than their physical functioning (McLeod

& Clarke, 2007) and dissatisfaction with information delivery can negatively influence patient's sense of hope (Soundy & Condon, 2015). Moreover, a review by Clayton et al. (2008) showed that although most patients approaching end of life prefer honest and accurate information, they are also able to maintain a sense of hope. The review suggested that healthcare professionals should recognise and foster different and realistic forms of hope relevant to the particular patient and their family by carefully assessing patients' information preferences and emphasising on what can be done for them.

Participants in this survey were also asked about the emotional aspects of delivering the diagnoses of MNDDs. More than half of professionals reported that they experienced moderate to high levels of stress during diagnosis delivery. This finding is supported by a review of studies that used self-report and psychophysiological measures and showed that during the communication of bad news, doctors experienced moderate levels of stress, with stress reactions lasting for hours or even days after the diagnosis (Struder et al., 2017). The experience of stress could potentially be linked to participants reporting 'perceived lack of time' and 'fear of causing distress' as the barriers they often experienced while breaking bad news and qualitative comments indicating that diagnosis delivery could sometimes be emotionally '*draining*'. Despite the emotional toll of breaking bad news, dealing with patients' emotional reactions did not seem to present a particular challenge for the participants of this survey. However, studies of patients with MNDDs have shown that patients are often dissatisfied with the lack of empathy shown by doctors during diagnosis delivery (Anestis et al., 2020). The seemingly contradictory finding here in that participants in this survey reported



strong competency in this domain could either be attributed to participation bias (see limitations below) or different views and expectations between patients and professionals regarding the emotional aspects of the consultation.

Finally, most participants in this study reported not following any specific strategy or guidelines when delivering an MNDD diagnosis. Although step-wise protocols for breaking bad news have been criticized for potentially focusing more on the process than the people involved, their contribution to the medical practice and their emphasis on empathy and individualised information provision is acknowledged (Dean & Willis, 2016). Despite their usefulness, these protocols, such as SPIKES (Baile et al., 2000), have been developed and have mostly been used within oncology settings. In addition, when it comes to MNDDs, only EFNS (Andersen et al., 2012) and NICE MND (2016) guidelines adequately addressed the topic of diagnosis delivery, while, for the other conditions, guidance was mostly limited to what kind of information to impart at diagnosis and we found no guidelines for HD. This could partially explain why most participants did not follow any specific strategies when breaking bad news for MNDDs. However, most participants in the survey indicated their interest in receiving further training on breaking bad news and responding to patients' emotions.

## **Implications for research and practice**

This exploratory survey highlighted several aspects of diagnosis delivery for MNDDs which could be improved. Limited consultation times and inability to offer early follow-ups were often reported by participants as factors that

hampered optimal diagnostic communication. This is potentially linked to staff shortages in neurology, services constraints and the NHS in general being under strain but highlights the need for organisational changes which acknowledge the importance of diagnosis delivery consultations for MNDDs. Beyond longer consultations, there is also a need for early follow-ups so the professional can provide all the relevant information and the reassurance that patients and their families need at diagnosis and will also provide the opportunity for patients to express their emotions, prepare questions and make informed decisions regarding their care (Seeber et al., 2019). When faced with limited consultation times at diagnosis, professionals should make sure that they provide tailored information to each patient, written information about their condition, discuss their plan of care, reliable sources of information and support and ensure an early follow-up, usually with a specialist nurse. Data from our survey also showed that, despite recommendations, patients were not routinely advised to bring someone to the consultation. It would be worth exploring whether this varies among conditions and what factors influence this policy. However, we suggest that for the diagnosis of all MNDDs, patients are always given the option to be accompanied by someone. Moreover, it is recommended that, when it would not cause serious diagnostic delay, doctors should avoid delivering the diagnosis before national holidays or important events for the patient, building on the good practice reported by the majority in this survey.

Regarding professionals' manner of delivering these diagnoses, our findings suggest that participants were reluctant to provide a sense of hope to patients with MND or HD. Despite the severe life-limiting and threatening nature

of these conditions, professionals should still try to explore and enhance patients' own concepts of hope and share information which could be deemed as positive (Clayton et al., 2008), such as providing reassurance for effective symptom management and long-term support by a multi-disciplinary team. This is a topic where more research and development of training would be particularly useful in order to explore professionals' working in neurology concepts of hope and how these affect their practice of breaking bad news. Professionals in this survey reported moderate levels of stress when communicating an MNDD diagnosis, they acknowledged the difficulty of the task and briefly discussed the emotional aspect of being the bearer of such bad news. Further qualitative research on professionals' lived experience of communicating these diagnoses would help develop a deeper understanding on their perspectives and how they cope with giving these diagnoses on an emotional level. Exploring the opportunity for psychological input and the involvement of a multidisciplinary team in the process of breaking bad news would also be beneficial. This knowledge would be useful for developments in the design of medical education in neurology, adequately supporting professionals with this challenging task and eventually improving the patient experience. In addition, although diagnosis delivery is a critical milestone in patients' care, future research could also address other forms of breaking bad news in MNDDs such as the initiation of discussions around advanced directives.

Finally, most participants in this study indicated an interest in receiving further training in breaking bad news and reported low familiarity with published protocols of best practice. Professionals are encouraged to familiarise themselves with such protocols and best practice guidelines for breaking bad news which

could be incorporated as a part of their training. Even though the SPIKES protocol (Baile et al., 2000) was initially developed for use within oncology, some data indicate its relevance for use within neurology. In particular, MND patients were more likely to judge neurologists' skills as 'above average' when they delivered the news in a way that resembled the steps described in SPIKES (Aoun et al., 2016a). Nevertheless, further research incorporating both professionals' and patients' and families' needs and perspectives could help develop more tailored guidelines for neurology.

## **Limitations**

The survey's relatively small sample size ( $N = 49$ ) could be considered one of the study's limitations. However, the recent ABN's Neurology Workforce Survey (Nitkunan & Reily, 2020) identified a serious lack of UK neurologists within the UK, with the second lowest number of neurologists per head of population in Europe. It is estimated that 958 are practising in the UK (Royal College of Physicians, 2018) and although 84% of them run general neurology clinics (Nitkunan & Reily, 2020), not all of them will deliver the diagnosis for the conditions included here. In addition, recruiting NHS healthcare staff in health research has been increasingly difficult due to often severe staff shortages and pressure being placed on clinicians (Sheard & Peacock, 2020). Ultimately, this is a descriptive survey which gave the opportunity to these professionals to report on a significant aspect of their clinical practice and, through qualitative comments, discuss how it has been affected by the current NHS climate. Moreover, the results of this survey could be affected by participation bias. In particular, it is likely that

most people who completed the survey were interested in the topic (Cunningham et al., 2015), and thus potentially better at breaking bad news and acknowledging the complexity of the task, and thus the findings may not be entirely representative of all neurology professionals.

## **Conclusion**

Medical professionals delivering the diagnosis of MNDDs are faced with the challenge of communicating effectively, but also sensitively, being honest, but also providing a sense of hope. This was the first survey in the UK to address neurologists' practice and experiences in communicating these diagnoses. It was clear that for participants of this survey giving such bad news was an intrinsically challenging and stressful task which became even harder due to long waiting times for appointments in neurology and limited consultation times. Participants reported often spending a sub-optimal amount of time for these diagnostic consultations and discussed how the incurable nature of MNDDs, the uncertainty about the rate of disease progression and the, occasionally, young disease onset made such diagnostic consultations more challenging. Nevertheless, participants in this study showed signs of good practice regarding the setting of the consultation and providing appropriate and honest information at diagnosis. Apart from time restrictions and issues related to capacity, this study highlights other areas of improvement such as including patient's family routinely in the appointments and providing some sense of hope even for conditions with a poor prognosis. Participants also reported low familiarity with breaking bad news

protocols and best practice guidelines but also indicated an interest for further training in this domain.

## Tables

**Table 1.** Summary of some of participants' demographics

<b>Participants' role:</b>	<b>Number of participants</b>
Consultant neurologist	43
Neurology specialist registrar	4
Consultant neuropsychiatrist	1
Clinical fellow	1
<b>Gender:</b> <i>*one response missing</i>	
Male	32
Female	16
<b>Age:</b> <i>*one response missing</i>	
31-40	13
41-50	23
51-60	11
61 or older	1
<b>Experience in delivering the diagnosis:</b>	
Parkinson's disease	44
Multiple sclerosis	41
Motor neurone disease	43
Huntington's disease	33

# Chapter Five

## Publishable Paper Three (PP3)

*Healthcare professionals' involvement in breaking bad news to newly diagnosed patients with motor neurodegenerative conditions: a qualitative study*

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### Statement of authorship:

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**Healthcare professionals' involvement in breaking bad news to newly diagnosed patients with motor neurodegenerative conditions: a qualitative study**

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## **Abstract**

**Purpose:** Research on breaking bad news (BBN) in healthcare has mostly focused on the doctor-patient interaction during a single consultation. However, it has been increasingly recognised that BBN is a wider process that also involves other healthcare professionals. This qualitative study explored non-medical<sup>1</sup> healthcare professionals' involvement in BBN to newly diagnosed patients with motor neurodegenerative conditions in the UK.

**Materials and methods:** 19 healthcare professionals working with people with motor neurone disease, multiple sclerosis, Parkinson's disease or Huntington's disease took part in individual, semi-structured interviews which were analysed using thematic analysis.

**Results:** Four themes were constructed: dealing with the diagnostic aftermath, unpacking the diagnosis, breaking bad news as a balancing act and empowering patients to regain control over their health and lives. Participants reported being broadly involved in BBN by supporting patients with negative diagnostic experiences, re-iterating diagnostic information and helping patients understand the impact of their condition. The challenges of effectively breaking bad news and how these difficult conversations could help empower patients were also emphasised.

**Conclusions:** BBN was a critical and challenging aspect of healthcare professionals' clinical work with newly diagnosed patients with motor neurodegenerative conditions. Besides providing information, BBN was perceived as a way to educate patients, encourage them to make decisions and prepare for the future.

**Keywords:** breaking bad news, neurodegenerative conditions, neurorehabilitation, motor neurone disease, multiple sclerosis, Parkinson's disease, Huntington's disease, communication

## **Introduction**

In healthcare, bad news is defined as “any information that adversely and negatively affects the patient’s view of the future” (Buckman, 1984, p. 1597). The process of delivering this news is usually called ‘breaking bad news’ (BBN) and is considered a critical aspect of patient-provider communication with long-term impact on patients’ satisfaction with care (Fallowfield & Jenkins, 2004; Schofield et al., 2003). Most of the research on this topic has focused on the consultation when a clinician delivers the serious diagnosis; however, this depiction of BBN as an isolated event between the patient and the clinician has been criticised (Warnock et al., 2010). Studies on patients’ experiences have indicated that receiving bad news is more of an ongoing process than a single event (Randall & Wearn, 2005; Tobin & Begley, 2008). In addition, viewing the process of BBN as a broader aspect of care (and not confined to a single episode) (Dean & Willis, 2016) might also better reflect both medical staff’s (Bousquet et al., 2015) and other healthcare professionals’ (HCPs’) clinical reality (Dewar, 2000).

It has been increasingly recognised that HCPs other than doctors are also involved in the process of BBN. Most of the research on non-medical HCPs involvement in BBN has been conducted within oncology (Fontes et al., 2017; Newman, 2016) and has focussed on nurses. Besides sometimes being present at the diagnosis delivery consultations, nurses are often also responsible for supporting patients post diagnosis (Warnock et al., 2010). This can include providing clarifications and clearing misunderstandings, explaining the impact of the diagnosis, sharing information on treatment options and prognosis,

encouraging decision-making, and offering emotional support (Gauthier, 2008; Newman, 2016; Warnock et al., 2017). Despite the stress and the emotional toll of BBN, nurses have reported finding that involvement in such conversations strengthens their relationship with patients and helps them become better professionals through self-reflection (Newman, 2016; Warnock et al., 2010). BBN has also been recognised as a common aspect of speech and language therapists' and audiologists' practice, mostly in the form of delivering bad news to parents of a child. A recent qualitative study highlighted the challenges that these professionals face both in terms of phrasing their message but also dealing with the emotional impact of BBN (Gold & Gold, 2021).

The communication of bad news can be a critical issue for other specialities as well, such as neurology. A review of qualitative studies on HCPs' experiences in delivering information about recovery in acquired neurological conditions showed that professionals were mostly challenged by the uncertainty in predicting recovery potential, assessing patients' readiness to receive information and being honest without taking away hope (Burton et al., 2021). Professionals were concerned that BBN could undermine patients' hope, which was considered vital for neurorehabilitation, helping patients remain motivated and engaged in therapy. However, findings from a qualitative study that explored the meaning of hope in neurological physiotherapy practice suggested that there are different types of hope beyond the hope for physical recovery and that hope is a dynamic concept embedded in interaction and cultivated through communication (Soundy et al., 2010). In another qualitative study, neurological occupational therapists reported being routinely involved in difficult bad news conversations without

having received adequate formal training on how to break bad news effectively (Sexton, 2013). Participants in that study reported being usually involved in such conversations when discussing plans for discharge and the end of active treatment, however the authors suggested that future research should address therapists' experiences in BBN for specific conditions, such as progressive neurodegenerative conditions.

Progressive motor neurodegenerative conditions (MNDDs), such as motor neurone disease (MND), Huntington's disease (HD), multiple sclerosis (MS) and Parkinson's disease (PD), are at present considered as incurable and can result in a gradual physical and often cognitive decline (Batista & Pereira, 2013). Besides their similarity in terms of their neurodegenerative nature and impact on motor and cognitive functions, there are major differences among these MNDDs, for example in terms of their prognosis and how they are diagnosed. Among these conditions, MND is the most directly life-threatening and has the shortest life expectancy with 50% of patients dying within 30 months from symptom onset (Talbot, 2009). On the other hand, HD is different from other MNDDs in that it is inherited and can be confirmed through genetic testing years before disease onset, which is often characterised by the manifestation of motor symptoms around the age of 40 (Nopoulos, 2016). Therefore, BBN for these conditions can be a challenging task for professionals (Storstein, 2011) especially since patients with MNDDs have often experienced a long and stressful pre-diagnostic journey (Aires et al., 2019; Breen et al., 2013; Kelly et al., 2011; Mitchell et al., 2010). In addition, due to the growing recognition of the potential positive outcomes of introducing palliative care in the early stages of these conditions (especially MND),

professionals are often required to have early conversations around disease progression and advance care planning (Dallara & Tolchin, 2014; Oliver et al., 2016). A scoping review of patients' and doctors' perspectives on diagnosis delivery for these conditions showed that although most best practice standards in BBN were reported as being met by doctors, patients were often dissatisfied with the manner the diagnosis was delivered, the time invested, and the information provided at that point (Anestis et al., 2020). However, there are currently no studies that focus on the involvement of non-medical HCPs in BBN specifically for these progressive conditions.

Due to the complex and progressive nature of MNDDs, patients have constantly to adapt to their declining physical, cognitive and psychological functioning and deal with a series of 'losses', depending on the condition, such as the loss of speech (Ball et al., 2004), the inability to drive (Jacobs et al., 2017) or walk and the loss of independence (Bjornestad et al., 2016; Edmonds et al., 2007). Guidelines acknowledge the need for healthcare support across the trajectory of the condition and recommend that MNDDs are managed by multidisciplinary teams (MDTs) which can include medical professionals, clinical nurse specialists, physiotherapists, occupational therapists, speech and language therapists, nutritionists and psychologists (Andersen et al., 2012; Bachoud-Lévi et al., 2019; NICE, 2014; Onarheim et al., 2014). Beyond pharmacological treatment and symptom-management, MDT approaches are patient-centred; they aim to minimise the disease's impact in all aspects of patients' lives and increase their participation in activities while also actively involving and addressing carers' needs (Hoden et al., 2017; van der Marck, 2009). Despite having varying

methodological rigour, studies have reported evidence that MDT approaches to the management of different MNDDs can have a positive impact on patient outcomes, such as quality of life, physical and psychological symptoms, reduced hospital admissions, reduced activity limitation and even increased survival for the case of MND (Kham et al., 2007; Ng et al., 2009; Thompson et al., 2013; van der Marck, 2013).

Given the considerable MDT involvement in MNDDs, many HCPs other than doctors are involved in BBN conversations with patients. In this study, viewing BBN as a wider episode of care, we use a qualitative research approach to explore healthcare professionals' involvement in BBN to newly diagnosed patients with MNDDs.

## **Methods**

### **Study design and ethical approval**

A qualitative design using individual, semi-structured interviews was adopted in order to answer the research question; what is non-medical HPCs' involvement in BBN to newly diagnosed patients with MNDDs? The interview guide (see appendix 4) was designed based on previous research on BBN (Fallowfield & Jenkins, 2004; Warnock et al., 2010) and followed an exploratory approach to establish healthcare professionals' range of involvement in this task. A PD specialist nurse provided feedback on the interview schedule's relevancy and the overall study design before study initiation. The study received ethical



approval by the authors' host institution's research ethics committee (FHMREC18) and research governance approval by the Health Research Authority (Project ID 266719), a unified system for health research governance in the UK.

## Participants and recruitment

UK based, non-medical HCPs working clinically with newly diagnosed patients with at least one of the MNDD diagnoses were eligible for participation. We maintained an open approach regarding the range of HCPs we would include in the study (specialist nurses, allied health professionals, psychologists), and we were also guided by the first interviews with specialist nurses who reported on the different HCPs patients consulted soon after being diagnosed. Participants were recruited through collaborations with NHS Trusts, snowball sampling and advertisement of the study in social media. A participant information sheet and an online consent form to be completed prior to participation were sent to potential participants before an interview was arranged. In total, 19 HCPs were recruited in this study. Participants' characteristics can be found in Table 1. The sample size for this study was mostly based on pragmatic considerations (Braun & Clarke, 2021). We aimed to recruit participants who represented most of the different MDT members involved in the care of newly diagnosed patients with MNDDs and we also made sure to recruit specialists who worked with individuals with all four conditions. At 19 interviews, we felt that these goals had been met.

## Data collection and analysis

Data were collected through individual, face to face ( $n = 3$ ) and phone or video call ( $n = 16$ ) interviews whose length ranged from 35 to 70 minutes ( $M = 46$  minutes). Interviews were audio-recorded and transcribed verbatim. The research was conducted within a critical realist paradigm (Bhaskar, 2013), taking a realist, phenomenological perspective – i.e., where a close relationship is assumed between how people think and behave, and the language they use to describe this. Data were analysed both inductively and deductively using thematic analysis and specifically the steps described by Braun and Clarke (Braun & Clarke, 2006, 2019). An inductive approach was mostly followed in terms of exploring professionals' range of involvement in BBN, whereas deductive analysis was more prominent in specific aspects of participants' practice, e.g., information giving, which have been identified as critical by previous studies on patient and doctor perspectives (Anestis et al., 2020). Familiarisation with the data was achieved through listening and transcribing the interviews and re-reading the transcripts before proceeding to the coding phase. The entire data set was coded semantically (focusing on the explicit rather than the latent meaning of the data) before codes were collated into potential themes. Themes were generated by going back and forth from data to codes and considering different potential themes in relation to the research question and the clinical reality described in the participants' accounts. The four final themes were reviewed and defined by the entire research team before naming them and proceeding to writing up. Throughout the process of designing and conducting the study, Yardley's (2008) criteria of validity in qualitative research were used to ensure quality. Due to this study's exploratory

nature, special attention was given to reflexivity, reflecting on how the researchers' perspectives and motivations could influence the interviews and the subsequent analysis and interpretation of data. Although every attempt was made to avoid directing participants and be grounded in the data, we acknowledged how our subjectivity and prior knowledge of the relevant scientific literature might have influenced coding and theme development.

## **Results**

Four themes were constructed from the data: 1) Dealing with the diagnostic aftermath, 2) Unpacking the diagnosis, 3) Breaking bad news as a balancing act, and 4) Empowering patients to regain control over their health and lives.

### **1) Dealing with the diagnostic aftermath**

This theme illustrates the challenges healthcare professionals faced concerning patients' experiences of the diagnostic pathway up to their contact point and how their diagnosis was communicated.

Participants reported usually seeing patients with MNDDs one week to several months post-diagnosis, depending on the severity of their condition, the symptoms they were presenting and the referring medical consultant. Some professionals indicated that they were frequently the first HCP patients saw post-diagnosis and they often found themselves bearing the brunt of the patients' annoyance and irritation after the long pre-diagnostic journey and negative

diagnostic experiences. Participants described how they often had to manage patients who wanted to “*let off steam*” (Participant 6) and were “*angry*” (P1, P5, P13), “*frustrated*” (P13), “*mistrustful*” (P5) and “*dissatisfied*” (P6, P19) due to diagnostic delays and misdiagnoses or feeling that their symptoms had not been taken seriously for a long time.

*“I had one young woman who's been saying for years there's been something radically wrong and she was then transferred to, erm, psychology, for health anxiety [...] and then there was a significant incident and she was rushed into hospital and it turned out that she had MS and that she was right, there was something far wrong. And, so therefore, she was very mistrustful then.”* (P5)

Besides diagnostic delay, participants also explained that patients were angry and frustrated or even scared and withdrawn because of how they had received their diagnosis. In particular, professionals mentioned cases when patients had received their diagnosis over the phone or via a letter but mostly reported doctors’ “*blunt*” (P14, P18) approach and inadequate information provision at diagnosis as the two most common patient complaints.

*“One particular bad sort of... was a patient that felt as though, erm, the consultant (in private practice) gave her diagnosis and she said, ‘all I remember them saying is’, ‘well, how are you going to pay?’.”* (P7)

HCPs, in these cases, felt they had to deal with the “*aftermath*” (P5, P7) of a sub-optimal diagnostic experience. They highlighted the importance of allowing

patients express their anger and dissatisfaction, empathise with them, and de-escalate the situation, hold a 'neutral ground', and reassure them that they were going to support patients for the entire illness journey in order to gain back patients' trust. A few specialist nurses also mentioned that specific doctors, usually general neurologists working in the NHS or privately, often did not refer newly diagnosed patients. As a result, patients were left to cope independently for several months, and nurses had to deal with that 'mess' or even misinformation that patients had received at diagnosis.

*"Some of our patients see a neurologist privately because perhaps it's taken them a longer time to get to their actual appointment, this is just an example. It may be that particular person hasn't had the knowledge of who to refer them onto afterwards. So, it could be that I get to then go and see that patient six months down the line opposed to six weeks, and by that point they've lost faith in the system a bit, they've not known who to contact, they may have been on their medication and not known whether it was working or not. So, you have to kind of then, erm, you do have a bit more of a mess, if you like, rather than it being straight forward." (P7)*

However, most participants emphasised that, in general, neurologists were competent in communicating the diagnosis, but did not always have the time needed to provide enough information and some patients might have just been angry towards the bad news, not necessarily the way it was broken. When patients had a positive diagnostic experience, this made HCPs' first appointment with patients easier. A positive experience was exemplified when patients had received

the information they needed at diagnosis, were prepared to ask questions and were generally adjusting better to their condition.

*“I think anecdotally, the better the delivery of diagnosis, the better the support at the beginning, the better- the more involved the patient is, the better the prognosis and how they're managing, how they cope.” (P6)*

## **2) Unpacking the diagnosis**

This theme describes how HCPs helped newly diagnosed patients understand their diagnosis through often difficult conversations. These conversations were often distressing for both HCPs and patients but were acknowledged as a vital to the participants' role. The nature of information communicated during these conversations was often different depending on the professional's expertise. However, it was generally related to the incurable nature of MNDDs, the impact of the condition on patients' daily lives and issues related to prognosis.

Participants reported that when they first saw patients, not all of them had fully understood their diagnosis. Despite short diagnostic consultations, which hampered adequate information provision, they believed patients' state of shock when receiving the diagnosis did not allow for information to be absorbed, and some patients were reluctant to look for further information post-diagnosis. In contrast, HCPs felt *“lucky”* (P3) and *“privileged”* (P11) to be able to dedicate enough time for their appointment and even offer double-slot appointments to meet the needs of newly diagnosed patients.

*"We 're fortunate that we have a lot more time with patients, than certainly the consultants do. Our appointments can be 45, routinely they are 45 minutes, but I have been with some patients an hour and a half, 2 hours, because they had that many questions and they just wanted to know and wanted to share information."*  
(P3)

Patients' limited understanding of their diagnosis as described above, and sometimes due to cognitive changes as a result of the condition, meant HCPs often had to re-iterate what was said to them at diagnosis, explain the nature of their condition and clarify what could be done for them in terms of medication. An MS specialist nurse (P5) reported that she had even seen newly diagnosed patients who did not know what type of MS they had, and she sometimes had to break the bad news to people with progressive MS regarding their ineligibility for disease-modifying treatments<sup>2</sup>. In general, HCPs were often responsible for managing patients' expectations regarding medication or therapy's scope and explaining the incurable and progressive nature of MNDDs. These conversations were often believed to be *"the hardest thing to say"* (P4) and *'the final blow'* (P5) for patients.

*"Sometimes patients go from one doctor to another, one neurologist to another, they, they travel far away for this magic pill... that doesn't exist and I 've also been in that position, where I 've been the one who said, there isn't a magic pill and, you know, I think, it's important that we are transparent with patients and not give them false hope."* (P6)

Besides reiterating information given at diagnosis, HCPs' primary role in the first appointments with patients was to help them understand the implications of their diagnosis and its impact on different aspects of their lives. One participant used a metaphor to illustrate this by comparing the diagnosis to a seed that was given to the patient, and the HCPs' role was to "*unpack the news*" and assist patients to explore what would grow out of that "*seed*" (P9). Sharing information about the impact of an MNDD diagnosis and responding to patients' questions and concerns often inevitably led to BBN conversations. These conversations' content was often different depending on the participants' role and patients' circumstances and the questions patients asked. Patients often wanted information about their prognosis and the impact of their diagnosis on their family life and work. Discussing how the diagnosis might disrupt patients' life plans and decisions was particularly difficult for participants.

*"You know, there is a lot of discussion around prognosis, around 'How long will I be able to do this? And what happens if I'm no longer to do that?' [...] 'Will I be able to stay in work?', 'Will I be able to see my family grow up? I have quite young children; will I be able to see them grown up?'" (P11)*

*"I saw them for a first consultation and his speech was already quite dysarthric and he was talking about getting a new job in a call centre and then he was gonna be starting that the next week. And that was a difficult conversation to have, cause obviously I can't, I couldn't say, 'well, you can't possibly do that' ... but also to give some advice around 'oh that might be tricky, would they have any more sort of admin*



*type work rather than on the phone? People are going to struggle to understand you.'*  
*That you, know, that's difficult."* (P3)

Participants whose professional focus was patients' movement and physical function were often involved in difficult conversations when they had to clarify patients' misconceptions or validate their concerns, often related to the loss of independence. Because of the progressive nature of MNDDs, physiotherapists, for example, had to explain that, most of the time, therapy would not improve their movement, but it would help them maintain as much mobility as possible, prevent falls and aid everyday mobility problems. HCPs would also perform assessments and share information about disease progression and the potential future need for home adjustments and the use of equipment such as a hoist or a wheelchair. This information was not always welcomed by patients and could trigger more detailed difficult conversations about future losses.

[Participant quoting how they would introduce the possibility of home adjustments to newly diagnosed patients.] *"Well, I know you don't need it right now, but and that's absolutely fine, but thinking ahead, you know, that could be a challenge.'* And it depends on how and where the person is in terms of their sort of acceptance and adjustments because they might say 'I don't want to go there; I don't even want that conversation'. And you're like, 'Okay, that's fine.' And there are other people who might say, 'Well, do you think, I'm going to get worse?' or 'Do you think that's going to happen?.'" (P11)

Similarly, when seeing newly diagnosed patients with MND, speech and language therapists discussed the difficulty of introducing patients to sensitive but critical topics such as the potential loss of speech and the changes and dangers around swallowing. Participants mentioned that there was no easy way to deliver this information and even discussing ways to manage these, such as augmentative and alternative communication aids and Percutaneous Endoscopic Gastrostomy [a surgical insertion of a feeding tube into the stomach through the abdominal wall], could be very emotional for patients.

*“We have to break the bad news, of... ‘yes, actually, eating and drinking can kill you’ and ‘yes, you will most likely lose your ability to communicate verbally as well’.” (P3)*

Another sensitive topic that participants usually discussed with newly diagnosed patients was driving and the need to inform the UK Driver and Vehicle Licensing Agency about their diagnosis. Even when patients were still fit to drive, HCPs believed it was their professional obligation to discuss this even though it could often trigger patients’ fears about future loss of independence.

*“Talking about driving can be very difficult, it’s a sensitive issue for many patients, but I think, you know, it fits into the same sort of category as offering pieces of equipment to the patient for the first time, you know, it’s a very emotive subject for many patients, you know, it’s a real symbol of, you know, things are moving on.” (P10)*

Psychologists referred to the difficult discussions they often had with newly diagnosed patients about the cognitive changes associated with MNDDs. Patients were often referred to their service for a cognitive screening, so part of their role was to explain the rationale behind neuropsychological assessments - which sometimes included a mental capacity assessment - and then share the results. Professionals acknowledged the stress surrounding these discussions, especially with patients who had just received their diagnosis, who were experiencing physical symptoms and were now discovering cognitive symptoms as well.

*“Sharing the cognitive results after the neuropsychological assessments, sometimes these conversations can be difficult, for example some people with MND they have also got cognitive impairment, and this can be a difficult conversation for people to have. You know, they worry that this means they are going to develop dementia and you can't necessarily reassure them that it won't, we can't guarantee that the cognitive side won't get worse.” (P11)*

Some participants also mentioned that it had become increasingly common to have end of life and advance care planning conversations early on, especially with MND patients and other newly diagnosed patients whose condition had significantly progressed. Such discussions could include do-not-resuscitate orders, gastrostomy, non-invasive ventilation and palliative care referral. Participants acknowledged the importance and benefits of having these discussions but also detailed the difficulty of initiating them. Some participants

felt this would always be a challenging task for them, while others believed experience had increased their confidence in initiating these conversations.

*"I'm having conversations about advance care planning, end of life, decisions and alternatives... I'm triggering the conversation and I am doing it early. That's relatively new, I think, in health, because one thing you didn't do, is talk about, you know, death and dying and so on, but certainly over the last couple of years and it is, it is difficult when you first start talking about it and raising it, but once you 've done it several times you get a feel for it." (P1)*

Nevertheless, all participants agreed that BBN was emotionally difficult, an unavoidable but significant part of their role. During and after BBN, HCPs reported sometimes feeling *"drained"* (P5, P19), *"exhausted"* (P5), *"sad"* (P1, P7, P8) and *"anxious"* (P8) and had sympathy for the patients, especially knowing how these conditions would progress and that they would have to give more bad news as the condition deteriorated.

### **3) Breaking bad news as a balancing act**

This theme details the shared experience among all participants regarding the challenges of sensitively and effectively BBN. Providing critical information to newly diagnosed patients was described by HCPs as a balancing act that required good communication skills, experience and empathy. In particular, when BBN, participants reported having to find a balance in terms of their approach and

language they used and the amount of information they shared and during the process by effectively assessing patients' information needs.

Being pragmatic and accurate when explaining the progressive and incurable nature of MNDDs, the uncertainties around progression rate and the potential impact was perceived as professional duty and responsibility that helped patients '*know where they stand*' and "*make plans for their life*" (P1). In their experience, conversations around bad news had to be carefully worded to reflect the unpredictable nature of MNDDs.

*"They're hanging on your every word really, 'cause they see you as the expert so you have to be careful exactly what you're saying and try not to say things too... you know, in too much of a concrete way, black and white way, when the issue is a bit more grey than that."* (P9)

Giving honest and straightforward information about such critical topics was believed to be appreciated by patients and helped HCPs build a long-term relationship with them based on trust. However, participants also acknowledged the distressing nature of the information they often provided and underlined the need to adopt a sensitive approach, mostly because patients "*will never forget the way they were told the news*" (P19).

*"Actually, it's nice if you can do it in a way that you'd want to be told or you'd want to be cared for, if it was for your family members. I think it's all you can do, human nature, really. I don't think there's ever a one-stop-shop for that."* (P17)

Moreover, participants often discussed the need to balance BBN by also providing some positive information to instil hope. They described the challenge of achieving a “*fine line*” of being pragmatic and motivating at the same time so that people could focus on the present but also plan for the future:

*I try to encourage them to have a realistic mindset and practically plan for the future, but at the same you don't want to absolutely destroy somebody's hope as well. So, again, I think that's quite a fine line of, you know, being practical and planning ahead, but at the same time keeping somebody's motivation up to keep doing, you know, not just give up basically, 'cause you want them to focus on the here and now and what I can do right now but then also with an eye ahead to the future'. (P16)*

Hope in this context was not associated with curative treatments, but it was conceptualised by HCPs as focussing on what realistic goals patients could achieve and what could be done to improve their quality of life. This information could include what support was available from the services, how symptoms could be managed, how the disease progression rate could be different for different people, the positive effects of lifestyle changes and information about ongoing research. Participants reported trying to “*give a balanced view of the future which is truthful but hopeful*” (P9). However, this was not always an easy task, especially when patients presented with rapid progression or severe symptoms. In these cases, participants discussed the challenge of getting the balance right in terms of providing hope, but not “*unrealistic*” (P1, P11) or “*false*” (P6, P16) hope.

*"I think being able to give people hope is really, really important in rehabilitation. And sometimes it is hard to be hopeful when people are seeing all manners of aspects of their life changing It's how you balance that hope giving within the context of not being unrealistic either." (P11)*

Deciding the nature and the amount of information they provided when BBN was another challenge that professionals faced in these initial appointments. This could depend on how each patient's condition had progressed and the symptoms they were experiencing, but participants were mostly challenged by how much patients' communication preferences could vary. HCPs agreed that it was essential to adopt a flexible approach and establish patients' communication preferences and information needs before BBN.

*"Rather than bombard someone, it's really important to kind of judge what kind of information they need from you." (P14)*

*"Yeah, you have to be really flexible around, erm, what information you give and also what information you don't give." (P4)*

Assessing newly diagnosed patients' preferences and needs was deemed a difficult task for several reasons. HCPs reported that knowing the person, their personality and having a relationship with them helped with this process. However, this was not the case with newly diagnosed patients. In these first appointments, participants detailed the importance of establishing patients' understanding of their condition and their needs in terms of topics they wanted to

discuss. For example, clinical neuropsychologists asked patients why they thought they were referred to them and explored their understanding of the impact of MNDDs on their cognition before they shared information about neuropsychological assessments. In addition, participants reported tailoring their practice concerning patients' emotional state and body language and mostly being guided by patients' questions. At the same time, they understood that patients who seemed calm or asked questions about prognosis might have not necessarily been ready to receive bad news. Before giving such information, HCPs would usually "double-check" (P3) if patients wanted this information.

Mis-assessing patients' information needs could have an impact on building a relationship with them. Some HCPs in this study admitted that they had at one point '*got it wrong*' (P3) by sharing more information that the patient was able to process at that time and highlighted the importance of giving the bad news at the right time.

*"I went away from this meeting thinking, 'I've done the wrong thing really', because it really stifled my relationship with her at the early stages, kind of went away thinking, 'Was that necessary?', it was true but was it necessary, at this point to break bad news to her or could I just left it a bit longer."* (P14)

At the same time, other professionals believed it was their duty to share information that could prevent future crises, even though the patient might not have been ready or keen on discussing these topics. For example, occupational therapists felt they sometimes had to share information on mobility equipment



and house adaptations early on, despite patients' often negative reactions. Sharing such information could prevent patients from making uninformed decisions in the future, such as buying expensive equipment that would be ineffective for their condition.

*"I get people to think quite far ahead when they are quite well, or they don't have that level of ability issues and I think that's quite hard for them to think about it at that time. [...] What I want them to, or what I don't want to happen is for them to get to that point and for them to say 'Well, no one told me that would happen, or no one told me this wouldn't work'. So, I think we need to be honest with them, make sure they are informed, and they can make the right choice for them." (P12)*

Moreover, although participants acknowledged the benefits of involving the patient's family in these appointments, they also detailed the challenges that they could bring to the process of BBN. For example, an HD specialist nurse reported how a patient's mother was clearly against the patient knowing that they had started presenting movements that were signalling the disease onset. On the contrary, family members sometimes could "fire" questions, which could trigger the delivery of information that patients might not have been ready or wanted to receive at that point. In these cases, HCPs had to balance the conversation by clarifying what information the patient wanted and sometimes also supported the relatives by having a separate discussion with them.

*"Their partner might be wanting lots of information about how to practically manage, 'how am I gonna care for the person further down the line?', whereas the*

*patient themselves might be like, 'I don't want to think about that, I don't even want to know, I don't wanna discuss that' and then you can get these two levels of conversations happening, which can be quite difficult to manage.” (P12)*

Participants agreed that there was no easy way to give bad news. Although some followed relevant guidelines, they avoided following “*rigid pathways*” (P10) because of the differences in patients’ communication preferences and the complexity of MNDDs, and the different disease progression rates. Every newly diagnosed patient appointment required a unique balancing act for the bad news to be delivered effectively for that specific person. Despite this challenge, HCPs believed that achieving this balance could help participants feel supported, accept their diagnosis and move on knowing a plan they could work on together.

*“This is gonna sound really strange, I actually feel that... If it's done probably, it can help the patient and I like to think that I 've got enough experience and I 've got enough understanding and empathy that I do it well and there is no easy way to give bad news [...] but I 'd like to think that if done well it can help the patient accept the diagnosis and the journey, but it's hard isn't it?” (P4)*

#### **4) Empowering patients to regain control over their health and lives**

This theme describes how conversations around bad news were often interwoven or followed by HCPs providing support and empowering newly diagnosed patients to regain a sense of control over their health and lives. Alongside providing important information, professionals performed holistic

baseline assessments, identified areas they could provide support, encouraged patients to make decisions and plans for the future, and provided links to other HCPs and support sources.

As previously mentioned in themes two and three, participants believed that BBN in these initial appointments helped patients make sense of their diagnosis and its impact and develop an understanding of what to expect in the future. Although often distressing for patients, HCPs' rationale behind having some of these difficult conversations was to instil a sense of control. Providing information on communication aids, for example, was viewed positively by participants as a tool to manage the loss of speech for MND patients. Similarly, sharing information on home adjustments and the use of mobility equipment aimed to prepare patients for potential future loss of or difficulty in movements and to reassure them that their independence would be maintained as much as possible. Early discussions about advance directives were also difficult for patients. However, participants believed they gave patients a sense of control through communicating their preferences and making decisions about their end-of-life care.

*"It's hard to do (end of life conversations) and it's hard for some patients, but they do not regret doing it and they gain from it. It gives them a sense of control in a condition that is out of their control." (P15)*

BBN also helped HCPs educate patients and involve them in decision-making effectively. After explaining the nature and impact of MNDDs and the

scope for treatment, participants often had extensive conversations with patients regarding treatment options and their side-effects, and ways they could manage their condition. Following a patient-centred approach, the goal of these conversations was to involve patients actively in the consultations, enabling them to make informed decisions about how they wanted to manage their condition and plan their lives.

*“It's obviously supporting people to make the decisions that they feel are in their best interests at the time. There are a lot of people who choose a riskier option because they feel they get more quality of life, more enjoyment from eating and drinking than they would from having it via a tube...so they, they would prefer to take the risk of shortening their life for, for a little bit more quality of that life.” (P3)*

HCPs in these initial appointments, especially specialist nurses, also reported performing holistic assessments, which included questions about the patients' family, work, hobbies and life in general. Participants emphasised the importance of giving the patient time to talk about their lives and actively listen to their stories, concerns and matters to them. This way, participants could identify areas of the patients' lives to provide support and even act as the patient's advocate. For example, HCPs highlighted the importance of helping patients continue working for as long as possible, getting in touch with occupational health departments and putting in workplace arrangements, or providing practical information about benefits.

*"There's also, I mean, there's practical stuff like liaising with... work is a huge thing, people start to need reasonable adjustments in their workplaces so I'm helping them in the benefits, helping them stay at work and liaising with the occupational health department, advocating for them on their behalf, just doing pragmatic [...] supporting them to continue driving..." (P9)*

After completing holistic assessments with newly diagnosed patients, professionals were also able to signpost them to other HCPs and support sources such as local groups and disease associations, depending on their specific needs. Participants wanted patients to be well-informed about all the support available to them and enable them to decide how much support to receive and what referrals they wanted to be made for them.

*"If a new client comes through this door, what we do is we go through a very robust assessment for them, including all of the symptoms, all of the difficulties, it's not a 10-minute or 15-minute hospital appointment, it is very much a holistic looking at their life as it is now and things that we can do to help, we put in place, so for instance, they might leave with a whole pile of appointments that are gonna take place within the next six months." (P5)*

Also, the importance of self-management in appointments with newly diagnosed patients was highlighted. HCPs reassured patient services would support them throughout their 'journey', but they also stressed the need for patients to manage their condition. Participants encouraged patients to adhere to

medication regimes, lead a healthy lifestyle through physical activity, eat healthily, look after their mental health and seek support and advice when needed.

*'I feel [what] we [have] also got to do is give people, empower people to self-manage. [...] I say that with good management that comes from both the healthcare professional and the patient who needs to take some responsibility, we can, we can preserve a good quality of life. They have to take some responsibility in terms of adhering to the medication regimens and engage in some form of physical activity.'*  
(P6)

Finally, HCPs emphasised that a significant part of their supporting work included motivating and encouraging patients to maintain a positive outlook. Participants discussed that despite the challenging and emotionally-loaded bad news conversations, their initial appointments with patients were not just “*doom and gloom*” (P3). Working with newly diagnosed patients often included helping them accept their diagnosis and focus on maintaining or improving their quality of life. For example, psychologists reported using several models used in rehabilitation to help patients cope with their diagnosis and promote psychosocial adaptation to the condition. HCPs, in general, encouraged patients to keep setting and achieving meaningful goals, engage in activities they enjoyed and not let their diagnosis “*take over their life*” (P14).

*“So, I guess it's about reframing it, isn't it? So, inevitably, it's sad, but people will die, but it's about making sure they were able to go on that last family holiday, it was about making sure they were able to go on that - to go to that wedding, or whatever*

*and what do we need to put in place to allow that to happen? So, it's about supporting people to make, you know, plans.” (P11)*

## **Discussion**

To our knowledge, this is the first study to address non-medical HCPs' perspectives on BBN and supporting newly diagnosed patients with MNDDs. Although HCPs' involvement in BBN in neurorehabilitation has been addressed by other studies, these focused on acute neurological conditions such as stroke and traumatic brain or spine injury and specifically on BBN in relation to rehabilitation potential and recovery (Cheng et al., 2020; Grainger et al., 2005; Peel et al., 2020, Phillips et al., 2013). The analysis constructed four themes. HCPs working in the care of patients with MNDDs were broadly involved and had a significant role in the process of BBN: from managing patients who had a negative diagnostic experience, to re-iterating diagnostic information, discussing the impact of the condition and further supporting patients to adjust to their diagnosis and regain a sense of control. BBN was not perceived as a straightforward task but as a dynamic process that required empathy, strong communication skills and a unique balancing act, tailored to the specific diagnosis, patient information needs and communication preferences. By having these difficult conversations early HCPs aimed to help patients regain a sense of control, make decisions regarding their treatment, plan and prepare for the future but also maintain a sense of hope. We believe that the results of this study will help increase awareness of non-medical HCPs' involvement in BBN for MNDDs, how these difficult conversations can

benefit patients and how to support professionals to approach effectively this challenging aspect of their practice.

#### *Listening to patients' stories on diagnosis communication*

Previous qualitative studies on patients' experiences have shown how receiving an MNDD diagnosis was viewed by patients as the drop of a "*bombshell*" (Mistry & Simpson, 2013; Phillips, 2006). Interestingly, using another war-related metaphor, HCPs in this study discussed their experiences of dealing with the "*aftermath*" of the diagnosis, especially when patients had negative diagnostic experiences. Participants explained how, having moved from the initial shock of the diagnosis (Aoun et al., 2018a), patients needed to express their emotions of fear about the future and often anger and dissatisfaction regarding how their diagnosis was communicated. Similarly, in a qualitative study about the challenges of BBN, HCPs working in a variety of settings (including neurology but with no specific mention of MNDD care) discussed how they sometimes had to '*pick up the pieces*' when information-giving had been mishandled by other professionals (Warnock et al., 2017). According to participants in the current study, diagnostic delays, inadequate information provision and doctors' approach to diagnosis delivery were the primary sources of dissatisfaction, which have also been documented in other studies with patients with MNDDs (Anestis et al., 2020). HCPs highlighted the importance of showing a genuine interest and listening to patients' stories about their diagnostic experiences and allowing them to express their emotions. This helped them empathise with patients, build the base of a relationship with them and regain their trust, factors which have been found to



facilitate bad news conversations between HCPs and patients (Mishelmovich et al., 2016). Moreover, in the context of chronic conditions, illness narratives can be valuable in assessing patients' psychological adaptation, hope and mental well-being (Soundy, 2018) and therefore help HCPs tailor their communication and address patients' psycho-emotional needs.

*Difficult but essential conversations: helping newly diagnosed patients with MNDDs understand their diagnosis, gain a sense of control and prepare for the future*

All HCPs in this study were involved in a range of tasks which could be considered BBN, such as re-iterating and supplementing information that was given at diagnosis, sharing prognostic information, discussing the impact of the diagnosis, correcting patients' misconceptions (often regarding the scope of treatments) and validating their concerns. Their accounts supported the concept of BBN as a dynamic process that involved several MDT members and covered various topics related to the diagnosis and the professional's expertise (Rassin et al., 2013; Warnock et al., 2017). Besides sharing information about the nature of MNDDs and symptoms, participants adopted a holistic and patient-centred approach to BBN by addressing topics which other studies have also highlighted as necessary for patients such as the impact of the diagnosis on their daily lives, their family, relationships and work, the availability of benefits and help with planning for the future (Soundy et al., 2016). Unlike doctors (Bousquet et al., 2015; Aoun et al., 2016b) and other healthcare professionals (Warnock et al., 2017) who have reported lack of time as a factor that affects their practice in BBN, HCPs in this study felt '*lucky*' to be able to invest adequate time for these initial

consultations and cover all aspects of the diagnosis that patients wanted to discuss.

Nevertheless, effective and tailored information provision is a crucial component of the neurological rehabilitation process (Barnes, 2003) and patient-centred care in general (van der Eijk et al., 2011). Despite the often-distressing nature of these conversations, participants argued that these were crucial to help patients understand the current situation, what to expect in the future, and how they could be more actively involved in their care. BBN for HCPs in this study was also considered a part of their patient education role and a prerequisite for supporting self-management and shared decision-making regarding treatments and goals, which were also significant elements of the neurorehabilitation process (Barnes, 2000) and the long-term management of chronic conditions (Dwarswaard et al., 2016). Patients who have developed an understanding of their condition can make informed decisions about their treatments (Hancock et al., 2007), and well-supported patient involvement and shared decision making have been linked to better patient-provider communication and clinical outcomes, increased treatment compliance, and reduced healthcare costs (Stacey et al., 2017). By having these difficult conversations early on and enabling patients to make decisions, plan their lives and future, consider the realities of their condition and set goals for their therapy, participants in this study tried to help patients regain a sense of control. Perceived control has been positively associated with well-being in patients with MNDDs (Eccles & Simpson, 2011) and being well-informed about PD has been established as an essential factor for perceived control in PD patients (Simpson et al., 2018). Several participants in this study also

mentioned initiating discussions about advance care planning with newly diagnosed patients as a form of increasing patients' sense of control. Indeed, having advance care planning conversations around diagnosis when cognitive function is usually preserved is critical for conditions with a relatively short life expectancy such as MND. However, their significance has also been increasingly recognised even for MNDDs which are not immediately life-threatening such as PD (Kluger et al., 2019; Sokol et al., 2019).

*The challenge of tailoring bad news conversations to meet individual patients' needs: the potential role of illness uncertainty*

Integral to the participants' accounts were also the challenges they faced in finding the right balance for each patient regarding their approach to having difficult conversations and establishing how much information to give. This has also been highlighted as an important issue for both doctors and clinical nurse specialists working in cancer, palliative care and other fields, especially the challenge of communicating bad news honestly without taking away hope (Bousquet et al., 2015; Warnock et al., 2017; Mishelmovich et al., 2016). Similarly, participants in this study discussed the importance of being transparent and honest when breaking bad news and allowing space for hope. Unlike some neurologists who have expressed some reluctance in conveying hope when delivering the diagnosis of MND and HD specifically in a recent UK survey (Anestis et al., 2021), HCPs in this study stressed the need to instil a sense of hope regardless of diagnosis. Participants reported trying to promote a sense of hope by emphasising what could be done for patients in terms of managing their

condition and having a positive outlook regardless their diagnosis. Their practice aligns with findings from studies that have shown that even patients with life-threatening diagnoses prefer truthful information regarding their prognosis yet also want to be given hope (Brown et al., 2011; Spiegel et al., 2009). Besides honesty and hope, HCPs also discussed the challenge of effectively assessing patients' information needs and preferences and deciding how far to go with BBN conversations in these initial consultations. Having a relationship with the patient helped HCPs better assess patients' needs (Mishelmovich et al., 2016) and preparedness for bad news. However, this was not possible for participants in this study who were meeting patients with MNDDs for the first time. Patients' varied information preferences along with the unpredictability regarding the prognosis, potential impact and rates of progression of MNDDs added to the complexity of this task.

The variation in patients' information preferences and participants' reported challenges of tailoring their approach and finding the perfect balance when BBN can be partially explained by the illness uncertainty (IU) (Mishel, 1988) and uncertainty management theory (UMT) (Brashers, 2001). UMT is an interpersonal communication theory which suggests that uncertainty is not inherently negative, and people are not always striving to decrease it (Brashers, 2001). In the context of illness, uncertainty has been mostly associated with negative psychological outcomes (Mullins et al., 2001) and is less commonly perceived as positive (maintaining hope and optimism). During an interaction with HCPs, patients can present different information needs and information seeking behaviours depending on whether they want to increase or decrease their

uncertainty (Bylund et al., 2012). Based on our findings, we could argue that for some newly diagnosed patients' uncertainty is not always experienced negatively. Although most patients will feel the need to decrease their uncertainty by developing a better understanding of their condition and their prognosis, other patients might prefer to maintain their levels of uncertainty at that point as part of a slower process of accepting and adjusting to their diagnosis. Patients might also want to decrease their IU in general (by obtaining information about their condition) but maintain their uncertainty about specific aspects of their diagnosis and its impact (e.g., driving), thus using what the IU theory defines as 'buffering coping strategies' (Mishel, 1988) such as avoidance, selective ignoring or even shutting down specific BBN discussions. Patients' perception of uncertainty and consequently their information needs and information seeking behaviour can change over time (Bylund et al., 2012); it is therefore important for HCPs to maintain open communication channels and potentially BBN when patients are prepared to receive it. HCPs in this study mostly respected newly diagnosed patients' readiness for receiving bad news on specific topics but were also faced with moral dilemmas when the ethical values of autonomy, beneficence and non-maleficence seemed conflicting (Brown-Saltzman et al., 2012; Jameton, 1984). Professionals reported trying to tackle such dilemmas by mostly being led by patients' questions and needs (respecting autonomy) and double-checking before sharing distressing information (non-maleficence). However, there were instances when they felt it was their professional obligation to initiate difficult discussions early on in order to prepare the patient and avoid future crises even when patients were not willing to receive such information (prioritising future beneficence over present autonomy and non-maleficence).

### *Training and supporting healthcare professionals*

Participants agreed that giving bad news to newly diagnosed patients with MNDDs was a demanding task in terms of communication skills and an emotionally challenging experience. Despite the challenging nature of the task, HCPs have reported being inadequately trained in this domain (Abbaszadeh et al., 2014; Price et al., 2006; Warnock et al., 2010). Similarly, participants in this study reported not having received specific training for BBN to patients with MNDDs but had instead learned how to do it effectively through experience or had received training on BBN in general as part of a previous role in palliative or cancer care. Our sample's overrepresentation of experienced HCPs could explain the high standards of practice reported and we are unsure whether these would be the same if less experienced professionals had been recruited. Indeed, a qualitative study of HCPs' perspectives on BBN has indicated that more senior members of the MDT were more able to break bad news about rehabilitation potential after traumatic brain injury or spinal injury and could manage patients' expectations better (Peel et al., 2020). Based on our findings on the broad range of involvement of HCPs in BBN and the participants' reported willingness to receive more training in this domain, we believe HCPs working with patients with MNDDs would benefit from further training. In addition, HCPs would benefit from training and BBN guidance specifically designed to reflect their clinical reality and specific challenges of MNDDs. The most commonly used guidelines focusing on cancer care seem to mostly represent the traditional view of BBN as a doctor-patient interaction related to diagnosis delivery (Baile et al., 2000) and have been

criticised for not adequately addressing the emotional and supportive aspects of this task. (Arber & Gallagher, 2003). Building upon existing protocols of BBN and using the principles of the interaction adaptation theory as a basis, the COMFORT model for the communication of bad news proposes a set of core competencies that should be achieved through communication skills training (Communication, Orientation, Mindfulness, Family, Ongoing, Reiterative messages, and Team) (Villagran et al., 2010). COMFORT adopts a more dynamic view of BBN, addresses the family's and MDT's involvement and has been therefore considered to be appropriate in neurorehabilitation training and practice (Pelaez et al., 2017). Moreover, although exploring HCPs' experiences was not the main focus of the current study, all participants agreed that BBN was an emotionally challenging task. HCPs would often seek informal support from their colleagues after having difficult and emotional conversations with patients and only a few, mostly psychologists, mentioned using formal supervision and support. It is possible that BBN is an under-recognised aspect of HCPs clinical work, we therefore argue that besides training, formal forms of support could help professionals deal with the emotional demands of BBN.

### *Limitations and implications for further research*

This study has several limitations mostly related to possible omissions in terms of topics covered by the interviews and the broad focus of addressing four different MNDDs. Firstly, although cultural factors can be critical in healthcare provider-patient interactions (Ferguson & Candib, 2002), participants in this

study did not discuss their influence in BBN. Also, although we focussed on newly diagnosed patients, BBN for these conditions is an ongoing process and professionals have to give more bad news as the disease progresses, new difficulties arise, and patients move through the different 'stages' of their condition and potentially onto palliative care. Future studies could explore this more dynamic view of BBN in MNDDs. Moreover, all participants in this study worked in the UK, so findings might not be applicable in other countries with different healthcare systems and strategies for the management of MNDDs. Finally, although this study's main aim was to establish HCPs range of involvement in BBN to newly diagnosed patients with MNDDs, we acknowledge that there are significant differences among these conditions that can impact the nature and the timing of BBN. Future studies could focus on these conditions separately and shed light on the specific topics, challenges and practices around BBN, e.g., in relation to different types of MS or focussing on dementia related to MNDDs.

### *Conclusion*

This study has been the first to explore the experiences of a range of health professionals in BBN to individuals with MNDDs. Participants' accounts in this exploratory study revealed that HCPs were involved in the process of BBN in a variety of ways and outlined the complexities and challenges they encountered during this clinical task. As well as confirming concepts found in studies of health care professionals working with different patient groups such as the challenges of tailoring information giving and breaking bad news empathically and sensitively, this study has emphasised the positive outcomes of BBN effectively. Participants



emphasised that despite the often-distressing nature of information they provided to newly-diagnosed patients, BBN was a critical aspect of patient education which could also help patients make informed decisions, plan for the future and regain a sense of control. Thanks to the participants' significant length of professional experience, we believe that other HCPs can learn from our findings, identify challenging aspects of BBN and strategies used to manage these. Finally, we hope that this study will aid to the recognition of BBN as a critical task for non-medical HCPs working with patients with MNDDs and lead to the development of appropriate professional training and support.

Footnote 1: Although nurses are sometimes considered medical staff, for definitional clarity we use the term 'non-medical' throughout the paper to describe any healthcare professionals other than medical doctors.

Footnote 2: There are three main types of MS, relapsing-remitting MS, secondary progressive MS and primary progressive MS. Most disease-modifying treatments reduce the number of relapses, therefore only patients with the relapsing type of MS are eligible for treatment. (De Angelis F, John NA, Brownlee WJ. Disease-modifying therapies for multiple sclerosis. *BMJ*. 2018 Nov 27;363.)

## Tables

**Table 1.** Participant profile

No.	Role	Age	Gender	Years of experience*
1	PD nurse specialist	59	Female	23
2	PD nurse specialist	61	Female	43
3	Speech and language therapist	41	Female	19
4	Community matron (supportive and palliative care)	61	Female	40
5	MS nurse specialist	55	Female	34
6	PD nurse specialist	50	Female	26
7	PD nurse specialist	28	Female	6
8	Clinical psychologist	35	Female	9
9	HD nurse specialist	46	Male	25
10	MND nurse specialist	53	Male	32
11	Occupational therapist	58	Female	36
12	Occupational therapist	54	Female	33
13	Clinical psychologist	37	Female	14
14	MS nurse specialist	31	Female	10
15	Physiotherapist	32	Female	10
16	Physiotherapist	30	Female	9
17	Physiotherapist	34	Female	12
18	Clinical psychologist	64	Female	41
19	MND nurse specialist	59	Female	37
Mean age: $M = 47$ (28-64), $SD = 12.5$				
Mean years of experience: $M = 24$ (6-43), $SD = 12.7$				

\*Experience reflects years of overall post-qualification experience

## Chapter Six

### Publishable Paper Four (PP4)

*Neurologists' lived experiences of communicating the diagnosis of a motor neurodegenerative condition: an interpretative phenomenological analysis*

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**Neurologists' lived experiences of communicating the diagnosis of a motor neurodegenerative condition: an interpretative phenomenological analysis**

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## **Abstract**

**Background and Objective:** Receiving the diagnosis of a motor neurodegenerative condition (MNDD) such as Parkinson's disease, multiple sclerosis, Huntington's disease or motor neurone disease, can be a critical process for patients. Several studies of patients' experiences have indicated patients' dissatisfaction with aspects of how their diagnosis was communicated. However, there is a significant research gap in studies addressing the doctors' experiences of breaking bad news for these conditions, especially from a qualitative perspective. This study explored UK neurologists' lived experience of delivering an MNDD diagnosis and being the bearer of bad news.

**Methods:** 8 consultant neurologists working with patients with MNDDs took part in individual, semi-structured interviews which were analysed within an interpretative phenomenological analysis framework.

**Results:** Two themes were constructed from the data: Meeting patients' emotional and information needs at diagnosis: a balancing act between disease, patient and organisation-related factors', and 'Empathy makes the job harder: the emotional impact and uncovered vulnerabilities associated with breaking bad news'.

**Conclusion:** Breaking the news of an MNDD diagnosis was challenging for participants, both in terms of achieving a patient-centred approach and in terms of dealing with their own emotions during the process. Based on the study's

findings an attempt to explain sub-optimal diagnostic experiences documented in patient studies was made and how organisational changes can support neurologists with this demanding clinical task was discussed.

**Keywords:** Breaking bad news, Diagnosis communication, Patient-provider communication, Neurodegenerative, Motor neurone disease, Multiple sclerosis, Parkinson's disease, Huntington's disease, Neurologists

## **Introduction**

Breaking bad news (BBN) has been recognised as a critical aspect of healthcare communication and one of the most difficult tasks doctors face (Sparks et al., 2007). Bad news has been commonly defined as “any news that drastically and negatively alters the patient’s view of his or her future” (Buckman, 1984, p. 1597) such as the delivery of a medical diagnosis. Because how such news is delivered can have both a short- and long-term impact on patient outcomes (Butow et al., 1996; Bredart et al., 2005; Mager & Andrykowski, 2002; Schmid et al., 2005), the topic has attracted considerable attention from healthcare and medical education researchers. Research on BBN has mainly focused on patient perspectives and preferences and the development and evaluation of doctors’ training; however, doctors’ experiences and perspectives on breaking bad news have been less commonly investigated (Vegni et al., 2005).

It is acknowledged that BBN is a complex communication task that requires multiple competencies beyond just disclosing the name of a diagnosis. These can include delivering potentially distressing information in a sensitive way, assessing patients’ information needs and capability to absorb bad news, identifying and managing the emotional impact of bad news on all parties involved in the consultation, discussing prognosis and facilitating shared decision-making (Karnieli-Miller et al., 2018). In order to meet patients’ preferences, doctors need to face the challenge of breaking bad news truthfully but at the same time empathically and without taking away hope (Baile et al., 2000). Despite the

challenging nature of BBN, a recent international survey of more than 10,000 healthcare professionals, including doctors, showed that only about a third had received formal training on BBN (Alshami et al., 2020). It is, therefore, not surprising that doctors often feel they lack the necessary skills (Mostafavian & Shaye, 2018) and feel underprepared for the responsibility of BBN (Almaguer et al., 2017; Gonçalves et al., 2017). Moreover, studies have shown that BBN can be a stressful task with stress reactions lasting beyond the actual consultation and potentially contributing to symptoms of burnout (Studer et al., 2017). Doctors sometimes also fear eliciting strong emotional reactions from their patients or being blamed when breaking bad news (Berkey et al., 2018) and can experience intense emotional reactions themselves such as guilt, failure, frustration (Bousquet et al., 2015).

Although the majority of research on BBN has been conducted within oncology, the importance of breaking bad news in other specialties, such as neurology, is increasingly recognised (Storstein, 2011). Motor neurodegenerative diseases (MNDDs), such as Parkinson's disease (PD), multiple sclerosis (MS), Huntington's disease (HD) and motor neurone disease (MND), are incurable and progressive, impacting patients' movement, cognition and psychological functioning (Batista & Pereira, 2016). HD and MND are also more directly life-threatening, with MND patients' life expectancy, for example, estimated at three years on average after symptom onset (Hobson & McDermott, 2016). Our recent review on patients' perspectives on diagnosis delivery showed that receiving an MNDD diagnosis can be the end-product of a long and distressing process, with the diagnostic consultation an easily-recalled, critical and often shocking moment



for patients (Anestis et al., 2020). This review also revealed mixed views on patients' satisfaction with doctors' approach to BBN, with negative experiences highlighting inadequate information and time provision and lack of emotional support and sensitivity at diagnosis.

MNDDs are most commonly diagnosed by neurologists whose perspectives on BBN have been sparsely addressed by research. Our review found very few studies of neurologists' perceptions of BBN; most were quantitative and focussed more on the parameters of their practice such as the terminology used and the timing of the diagnosis and less on their actual experience of BBN. Further, a survey study we conducted on UK neurologists' perspectives showed that most participants considered BBN to be a difficult and stressful task, with being honest without taking away hope and spending the right amount of time being the main challenges (Anestis et al., 2021). Although the survey was useful in that it identified several areas of improvement, it did not adequately capture neurologists' in-depth experience of BBN for MNDDs.

Exploring neurologists' experiences and emotions when breaking bad news can help create a deeper and more holistic understanding of the doctor-patient interactions during BBN which can ultimately lead to the development of appropriate training and support for professionals and more effective and patient-centred practices. Borrowing from the ideas within narrative medicine, we argue that doctors bring their own 'stories' to a consultation, based on their personality and their life and clinical experiences (Zaharias, 2018). Addressing doctors' subjectivity, understanding them as a person and not just as a skilled

professional has been suggested as one of the key dimensions of patient-centredness (Mead & Bower, 2000). Physicians deal with patients' needs and expressed emotions using their own emotions, such as a need to 'rescue' the patient or feelings of failure, frustration and powerlessness when an illness is progressing or is untreatable (Meier et al., 2001). Doctors' emotions, their 'inner life', can thus have a crucial role in the doctor-patient interaction and the overall quality of care and when unexamined, emotions can affect doctors' well-being and clinical judgment (Meier et al., 2001; Sanchez-Reilly et al., 2013). For this reason, qualitative approaches are best suited to exploring the essentially subjective experience (Gough & Madill, 2012).

Consequently, the primary aim of this study was to explore UK neurologists' lived experience of delivering an MNDD diagnosis and being the bearer of bad news, with the specific research question being: *How do neurologists make meaning out of their experiences of breaking bad news and how is their practice shaped by this meaning-making process?*

## **Methods**

### *Study design and ethical approval*

A qualitative study design using semi-structured interviews and an interpretative phenomenological analysis (IPA) approach were adopted in order to allow a detailed exploration of neurologists' lived experiences of BBN in the context of MNDDs. IPA was chosen as it has been widely used in health research

and its phenomenological, hermeneutical and idiographic underpinnings make it an ideal approach for the study of lived experience (Peat et al., 2019). The interview schedule was developed based on previous research on doctors' perspectives on BBN (Aoun et al., 2016; Bousquet et al., 2015), models of BBN (Baile et al., 2000; Villagran et al., 2010) and our review of patients' with MNDDs perspectives on diagnosis delivery (Anestis et al., 2020). Two neurologists gave initial feedback on the relevance and appropriateness of the questions and adjustments were made. The study received ethical approval by the authors' host institution.

### *Sampling and participants*

Due to IPA's idiographic nature and its emphasis on detailing individuals' experiences and meaning making processes, it is generally recommended that IPA studies have a homogenous and small sample size (Pietkiewicz & Smith, 2014). For this study, consultant neurologists who practised in the UK and delivered at least one of the diagnoses of interest (PD, MS, MND or HD) were eligible for participation. To ensure the sample's homogeneity, we chose to exclude neurologists in training (neurology registrars) as their experiences of BBN were expected to be both quantitatively and qualitatively different. Participants were approached through collaborations with National Health Service neurology departments and centres for MNDDs and also through snowball sampling and advertisement of the study on social media. Prior to the interviews, potential participants were sent an information sheet and were asked to complete a consent form. Eight neurologists took part in the study, a

sample size within the recommended IPA sample sizes (Murray & Wilde, 2020), which allowed for an elaborate idiographic analysis. Participants' demographic characteristics are provided in table 1.

### *Data Collection*

All participants were interviewed by the first author, one interview was conducted in person and the rest over the phone or through video calls. Interviews lasted from 27 to 79 minutes ( $M = 52$  minutes). Interviews were audio-recorded and transcribed verbatim by the first author. The semi-structured interviews included open-ended questions and additional prompts, with closed questions asked to explore further and clarify individual participant experiences. The interview schedule can be found in the Appendix.

### *Data Analysis*

Data were analysed following the guidance and steps outlined by Murray and Wilde (2020). Familiarisation with the data was achieved by listening to and transcribing the interviews and reading the transcripts. Following an idiographic approach, each transcript was coded line-by-line using descriptive, interpretative and linguistic comments. After coding was completed, codes were reviewed and patterns of meaning and themes related to the research aims were identified, summarised into text and given a title. This process was followed for every transcript before moving to the next, trying to focus as much as possible on individual participants' unique experiences and meaning-making processes

without being preoccupied by findings from previous transcripts. Finally, a cross-transcripts analysis was completed by identifying points of convergence and divergence which allowed for a more complete and in-depth understanding of the research phenomenon. During a process of experimentation, themes from different transcripts were clustered together and constructed themes which reflected salient aspects of participants' experiences. Quotes from individual interviews were then incorporated within these themes to evidence the interpretation and analysis and illustrate the points made.

### *Quality, rigour and reflexivity*

In order to ensure quality and rigour, both generic qualitative research and IPA-specific quality indicators were used during the entire research process. *Rigour* (Yardley, 2000, 2008) was ensured through intense familiarisation with the transcripts, line-by-line coding and an in-depth idiographic analysis performed by the first author. The first author also had regular meetings with the other authors who gave feedback and initial thoughts on the first two interviews, reviewed and added comments for each transcript during the coding phase and discussed potential theme development. When writing up the themes, special consideration was given to *transparency* (Yardley, 2000, 2008), helping the reader understand how interpretations were derived from the data (e.g., through the use of quotes) and producing themes with a *coherent* and *compelling narrative* which addressed both *convergence* and *divergence* across participants' accounts (Nizza et al., 2021). Moreover, *reflexivity* was an integral part of both data collection and analysis (Finley & Gough, 2008). The lead author had previously conducted a

scoping review on patients' with MNDDs perspectives of diagnosis delivery and had developed a broad understanding on why their experiences were not always positive (see Introduction). Through reflection, the lead author realised that this understanding could potentially narrow down the topics discussed during interviews which could appear as critical interrogations of neurologists' practice of breaking bad news. Instead, a genuinely 'curious' attitude was maintained during the interviews which aimed at exploring doctors' lived experiences and understand how their practice was shaped by their experiences and meaning-making processes. Also, taking into account the process of the 'double hermeneutic' in IPA (where the researcher tries to make sense of participants who are also trying to make sense of their experiences), coding, interpretations and theme development were completed through a process of ensuring constant and '*close proximity to the data*' (Engward & Goldspink, 2020) and acknowledging the role of the researchers' preconceptions in the analysis. This intended to minimise (but not eliminate, as this would be impossible according to IPA) the researchers' preconceptions and produce interpretative accounts grounded in participants' understandings and meanings of their experiences (Murray & Wilde, 2020). Finally, our study was committed to generating findings that were *novel* and potentially *impactful* (Yardley, 2000), by addressing a research gap on neurologists' lived experiences of breaking bad news in MNDDs which could help advance BBN training, improve available support for doctors and eventually optimise patient care at diagnosis.

## Results

Two themes which focussed on different aspects of participants' experience of breaking bad news were developed; *'Meeting patients' emotional and information needs at diagnosis: a balancing act between disease, patient and organisation-related factors'*, and *'Empathy makes the job harder: the emotional impact and uncovered vulnerabilities associated with breaking bad news'*.

### **Meeting patients' emotional and information needs at diagnosis: a balancing act between disease, patient and organisation-related factors**

This theme explores participants' experiences of balancing disease, patient and organisation-related factors, along with the inherent challenges in breaking bad news, in order to provide an effective, empathic and patient-centred consultation.

All participants considered breaking bad news as a challenging yet crucial aspect of their role which they took seriously. It was generally acknowledged that receiving an MNDD diagnosis could be a life-changing process for patients, even the *'worst moment in their lives'* (Participant 8, P8). Drawing from conversations with colleagues and his father's negative experience of being diagnosed with PD from a blunt neurologist, one participant supported the idea that suboptimal diagnostic experiences *'stick'* with both patients and doctors (P6). Emphasising the importance of the diagnostic encounter, other participants mentioned that the quality of their interaction with patients at diagnosis could *'hugely'* affect their

future doctor-patient relationship (P3) and that how diagnosis delivery was handled was equally as important as patients' end-of-life care (P4).

P8: *'One thing I was told as a medical student is that patients forget your name, they might forget, you know, the stuff you say, the details, but they'll remember how you were, they'll remember how information was delivered and what you did afterwards.'*

Participants agreed that because of the potential long-term ramifications of the experience of these consultations, it was crucial to deliver these diagnoses with empathy, warmth and sensitivity. However, this was considered the biggest challenge of breaking bad news by P1 (MND specialist) who explained the paradox of having to give 'terrible' news in a gentle way.

Interviewer: *'So, what are the most challenging aspects of delivering a diagnosis of MND?'*

P1: *'It's knowing how to do it right, that's the most challenging. How do you, how do you best give terrible news to somebody in a way that allows them to absorb the information without shutting down emotionally and without it being such a traumatic experience that they can't, they just re-live it or they can't even think about it? It's that, how do you give that information in a gentle way. Because that's in the end what you have to be, you have to be gentle, you're giving someone a massive blow. It's like trying to punch someone so hard to knock them out but you have to do it very, very gently.'*



An MND diagnosis was viewed as a destructive force which was not only emotionally traumatising for patients but could also hinder their ability to absorb important information. The paradoxical challenge of giving such '*terrible*' news gently can be experienced as a no-win situation by doctors who are faced with a task that seems unattainable.

Adopting a gradual approach to giving the name of the diagnosis was described by all the participants as a way to mitigate this challenge. They usually started the consultation by asking patients to give their perspective, talk about their symptoms and share their thoughts on what their diagnosis might be. This helped doctors establish patients' current knowledge, form an initial assessment of the patient's circumstances and personality and tailor the rest of the consultation. Using simple language and avoiding medical jargon, participants then explained the neurological basis of the patient's symptoms while they included some '*warning shots*' (e.g., mentioning the motor nerve before they disclosed an MND diagnosis). Participants believed that these warning shots '*softened the blow*' (P2, P8) and prepared patients for the disclosure of the name of the diagnosis, making it a less '*explosive*' (P1) moment. Participants believed that this gradual approach served two main purposes. Firstly, it helped patients understand and accept their diagnosis which came as a rational conclusion backed up by test results and/or a clinical examination and, secondly, it minimised reactions of shock which could hamper information absorption.

However, despite participants' gradual approach to breaking bad news, patients often reacted with shock or other intense emotions when they heard the

name of their diagnosis. It was generally agreed that it was important at that stage to give patients and families time and allow them to express these emotions of sorrow, despair, mourning or anger over the losses that an MNDD diagnosis might signal. Letting these emotions run their course was considered essential in aiding patients' acceptance of the diagnosis. Participants' accounts showed that providing emotional support was mostly a task that did not include speech but focussed on listening to and being there for patients.

P8: *'Some people cry, some people say nothing, you wonder if they heard you, people get angry. And the thing, the important thing is as well that, you know, none of us know how we would react given news like this. You can't judge or tell people what the right reaction is because there isn't a right reaction, you just need to give them space to have the reaction and then be there. You shouldn't just rush out if at all possible. And even if everyone's sitting there not saying anything, you're being there, you're available. And sharing that time is important.'*

However, the same participant later in the interview also admitted that she was surprised when people had intense emotional reactions when receiving a PD diagnosis.

P8: *'Sometimes, when somebody has quite a violent response to a diagnosis of Parkinson's disease that can be quite surprising for you and that's awful, because we see so much Parkinson's that it's almost one of the more benign diagnoses in terms of neurodegenerative diseases. So, that can sort of calibrate you when somebody is utterly devastated by a diagnosis of PD.'*

There was generally a sense that some participants could not always empathise with patients and understand their strong emotional reactions to the news. As discussed earlier, diagnosis for participants was a rational and often expected outcome, so they were sometimes surprised when patients reacted with shock to bad news, especially after the gradual approach they followed and the cues they offered. This was more often the case for conditions such as PD or MS which participants even mentioned perceiving as a '*good news diagnosis in neurology terms*' (P5) unless patients were young. PD and MS were considered benign in neurology terms because of advances in the treatments available for these conditions and their better prognosis compared to HD and MND. In these instances, there could be a fundamental mismatch between neurologists' and patients' experiences, as professionals viewed the diagnosis from a biomedical lens and based on their clinical experience while for patients this could nevertheless be a life-changing moment.

Overall, participants gave detailed responses in describing patients' emotional reactions but provided less information on how they managed these reactions besides allowing patients' time and space for emotional expression. For one participant (P4) emotional support was solely provided by nurses who were involved in the consultation and spent some time with patients and their families afterwards. Despite being prompted, other participants gave no information at all in terms of how they dealt with patients' emotional reactions and needs or even thought that these could not be managed.

Interviewer: *'Some people have said that they find it challenging to respond to patients' emotions and manage the consultation when things are getting emotional, what is your approach to this?'*

P7: *'Well, I don't know if you can really manage it, I think you just have to let them respond in the way that they're going to respond. If they're, you know, if they're extremely devastated, you can't really manage it in a sense, you've just got to let them get on with it.'*

This could potentially be an aspect of breaking bad news with which not all participants felt comfortable or confident with. However, participants agreed that patients' emotional reactions were useful in helping them structure the rest of the consultation.

P6: *'They are, you know, panicking and anxious and fearful. And, you know, how you proceed from that point sort of depends on what you get back at that moment of pause, right? Because if they're not, if they're in that shut down state, it's just pointless carrying on, trying to get too much more information.'*

Information-giving was generally perceived as a great responsibility by participants who wished to help patients understand their diagnosis but without further devastating them. Because of MNDDs' progressive and often life-threatening nature, participants were *'wary of bombarding people with information'* (P7) which could be burdensome. Therefore, participants did not have a specific agenda of items that needed to be discussed after a diagnosis was communicated, so patients' emotional reactions and questions were useful in

indicating patients' readiness to receive further information. Even when patients explicitly asked questions on a sensitive subject such as their prognosis, participants often showed a reluctance to answer them. Some participants mentioned double-checking before imparting distressing information whereas another participant reported never answering patients' with MND questions on life-expectancy. This appeared to be an exception to the overall patient-centred approach described in the interviews. Participants supported their practice either by explaining that the unpredictability around how (and how quickly) MNDDs progress would not allow them to give an accurate prognosis or by expressing their intention to protect patients:

P8: *'Patients can't know what they don't know. And you can't take away knowledge once it is given. You can't protect people from an outcome that may happen, but it's important to remember particularly near the beginning of the illness, that some knowledge can be so burdensome, damaging, that only providing it when it needs to be delivered or when the patient comes to you and says, 'I've heard about this thing'. So yeah, I think knowing, gauging what people want to know, is very hard. Because what they say they want to know, might not be what they really want to know.'*

This participant acknowledged the challenge of assessing patients' information preferences and suggested that timing was also important in information giving, being sensitive to the vulnerability of patients who have just been diagnosed and the damage that some information can cause. Another exception to patient-centred care in information giving was described by P3 who

noted that in the case of MND, she often had to provide more information that patients could potentially handle at diagnosis:

P3: *'With MND I talk about advance directives early on. So, I say, 'This is a devastating diagnosis, I can see this is a big shock, but I want you to start thinking about what you want to do with your time and then plan things'. I want you to start thinking about which things you want in terms of the peg or the non-invasive ventilator... Unless they expressively bring up death, I wouldn't.'*

Although such information could burden patients who had just received an MND diagnosis, the participant believed it was crucial for them to be prepared and start making decisions early on. Based on her clinical experience and with an intention to engage patients into shared decision-making, she felt it was her professional duty to initiate such conversations early on. Interestingly, death itself was considered a more sensitive topic which she chose not to discuss unless patients explicitly asked about it.

Nevertheless, information at diagnosis was not always negative. As another strategy to soften the blow of the diagnosis, participants offered patients reassurance by explaining what support was available to them and how their symptoms were going to be managed, sharing useful contacts and signposting to other professionals, information sources and charities. P1 noted that, ideally, he wanted people to leave the consultation not just having understood their diagnosis, but also feeling *'a bit positive'* and able to cope with it. Despite MND's life-threatening nature, he tried to instil a sense of hope by providing information

on current research on potential cures, current trials and alternative therapies that were safe to try. However, other participants believed that although they could promote optimism when delivering a PD or MS diagnosis, there was little scope for hope for HD and MND.

P4: *'No, I don't give any hope in MND. I think it's unfair, because then they'd have an unrealistic expectation. I don't take away hope, but I don't give false hope. I try to encourage them to take each day at a time and do the things they want but I can't give them hope.'*

Participants who considered hope in the context of HD and MND to be unrealistic or false reflected a traditional view of hope as solely associated with the possibility of a cure. Some participants, such as P4 above, tried to encourage patients with these conditions to still try to enjoy life and focus on what they could still do, however patients' need for hope was not explored.

Time was an essential factor which affected the quality of the BBN consultations that participants could offer. Neurologists believed that an ideal, patient-centred breaking bad news consultation should not feel rushed and should meet patient's needs for both information and support. This was not a problem for P1 who worked in a specialist MND clinic that gave him the flexibility to spend as much time as needed with patients at diagnosis. However, for other participants who worked in hospital settings, optimal diagnosis delivery was often hampered by organisational factors such as limited-service capacity and short time slots.

Some participants reported having to break bad news in short, even 15-minute, consultations.

P2: *'These are fixed times; we don't have any options there. You're always clock-watching as a doctor the whole time. It's the biggest single negative of the job probably, the lack of time to do anything properly. You just don't get long enough to do anything. 15 minutes is just not enough time to tell – and in that 15 minutes, the first 10 minutes might be spent examining patients if I want to just clarify some issue or looking at the scan. Similar with PD, you're looking at 5 minutes with them to have a chat which is nowhere near enough.'*

In general, based on their perceived hierarchy of the severity of different MNDDs, participants spent more time delivering MND and HD diagnoses compared to PD and MS. For example, P3 mentioned investing one hour for the diagnosis of MND and HD and half of that for PD and MS and P5 believed that even five to ten minutes was sometimes enough to convey a PD diagnosis. This seemed to be another exception to participants' overall patient-centred approach as the time dedicated for the diagnostic consultation was usually decided based on their clinical experience and the clinical characteristics of a diagnosis and potentially not the specific information and emotional needs of individuals. Also, knowing that a follow-up with the patient could be after a year, doctors who reached a diagnosis during a consultation sometimes had to break bad news to unaccompanied patients there and then, a factor which also contributed to sub-optimal diagnostic experiences. Other participants who also reported unrealistic time slots explained that they sometimes had to be 'resourceful' (P5), 'clock-watch'



(P2), be ready for their clinics to overrun (P6) and even be 'naughty' by breaking rules and booking double appointments (P8) in order to provide an effective consultation. These organisational restrictions arguably intensified an already challenging task, particularly as participants knew that best practice could not always be achieved at such a critical time in patient's lives.

### **Empathy makes the job harder: the emotional impact and uncovered vulnerabilities associated with breaking bad news**

As discussed in the previous theme, participants emphasised providing a supportive consultation and maintaining an empathic approach in order to break bad news sensitively and effectively. Being empathic, however, was also a challenge that '*made the job harder*' (P6) as participants had not only to deal with patients' emotions but also their own. This theme explores how breaking bad news was emotionally experienced by participants, how it felt to be the bearer of bad news and the impact that this task had on them.

Overall, participants acknowledged that breaking bad news for MNDDs was an emotionally burdensome task. There were, however, both similarities and differences in the nature and the intensity of the emotions and the stage of the consultation when these were experienced. For example, even preparing to communicate an MND diagnosis or an unexpected MNDD diagnosis to young patients was an experience that sparked dread, causing fear and anxiety to even senior specialists. P8 reported that her '*state of mind and demeanour are very different*' when she knew she had to break bad news. She experienced tension

which started to build before the actual consultation and peaked at the moment right before she gave the name of an MNDD diagnosis:

P8: *'There's always a moment, just before you say the name of the disease, where you feel terribly responsible. Like you've done it to them, that you've given it to them, I don't know if it's just me. I don't know why it feels like in diagnosing that you own the disease, or sort of passing it through to them. That's very sad'.*

This seemed to be a recurrent theme among participants who, while not always expressing the feelings as overtly as P8, did use phrases indicative of a belief they were causing harm (P1: *'punching someone so hard to knock them out'*, P2: *'cutting someone's life off'*, P3: *'dropping a bomb into the room'*, P6: *'wrecking someone's life'*); clearly linguistically these emphasise the destructive nature of these diagnoses. These metaphors indicate that, for participants, communicating an MNDD diagnosis could feel like physically harming patients, a contradiction to their professional caring role and the 'do no harm' principle. Experiencing this contradiction could contribute to their reported feelings of responsibility and guilt when breaking bad news. Moreover, after diagnosis disclosure, participants were often emotionally challenged by having to witness patients' reactions to the news, which could be understood as an immediate consequence of their actions. One participant vividly described the difficulty of giving an unexpected diagnosis and seeing patients reacting with shock.

P6: *'I think it's particularly challenging if the individual has no idea that it's coming. I think that that is really hard. That doesn't get any easier. Because it's because you*

*know, that there's no, the warning shot, there's nothing there. There's no, you just basically, you can just see the bottom drop out of somebody's life in front of you and that's not nice.'*

Several participants also discussed that after bad news was broken, they were often exposed to patients' intense emotional reactions. This was experienced as an additional source of distress for professionals, eliciting sadness and sympathy for patients but also a feeling of powerlessness. Because of the incurable nature of MNDDs, participants were often faced with the challenge of not being able to balance bad news with discussions about therapeutic options.

Interviewer: *'So, in your opinion, what are the most challenging aspects of delivering a diagnosis for these incurable conditions?'*

P3: *'Erm, I think it's feeling powerless. So, you know that you're... People say that knowledge is power, but with incurable conditions, it doesn't feel like that. So, I'm dragging them into giving them bad news and I can't really make anything better.'*

Feeling powerless was associated with a feeling that her specialist knowledge could only contribute to reaching the diagnosis and was no longer a 'power' that could substantially help patients at that point. This was particularly intense when delivering MND and HD diagnoses where a '*substantial treatment story was absent*' (P5), in contrast with MS and PD which can usually be more effectively managed by disease modifying therapies and medication respectively.

Other participants, such as P1, had a milder emotional experience during a consultation of bad news but explained that he experienced the impact of breaking bad news after a consultation had finished.

*P1: When I'm in the interaction that's fine, I don't mind it. It's afterwards, I find it incredible draining.*

*Interviewer: Do you mean after the consultation?*

*P1: Yeah. During the consultation I'm fine cause I'm in the moment and I can, and I feel prepared. I understand people are going to react in different ways. [...] I always feel, erm, I always wonder if I did it well, or if not, and how could I have done it better. I always feel completely exhausted, and I've noticed my communication skills plummet after this. So, if I look at texts that I've sent straight after a clinic, my responses in a text are very different from a normal day.*

*Interviewer: Do you actively think about it afterwards?*

*P1: Yes. A lot. Yeah. I replay it in my head and think 'could I have done it better?', 'was that the right thing?'. Especially if someone has a terrible reaction where they shut down.*

Unlike other clinical tasks with which P1 might have felt more confident, BBN was a task that could induce feelings of self-doubt. This could illustrate the complexity of BBN as a communication task but also indicate that BBN was an aspect of his practice which made him feel vulnerable as a professional, doubting whether his practice was optimal (*'could I have done it better?'*). Apart from self-doubt, P1 could also observe feeling affected on cognitive and physical levels after diagnostic consultations, effects which were also common for other participants

who mentioned feeling drained and experiencing migraines and stomach cramps. The overall impact of breaking bad news also seemed to be more profound when clinicians had to do it on multiple occasions within a day:

Interviewer: *'Have you ever been emotionally affected after a challenging breaking bad news consultation?'*

P3: *'Yes, well, often, really. I would say that they're cumulative. So, you give bad news and you dust yourself down, you feel okay, and then that might happen a few times and then something will happen, and I'll feel very upset and all of those hurts and emotions will appear.'*

Additionally, participants spoke of a variety of other factors which could intensify the emotional aspects/experience of breaking bad news. Communicating an MNDD diagnosis was generally considered more difficult and emotionally draining when patients were young, were already facing personal challenges or lacked a supportive network which would help them cope with the news and the condition in the long term. Communicating MNDD diagnoses to younger people was generally considered 'unfair' and an experience that stayed with clinicians:

Interviewer: *'Have any experiences of breaking bad news been more memorable to you throughout your career?'*

P2: *'You know young people with MND are the ones that live with you, like people in their 20's which I have done but there's nothing that specific really. It just seems much more unfair, I suppose. You're cutting someone's life off in their 20's, compared to cutting someone's life off in their 80's. It just seems more unfair. As I get*

*older you maybe re-adjust that a little bit, but the fact is that getting MND is your 80's is not as bad a thing as getting MND in your 20's.'*

Some participants also explained how they found it emotionally difficult when they had to break bad news to patients with severe cognitive impairments or patients who experienced apathy:

P8: *"In some cases, particularly if there's a cognitive element, patients might be apathetic or not really understand, the families just fall apart and the patient just sits behind, 'oh everybody's crying'. That's very hard as well. I wouldn't say it makes things more difficult, but it's more poignant."*

Identifying with patients when breaking bad news was also perceived as an added difficulty which emotionally affected some participants. Delivering a diagnosis to patients with a similar age, gender or family circumstances to them was more upsetting for some neurologists. Breaking bad news in these cases 'brought it home' (P3) and acted as a reminder of participants' own vulnerability and their own fears regarding the unpredictability of life. One participant discussed how becoming a parent made breaking bad news to parents more challenging:

P6: *'It's impossible not to become a bit emotional sometimes, you know, I don't know whether other clinicians would have said, but I found medicine a lot easier until I became a parent. So, you know, if I see patients my age, with, you know, if I'm diagnosing Parkinson's, and somebody's age is X (participant's age), and*

*they've got a young family, that's harder for me now than it was. When I was 35, I didn't have any kids and I was diagnosing Parkinson's in the X-year-old with kids that had less kind of direct kind of parallels with my life. So, it was easier to be a little bit objective about that. Now, I can't help but go there too. You know, well, what if that was me? Naturally your brain goes there. [...] I think that's hard then, because you got a clinic, you know, you've got another four patients waiting. It's harder to get your brain back on track again, after a consultation like that, I think.'*

Identifying with patients can be arguably considered as a way to empathise truly with patients and realistically acknowledge the magnitude of the impact that receiving an MNDD diagnosis can have. However, identifying was mostly conceived as a challenge. Due to their professional reality/job demands, participants had to disengage from these emotions in order to move on to the next patient. While reflecting on the challenges of maintaining an empathic approach when breaking bad news, another participant admitted that it was easier for him to actually detach himself emotionally:

*'Well, you just look at them and imagine yourself in that seat. Just before I start talking, I try to flip the seats round and imagine me sitting there, but you can't get it too far because you have to carry on and be objective so there's a balance. It's very easy to just close yourself off and break some bad news and then walk out. It's not hard to do that. It's harder to open yourself up a bit.'* (P2)

Some participants noted that being emotionally affected when breaking bad news could be an under-recognised aspect of their practice potentially

because professionals were expected to put patients at the centre of every consultation. One participant stressed the need for his colleagues to recognise that they are '*only human*':

P6: *'I think, you just have to recognise you're only human, you're going to get affected and if you are affected, well, okay, welcome, welcome to the human race!'*

Similarly, another participant (P3) spoke of understanding why patients might be angry towards her when they receive a delayed diagnosis, but she did feel upset about it as she was '*still human*'. Being human for these participants was associated with being vulnerable to emotions when breaking bad news. There was generally a sense that, as doctors, participants were not allowed to express their emotions, be emotionally affected by these consultations and there was a fear of becoming emotionally over-involved when breaking bad news. Even participants who believed it is normal to be emotional felt the need to highlight the fact that they had never been affected to the point of losing their objectivity and others reported that they experience but do not express their emotions:

P3: *'I have to stay there (after diagnosis disclosure) and probably manage my emotions by trying to feel a bit numb. So, using a kind of - "I'm watching myself giving bad news" rather than "I'm feeling myself giving bad news". I think that's probably a common technique that doctors use, so that you don't sort of cry badly, you can look empathetic and you can be open and you can be appropriately warm, but the only way to not feel that upset whenever people are really upset is to do this sort of 'imagine watching yourself', it's quite body-motion control technique.'*



Besides numbing her own emotions, P3 stated that she had to remain warm and look empathetic, therefore regulating her emotional expression in order to be able to carry on. Imagining herself breaking the news was another technique she used to detach herself emotionally and avoid getting overly upset so she could both continue with the consultation but also protect herself from the emotional impact of BBN. Similarly, another participant believed that '*you have to be strong for the patient*' despite experiencing intense emotions of sadness. Such accounts showed that maintaining their composure was important for participants and potentially the expected norm for doctors.

It is noteworthy that although - to some extent - all participants addressed the emotional aspects of being the bearer of bad news, some were reluctant to discuss this topic. This reluctance could be as subtle as switching from first person to third person when addressing the emotional experience of breaking bad news or more prominent. For example, P2 initially viewed BBN just as a part of his job, stripped of emotion, as a task which he did not find stressful or emotional. This could be considered an attempt to 'dehumanise' the experience, detach himself emotionally and view breaking bad news as simply a sterile exchange of information. Similarly, at the start of our interview, another participant viewed BBN just as part of his job (P5: '*This is what I'm paid to do*') and it would be '*frivolous*' for him to be anxious about it. This kind of sterile and rational conceptualisation of his experience of breaking bad news, however, changed as the conversation developed:

P5: *I suppose it's a bit like going to funerals. I don't know if you've been to many, but, you know, whenever you go to a funeral, it reminds you of all the others that you've ever been to, including those of your nearest relatives. And, whenever you break bad news, it sort of reminds you of all the others. And it reminds you of your own predicament in life and of life, your fragility. You know, is it existential angst in a sort of way?*

This 'funeral' metaphor illustrates the emotions of shared sorrow that surround the diagnosis of MNDDs which can act as a reminder of our own fragility and induced feelings of existential angst. This is in alignment with accounts from other participants which suggest that breaking bad news was an experience which could uncover doctors' professional and personal vulnerabilities. Reflecting and admitting these vulnerabilities and reliving the sad memories of previously breaking bad news could explain why some participants showed this initial reluctance in addressing emotional topics.

Because of how emotionally demanding BBN could be, participants mentioned that, although essential, it was often considered as an unwanted or 'not enjoyable' task among doctors. However, one participant highlighted some positive aspects of the task.

P8: *'A clinic can be fulfilling and valuable because you feel like you've given people a diagnosis that is difficult and you've done it to the best of your ability and probably, you've done it as best you can and you take comfort from that, or you've*

*discussed a difficult issue sensitively and the patient trusts you and you've worked together to come to a decision about the next stages.'*

Her account suggests that through a change of perspective and good BBN practice, doctors can actually gain job satisfaction, feel confident about their practice and build trusting relationships with patients.

## **Discussion**

This was the first qualitative study to explore neurologists' lived experiences of delivering an MNDD diagnosis and being the bearer of bad news, emphasising the experiential and emotional aspects of BBN for these conditions. The analysis generated two main themes; the first theme focussed on participants' patient-centred practice as a balancing act and the second theme focussed on the emotional experience and the emotional impact of BBN.

BBN was perceived by participants as a challenging, yet crucial aspect of their role which they took seriously. Patients' varying information preferences and intense emotional reactions, time constraints, MNDDs' incurable nature and a perceived limited scope for hope for conditions such as HD and MND were some of the challenges discussed by participants. Despite these difficulties and similarly to findings from other quantitative studies on neurologists' perspectives on breaking bad news (Anestis et al., 2020, 2021), neurologists reported good standards of practice, following a patient-centred approach and being sensitive to patients' needs for information and support at such a critical time in their lives.

However, patient studies have shown that a significant proportion of patients with MNDDs are still dissatisfied with how they received their diagnosis (Anestis et al., 2020). This study's qualitative nature, participants' in-depth reflections regarding their practice and the interpretative, inter-subjective understanding of participants' accounts can help shed light on the seemingly contrasting findings between doctor and patient studies.

### *Information provision at diagnosis*

Inadequate information provision at diagnosis has been highlighted by patients with MNDDs as an aspect of diagnostic consultations that needs improvement (Anestis et al., 2020). Although participants in our study reported providing additional information and answering patients' questions, this was not always possible due to short consultation times, especially for MS and PD diagnoses for which participants invested significantly less time. Even though doctors might signpost patients to other professionals for follow-up support, receiving an MNDD diagnosis in such short consultations and not being provided with additional information can be experienced as abandonment by patients (Pavey et al., 2013; Peek, 2017). In addition, some participants in this study were particularly reluctant in disclosing prognostic information even when patients explicitly asked for it. In part, this can be explained by inherent difficulties estimating MNDD's prognosis (Chio et al., 2009; Degenhardt et al., 2009), but participants also explained that they felt that disclosing prognostic information for life-shortening conditions such as MND could have detrimental effects on patients. Although not all patients with MNDDs want to receive prognostic

information at diagnosis (Dennison et al., 2016), some might experience dissatisfaction with the consultation when their autonomy is being compromised, their prognosis-related questions are left unanswered, or they feel they have to push for information (Pretorius & Joubert, 2014). In general, doctors find conveying a prognosis more difficult than a diagnosis (Schofield & Butow, 2004) and they often only disclose prognostic information when patients broach the topic (Gordon & Daughtery, 2003), delay giving it or even choose to withhold it completely (Baile et al., 2002). Doctors' stress, lack of training and fear of distressing patients and taking away hope have all been previously cited as potentially contributing to such practices (Holloway et al., 2010; Hancock et al., 2007); however engaging in prognostic discussions has been associated with a variety of positive outcomes (van Eenennaam et al., 2020) and can help patients gain a sense of control (Curtis et al., 2008; Walczak et al., 2013), plan for the future (Mitchison et al., 2012; Walczak et al., 2013), and redefine what they hope for (Clayton, et al., 2005; Coulourides et al., 2015).

### *Divergence of doctors' and patients' perspectives at diagnosis*

Another frequently cited reason that contributes to sub-optimal diagnostic experiences for patients with MNDDs is professionals' manner, specifically a blunt approach or a lack of empathy (Anestis et al., 2020). Although all participants in our study acknowledged the potentially life-changing nature of these diagnoses and the need to be sensitive, our previous findings suggest that there is a significant divergence in terms of how professionals and patients perceive and experience diagnosis delivery. For participants, gradually explaining and naming

a diagnosis was a rational process based on medical knowledge and clinical experience, especially when a diagnosis was suspected. Participants were therefore surprised when patients were still shocked and had 'violent reactions' to it. This was particularly the case for MS and PD, which were even considered 'good news' diagnoses by some participants since they were not directly life-threatening. This is in line with the findings of an early qualitative study on diagnosing PD which showed that reaching and explaining the diagnosis was perceived as a moment of 'theoretical coherence' by general practitioners, with PD diagnosis being considered less 'emotionally loaded' when compared to other neurological diagnoses (Pinder, 1992). Similarly, participants in our study reported finding MS and PD diagnoses less emotionally challenging and more benign in neurological terms, so they spent significantly less time communicating these (even 5-10 minutes for PD). Despite their emphasis on being empathic, MS and PD diagnoses were mostly viewed through a biomedical lens, not fully acknowledging the impact of these conditions on daily living and the stigma and identity disruption associated with them (Grytten, & Måseide, 2006; Leroi, 2017). Yet, although patients with PD might feel relief to receive an explanation and to start treatment for their symptoms (Habermann, 1996; Phillips, 2006) receiving a PD diagnosis can be a disrupting, irrational and shocking time in their lives (Gofton & Jog, 2008; Phillips, 2006). PD patients who received their diagnosis in such swift, business-like manner have experienced their doctor's approach as a lack of 'shared impact', a source of additional distress and abandonment (Peek, 2017; Warren et al., 2016). One participant acknowledged this as a weakness of her practice and believed it was due to PD being a common diagnosis and unavoidably comparing it with other, more severe neurological conditions, factors

which compromised her intention to show empathy and share the patient's perspective and emotions.

*Attending to patients' emotions at diagnosis*

Furthermore, although participants emphasised the importance of allowing patients to express their emotions, they gave little detail in terms of how they responded to these. This has been documented as one of the biggest challenges neurologists face when breaking the news of an MND diagnosis (Aoun et al., 2016) and an area in which neurologists would like to receive further training on (Anestis et al., 2021; Aoun et al., 2016,). Some participants emphasised the need to be there for patients and share these emotional moments - even the silence - with them while for others it seemed that emotional support was mainly the nurses' responsibility who could meet with the patient after the consultation. In addition, when prompted about this topic, other participants reported offering reassurance through giving information about the availability of services and the symptom-management they could offer. Doctors are often reported to ignore patients' emotional expression or respond to patients' concerns by providing biomedical information (Finset, 2012; Mjaaland et al., 2011). A study analysing neurologists' consultations with MS patients showed that 75% of patient expressions of concern were not attended by neurologists who switched topic, devalued these expressed emotions or offered generic reassurance (Del Piccolo et al., 2015). Such practices can discourage further disclosure of emotion (Pollak et al., 2007), despite evidence that has associated attending to patients' emotions with a variety of positive patient outcomes (Street et al., 2009). Detecting and

responding to patients' negative emotions can also have diagnostic value (Street et al., 2009), which could be particularly helpful in the early recognition and management of psychological difficulties common in patients with MNDDs (Beart et al., 2017). A study with oncologists showed that this lack of engagement with patients' emotions can be associated with doctors' difficulty in recognising emotions, worry that addressing emotions is time consuming and fear of becoming emotionally involved (Pollak et al., 2007), reasons which could also potentially explain the practice of the participants in our study.

#### *Acknowledging the emotional aspects of breaking bad news*

Apart from not always attending to patients' emotions, participants often left their own emotions during breaking bad news also unexplored. Off-the-record, some participants mentioned that taking part in the current study was useful as an opportunity to reflect on their experience of breaking bad news and the emotions that accompanied it. Similar to the findings of a US study on neurologists' well-being (Miyasaki et al., 2017), some participants in this study noted that the emotional parameters of working within neurology and breaking bad news were under-recognised. In general, healthcare professionals are in a unique position of vulnerability because of their constant exposure to other people's pain and loss, however this vulnerability is not always recognised (Carel, 2009). The expression of emotions among doctors can be perceived as a sign or weakness and incompetence (Wallace, 2010), especially in Western medicine which seems to favour the image of a skilful, rational and emotionally detached professional (Kerasidou & Horn, 2016). There seems to be a stigma around



admitting to emotional difficulties in medical practice which discourages professionals from seeking support (Department of Health, 2010) and contributes to a 'conspiracy of silence' among doctors (Wallace, 2010), despite the potential negative consequences on doctors' well-being (Kerasidou & Horn, 2016). This was reflected by some participants' initial reluctance to discuss the emotional experience and impact of BBN, viewing it just as a clinical task stripped of emotion. Participants felt that they had to remain strong while BBN, believing that their emotions were incidental to patients' well-being. However, other participants emphasised that being emotionally affected when breaking bad news was normal and part of being human.

#### *The emotional impact of breaking the news of an MNDD diagnosis*

In line with findings from other quantitative studies which have investigated neurologists' perspectives on BBN, participants generally experienced it as an emotionally burdensome and stressful task (Aoun et al., 2016; Anestis et al., 2021). The experience of stress extended beyond the actual consultation (Studer et al., 2017), affecting them on a cognitive and somatic level too. Apart from the distress derived from the task itself, participants arguably experienced moral distress too, a negative feeling evoked when clinicians cannot carry out what they consider to be ethically appropriate (Lamiani et al., 2017). Moral distress can be induced by organisational restrictions common in healthcare institutions (Mullet, 2016, as cited in Delgado, 2021) such as those discussed among participants in this study: work overload, inadequate consultation slots and unavailability of quick follow-up appointments. These

organisational restrictions arguably had an impact on both the standards of care professionals could offer at diagnosis (e.g., limited time to provide information and support) but also their experience of BBN (e.g., the stress of clock-watching). Acknowledging the experience of moral distress among doctors is critical as it has been identified as a risk factor for depression and job quitting and is associated with low job satisfaction (Lamiani et al., 2018). Moreover, BBN seemed to be a task that often uncovered participants' professional and personal vulnerabilities. As professionals, participants often experienced emotions of self-doubt, guilt and powerlessness, feeling that they could only offer bad news without being able to balance this with hope for an effective treatment plan. BBN for MNDDs was therefore not an enjoyable task as participants often felt they were 'causing harm' to patients through bad news without being able to offer treatment and fulfil the caring aspect of their job. Treating an incurable disease has been associated with feelings of inadequacy and limited treatment options generally make BBN consultations more difficult (Nisbet et al., 2017), which explains why participants found delivering HD and MND diagnoses more challenging. BBN heightened participants' personal vulnerabilities too, especially when participants identified with patients' circumstances. Delivering the diagnosis for MNDDs, which do not have clear causing factors, to patients of a similar gender, age or family circumstances to them, was a reminder of the unpredictability of life and neurologists' own vulnerability to disease and death. Identifying with patients was perceived as an additional challenge of BBN which often made it difficult for participants to recover emotionally and move on to the next patient. Participants had thus learnt how to suppress these emotions potentially as a way to protect themselves from the emotional impact and retain their objectivity (Coulehan,

2005). However, identifying with patients as a form of vulnerability can also help doctors better empathise with and understand a patient's situation, allowing them to offer genuine compassionate care and support (Malterud et al., 2009).

### *Empathy, emotional involvement and detachment when BBN*

Although empathy was recognised by participants as a prerequisite for effective BBN consultations, empathy was also believed to 'make the job harder' by uncovering the vulnerabilities discussed above and making doctors susceptible to distressing emotions. Empathy has been recognised as a vital component of therapeutic relationships (Yu & Kirk, 2009) and associated with a variety of positive outcomes for both healthcare professionals and patients (Derksen et al., 2013; Hickson et al., 2002; Riess et al., 2012). Not surprisingly, BBN protocols have emphasised its importance in meeting patients' emotional needs (Baile et al., 2000; Villagran et al., 2010). However, it is a common belief among doctors that empathy increases their vulnerability to patients' suffering and might act as a risk factor for their well-being (Tanriverdi, 2013), yet only one out of ten studies in a systematic review supported this claim (Wilkinson et al., 2017). It has been proposed that the false belief that links empathy with burnout can be explained by a confusion between empathy and sympathy (Kerasidou & Horn, 2016). Empathy encompasses both emotional and cognitive domains which allow an individual to understand and feel others' perspectives and experiences without losing the boundaries of the self (Hojat et al., 2001; Rogers, 1995), whereas sympathy is the emotional identification with others which can actually lead to secondary traumatic stress and emotional over-involvement (Crumpei & Dafinoiu,

2012; Switankowsky, 2000). Indeed, participants reported feeling sad and drained and showed sympathy when they were exposed to patient's intense emotional reactions or had to deal with a particularly emotional case, which indicates that it was probably sympathy and not empathy which had the more intense emotional impact on them. Nevertheless, across interviews, there was a fear of becoming emotionally over-involved when BBN, so participants reported either numbing their emotions or sometimes completely emotionally detaching themselves in order to be able to carry on and remain objective and professional. Similarly, a qualitative study within oncology described BBN as a task which could cause a loss of control in terms of doctors' emotions and professionalism (Friedrichsen & Milber, 2006). Although emotional over-involvement could indeed affect medical objectivity and clinical judgement and cause emotional exhaustion and compassion fatigue (Figley, 2012; Gleichgerrcht & Decety, 2012; Weilenmann et al., 2018), detachment can also lead to a loss of meaning, objectification of patients and cynicism, factors which could lead to burnout and depression (Weilenmann et al., 2018). Additionally, we could argue that participants' heavy workload and short consultation slots did not always allow space for genuine emotional involvement which could explain why detachment was considered easier than involvement. There is a fine difference, however, between detachment and disengagement from patients, with increased detachment potentially perceived as apathy and lack of understanding by patients (Maslach, 2003).

### *Implications for practice and organisational change*

Despite the good standards of practice reported in this study, participants did not always have access to resources that would allow for a truly empathic and patient-centred approach. Although not included as a finding in our results section, neurologists in this study reported rarely receiving any training in breaking bad news and managing emotions during their specialist training. This lack of training, along with differences in perspectives and organisational restrictions highlighted in our study, could potentially explain the contrast between doctor and patient studies regarding diagnosis communication in MNDDs. In order to respond appropriately to patients' information and emotional needs at diagnosis, neurologists firstly need to exercise their empathic approach by understanding patients' reactions to bad news without imposing their own judgment regarding the severity of a diagnosis. Professionals should be guided by patients' emotions, appropriately respond to these and offer tailored support and information, avoiding one-size-fits-all approaches (e.g., never promoting a sense of hope for MND or never discussing life expectancy at diagnosis). Neurologists can follow BBN protocols such as the COMFORT model, which adopts a relational approach to BBN that addresses the needs, expectations and desires doctors and patients bring in a consultation and can foster convergence between their perspectives (Villagran et al., 2010). Our findings also suggest that emotional vulnerability when breaking bad news should be recognised and not suppressed. Vulnerability theory suggests that vulnerability can be generative, promoting innovation, growth and fulfilment (Fineman, 2012), but it requires self-awareness and self-care in order to be utilised in therapeutic relationships (Barnard, 2016). Appropriate training should, therefore, not just focus on BBN but equip professionals with the appropriate skills of recognising their own vulnerabilities,

managing their own emotions and reflecting on how these affect their practice (Meitar et al., 2009). Training should educate professionals on the fine differences between sympathy and empathy and detachment and disengagement, potentially utilising the concept of detached concern, a strategy that incorporates empathic concern and detachment in a dynamic way that both addresses patients' needs without negatively impacting professionals' well-being (Lampert et al., 2019). Apart from offering such training, it is fundamental that organisations make space for empathy and attend to doctors' moral distress (Kerasidou & Horn, 2016) by tackling severe staffing issues in neurology in the UK (Nitkunan et al., 2020) and reconsidering current restrictions on time slots, especially for BBN consultations.

## **Limitations**

There are several limitations that should be considered in terms of the present study's methodology and focus. Firstly, because recruiting participants for this study was a major challenge, we could argue that the neurologists who did take part might be more interested in the topic or more confident in their practice of BBN. Although it was not an intention of this phenomenological study to produce generalisable results, we understand that the results presented might not reflect the typical professional. Secondly, although samples in IPA need to be homogenous, participants in our study practised in different types of settings and different parts of the UK, with participants practising in rural areas or specialist clinics having more time to invest in BBN consultations. This difference could potentially have a substantial effect on the experience of BBN and we observed that participants who were able to offer longer consultations were also able to

provide richer accounts compared to participants who practised in busy general hospitals in big cities. Thirdly, because of this study's exploratory nature we chose to group four MNDDs together, however results could be more refined if these diagnoses were examined in separate studies, for example, to address the impact of different types of MND or MS on the experience of BBN. In addition, other MNDDs, often lesser known and associated with a poor prognosis, such as multiple system atrophy, progressive supranuclear palsy and atypical parkinsonism were not included in this study. Fourthly, our interview schedule did not include a specific question about cultural factors (e.g., some cultures support the concealment of a diagnosis, Holmes & Illing, 2021) which may influence the process of BBN and because this was not addressed by participants either, we feel that it is an important omission of this study.

## **Conclusion**

Breaking bad news for MNDDs was a challenging task for neurologists who had to manage patients' varied information and emotional needs, while also managing their own emotions, a heavy workload and time restrictions. The IPA approach allowed an exploration of the intricacies of the experience of BBN and helped highlight how participants' practice was shaped by their perspectives and how the task uncovered their personal and professional vulnerabilities. Exploring the lived experience of being the bearer of bad news in the context of MNDDs also helped explain the observed differences between studies of doctors' and patients' perspectives on diagnosis delivery and suggest ways to support appropriately professionals with this task and eventually optimise the patient experience.

## Tables

**Table 1.** Participants' characteristics

<b>Participant</b>	<b>Gender</b>	<b>Years of experience as a consultant</b>	<b>Age</b>
<b>P1</b>	Male	20	54
<b>P2</b>	Male	13	49
<b>P3</b>	Female	12	47
<b>P4</b>	Male	12	48
<b>P5</b>	Male	10	46
<b>P6</b>	Male	8	44
<b>P7</b>	Male	6	43
<b>P8</b>	Female	2	38



# **Chapter Seven**

## **General Discussion**

This chapter will start with an overview of the research aim and objectives of this thesis and how these were achieved by the individual studies. An integration of findings from the different studies will then be attempted to further enhance our understanding on the topic of the thesis. The main findings will then be interpreted and positioned within the scientific literature on the topic of breaking bad news and the fields of healthcare communication and medical education. Finally, the limitations of the current thesis along with implications for practice and research will be discussed.

### **Overview**

The aim of this thesis was to develop an understanding of HCPs' perspectives on breaking bad news for MNDDs in the UK. Three research objectives were specified to facilitate the process of reaching the research aim: a) Establish pre-existing knowledge and identify potential research gaps on patients' with MNDDs and doctors' perspectives on diagnosis communication, b) Investigate neurologists' current practice, attitudes and lived experiences of communicating an MNDD diagnosis in the UK, and c) Explore non-medical

professionals' range of involvement in breaking bad news for MNDDs in the UK. To meet the research aim and objectives, a mixed-methods approach with a pragmatist critical-realist stance was adopted and four studies were conducted. Below an overview of how the research objectives were addressed by the individual studies (publishable papers, PPs) is provided.

**Research Objective 1:** Establish pre-existing knowledge and identify potential research gaps on patients' with MNDDs and doctors' perspectives on diagnosis communication.

Before the conduct of empirical studies that investigated professionals' perspectives in breaking bad news, it was considered essential to become familiar with the pre-existing knowledge, explore the breadth and nature of research and identify potential research gaps in the topic of diagnosis communication in MNDDs. A scoping review of studies from patients' and doctors' perspectives (PP1) was therefore conducted. Forty-seven studies were included in the review indicating that diagnosis delivery for MNDDs had attracted substantial research interest. However, looking more closely at the results, almost half of the studies included ( $n = 23$ ) were related to the diagnosis of MS, only six studies addressed doctors' perspectives and we had to exclude HD from the review as we found no studies that met the inclusion criteria. Only one study on doctors' perspectives was conducted in the UK and it was the only doctors' study which adopted a qualitative methodology, addressing general practitioners' experiences with diagnosing PD (Pinder, 1992). The identified research gap on UK neurologists' perspectives on breaking bad news for MNDDs informed the rationale for

consequent studies of the thesis (PP2 and PP4). Moreover, the scoping review provided a summary of available evidence which highlighted that a significant proportion of patients were dissatisfied with how they received their diagnosis, especially with the information provided, the duration of the diagnostic consultation and the lack of compassion shown by doctors. These findings were used to inform the design of the empirical studies of the thesis (PP2, PP3, PP4).

**Research Objective 2:** Investigate neurologists' current practice, attitudes and lived experiences of communicating an MNDD diagnosis in the UK.

This research objective was addressed by PP2, a quantitative survey study and PP4, a qualitative study adopting an IPA approach. Although there was an overlap between the focus of these studies in that they both addressed neurologists' current practice in BBN for MNDDs, the qualitative study provided an in-depth exploration of their lived experiences and the emotional aspects of BBN which had only been briefly addressed by previous quantitative studies identified in the scoping review (PP1).

The survey was completed by 49 participants who acknowledged the difficult and stressful nature of BBN, but reported good standards of practice, especially in terms of setting-related factors (providing a private space, avoiding interruptions, arranging suitable seating and maintaining eye contact). Challenging aspects of the task (e.g., perceived lack of time) and aspects of the consultation where standards of practice were sub-optimal (e.g., a reluctance to promote a sense of hope for HD and MND and not always asking patients to bring

family members to the consultation) were identified. These findings were further explored in the IPA study where participants elaborated on their lived experiences of BBN. Specifically, although participants intended to offer patient-centred consultations, BBN was perceived as an almost impossible balancing act due to the progressive and incurable nature of MNDDs, the variety of patients' communication preferences and often severe time constrictions and limited service capacity. Findings from the IPA study also suggested that neurologists often struggled to respond to patients' emotional needs and were challenged by the emotional impact of being the bearer of bad news and the vulnerabilities that this task uncovered.

**Research Objective 3:** Explore non-medical professionals' range of involvement in breaking bad news to newly diagnosed patients with MNDDs in the UK.

We acknowledged the need to explore non-medical HCPs' involvement in BBN for MNDDs while conducting the scoping review (PP1), coming across findings from patient studies that praised specialist nurses for their practice in providing information and support at diagnosis. This research objective was addressed by a qualitative, thematic analysis study which aimed at exploring HCPs' involvement in BBN to newly diagnosed patients with MNDDs in the UK. Since MNDDs are usually managed by multidisciplinary teams, a variety of HCPs took part in the study, who identified BBN as a vital part of their practice. Findings suggest that non-medical HCPs were involved in a range of tasks that could be considered BBN, from re-iterating diagnostic information and explaining the impact of MNDDs on different aspects of patients' daily lives to initiating

prognostic and end-of-life discussions. Participants discussed the challenges of facilitating such difficult discussions, assessing and responding to patients' information needs, but also highlighted the importance of BBN as a way of supporting and empowering newly diagnosed patients.

## **Integration of Findings**

The integration of quantitative and qualitative findings in mixed methods research can enable a more in-depth understanding of the subject matter (Fetters, Curry & Creswell, 2013). Integration can be achieved at different levels and through the use of different techniques depending on the study design. The first level of integration in this thesis was achieved at design level, as findings from the earlier studies informed the design of the others. Attempts at integration can also be found in the discussion sections of PP2, PP3 and PP4 where findings from each study were interpreted through contrasting and comparing with findings from earlier studies of the thesis. Here, an integration of the findings from all four studies will be attempted. Integration will be achieved through a 'weaving technique': presenting and contrasting the main findings from different studies through narrative, on a theme-by-theme basis (Fetters, Curry & Creswell, 2013; Othman, Steen & Fleet, 2021). During the process of integration, the main findings from different methods were contrasted to reveal convergence, complementarity, silence or discrepancies between them.

## **Overall professionals' attitudes towards BBN for MNDDs**

Participants from all the empirical studies of the thesis viewed BBN as a critical aspect of their practice with qualitative accounts acknowledging the potential long-term effects of these consultations. Based on their clinical experience, participants believed that the quality of these conversations could influence their future relationship with patients and patients' adjustment to the news, outcomes which empirical research has indeed associated with the perceived quality of BBN (Schofield et al., 2003). Addressing the life-changing nature of these diagnoses, participants in the qualitative studies reported following a patient-centred, sensitive and empathic approach to giving bad news. Although BBN was generally perceived as a difficult task (77% of participants in the survey study believed it was 'probably' or 'definitely' difficult), 94% of survey respondents believed they were 'good' to 'very good' at it, similarly to another survey of neurologists in Italy where 79% of respondents considered their MS diagnosis delivery practice as competent (Martinelli et al., 2012). Participants in our survey study also believed that 81% of patients were 'somewhat' to 'very satisfied' with how the diagnosis was delivered. Although some were conducted in different countries, it is worth noting that patient studies have reported significantly smaller percentages in terms of satisfaction with diagnosis delivery (45% - 68%) (Anestis et al., 2020) with only one study reporting that 91% of patients were satisfied with how their diagnosis was communicated (Lorefice et al., 2013). This difference could be attributed to doctors' tendency to overestimate their communication competence (Tongue, Epps & Forese, 2005) and differences between doctors and patients' views in terms of what constitutes

effective communication, with patients usually preferring a psychosocial approach while doctors follow a biomedical model of communication (Kee, Khoo, Lim & Koh, 2018).

### **Information provision**

A recent UK patient experience survey with a variety of neurological patients (The Neurological Alliance, 2019) and our scoping review of patients' with MNDDs perspectives on diagnosis communication (PP1) showed that a significant proportion of patients were dissatisfied with the amount of information they received at diagnosis. Our empirical studies on HCPs' perspectives indicated that the process of effectively assessing and responding to patients' information preferences was potentially the most central and one of the most challenging aspects of their BBN practice. Information giving was generally perceived as a great responsibility due to the potentially distressing nature of the information that needed to be imparted to patients' with MNDDs. Participants in all three HCPs' studies (PP2, PP3, PP4) spoke of the need for clarity and honesty when providing information and acknowledged patients' fundamental right to receive information about their diagnosis. At the same time, professionals were faced with a challenge reported commonly in studies on breaking bad news (Baile et al., 2000; Bousquet et al., 2015), providing realistic information, without taking away hope, which was considered the most difficult aspect of BBN by the neurologists in the survey study (PP2). Participants in the qualitative studies (PP3, PP4) also discussed the challenge of effectively assessing patients' information needs, especially as these could significantly vary among patients. Explicitly

asking about what information patients wanted, double-checking before imparting information and being guided by patients' questions, cues and emotional state were some of the strategies that HCPs followed to make sure they followed a patient-centred approach.

However, although 90% of respondents in PP2 reported that the course and prognosis of the disease should be discussed at diagnosis, some neurologists in PP4 discussed their reluctance to provide prognostic information, especially regarding life expectancy, for life-threatening conditions such as MND and HD, even when patients asked for such information. Participants explained that it would be difficult to give accurate predictions as the progression of MNDDs can be unpredictable in early stages, but they would also withhold prognostic information if they felt that it would cause significant distress. However, our scoping review showed that most (even MND) patients with MNDDs required prognostic information at diagnosis (PP1). Arguably, patients might feel dissatisfied with not having their prognostic questions answered, even when they were provided with an explanation regarding the prognostic uncertainty in MNDDs. On the other hand, non-medical HCPs in PP3 seemed more willing to have prognostic conversations with newly diagnosed patients to help them '*know where they stand*' and '*make plans for their life*'. However, these conversations mostly focussed on the impact and course of the disease, not life expectancy. In addition, neurologists in PP4 probably felt that an MNDD diagnosis was already difficult to digest, whereas patients might have been more ready to receive prognostic information in their subsequent appointments with non-medical HCPs. Some participants in PP3 and a participant in PP4 reported another 'deviation'



from their overall patient-centred approach to information giving. These HCPs often felt it was their professional duty to provide information in order to prevent future crises or encourage decision-making for end-of-life care when patients were already at advanced stages of the disease, regardless of patients' readiness to receive such information. Professionals' accounts, therefore, indicate that although patient-centred care was generally supported, information giving was an aspect of BBN which could raise ethical dilemmas, with more paternalistic practices or a sense of professional obligation sometimes outweighing patient-centredness.

Overall, all HCPs reported good standards of practice, providing plenty of information that could help patients understand their diagnosis, however neurologists' ability to provide an adequate amount of information was often hindered by time restrictions (discussed in another section below) which non-medical HCPs did not experience. In addition, although the findings of this thesis suggest that even if patients did not receive enough information from their doctor at diagnosis, subsequent appointments with other HCPs could help fill this information gap. Besides often reiterating diagnostic information, information provision for non-medical HCPs focussed on '*unpacking the diagnosis*', explaining the impact of an MNDD diagnosis on different aspects of a patient's life. Although the provision of written information could help in cases of limited consultation times with neurologists, only 28% of participants in PP2 reported 'always' providing such information. Nevertheless, we believe that not being provided with information at diagnosis could still be experienced as '*abandonment*' by some patients (PP1) even if they were aware that further appointments had been

scheduled for them. Moreover, some participants in PP3 mentioned that, unfortunately, not all MNDDs patients were immediately referred to other HCPs post diagnosis, which can be a missed opportunity for patients to receive tailored information and support at such a critical stage of their illness journey.

### **The emotional experience of BBN: empathy, emotional involvement and emotional impact**

Acknowledging that receiving an MNDD diagnosis could be a life-changing process for patients, participants in the qualitative studies (PP3, PP4) emphasised that bad news should be broken in a sensitive and empathic manner. Although this approach seems sensible, from the professional's point of view, it could be experienced as a paradox. One participant vividly compared sensitively delivering an MND diagnosis to '*punching someone, but gently*', indicating that such '*terrible*' (their words) diagnoses will always be hard for patients to receive and for professionals to give. However, professionals still tried to offer empathic and sensitive consultations, for example by breaking the news gradually. Neurologists in the IPA study (PP4) hoped that by assessing patients' knowledge and suspicions, explaining the neurological basis of their symptoms and including some 'warning shots' before giving the name of the diagnosis, patients would be more prepared and less shocked when hearing their diagnosis. Participants of the qualitative studies also emphasised the need to both appear warm and understanding, but also try to empathically understand the patient's emotional reactions to the news.

Generally, professionals appeared competent in naming the different emotional reactions patients might exhibit and recognised that an MNDD diagnosis could be shocking, triggering patient's fears for all the different losses that these diagnoses might signal. However, findings from the IPA study (PP4) indicated that neurologists could not always empathise with patients. Participants could not always understand patients' intense reactions when they received a PD or an MS diagnosis, or they could not attune their emotions and perspectives to those held by patients. Although patients could be shocked or devastated by a PD diagnosis, professionals sometimes viewed these diagnoses in more positive light, comparing them with other more serious diagnoses. Participants viewed PD and MS as benign diagnoses compared to MND and HD as they were not directly life-threatening and could be treated. In addition, one participant admitted that her difficulty in empathising with PD patients was also due to PD being a diagnosis she commonly delivered multiple times a week. Professionals' perspectives towards these two conditions were therefore mostly based on their clinical experience and a biomedical perspective which did not allow for a truly empathetic approach that would acknowledge the physical and psychosocial connotations attached to these diagnoses from the patient's perspective. This considerable difference between patients' and doctors' perspectives can potentially explain why some patients with MS and PD have expressed their dissatisfaction with doctors who delivered the diagnosis '*routinely*', in '*casual*', '*business-like*' and '*swift*' appointments (Edwards et al., 2008; Peek, 2007) (PP1).

Although empathy was considered vital in BBN effectively, neurologists also believed it '*made the job harder*', making them vulnerable to distressing

emotions and prone to losing their objectivity and becoming emotionally over-involved. There was a sense from some interviews that participants were - at least initially - reluctant to address their own emotions when BBN, presenting an experience of delivering bad news that was purely rational, stripped of emotion. For example, one participant viewed it just as part of his job and another one mentioned that it was easier to be emotionally detached than maintaining an empathic approach when BBN. In addition, participants who felt comfortable in discussing their emotions talked about the need for doctors to admit they are '*only human*' and therefore susceptible to emotions. At the same time, they believed that because patients should be the centre of the consultation, they had to remain '*strong*' and be wary of becoming overinvolved. Participants' accounts suggested that it was the expected norm for doctors to hide their emotions, yet at the same time they were expected to show empathy. These findings could potentially explain why patient studies in the scoping review (PP1) often presented doctors as being emotionless. Arguably, doctors do experience emotions during BBN consultations but they either identify and then detach themselves from them to remain objective and prevent emotional distress or they hide or '*numb*' their emotions to appear strong for the patient. In the first instance, doctors choose to not engage or experience an emotion at all and in the second instance they do experience an emotion but regulate their emotional expression to appear composed. Nevertheless, both strategies could potentially be perceived negatively by patients who prefer an empathic approach when receiving bad news.

Healthcare professionals across all the empirical studies of the thesis agreed that BBN for MNDDs had an emotional impact on them. Although it was

not within the main aim of the TA study (PP3) to explore non-medical HCPs' emotional experience of BBN, participants did mention that BBN was emotionally difficult, using emotionally intense words to describe feeling '*drained*', '*exhausted*', '*sad*' and '*anxious*' when engaging with this task. The studies of neurologists' perspectives (PP2, PP4) reported similar results, however IPA's emphasis on lived experience helped yield more nuanced findings on the emotional impact of being the bearer of bad news. In the survey, more than half of respondents reported experiencing at least moderate levels of stress and anxiety when BBN, while participants in the IPA study discussed the experience of a build-up of tension that peaked right before the name of the diagnosis was given. The impact of these consultations could also stretch beyond the actual appointment, often leaving doctors feeling exhausted and drained both mentally and physically. Apart from the impact of delivering an MNDD diagnosis, participants also explained that being exposed to patients' emotional reactions to the news amplified their emotional distress and feelings of sadness and sorrow. These two, active and passive, aspects of breaking bad news, giving an MNDD diagnosis (active) and witnessing patients' reactions to the news (passive) uncovered neurologists' professional and personal vulnerabilities. Because of the incurable and progressive nature of MNDDs, participants experienced giving these diagnoses as causing harm ('*punching someone*', '*cutting someone's life off*', '*wrecking someone's life*'). Participants experienced guilt, responsibility and even powerlessness as professionals, feeling that they could only offer a diagnosis without being able to balance it with a curative treatment plan. Moreover, their exposure to patients' suffering at diagnosis, and the lack of clear causative factors for MNDDs, was a reminder of their own vulnerability and mortality, especially when participants identified with

patients that had similar age, gender or life circumstances to them. These findings regarding the intense emotional impact of BBN could further support the idea that some professionals might choose to detach themselves emotionally to mitigate the risk of emotional overload.

### **Providing emotional support**

Apart from effective information provision and maintaining an empathic approach, offering emotional support was another critical aspect of BBN consultations. However, it was common across qualitative patient studies included in our scoping review (PP1) to report patients' dissatisfaction with the lack of emotional support they received at diagnosis. Overall, dealing with patients' emotions was only perceived as a challenge by 25% of neurologists in the survey study, yet participants in the IPA study did not provide information about how they responded to patients' emotions. Most participants emphasised the need to allow patients to express their emotions and offer support through being there and listening to them but did not discuss whether they further explored these emotions with patients. This could potentially be linked with some professionals' reluctance to be emotionally involved with patients and lack of time to engage in such discussions, while one participant in the IPA study believed that the provision of emotional support was nurses' responsibility and another one believed patients' emotions at diagnosis could not be managed at all. Information provision about the healthcare support that patients could access and how their symptoms could be managed were also considered as a form of emotional support

by neurologists and as a way to instil a sense of hope. Yet, findings from both neurologist studies (PP2, PP4) suggested that some participants did not consider promoting a sense of hope to patients with HD or MND, suggesting that hope in the context of these two conditions would be false and unrealistic.

On the contrary, how non-medical HCPs offered emotional support when BBN to newly diagnosed patients with MNDDs was a significant aspect of their qualitative accounts. An entire theme of the TA study (PP3) was developed around how participants empowered patients and helped them regain a sense of control over their health and lives. HCPs offered emotional support not just through information provision, but also through offering holistic assessments, allowing patients to discuss what mattered to them the most and motivating and encouraging them to sustain a positive outlook. Participants tried to instil a sense of hope to all patients regardless of their diagnosis by focussing on what goals could be achieved and on ways that a patient's quality of life could be maintained or improved. Non-medical HCPs were mostly working within a neuro-rehabilitation model (Barnes, 2003) which they believed required from them to be positive and motivating. This, along with the much longer appointments they could offer, could potentially explain why their practice in terms of emotional support differs significantly from that reported by neurologists.

### **Consultation duration and organisational factors**

Maintaining a systems-informed approach throughout the research process encouraged participants in all studies to reflect on the wider systems

factors that affected their practice. Organisational factors, mainly short consultation slots and incapacity to offer quick follow-up appointments, severely affected all aspects of neurologists' practice of BBN for these conditions. Despite the need for these diagnoses to be communicated effectively and the multi-faceted and challenging nature of BBN as a communication task, neurologists were not always provided with adequate time resources for these consultations. Although the survey study (PP2) reported an average consultation time of about 30 minutes for PD, MS and HD and 41 minutes for MND, a significant proportion of neurologists (20% - 39% depending on the condition) reported spending 15 to 20 minutes to deliver a diagnosis. Additionally, participants in the IPA study explained that they were sometimes only given 15-minute slots for these appointments and another participant believed that five to ten minutes were enough to deliver a PD diagnosis. Interestingly, some of the participants in the IPA study (PP4) reported a flexibility in terms of the time they could dedicate for BBN, but these participants either practised in a specialist clinic or in a rural area. On the other hand, neurologists who ran general neurology clinics and practised in large cities faced significant time restrictions, so they had to '*clock watch*' and often let their clinics overrun in order to deliver these diagnoses effectively. Besides the IPA study, the impact of such organisational factors was also highlighted by the plethora of qualitative comments provided by participants in the survey study (PP2). It was generally felt that the optional space provided for these comments was used by many participants to 'defend' themselves and their practice and raise their concerns regarding the short time slots they were required to adhere to and the long waiting lists for appointments. The waiting time for a follow-up appointment for a patient with PD could be as long as 15 months, which



meant that professionals often had to break bad news to patients who were unaccompanied to prevent additional diagnostic delay. Patients with MNDDs have expressed their frustration with such short consultations (PP1) especially knowing that it would be several months before they could see a doctor again. These organisational restrictions arguably affected the quality of the consultations that neurologists could offer as there was not always time for an adequate explanation of the diagnosis or time for patients to ask questions and raise their concerns. Moreover, being time-restricted when engaging in such a critical task could be an additional distressing factor to an already emotionally burdensome task. It is noteworthy that non-medical professionals mentioned feeling '*lucky*' and '*privileged*' to be able to offer long consultations in their first appointments with newly diagnosed patients, acknowledging that doctors did not have this 'luxury'.

### **Training and BBN guidelines**

Although most professionals in the empirical studies reported receiving some training in BBN (83% of neurologists in the survey study, PP2), this was mostly as a part of their core training. Participants rarely reported receiving training during their specialist training, however neurologists did not believe that lack of sufficient training had an impact on their practice. Nevertheless, both medical (78.5% of survey participants) and non-medical professionals reported at least moderate interest in receiving further training on BBN specifically for MNDDs and responding to patients' emotions. Professionals across studies reported usually not following any specific guidelines for BBN and believed that the best approach was to tailor their practice based on individual patients' needs.

In addition, HCPs in the qualitative studies (PP3, PP4) reported engaging in self-care activities and discussing difficult conversations with their colleagues as ways to deal with the emotional toll of BBN, but no formal sources of emotional support were identified.

### **Understanding HCPs' perspectives on BBN for MNDDs using communication models**

Communication can be understood as a goal-oriented, problem-solving behaviour (Kellerman, 1992). Within healthcare, the overarching goal of communication between HCPs and patients is the provision and receipt of high-quality care that includes both the medical management of the disease and attending to its psychosocial impact (Hack, Degner & Parker, 2005). Viewing healthcare communication as goal-oriented behaviour, Hulsman (2009) proposed a model that explained how HCPs detect goals and form responses in healthcare encounters. This model can help summarise and interpret the main findings of the thesis, especially regarding neurologists' perspectives in delivering an MNDD diagnosis.

The main reason for a healthcare encounter is called the *primary goal*, which in our case is the delivery of an MNDD diagnosis. *Secondary* or *sub-goals* are derived from the primary goal and reflect the different steps required to meet the primary goal. In the context of BBN, assessing patients' information preferences, providing information and responding to patients' emotional reactions are some of the secondary goals of the encounter. The content of a consultation can

therefore depend on the set of secondary goals that a HCP believes are essential in achieving the primary goal, but also the professional's ability to identify additional goals that arise from the interaction with patients, from their cues and expressed needs (Hulsman, 2009). Cues often reflect patients' concerns or emotions and can be an important source of information for the detection of goals, yet they are often missed by HCPs (Zimmermann, Del Piccolo & Finset, 2007). Healthcare communication can be considered complex as HCPs are expected to reach multiple goals, but also identify and shift through goals as the encounter develops by appraising their qualities (Hulsman, 2009). Goals can be evaluated and prioritised based on different properties such as their importance, difficulty and specificity (Austin & Vancouver, 1996). Identifying goals and forming a response is usually an automated process through the activation of cognitive schemata or scripts (Kinderman & Humphris, 1995). Scripts reflect knowledge structures that have been developed through experience and aid the identification of goals and the selection of effective responses and behaviours to achieve these goals. The process of shifting through and achieving goals via the formation of effective responses relying on scripts can be affected by internal and contextual factors, such as HCPs' attitudes, social norms, stress and insufficient time (Hulsman, 2009).

In the context of BBN, delivering a diagnosis is the primary goal and secondary goals are determined by the set of sub-tasks that a HCP believes are needed to effectively break bad news. Published guidelines for BBN (Baile et al., 2000; Villagran, Goldsmith, Wittenberg-Lyles & Baldwin, 2010) can help professionals by specifying the series of secondary goals and appropriate

responses which can facilitate an optimal diagnosis delivery. However, participants in our empirical studies were not familiar with such guidelines. Nevertheless, they acknowledged that alongside effective information provision other important goals should be met when BBN for MNDDs, such as appropriately assessing patients' information needs and preferences and maintaining an empathic approach. Yet, reported secondary goals, such as 'showing empathy' or 'responding to patients' emotions', often lacked specificity, especially compared to the goal of effectively assessing information needs, which participants could break down into several sub-tasks (explicitly ask patients, double-check, assess cues etc.). Lack of specificity can act as a constraint in the process of attaining a goal and it could be linked with the unavailability of cognitive scripts that include a repertoire of actions (e.g., ways to respond to patients' emotions). A lack of such scripts could be associated with minimal previous experience, avoidance of responding to patients' emotions or lack of relevant training. The perceived difficulty of a goal can also determine whether it is achieved, for example one participant mentioned that patients' emotional reactions cannot be managed at diagnosis whereas another one mentioned that it is hard to show empathy when BBN. Such attitudes regarding the difficult of attaining emotion-related goals can explain why patients' emotional needs were not always attended to at diagnosis.

Moreover, the process of goal appraisal is prone to errors as goals can be missed, different goals might be conflicting or there might be a mismatch between patients' and HCPs' perspectives regarding the importance of different goals (Burgoon, Berger & Waldron, 2000). Due to the impact of MNDDs on a physical, cognitive and psychological level but also the uncertainty regarding their course

and prognosis, the amount of information and clarifications to be imparted at diagnosis could be overwhelming. Information provision could therefore be perceived as more important than providing emotional support, especially taking time constraints into account. For participants in the IPA study, conflicting goals was a common aspect of their experience of BBN which affected their practice. Neurologists had to provide a comprehensive explanation of the diagnosis, but also be wary of not providing more information than patients could handle. For some of these goals, the perceived conflict was so intense that goals seemed almost unattainable (e.g., delivering such devastating diagnoses while adopting a sensitive approach and minimising patients' distress). Some participants also had to meet externally imposed goals to keep the consultation short (as short as 15 minutes), which made it impossible to meet the aim of adequately informing patients about their diagnosis or investing time in exploring patients' emotions. On an emotional level, doctors also felt they had to conform to the cultural norm within medicine that expects them to remain objective, avoid emotional involvement or hide their emotions, while also showing an empathic understanding of patients' reactions (Kerasidou & Horn, 2016). The experience of stress during healthcare encounters has been shown to be further intensified by patients' emotional cues and can limit professionals' capacity to form a response. Therefore, emotional detachment for some participants might have been the chosen coping mechanism in order to meet the goal of 'surviving' a day full of appointments, potentially having to manage several BBN consultations within a day. Healthcare professionals' attitudes can also help explain their communicative behaviour. Professionals' attitudes regarding psychosocial aspects of care can affect their detection and response to emotional cues and their overall expression

of empathy (Levinson & Roter, 1995). Some participants in the IPA study showed a reluctance to acknowledge the emotional aspects of BBN and one participant believed emotional support was not within his professional remit, factors which have probably influenced their practice in terms of identifying and managing psychosocial goals in BBN consultations.

In summary, Hulsman's (2009) model illustrates the complexity of BBN as a task that requires the identification and management of multiple, often conflicting goals. Using this model permits an interpretation of professionals' experience and practice. The multiple components of the model and the recognition of both internal and external factors influencing the process of healthcare communication can help identify areas of improvement and suggest clinical and research implications of the findings of this thesis which will be explored in the next section.

## **Implications for clinical practice**

Implications for clinical practice have been presented within each individual PP, however here we will provide a summary of these implications, also drawing from the integration and interpretations of the findings from all studies. Overall, clinical implications presented here are based on our findings on professionals' perspectives on BBN and also on comparing these findings with those reported by pre-existing MNDD patient studies who have identified aspects of BBN that could be improved.

In terms of information provision, neurologists in empirical studies of the thesis seemed to provide a rich amount of information considering the often-restricted consultation times. However, given the complex nature of MNDDs, most participants agreed that they would need more than one consultation to deliver the diagnosis effectively, an approach that has shown positive results in patients with MND (Seeber et al., 2019). Providing an early follow-up consultation could help patients prepare questions and absorb and retain information better. Participants discussed the challenges of providing information about prognosis because of the unpredictability of MNDDs, with some completely avoiding providing information on prognosis and life expectancy to patients with HD and MND. We suggest that providing information regarding the prognostic uncertainty of MNDDs should be an essential part of patient education at diagnosis, tailored to the specific questions and concerns expressed by patients. A communication guide which aims to facilitate the discussion of personalised prognosis in MND (van Eenennaam et al., 2020) could also help neurologists navigate these conversations. In addition, the use of general information aids at diagnosis (e.g. going through a navigable CD with information with the doctor) have also shown promising results in increasing patients' with MS knowledge about their condition and satisfaction with diagnosis delivery (Boreanni et al., 2014; Solari, 2014). The development and use of similar information aids for other MNDDs could be beneficial. Based on previous patient feedback (Anestis et al., 2020; The Neurological Alliance, 2019) we also suggest that written information about the diagnosis and support organisations should also be provided at diagnosis as a standard.

Findings from the current thesis suggest that professionals could benefit from appropriate training and organisational support with managing the emotional aspects of BBN, from providing emotional support to patients to dealing with their own emotions during the process. Neurologists' responses regarding how they provided emotional support to patients often lacked detail which indicated that they probably lacked the cognitive scripts and skills which could allow them to manage this aspect of BBN. Increasing neurologists' familiarity with BBN guidance that emphasises the importance of emotional support (Villagran, Goldsmith, Wittenberg-Lyles & Baldwin, 2010) during their formal specialist training could be a start. In addition, training does not always have to be formal, and neurologists can learn from each other's practice and perspectives. The attendance of Swartz Rounds, reflective staff meetings where the emotional and social aspects of working in healthcare are discussed, has been associated with increased management of emotional and psychosocial aspects of care and an enhanced belief about the importance of empathy (Lown & Manning, 2010). Providing hope, even to patients with MNDDs associated with a poor prognosis, can be a way of providing emotional support. Professionals working with patients with these conditions could reflect on their own conceptualisation of hope, enhance their understanding of hope based on recent research findings (Soundy et al., 2010) and adjust their practice based on patients' need for different types of hope (e.g., hope that support would be readily available throughout the disease journey). Additionally, when providing emotional support, neurologists are encouraged to set aside their own perspectives regarding the severity of a condition and try to empathically adjust their approach to how patients experience diagnosis delivery. Based on patients' experiences highlighted by the



scoping review, it is likely that diagnosing doctors often avoid or fail to identify and respond to patients' existential pain and suffering at diagnosis. Suffering can be defined as a '*specific state of severe distress induced by the loss of integrity, intactness, cohesiveness, or wholeness of the person, or by a threat that the person believes will result in the dissolution of his or her integrity*' (Cassel, 1982, p. 639). Besides focussing on how to treat physical suffering caused by the disease, it has been argued that it is within doctors' responsibility to also treat suffering on an existential level (Coulehan, 2009). Neurologists could therefore explore what receiving an MNDD diagnosis means for each individual patient, help patients feel heard and understood through active listening and asking further questions on the fears or concerns that patients might bring up (Coulehan et al., 2001).

However, the studies of this thesis showed that fear of becoming overinvolved or emotionally overloaded and lack of time often hindered neurologists' intentions to provide a patient-centred and empathic diagnosis delivery. Developing self-awareness, an understanding of one's own beliefs, emotions, response patterns, attitudes and values, can increase doctors' empathy (Davis, 1990) as well as their ability to maintain an emotional balance during emotionally taxing tasks (Cole, 1997; Dobkin, 2011; Novak et al., 1997) and is associated with lower levels of compassion fatigue and burnout (Sanzo et al., 2015). Studies have shown that such self-awareness could be developed through both mainstream approaches such as training on emotional management, also more alternative approaches, such as spiritual and meditation practices (Sanzo et al., 2015). In addition, self-awareness can be nurtured through reflection on one's practice (Sandars, 2009) and writing detailed reflective narratives after BBN

encounters could enhance medical trainees understanding of the complexity of BBN and the emotional aspects of the process (Karnieli-Miller, Palombo & Meitar, 2018). Nevertheless, apart from investing in doctors' training, organisations should also provide working conditions which protect professionals from moral distress and allows space for empathy and patient-centred practice. Kerasidou and Horn (2016) argue that a general cultural change within medicine is still needed so that the expression of compassion and empathy is not seen as a supererogatory requirement or secondary to technical knowledge. As discussed earlier, when breaking bad news, professionals were often expected to deal with conflicting communication goals which could seem unattainable. Being time-restricted and facing a heavy workload does not only affect the empathy shown by professionals (Haslam, 2007) but can arguably limit the possibility of professionals engaging in activities such as self-reflection and attending Swartz Rounds groups. Limited consultation times and increased workload are associated with current staff shortages in neurology which organisations urgently need to tackle, especially within the context of the ageing population (Burton, 2018; Majersik et al., 2021; Miyasaki et al., 2007; Nitkunan et al., 2020). Moreover, based on patients' often negative feedback (Anestis et al., 2020) which were confirmed by professionals in this thesis reporting shorter consultation slots for people with PD and MS, current consultation slots offered for patients with these conditions should be reappraised.

Our findings from PP3 suggest that BBN for MNDDs should be perceived as an ongoing process beyond the diagnostic consultation between the patient and a neurologist. Non-medical HCPs had a critical role in providing information and

support to newly diagnosed patients. Their involvement in the process of BBN and their ability to offer holistic and long consultations means they could have a 'corrective' role, especially in supporting patients who might have experienced dissatisfaction with a blunt or short diagnostic consultation where minimal amount of information was provided. In our opinion, referrals to specialist nurses as the first point of contact soon after the diagnosis should be made as a standard and assessing shortages of local availability of specialist nurses should be one of the priorities of future evaluations of care. Furthermore, although currently underrecognised, BBN should be acknowledged as a vital aspect of non-medical HCPs' practice. Non-medical HCPs who work with patients with MNDDs could be supported with this aspect of their clinical work through the development of training specifically for BBN for these conditions and through clinical supervision that acknowledges the challenges and emotional impact of having these challenging conversations.

### **Limitations and implications for future research**

One of the strengths of the current thesis, its focus on BBN for four different MNDDs, could also be considered one of its limitations. Although participants in the empirical studies of the thesis were encouraged to provide elaborate answers considering all four conditions, it is possible that specific challenges or intricacies of the experience of BBN for a specific MNDD were not captured. Participants also focussed less on difficult conversations in the context of HD, potentially because it is a rarer condition. In addition, other rare MNDDs associated with a poor prognosis, such as multiple system atrophy, progressive supranuclear palsy and

atypical parkinsonism, were not included in this study, mostly because of the absence of empirical research on patients' experience of diagnosis communication. Future research could address more specific issues in relation to BBN for specific conditions or disease phenotypes (e.g., primary progressive MS) but also help develop an understanding of healthcare communication for the lesser known MNDDs.

The survey's relatively small sample size could also be considered a limitation of the thesis. Although the survey findings were useful in providing a context for the rest of the studies and helped inform the qualitative studies, the sample size did not allow for any robust statistical analyses which could identify statistically significant factors that affect neurologists' reported practice. Future quantitative investigations could also explore whether and how emotional aspects of BBN highlighted by the IPA study, such as professionals' emotional involvement, affect their practice. A quantitative assessment of professionals' (including professionals in training) needs in terms of guidance and support when delivering an MNDD diagnosis could also help the development of specialised guidelines for BBN and the establishment of support systems.

One of the main limitations of this thesis is that we did not conduct any empirical studies on UK patients' perspectives on diagnosis delivery and we relied on data from pre-existing studies. Findings of the current thesis were therefore often interpreted and contrasted to findings from patients' studies which were often conducted in the previous decade and in different countries, so they might not fully reflect current UK patient experiences. Nevertheless, a large patient

experience survey conducted by The Neurological Alliance (2019) in the UK advocated that diagnosis communication is still an aspect of neurological care that requires improvement. Future research could adopt a dyadic, conversation analysis methodology to address the findings of the current thesis and other patient studies and explore how patients and HCPs influence each other's emotions, thoughts and behaviours, how HCPs respond to patients' needs and how principles of patient-centred care are reflected in such BBN consultations. The consultations could be either audio (Schoenthaler, Basile, West & Kalet, 2018) or video-recorded (Dooley, Bass & McCabe), therefore minimising the methodological and ethical concerns that observation methodologies could raise. Such qualitative explorations could also be enriched with the use of instruments assessing HCPs' skills in breaking bad news (Gutierrez-Sanchez, García-Gáme, Leiva-Santos & Lopez-Leiva, 2021) and longitudinal designs linking the diagnostic experience with future outcomes in patients with MNDDs.

Moreover, although the thesis encompassed a contemporary approach that viewed BBN as a process which is not confined to doctor-patient interactions at diagnosis, it still focussed on the communication of bad news at early stages of MNDDs. Further research could explore other forms of BBN at more advanced stages of these conditions, such as the point that medication for PD is no longer effective in managing symptoms or the transition into palliative care.

## **Conclusion**

This thesis explored HCPs' perspectives on breaking bad news to patients with MNDDs. Providing data on neurologists' current practice in the UK, exploring non-medical HCPs' involvement in BBN conversations with these patients and qualitatively exploring neurologists' lived experiences in giving these diagnoses are the main contributions to knowledge of this thesis. Overall, professionals viewed BBN as a critical aspect of their role and strived to maintain high standards of practice. Yet, findings from the empirical studies of the thesis can help explain why patient studies have often reported sub-optimal diagnostic experiences. Besides the incurable and progressive nature of MNDDs and the uncertainty surrounding their prognosis, professionals were also challenged by time pressures, the emotional impact of BBN and difficulties in sharing the same perspective with patients. Non-medical HCPs had a vital role in breaking bad news to newly diagnosed patients with MNDDs, helping them understand the impact of their condition and providing emotional support through these difficult conversations. Enhancing our understanding on HCPs' perspectives on BBN for MNDDs can help in the development of appropriate training and organisational changes to support professionals with this challenging aspect of their practice which can eventually contribute to better patient care at diagnosis.

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## **Appendix 1**

### **Ethics Applications and Ethics Approval Letters**

- ☒ Scotland
- ☐ Wales
- ☒ Northern Ireland

**3a. In which country of the UK will the lead NHS R&D office be located:**

- ☒ England
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland
- ☐ This study does not involve the NHS

Please see information button for further details.

**5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?**

Please see information button for further details.

☒ Yes ☐ No

*The NIHR Clinical Research Network (CRN) provides researchers with the practical support they need to make clinical studies happen in the NHS in England e.g. by providing access to the people and facilities needed to carry out research "on the ground".*

*If you select yes to this question, information from your IRAS submission will automatically be shared with the NIHR CRN. Submission of a Portfolio Application Form (PAF) is no longer required.*

**6. Do you plan to include any participants who are children?**

☐ Yes ☒ No

**7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?**

☐ Yes ☒ No

*Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.*

**8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?**

☐ Yes ☒ No

**9. Is the study or any part of it being undertaken as an educational project?**

☒ Yes ☐ No

Please describe briefly the involvement of the student(s):  
The student (also applicant) is undertaking this study as a part of his PhD in Health Research.

**9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?**

☒ Yes ☐ No

**10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?**

☐ Yes ☒ No

**11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?**

☐ Yes ☒ No

DRAFT

**Integrated Research Application System**  
**Application Form for Research administering questionnaires/interviews for quantitative analysis or mixed methodology study**

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

**Short title and version number:** (maximum 70 characters - this will be inserted as header on all forms)  
 Neurologists' practice and experiences in breaking bad news (V1)

**PART A: Core study information**

**1. ADMINISTRATIVE DETAILS**

**A1. Full title of the research:**

Neurologists' current practice and perspectives on communicating a diagnosis of a progressive neurological condition: a survey study

**A2-1. Educational projects**

Name and contact details of student(s):

**Student 1**

	Title	Forename/Initials	Surname
	Mr.	Eleftherios	Anestis
Address	17 Kingsley House		
	15 Newton Street		
	Manchester		
Post Code	M1 1HE		
E-mail	e.anestis@lancaster.ac.uk		
Telephone	07596237204		
Fax	0		

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:  
 PhD in Health Research

Name of educational establishment:  
 Lancaster University

Name and contact details of academic supervisor(s):

**Academic supervisor 1**

	Title	Forename/Initials	Surname
	Prof	Jane	Simpson



Address Furness College, Lancaster University, Bailrigg  
 Lancaster  
 United Kingdom  
 Post Code LA1 4YG  
 E-mail simpson2@lancaster.ac.uk  
 Telephone +44 (0) 1524 592858  
 Fax 000000000

**Academic supervisor 2**

Title Forename/Initials Surname  
 Dr. Ian Fletcher  
 Address Furness College, Lancaster University, Bailrigg  
 Lancaster  
 United Kingdom  
 Post Code LA1 4YG  
 E-mail i.j.fletcher@lancaster.ac.uk  
 Telephone +44 (0) 1524 593301  
 Fax 000000000

**Academic supervisor 3**

Title Forename/Initials Surname  
 Dr. Fiona Eccles  
 Address Furness College, Lancaster University, Bailrigg  
 Lancaster  
 United Kingdom  
 Post Code LA1 4YG  
 E-mail f.eccles@lancaster.ac.uk  
 Telephone +44 (0)1524 592807  
 Fax 000000000

Please state which academic supervisor(s) has responsibility for which student(s):

*Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.*

Student(s)	Academic supervisor(s)
Student 1 Mr. Eleftherios Anestis	<input checked="" type="checkbox"/> Prof Jane Simpson <input checked="" type="checkbox"/> Dr. Ian Fletcher <input checked="" type="checkbox"/> Dr. Fiona Eccles

*A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.*

**A2-2. Who will act as Chief Investigator for this study?**

- ☐ Student  
☒ Academic supervisor  
☐ Other

**A3-1. Chief Investigator:**

	Title Forename/Initials Surname
	Prof Jane Simpson
Post	Professor in Psychology of neurodegenerative conditions, Director of Education, Division of Health Research, Lancaster University Assistant Dean, Faculty of Health and Medicine, Lancaster University
Qualifications	PhD in Psychology DClinPsy
ORCID ID	0000 0001 5071 4077
Employer	Lancaster University
Work Address	Furness College, Lancaster University, Bailrigg Lancaster United Kingdom
Post Code	LA1 4YG
Work E-mail	simpson2@lancaster.ac.uk
* Personal E-mail	
Work Telephone	+44 (0) 1524 592858
* Personal Telephone/Mobile	
Fax	0

*\* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

*A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

**A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?**

*This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.*

	Title Forename/Initials Surname
	Mrs Becky Gordon
Address	Head of Research Quality and Policy Lancaster University
Post Code	LA1 4YW
E-mail	sponsorship@lancaster.ac.uk
Telephone	+44 (0)1524 592981
Fax	0

**A5-1. Research reference numbers. Please give any relevant references for your study:**

Applicant's/organisation's own reference number, e.g. R & D (if available):	FHMREC17106
Sponsor's/protocol number:	n/a
Protocol Version:	0.1
Protocol Date:	01/07/2019
Funder's reference number (enter the reference number or state not applicable):	N/A
Project website:	N/A

**Additional reference number(s):**

Ref.Number	Description	Reference Number
<p><i>Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.</i></p>		

**A5-2. Is this application linked to a previous study or another current application?**

☒ Yes ☐ No

Please give brief details and reference numbers.  
266719

**2. OVERVIEW OF THE RESEARCH**

*To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.*

**A6-1. Summary of the study.** Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.

How healthcare professionals deliver a diagnosis can affect the patient's understanding of the disease, involvement in decision making and psychological adjustment. Although research has focused in bad news in oncology, studies of patients with neurological conditions have reported a general dissatisfaction with how their diagnosis was disclosed. On the other hand, research on doctors' perspectives on breaking bad news is limited, especially in the field of neurology. This study is employing a survey research design to assess neurologists' current practice in the UK and experiences in delivering a diagnosis (focusing on Parkinson's disease, multiple sclerosis and motor neurone disease). Participants will be consultants and in-training neurologists practicing in the UK and will be asked questions regarding the timing, duration, content and also the challenges of a consultation of this nature. This work will provide details on current practice of delivering a diagnosis of a neurological condition but also an understanding on clinicians' perspectives on this challenging clinical task.

**A6-2. Summary of main issues.** Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

*Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.*

**Research purpose and design**

The need for this project emerged after a number of patient studies with progressive neurological conditions have indicated that the process of diagnosis delivery is not always optimal. Negative experiences of diagnosis communication can have an impact on patients' satisfaction with healthcare and long-term adjustment and management of the disease. However, although there is a respectable amount of studies from the patients' perspectives, health professionals' views have been somehow neglected by health research, especially those working in fields other than Oncology. This survey aims to give voice to neurologists practicing in the UK to report their current practice and their experiences of disclosing a diagnosis for Parkinson's disease, Motor neurone disease, multiple sclerosis or Huntington's disease. The survey was based on Aoun's et al. (2016) survey, which had similar aims to ours, but adjusted to include all conditions under study and other variables crucial to diagnosis delivery identified by studies on the topic and practice guidelines. In addition, two practising neurologists have provided feedback on earlier drafts of this survey in order to make sure that it would be sound from a medical perspective, understandable, relevant to their practice and interesting.

#### Recruitment

Participants will be recruited online mainly via survey advertisements on the website of the Association of British Neurologists (ABN) and British neurology-related twitter accounts. Face to face recruitment will include the promotion of the survey in professionals meetings of neurologists practising in the UK (such as the ABN annual meeting) and collaborations with neurology departments in the NHS. EA will get in contact with participating NHS sites to inform the R&Ds about the study and share the advertising materials who will then distribute them to potential participants and enable recruitment, for example by approaching them face to face or sending emails with the advertising material to potential participants.

#### Inclusion/exclusion

Qualified neurologists practising in the UK and neurology trainees with experience in delivering diagnoses for motor neurodegenerative disorders will be recruited for this study. Participants need to have experience in giving diagnoses for at least one motor neurodegenerative disease. There will be no age (the minimum age is the earliest someone can begin the training in neurology, at about 25 and the maximum is the age of retirement, at about 65) or gender restrictions or restrictions related to the country where the participants were trained, but they will need to be currently practising in the UK. Additionally, there will be no excluding criteria based on neurologists' practising within the private or public sector.

#### Consent

In the online form of the survey, a participant information sheet will be presented to the participants before completing any questions. This will inform participants about the aims and content of this survey. Before proceeding to the survey participants will have to read the consent form and confirm that they have understood the aim and the nature of the survey as well as the ethical implications of taking part in the study. If they do not confirm and therefore do not give consent to participate, they will be transferred to the end of the survey and will not be able to participate. The same introductory text and consent form will be used in a cover sheet for the printed version of the survey. Participants will have to tick the consent form box but since this is an anonymous survey they will not have to provide their name.

#### Risks and benefits

Surveys will be completed anonymously and it will not be possible to identify participants through their responses. At the same time, since data is collected anonymously, it is impossible for them to withdraw from the study once they have submitted their answers. In addition, demographic data required for participation in this study do not contain any elements that participants could find intrusive. In general, we feel that assessing neurologists current practice does not raise any serious ethical considerations and risks. It might be possible for participants to feel their practice is being judged, but we hope they will view completing the survey as an opportunity to reflect on their own practice in breaking bad news. Moreover, the questions have been carefully worded so that they do not reflect a judgemental attitude. Additionally, in the rare case that the questions regarding their personal experiences and emotions in response to delivering a diagnosis induces significant distress, we will encourage neurologists to seek professional help through their professional organisation or contact a NHS approved helpline, whose link we are going to provide both in the participant information and the debriefing sheet.

There are not any direct benefits to participants in this study, but we feel that the doctors completing the survey will consider it a positive experience in general. Firstly, they will get the chance to reflect on this aspect of their clinical work and possibly identify areas of improvement and/or feel confident about their overall performance in delivering a diagnosis. Moreover, we hope that they will find looking back on their experiences and emotions involved in this task as a beneficial process. Furthermore, the survey gives doctors the opportunity to address potential barriers in delivering an optimal consultation such as time constraints and excessive workload. Finally, the project whose this study is a part of, aims at the development of a better understanding of the neurologists' perspectives on breaking a diagnosis, so they can be better supported/trained in delivering more efficient diagnostic consultations.

#### Confidentiality

The surveys will be completed anonymously and no sensitive personal information that would lead to the identification of a participant will be asked. Any data provided by the participants will be treated as confidential and only the research team will have access to the raw data, which will be securely stored in the university's server. However, in case that a participant provides identifying information to an open-ended question, these will be anonymised if they are going to be used as direct quotations. Prior to completing the survey, participants will be asked to read the introductory text which includes information about confidentiality and anonymity and give consent to participate in the study by proceeding to complete the survey.

## 3. PURPOSE AND DESIGN OF THE RESEARCH

**A7. Select the appropriate methodology description for this research. Please tick all that apply.**

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☐ Qualitative research
- ☒ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

**A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.**

The survey's main objective is to develop an understanding on neurologists' practice and experiences in delivering the diagnosis of motor neurone disease, Parkinson's disease, Huntington's disease and multiple sclerosis in the UK.

**A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.**

To examine how neurologists' practice in the UK compares to international diagnosis communication guidelines and patients' preferences, which have been expressed through health research.

To investigate potential factors which influence neurologists' practice and challenges that they may be facing such as time constraints, emotional burden, need for further training etc.

**A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.**

The communication of a diagnosis of a severe condition is a critical moment for the patient receiving the news, but also a challenging clinical task for doctors, especially when the diagnosis. Most research on this topic has been conducted within the field of oncology and especially from the patient's perspective. Studies have shown that the perceived quality of the diagnosis delivery has been associated with enhanced patient satisfaction, understanding of the disease, involvement in decision making, better psychological adjustment but also, when conducted poorly, with prolonged patient distress, confusion and poor treatment adherence. Studies from the professionals' perspective indicate that bad news delivery is an emotionally burdensome and stressful task and optimal diagnosis delivery is affected

Breaking bad news may refer either to the delivery of the diagnosis of a condition or the delivery of a poor prognosis or any other information that are generally considered negative, such as the death of a loved one or the transition to end of life care. After having expressed their disclosure preferences through health research, the majority of patients (especially in western countries) are now fully informed about their diagnosis (Keating, Nayeem, Gilmartin & O'Keeffe, 2005). However, the way health care professionals deliver this task can be critical. Patients seem to prefer professionals who seem honest, use simple language but are also empathic and knowledgeable (Girgis, Sanson-Fisher & Schofield, 1999). Studies have shown that when the delivery of a serious diagnosis is not delivered in an appropriate way, it can cause prolonged patient distress, confusion and poor treatment adherence (Fallowfield & Jenkins, 2004). How bad news is disclosed can also affect the patient's understanding of the disease (Kaplowitz,

Osuch, Safron & Campo, 1999), involvement in decision making and psychological adjustment (Roberts, Cox, Reintgen, Baile & Gibertini, 1994).

Breaking bad news is undoubtedly an emotionally burdensome task and, today, although several different protocols for breaking bad news have been suggested (Dean & Willis, 2016), this aspect of communication is still challenging for professionals; moreover, the effectiveness of training programs that aim to enhance their communicational skills is in some cases questionable (Fallowfield & Jenkins, 2004; Salmon & Young, 2017). Research regarding the doctor's perspectives on breaking bad news is limited and most of the research has been conducted within the field of oncology with findings highlighting the difficulty in achieving a balance between being honest and adequately informing patients while sustaining their hope for a successful recovery (Bousquet et al., 2015). Moreover, studies using self-report and studies using psychophysiological measures indicate that doctors experience moderate levels of stress during the delivery of bad news, with stress reactions lasting for hours or even days after the consultation (Studer, Danuser & Gomez, 2017). Apart from dealing with stress, physicians experience strong emotions of anger and guilt, powerlessness to make a positive difference and their own personal fear of death. It is also often that factors such as time constraints, intercultural differences in relation to the disclosure of a diagnosis and lack of private space can make such an intrinsically difficult consultation even more challenging (Bousquet et al., 2015; Ptacek & McIntosh, 2009).

As previously mentioned, most studies on the delivery of bad news have been conducted within the field of oncology. However, the delivery of bad news can be a critical issue in other medical specialties such as neurology. Shorstein (2011) argues that when breaking bad news, neurologists are dealing with specific challenges that relate to special medical considerations and the emotional aspects of neurological diseases. In particular, several chronic neurological conditions, such as Parkinson's disease (PD), Multiple Sclerosis (MS) and Huntington's disease (HD), are incurable, have a progressive nature and cause physical and cognitive disabilities (Shorstein, 2011), while others, such as motor neurone disease (MND), can also be life threatening (Winhammar, Rowe, Henderson & Kiernan, 2005).

The critical role of effective communication in breaking bad news in these diseases has been made apparent by studies of patients and their families that explore their experiences with receiving a diagnosis. In qualitative studies, patients with PD have reported a lack of compassion and sensitivity by doctors who delivered the diagnosis, who also dedicated inadequate time for the consultation and did not provide straightforward answers (Warren, Eccles, Travers & Simpson, 2016; Phillips, 2006). Similarly, patients with MS, in a qualitative study by Edwards, Barlow and Turner (2007), also reported negative experiences such as being informed through the telephone or in a 'casual' manner by 'unsympathetic' professionals, experiences that elicited emotions of shock, disappointment and anger towards the doctors. Furthermore, MND studies indicate that a great proportion of patients and their families expressed their dissatisfaction with the communication of the diagnosis, especially regarding the lack of empathy during the process and the insufficient time spent or neurologists' knowledge about MND (Mccluskey, Casarett & Siderowf, 2004; Aoun et al., 2016b; Aoun et al., 2017).

Despite all these critical issues and the notion that in order to improve the process of breaking bad news, the doctor's perspective should also be taken into account, little research has been conducted on the latter in the field of neurology. Empirical data on this topic are mostly derived from survey studies assessing neurologists' attitudes and current practices. In the case of MS, for example, the difficulty of reaching a 'clinically definite' diagnosis can affect the timing of disclosure of the bad news or the terminology used, with surveys indicating that neurologists often use vague terms such as 'demyelinating disease' and avoid talking about a possible MS diagnosis (Martinelli et al., 2012; Heesen, Kolbeck, Gold, Schulz & Schulz, 2003). However, such practices may trigger uncertainty or feelings of deception to patients, factors that could then have a negative impact on the patient-doctor relationship. Studies about delivering the diagnosis of MND indicate a lack of formal training on breaking bad news and a need to show greater empathy (Schellenberg, Schofield, Fang & Johnston, 2014). In addition, most neurologists in an Australian survey (Aoun et al., 2016a) seem to find the disclosure of an MND diagnosis as 'very to somewhat difficult' task that induces stress and anxiety. Being honest and sustaining hope, investing enough time to the consultation and dealing with the recipient's emotions were considered challenging aspects of the task. Moreover, a qualitative study of GPs (Pinder, 1992) describes how reaching a diagnosis for early PD is difficult and often comes as a relief for both themselves and the patients. The diagnosis was conceptualised as a point of maximum theoretical coherence for them, which could enable them to take action and initiate treatment. Factors such as the old age of the patient and the 'mild' nature of PD compared to other neurological conditions, such as MS or MND, made breaking bad news a less distressing task. The aim of this study is to assess UK neurologists' current practice on breaking a diagnosis of a neurological disease, in particular PD, MS, HD and MND. Currently there are no studies from the UK on this topic, so the aim of the study is to explore different aspects of the process, such as the timing, duration and challenges of communicating a diagnosis of this nature. In addition, potential factors affecting practice and differences between delivering the diagnosis for different conditions will also be explored and doctors' communication training needs will be assessed. Ideally, this work will provide detail on current practice of diagnosis but also clinicians' perspectives on whether this current practice currently works well. A further aim of the survey will be to inform the design of qualitative studies which will explore these issues in more detail using a different research method.

**A13. Please summarise your design and methodology.** *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

This study is going to employ a survey research design. The survey has been structured after a comprehensive review of the relevant literature and similar surveys assessing physicians' perspectives, such as Aoun et al. (2016a) who provided us with the survey they used, practices on breaking bad news and guidelines, such as the NICE guidelines for communicating with patients. The survey will comprise 44 questions grouped in four sections; basic demographic information, current practice, the experience of breaking bad news and education and training needs. The questions will be mainly closed with a few additional open-ended questions where participants will be asked to elaborate on their answers or provide any further comments if they want to.

According to a 2016-2017 census, about 850 neurology consultants are practising in the UK (Royal College of Physicians, 2017) and the expected return rate for studies of this nature is 10%. We believe that by recruiting consultants and some neurology registrars, we will have a sample of minimum 100 participants, which would be sufficient for this survey since we are mainly looking to generate descriptive statistics and associations.

**A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?**

- ☐ Design of the research
- ☐ Management of the research
- ☐ Undertaking the research
- ☐ Analysis of results
- ☐ Dissemination of findings
- ☒ None of the above

*Give details of involvement, or if none please justify the absence of involvement.*

This survey is going to be administered to neurologists and two consultant neurologists have been involved in the process of the construction and refinement of the survey. Data from patient studies which have highlighted important aspects of doctor-patient communication at the time of diagnosis have also informed the construction of the survey.

#### 4. RISKS AND ETHICAL ISSUES

##### RESEARCH PARTICIPANTS

**A15. What is the sample group or cohort to be studied in this research?**

Select all that apply:

- ☐ Blood
- ☐ Cancer
- ☐ Cardiovascular
- ☐ Congenital Disorders
- ☐ Dementias and Neurodegenerative Diseases
- ☐ Diabetes
- ☐ Ear
- ☐ Eye
- ☒ Generic Health Relevance
- ☐ Infection
- ☐ Inflammatory and Immune System
- ☐ Injuries and Accidents
- ☐ Mental Health
- ☐ Metabolic and Endocrine

- ☐ Musculoskeletal  
☒ Neurological  
☐ Oral and Gastrointestinal  
☐ Paediatrics  
☐ Renal and Urogenital  
☐ Reproductive Health and Childbirth  
☐ Respiratory  
☐ Skin  
☐ Stroke

Gender: Male and female participants  
 Lower age limit: 25 Years  
 Upper age limit: 120 Years

**A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).**

Currently practising in the UK as a consultant or in-training neurologist  
 Experience of giving bad news for at least one of the conditions under study (PD, MS, HD, MS)

**A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).**

No experience of giving bad news for at least one of the conditions under study  
 Practising outside the UK or practising in Wales

**RESEARCH PROCEDURES, RISKS AND BENEFITS**

**A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.**

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Reading the information sheet and deciding whether they want to proceed to the survey.	1	0	10'	The participants themselves
Completing the survey	1	0	10'-15'	Self-administered questionnaires

**A21. How long do you expect each participant to be in the study in total?**

Maximum 15 minutes

**A22. What are the potential risks and burdens for research participants and how will you minimise them?**

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps



would be taken to minimise risks and burdens as far as possible.

Surveys will be completed anonymously and it will not be possible to identify participants through their responses. At the same time, since data is collected anonymously, it is impossible for them to withdraw from the study once they have submitted their answers. In addition, demographic data required for participation in this study do not contain any elements that participants could find intrusive. In general, we feel that assessing neurologists current practice does not raise any serious ethical considerations. It might be possible for participants to feel their practice is being judged, but we hope they will view completing the survey as an opportunity to reflect on their own practice in breaking bad news. Moreover, the questions have been carefully worded so that they do not reflect a judgemental attitude. Additionally, in the rare case that the questions regarding their personal experiences and emotions in response to delivering a diagnosis induces significant distress, we will encourage neurologists to seek professional help through their professional organisation or contact a NHS approved helpline, whose link we are going to provide in the participant information sheet.

**A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?**

☒ Yes ☐ No

*If Yes, please give details of procedures in place to deal with these issues:*

Although we do not feel that the questions of the survey could be upsetting, some participants might feel that their practice is being judged and that questions about their experiences of breaking bad news are sensitive.

In the unlikely event of participants disclosing what appears to be unprofessional practice, this will be immediately discussed with the supervisory team.

**A24. What is the potential for benefit to research participants?**

There are not any direct benefits to participants in this study, but we feel that the doctors completing the survey will consider it a positive experience in general. Firstly, they will get the chance to reflect on this aspect of their clinical work and possibly identify areas of improvement and/or feel confident about their overall performance in delivering a diagnosis. Moreover, we hope that they will find looking back on their experiences and emotions involved in this task as a beneficial process. Furthermore, the survey gives doctors the opportunity to address potential barriers in delivering an optimal consultation such as time constraints and excessive workload. Finally, the project whose this study is a part of, aims at the development of a better understanding of the neurologists' perspectives on breaking a MNDD diagnosis, so they can be better supported/trained in delivering more efficient diagnostic consultations.

**A26. What are the potential risks for the researchers themselves? (if any)**

Neither the nature of this project nor the methodology employed are expected to pose any potential risks for the researcher.

#### RECRUITMENT AND INFORMED CONSENT

*In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.*

**A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of social care or GP records, or review of medical records. Indicate whether this will be done by the direct care team or by researchers acting under arrangements with the responsible care organisation(s).**

The research team intends to collaborate with NHS neurology departments around the country (starting with the R&D host for this project) so that the link for the survey is distributed to consultant neurologists and neurologist registrars (note that the researchers will not have access to potential participants' emails, the survey will be circulated by a member of the neurology team, a research nurse or admin staff of the participating site that already has access to these emails). We will also ask participating sites for permission to attend staff meetings of the neurology teams in order to inform potential participants about the nature and aim of the survey and ask if they would like to participate complete either the online or the print version of the survey.

**A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?**

☐ Yes ☒ No

*Please give details below:*

**A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?**

☒ Yes ☐ No

*If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).*

The survey is going to be advertised through the Association of British Neurologists website and UK neurology-related twitter pages. A copy of the advertising material has been enclosed.

**A29. How and by whom will potential participants first be approached?**

Apart from online recruiting, Eleftherios Anestis will be approaching potential participants through the establishment of collaborations with neurology departments in the NHS and the attendance of neurologists' meetings.

**A30-1. Will you obtain informed consent from or on behalf of research participants?**

☒ Yes ☐ No

*If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.*

*If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.*

In the online form of the survey, a participant information sheet will be presented to the participants before completing any questions. This will inform participants about the aims and content of this survey and will make clear that by proceeding to the survey they are providing consent for the use of their data for research. The same introductory text will be used in a cover sheet for the printed version of the survey and will be making clear that by completing the survey, they are giving consent to participate in this research.

*If you are not obtaining consent, please explain why not.*

*Please enclose a copy of the information sheet(s) and consent form(s).*

**A30-2. Will you record informed consent (or advice from consultees) in writing?**

☐ Yes ☒ No

*If No, how will it be recorded?*

The information sheet will make it clear to participants that by proceeding to complete either the online or print form of the survey, they are providing consent. A copy of the information sheet is enclosed.

**A31. How long will you allow potential participants to decide whether or not to take part?**

Potential participants completing the survey online can have as much time they want to decide whether they want to participate or not and can use the survey link to re-read the information sheet again. Potential participants approached in person will be given time to read the information sheet and decide if they want to participate and can be also informed about the online version and be provided with the link should they require more time to decide if they want to take part or not.

**A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)**

No translation or use of interpretation arrangements have been made. Since participants will be practising in the NHS they are most likely expected to be fluent in English.

**A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.**

- ☐ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ☐ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ☐ The participant would continue to be included in the study.
- ☐ Not applicable – informed consent will not be sought from any participants in this research.
- ☒ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

**CONFIDENTIALITY**

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

**Storage and use of personal data during the study****A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?(Tick as appropriate)**

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Access to social care records by those outside the direct social care team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☐ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☒ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☐ Use of audio/visual recording devices
- ☐ Storage of personal data on any of the following:
- ☐ Manual files (includes paper or film)
- ☐ NHS computers
- ☐ Social Care Service computers
- ☐ Home or other personal computers
- ☐ University computers
- ☐ Private company computers
- ☐ Laptop computers

*Further details:*

Apart from some basic demographic data, no personal information that could lead to participant identification will be asked in this survey. In case they provide identifiable information in the open-questions of the survey, these will be anonymised if they are going to be used as direct quotations in the publication of the research.

**A37. Please describe the physical security arrangements for storage of personal data during the study?**

Anonymized data collected through Qualtrics will be downloaded and stored in the student's secure, online storage system recommended by the university, the LU box, where they will be encrypted. Data from the printed version of the survey will be imported in SPSS in order to be saved in digital form and will be stored on the University server as well and completed printed versions of the survey will then be destroyed. Following the completion of the study, data will be encrypted and securely stored within the Division of Health Research in line with Lancaster University and Data Protection Act (1998). Data will be stored in a password protected file on the university's secure server for ten years and if the work is published, data will be stored for five additional years from the date of publication. Jane Simpson will be responsible for the protection of the data after the student has finished with his studies in Lancaster University.

**A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.**

The surveys will be completed anonymously and no sensitive personal information that would lead to the identification of a participant will be asked. Any data provided by the participants will be treated as confidential and only the research team will have access to the raw data, which will be securely stored in the university's server. However, in case that a participant provides identifying information to an open-ended question, these will be anonymised if they are going to be used as direct quotation

**A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.**

Only the research team.

**Storage and use of data after the end of the study****A41. Where will the data generated by the study be analysed and by whom?**

Data from the survey will be imported to SPSS and analysed by Eleftherios Anestis in his university computer. Data will not be transferred using USB sticks and will be stored in the secure online cloud service approved by Lancaster University (LU Box).

**A42. Who will have control of and act as the custodian for the data generated by the study?**

	Title Forename/Initials Surname
	Prof Jane Simpson
Post	Professor in Psychology of neurodegenerative conditions and Director of Education, Division of Health Research, Lancaster University Assistant Dean, Faculty of Health and Medicine, Lancaster University
Qualifications	PhD in Psychology DClinPsy
Work Address	Division of Health Research, Furness College, Lancaster University, Lancaster Lancaster United Kingdom
Post Code	LA1 4YG
Work Email	j.simpson2@lancaster.ac.uk
Work Telephone	+441524593301

Fax 0

**A43. How long will personal data be stored or accessed after the study has ended?**

- ☒ Less than 3 months  
☐ 3 – 6 months  
☐ 6 – 12 months  
☐ 12 months – 3 years  
☐ Over 3 years

**A44. For how long will you store research data generated by the study?**

Years: 10

Months: 0

**A45. Please give details of the long term arrangements for storage of research data after the study has ended. Say where data will be stored, who will have access and the arrangements to ensure security.**

Data will be stored in a password protected file on the university's secure server for ten years and if the work is published, data will be stored for five additional years from the date of publication. Jane Simpson will be responsible for the protection of the data after the student has finished with his studies in Lancaster University.

**INCENTIVES AND PAYMENTS****A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?**

- ☐ Yes ☒ No

**A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?**

- ☐ Yes ☒ No

**A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?**

- ☐ Yes ☒ No

**NOTIFICATION OF OTHER PROFESSIONALS****A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?**

- ☐ Yes ☒ No

*If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.*

## PUBLICATION AND DISSEMINATION

**A50-1. Will the research be registered on a public database?**

☐ Yes ☒ No

*Please give details, or justify if not registering the research.*  
This is non-clinical, questionnaire study

*Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.*

**A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:**

- ☒ Peer reviewed scientific journals
- ☒ Internal report
- ☒ Conference presentation
- ☐ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☒ Other (please specify)

Part of the PhD thesis of Eleftherios Anestis

**A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?**

Anonymisation of any direct quotations that could lead to participant identification

**A53. How and when will you inform participants of the study results?**

*If there will be no arrangements in place to inform participants please justify this.*  
Although we will not inform participants individually - since we will not have their personal data (e.g email addresses) to do so, we will inform the ABN about the publication of this study in case they want to include a link to the study in their newsletter.

## 5. Scientific and Statistical Review

**A54-1. How has the scientific quality of the research been assessed? Tick as appropriate:**

- ☐ Independent external review
- ☐ Review within a company
- ☐ Review within a multi-centre research group
- ☒ Review within the Chief Investigator's institution or host organisation
- ☒ Review within the research team

☒ Review by educational supervisor

☐ Other

*Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:*

The study has been designed under the supervision of Eleftherios' Anestis work by the rest of the research team (Prof Jane Simpson, Dr Ian Fletcher and Dr Fiona Eccles) and it has also received ethical approval by Lancaster University, Faculty of Health and Medicine Ethics Committee (approval letter enclosed).

*For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.*

*For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.*

**A56. How have the statistical aspects of the research been reviewed? Tick as appropriate:**

☐ Review by independent statistician commissioned by funder or sponsor

☐ Other review by independent statistician

☐ Review by company statistician

☐ Review by a statistician within the Chief Investigator's institution

☐ Review by a statistician within the research team or multi-centre group

☐ Review by educational supervisor

☐ Other review by individual with relevant statistical expertise

☒ No review necessary as only frequencies and associations will be assessed – details of statistical input not required

*In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.*

Title Forename/Initials Surname

Department

Institution

Work Address

Post Code

Telephone

Fax

Mobile

E-mail

*Please enclose a copy of any available comments or reports from a statistician.*

**A57. What is the primary outcome measure for the study?**

This is an exploratory quantitative study which mainly aims to generate descriptive statistics and has thus no hypotheses.

**A58. What are the secondary outcome measures?(if any)**

N/A

**A59. What is the sample size for the research?** *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 100

Total international sample size (including UK): 100

Total in European Economic Area: 100

*Further details:*

According to a 2016-2017 census, about 850 neurology consultants are practising in the UK (Royal College of Physicians, 2017) and the expected return rate for studies of this nature is 10%. We believe that by recruiting consultants and some neurology registrars, we will have a sample of minimum 100 participants, which would be sufficient for this survey.

Royal College of Physicians. 2016-17 Census (UK consultants and higher specialty trainees).  
www.rcplondon.ac.uk/projects/outputs/2016-17-census-uk-consultant-s-and-higher-specialty-trainees (accessed on 12th June 2018).

**A60. How was the sample size decided upon?** *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

Although there are no a priori hypotheses, the sample size of 100 would be sufficient to detect medium sized correlations (around .4) using Pearson's r correlations.

**A61-1. Will participants be allocated to groups at random?**

☐ Yes ☒ No

**A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.**

Quantitative data will be imported and analysed in SPSS. We are primarily interested in gathering a full range of descriptive statistics which will help us draw a picture of current practice of delivering a MNDD diagnosis (e.g duration of consultations) and doctors' perspectives on this challenging clinical task. However, there is also a possibility of using very basic exploratory inferential testing. Qualitative data from the open-ended questions of the survey will be used to enhance, explain and expand the findings from the analysis of the quantitative data.

## 6. MANAGEMENT OF THE RESEARCH

**A63. Other key investigators/collaborators.** *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

## A64. Details of research sponsor(s)

**A64-1. Sponsor**

### Lead Sponsor

Status: ☐ NHS or HSC care organisation

☒ Academic

☐ Pharmaceutical industry

Commercial status: ☐ Non-Commercial



- ☐ Medical device industry  
☐ Local Authority  
☐ Other social care provider (including voluntary sector or private organisation)  
☐ Other

*If Other, please specify:*

**Contact person**

Name of organisation Lancaster University  
Given name Becky  
Family name Gordon  
Address Lancaster University  
Town/city Lancaster  
Post code LA1 4YW  
Country United Kingdom  
Telephone +44 (0)1524 592981  
Fax 0  
E-mail sponsorship@lancaster.ac.uk

**Legal representative for clinical investigation of medical device (studies involving Northern Ireland only)**  
*Clinical Investigations of Medical Devices that take place in Northern Ireland must have a legal representative of the sponsor that is based in Northern Ireland or the EU*

**Contact person**

Name of organisation  
Given name  
Family name  
Address  
Town/city  
Post code  
Country  
Telephone  
Fax  
E-mail

**A65. Has external funding for the research been secured?**

*Please tick at least one check box.*

- ☐ Funding secured from one or more funders  
☐ External funding application to one or more funders in progress  
☒ No application for external funding will be made

What type of research project is this?

- ☐ Standalone project  
☐ Project that is part of a programme grant  
☐ Project that is part of a Centre grant  
☐ Project that is part of a fellowship/ personal award/ research training award  
☒ Other

Other – please state:  
Project as a part of a PhD thesis

**A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? Please give details of subcontractors if applicable.**

☐ Yes    ☒ No

**A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?**

☐ Yes    ☒ No

*Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.*

**A68-1. Give details of the lead NHS R&D contact for this research:**

	Title Forename/Initials Surname
	Mrs Gill Hamblin
Organisation	The Walton Centre NHS Foundation Trust,
Address	The Walton Centre NHS Foundation Trust
	Lower Lane
	Liverpool
Post Code	L9 7LJ
Work Email	gillian.hamblin@thewaltoncentre.nhs.uk
Telephone	0151 556 3389
Fax	00000000000
Mobile	07842052673

*Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>*

**A68-2. Select Local Clinical Research Network for NHS Organisation identified in A68-1:**

North West Coast

*For more information, please refer to the question specific guidance.*

**A69-1. How long do you expect the study to last in the UK?**

Planned start date: 10/09/2019  
 Planned end date: 01/03/2020  
 Total duration:  
 Years: 0 Months: 5 Days: 22

**A71-1. Is this study?**

- ☐ Single centre  
☒ Multicentre

**A71-2. Where will the research take place? (Tick as appropriate)**

- ☒ England  
☒ Scotland  
☐ Wales  
☒ Northern Ireland  
☐ Other countries in European Economic Area

Total UK sites in study unknown

**Does this trial involve countries outside the EU?**

- ☐ Yes ☒ No

**A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:**

- ☒ NHS organisations in England  
☐ NHS organisations in Wales  
☒ NHS organisations in Scotland  
☒ HSC organisations in Northern Ireland  
☐ GP practices in England  
☐ GP practices in Wales  
☐ GP practices in Scotland  
☐ GP practices in Northern Ireland  
☐ Joint health and social care agencies (eg community mental health teams)  
☐ Local authorities  
☐ Phase 1 trial units  
☐ Prison establishments  
☐ Probation areas  
☐ Independent (private or voluntary sector) organisations  
☐ Educational establishments  
☐ Independent research units  
☐ Other (give details)

Total UK sites in study: 0

**A73-1. Will potential participants be identified through any organisations other than the research sites listed above?**

☐ Yes ☒ No

**A74. What arrangements are in place for monitoring and auditing the conduct of the research?**

EA's academic supervisors (JS, IF & FE) will be monitoring and auditing the conduct of the research via weekly supervision meetings.

**A76. Insurance/ indemnity to meet potential legal liabilities**

*Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

**A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.**

*Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.*

- ☐ NHS indemnity scheme will apply (NHS sponsors only)  
☒ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

**A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.**

*Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.*

- ☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)  
☒ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

**A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?**

*Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.*

- ☐ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)  
☒ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

**A78. Could the research lead to the development of a new product/process or the generation of intellectual property?**

☐ Yes ☐ No ☒ Not sure

**A79. Please select the level of commercial participation in this project.**

- ☒ None  
☐ Industry funding, but not industry sponsored  
☐ Industry funding and industry sponsored  
☐ Industry sponsored, but not industry funded

**A80. Please select the main subject area of research. Additional sub-topics may be selected, if required**

- ☐ Age and Ageing  
☐ Anaesthetics  
☐ Cancer (includes malignant haematology)  
☐ Cardiovascular  
☐ Clinical  
☐ Critical Care  
☒ Dementias and Neurodegenerative Diseases  
☐ Dermatology  
☐ Diabetes  
☐ Ear, Nose and Throat  
☐ Gastrointestinal  
☐ Genetics  
☒ Health Services Research  
☐ Hepatology  
☐ Immunology and Inflammation  
☐ Infectious Disease and Microbiology  
☐ Injuries and Accidents  
☐ Medicines for Children (does not include Paediatrics)  
☐ Mental Health  
☐ Metabolic and Endocrine  
☐ Musculoskeletal (Rheumatoid Arthritis is a separate category)  
☐ Nervous System Disorders  
☐ Non-malignant Haematology  
☐ Ophthalmology  
☐ Oral and Dental  
☐ Paediatrics (does not include Medicines for Children)  
☐ Primary Care  
☐ Public Health Research  
☐ Renal

- ☐ Reproductive Health and Childbirth  
☐ Respiratory  
☐ Rheumatoid Arthritis  
☐ Stroke  
☐ Surgery  
☐ Urogenital

**9. Has the study been the subject of a scientific review/opinion (Expert Panel)?**

☐ Yes    ☐ No

*If yes, please provide a copy of the review as part of your application.*

**PART C: Overview of research sites**

**Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For further information please refer to guidance.**

Investigator identifier	Research site	Investigator Name
IN1	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site  Organisation name THE WALTON CENTRE NHS FOUNDATION TRUST Address LOWER LANE  LIVERPOOL MERSEYSIDE Post Code L9 7LJ Country ENGLAND	Forename Eleftherios Middle name n/a Family name Anestis Email e.anestis@lancaster.ac.uk Qualification BSc in Psychology (MD...) MSc in Health Psychology Country United Kingdom
IN2	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site  Organisation name SALFORD ROYAL NHS FOUNDATION TRUST Address SALFORD ROYAL STOTT LANE SALFORD GREATER MANCHESTER Post Code M6 8HD Country ENGLAND	Forename Eleftherios Middle name n/a Family name Anestis Email e.anestis@lancaster.ac.uk Qualification BSc in Psychology (MD...) MSc in Health Psychology Country United Kingdom

IN3

- ☒ NHS/HSC Site  
☐ Non-NHS/HSC Site

Organisation name SHEFFIELD TEACHING HOSPITALS NHS  
FOUNDATION TRUST  
 Address NORTHERN GENERAL HOSPITAL  
 HERRIES ROAD  
 SHEFFIELD SOUTH YORKSHIRE  
 Post Code S5 7AU  
 Country ENGLAND

Forename Eleftherios  
 Middle name n/a  
 Family name Anestis  
 Email e.anestis@lancaster.ac.uk  
 Qualification BSc in Psychology  
 (MD...) MSc in Health Psychology  
 Country United Kingdom

IN4

- ☒ NHS/HSC Site  
☐ Non-NHS/HSC Site

Organisation name KING'S COLLEGE HOSPITAL NHS  
FOUNDATION TRUST  
 Address DENMARK HILL  
 LONDON GREATER LONDON  
 Post Code SE5 9RS  
 Country ENGLAND

Forename Eleftherios  
 Middle name n/a  
 Family name Anestis  
 Email e.anestis@lancaster.ac.uk  
 Qualification BSc in Psychology  
 (MD...) MSc in Health Psychology  
 Country United Kingdom

IN5

- ☒ NHS/HSC Site  
☐ Non-NHS/HSC Site

Organisation name UNIVERSITY COLLEGE LONDON  
HOSPITALS NHS FOUNDATION TRUST  
 Address 250 EUSTON ROAD  
 LONDON  
 Post Code NW1 2PG  
 Country ENGLAND

Forename Eleftherios  
 Middle name n/a  
 Family name Anestis  
 Email e.anestis@lancaster.ac.uk  
 Qualification BSc in Psychology  
 (MD...) MSc in Health Psychology  
 Country United Kingdom

IN6

- ☒ NHS/HSC Site  
☐ Non-NHS/HSC Site

Organisation name ROYAL CORNWALL HOSPITALS NHS TRUST  
 Address ROYAL CORNWALL HOSPITAL  
 TRELISKE  
 TRURO  
 Post Code TR1 3LJ  
 Country ENGLAND

Forename Eleftherios  
 Middle name n/a  
 Family name Anestis  
 Email e.anestis@lancaster.ac.uk  
 Qualification BSc in Psychology (MD...)  
 MSc in Health Psychology  
 Country United Kingdom

IN7

- ☒ NHS/HSC Site  
☐ Non-NHS/HSC Site

Organisation name LEICESTERSHIRE PARTNERSHIP NHS TRUST  
 Address RIVERSIDE HOUSE  
 BRIDGE PARK PLAZA  
 BRIDGE PARK ROAD LEICESTER  
 LEICESTERSHIRE  
 Post Code LE4 8PQ  
 Country ENGLAND

Forename Eleftherios  
 Middle name n/a  
 Family name Anestis  
 Email e.anestis@lancaster.ac.uk  
 Qualification BSc in Psychology (MD...)  
 MSc in Health Psychology  
 Country United Kingdom

IN8

- ☒ NHS/HSC Site  
☐ Non-NHS/HSC Site

Organisation name UNITED LINCOLNSHIRE HOSPITALS NHS TRUST  
 Address LINCOLN COUNTY HOSPITAL  
 GREETWELL ROAD  
 LINCOLN  
 Post Code LN2 5QY  
 Country ENGLAND

Forename Eleftherios  
 Middle name N/A  
 Family name Anestis  
 Email e.anestis@lancaster.ac.uk  
 Qualification BSc in Psychology (MD...)  
 MSc in Health Psychology  
 Country United Kingdom





## Participant Information Sheet

### ***Neurologists' current practice in communicating a diagnosis of a neurological condition***

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: [www.lancaster.ac.uk/research/data-protection](http://www.lancaster.ac.uk/research/data-protection)

Thank you for showing interest to complete this survey! My name is Eleftherios Anestis, and I am conducting this research as a student in the PhD in Health Research programme at Lancaster University. Please read the information below before you provide consent to participate in this research by proceeding to complete this survey.

#### **What is the study about?**

The purpose of this study is to develop a better understanding of neurologists' current practice of delivering a diagnosis for a neurological condition in the UK, but also to explore their experience in carrying through with this challenging task of their clinical work. In particular, we are focusing on Parkinson's disease, multiple sclerosis and motor neurone disease, four chronic and progressive neurological conditions with a serious impact on patients' quality of life.

#### **Why have I been approached?**

You have been approached because the study requires information from consultant neurologists or neurology registrars who are currently practising in the UK.

#### **Do I have to take part?**

No. It's completely up to you to decide whether or not to take part.

#### **What will I be asked to do if I take part?**

If you decide you would like to take part, you would be asked to complete a survey which is divided in four sections: *basic demographic information, practice of delivering a diagnosis, personal experiences of delivering a diagnosis and education and training needs*. Most questions are closed but there are also open-ended questions and you will need approximately 15 minutes to complete it.

#### **Will my data be Identifiable?**

The surveys will be completed anonymously and no sensitive personal information that would lead to your identification will be asked. Any data provided will be treated as confidential, however, in case that a participant provides identifying information to an open-ended question, these will be anonymised if they are going to be used as direct quotations.

The data collected for this study will be stored securely.

- Hard copies of questionnaires will be kept in a locked cabinet.
- Only the researchers conducting this study will have access to the identifiable data

- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, hard copies of questionnaires will be kept securely in a locked cabinet for ten years. At the end of this period, they will be destroyed. In the meantime, anonymised data will be shared on request with investigators who contact the research team.

**What will happen to the results?**

The results will be summarised and reported in a thesis, will be submitted for publication in an academic journal and may be presented in an academic conference.

**Are there any risks?**

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

**Are there any benefits to taking part?**

There are no direct benefits in taking part. However, you may find the survey interesting and an opportunity to reflect on your practice.

**Who has reviewed the project?**

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

**Where can I obtain further information about the study if I need it?**

If you have any questions about the study, please contact the main researcher:

**Eleftherios Anestis**

PhD in Health Research student

Division of Health Research, Faculty of Health and Medicine

Address: Furness College, Lancaster University, Bailrigg, LA1 4YG. United Kingdom

Email: [e.anestis@lancaster.ac.uk](mailto:e.anestis@lancaster.ac.uk)

*Alternatively, you can contact one of the supervisors of this project:*

**Dr Jane Simpson**

Director of Education, Senior Lecturer Division of Health Research, Faculty of Health and Medicine

Address: Furness College, Lancaster University, Bailrigg, LA1 4YG. United Kingdom

Telephone: +44 (0) 1524 592858

Email: [simpson2@lancaster.ac.uk](mailto:simpson2@lancaster.ac.uk)

**Dr Ian Fletcher**

Senior Lecturer, Division of Health Research, Faculty of Health and Medicine

Address: Furness College, Lancaster University, Bailrigg, LA1 4YG. United Kingdom

Telephone: +44 (0) 1524 593301

Email: [i.j.fletcher@lancaster.ac.uk](mailto:i.j.fletcher@lancaster.ac.uk)

**Dr Fiona Eccles**

Lecturer, Division of Health Research, Faculty of Health and Medicine

Address: Furness College, Lancaster University, Bailrigg, LA1 4YG. United Kingdom

Telephone: +44 (0)1524 592807

Email: [f.eccles@lancaster.ac.uk](mailto:f.eccles@lancaster.ac.uk)

VO.1 (2/9/2019) | IRAS ID: 262063| Neurologists' current practice in communicating a diagnosis of a neurological condition

**Complaints** If you wish to speak to someone outside of the Health Research Doctorate Programme, you may also contact:

**Professor Roger Pickup**

Associate Dean for Research

Division of Biomedical and Life Sciences, Faculty of Health and Medicine

Tel: +44 (0)1524 593746

Email: r.pickup@lancaster.ac.uk

Thank you for taking the time to read this information sheet.

**Resources in the event of distress** Should you feel distressed either as a result of taking part, or in the future, you could either contact your professional organisation (Association of British Neurologists) or contact one of the helplines provided by the

NHS: <https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/>

### Consent Form

#### ***Neurologists' current practice in communicating a diagnosis of a neurological condition***

We are asking if you would like to take part in a research project about neurologists' practice and experiences in communicating bad news. Before you consent to participate in the study, we ask that you read the participant information sheet and mark each box below with a tick if you agree. If you have any questions or queries before signing the consent form please speak or send an email to the principal investigator, Eleftherios Anestis (e.anestis@lancaster.ac.uk).

You have read the information sheet and understand what is expected of you within this study

☐

You confirm that you understand that any responses/information you give will remain anonymous

☐

Your participation is voluntary

☐

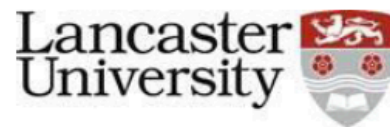
You consent for the information you provide to be discussed with my supervisor at Lancaster University

☐

You consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished

☐

Name of Researcher \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_



Applicant: Eleftherios Anestis  
Supervisor: Jane Simpson and Ian Fletcher  
Department: Health Research  
FHMREC Reference: FHMREC17106

31 August 2018

Dear Eleftherios

**Re: Neurologists' current practice in breaking a diagnosis of a neurological condition**

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987

Email:- [fhmresearchsupport@lancaster.ac.uk](mailto:fhmresearchsupport@lancaster.ac.uk)

Yours sincerely,

A handwritten signature in black ink that reads "R.E. Case".

Becky Case  
Research Ethics Officer, Secretary to FHMREC.



Ymchwil Iechyd  
a Gofal Cymru  
Health and Care  
Research Wales



Prof Jane Simpson  
Furness College, Lancaster University, Bailrigg  
Lancaster  
United Kingdom  
LA1 4YG

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)  
[HCRW.approvals@wales.nhs.uk](mailto:HCRW.approvals@wales.nhs.uk)

29 October 2019

Dear Prof Simpson

**HRA and Health and Care  
Research Wales (HCRW)  
Approval Letter**

<b>Study title:</b>	<b>Neurologists' current practice and perspectives on communicating a diagnosis of a progressive neurological condition: a survey study</b>
<b>IRAS project ID:</b>	<b>262063</b>
<b>Protocol number:</b>	<b>n/a</b>
<b>REC reference:</b>	<b>19/HRA/5761</b>
<b>Sponsor</b>	<b>Lancaster University</b>

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

**What are my notification responsibilities during the study?**

The "[After HRA Approval – guidance for sponsors and investigators](#)" document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **262063**. Please quote this on all correspondence.

Yours sincerely,  
Barbara Cuddon

Approvals Specialist

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

*Copy to: Mrs Becky Gordon*



## Welcome to the Integrated Research Application System

## IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

**Please enter a short title for this project** (maximum 70 characters)

Healthcare professionals' experiences in breaking bad news for MNDDs 1

**1. Is your project research?**

☒ Yes ☐ No

**2. Select one category from the list below:**

- ☐ Clinical trial of an investigational medicinal product
- ☐ Clinical investigation or other study of a medical device
- ☐ Combined trial of an investigational medicinal product and an investigational medical device
- ☐ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- ☐ Basic science study involving procedures with human participants
- ☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- ☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- ☐ Study limited to working with data (specific project only)
- ☐ Research tissue bank
- ☐ Research database

**If your work does not fit any of these categories, select the option below:**

☐ Other study

**2a. Please answer the following question(s):**

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

**3. In which countries of the UK will the research sites be located?(Tick all that apply)**

☒ England



- ☒ Scotland  
☐ Wales  
☒ Northern Ireland

**3a. In which country of the UK will the lead NHS R&D office be located:**

- ☒ England  
☐ Scotland  
☐ Wales  
☐ Northern Ireland  
☐ This study does not involve the NHS

**4. Which applications do you require?**

- ☒ IRAS Form  
☐ Confidentiality Advisory Group (CAG)  
☐ Her Majesty's Prison and Probation Service (HMPPS)

**Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?**

- ☒ Yes ☐ No

**4b. Please confirm the reason(s) why the project does not require review by a REC within the UK Health Departments Research Ethics Service:**

- ☐ Projects limited to the use of samples/data samples provided by a Research Tissue Bank (RTB) with generic ethical approval from a REC, in accordance with the conditions of approval.  
☐ Projects limited to the use of data provided by a Research Database with generic ethical approval from a REC, in accordance with the conditions of approval.  
☐ Research limited to use of previously collected, non-identifiable information  
☐ Research limited to use of previously collected, non-identifiable tissue samples within terms of donor consent  
☐ Research limited to use of acellular material  
☐ Research limited to use of the premises or facilities of care organisations (no involvement of patients/service users as participants)  
☒ Research limited to involvement of staff as participants (no involvement of patients/service users as participants)

**5. Will any research sites in this study be NHS organisations?**

- ☒ Yes ☐ No

**5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out the research e.g. NHS support costs) for this study provided by a NIHR Biomedical Research Centre (BRC), NIHR Applied Research Collaboration (ARC), NIHR Patient Safety Translational Research Centre (PSTRC), or an NIHR Medtech and In Vitro Diagnostic Co-operative (MIC) in all study sites?**

Please see information button for further details.

- ☐ Yes ☒ No

Please see information button for further details.

**5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?**

Please see information button for further details.

☒ Yes ☐ No

*The NIHR Clinical Research Network (CRN) provides researchers with the practical support they need to make clinical studies happen in the NHS in England e.g. by providing access to the people and facilities needed to carry out research "on the ground".*

*If you select yes to this question, information from your IRAS submission will automatically be shared with the NIHR CRN. Submission of a Portfolio Application Form (PAF) is no longer required.*

**6. Do you plan to include any participants who are children?**

☐ Yes ☒ No

**7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?**

☐ Yes ☒ No

*Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.*

**8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?**

☐ Yes ☒ No

**9. Is the study or any part of it being undertaken as an educational project?**

☒ Yes ☐ No

Please describe briefly the involvement of the student(s):  
This study is a part of Eleftherios' Anestis PhD thesis

**9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?**

☒ Yes ☐ No

**10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?**

☐ Yes ☒ No

**11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?**

Full Set of Project Data

IRAS Version 5.21

☐ Yes ☒ No

DRAFT

**Integrated Research Application System**  
**Application Form for Research involving qualitative methods only**

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

**Short title and version number:** (maximum 70 characters - this will be inserted as header on all forms)  
Healthcare professionals' experiences in breaking bad news for MNDDs 1

**PART A: Core study information****1. ADMINISTRATIVE DETAILS****A1. Full title of the research:**

Healthcare professionals' perspectives and experiences of breaking bad news and supporting newly diagnosed patients with motor neurodegenerative conditions

**A2-1. Educational projects**

Name and contact details of student(s):

**Student 1**

	Title	Forename/Initials	Surname
	Mr	Eleftherios	Anestis
Address	Kingsley House 17 15 Newton Street Manchester		
Post Code	M1 1HE		
E-mail	e.anestis@lancaster.ac.uk		
Telephone	07596237204		
Fax	0		

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:  
PhD in Health Research

Name of educational establishment:  
Lancaster University

Name and contact details of academic supervisor(s):

**Academic supervisor 1**

	Title	Forename/Initials	Surname
	Prof	Jane	Simpson
Address	Furness College, Lancaster University, Bailrigg		

Lancaster  
United Kingdom  
Post Code LA1 4YW  
E-mail j.simpson2@lancaster.ac.uk  
Telephone +441524592858  
Fax 000000000

**Academic supervisor 2**

Title Forename/Initials Surname  
Dr Ian Fletcher  
Address Furness College, Lancaster University, Bailrigg  
Lancaster  
United Kingdom  
Post Code LA1 4YG  
E-mail i.j.fletcher@lancaster.ac.uk  
Telephone +44 (0) 1524 593301  
Fax 000000000

**Academic supervisor 3**

Title Forename/Initials Surname  
Dr Fiona Eccles  
Address Furness College, Lancaster University, Bailrigg  
Lancaster  
United Kingdom  
Post Code LA1 4YG  
E-mail f.eccles@lancaster.ac.uk  
Telephone +44 (0)1524 592807  
Fax 000000000

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Mr Eleftherios Anestis	<input checked="" type="checkbox"/> Prof Jane Simpson <input checked="" type="checkbox"/> Dr Ian Fletcher <input checked="" type="checkbox"/> Dr Fiona Eccles

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

**A2-2. Who will act as Chief Investigator for this study?**

- ☐ Student  
☒ Academic supervisor  
☐ Other

**A3-1. Chief Investigator:**

	Title Forename/Initials Surname
	Prof Jane Simpson
Post	Professor in Psychology of neurodegenerative conditions, Director of Education, Division of Health Research, Lancaster University Assistant Dean, Faculty of Health and Medicine, Lancaster University
Qualifications	PhD in Psychology DClinPsy
ORCID ID	0000 0001 5071 4077
Employer	Lancaster University
Work Address	Furness College, Lancaster University, Bailrigg Lancaster United Kingdom
Post Code	LA1 4YW
Work E-mail	j.simpson2@lancaster.ac.uk
* Personal E-mail	
Work Telephone	+441524592858
* Personal Telephone/Mobile	000000000
Fax	0

*\* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

*A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

**A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?**

*This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.*

	Title Forename/Initials Surname
	Mrs Becky Gordon
Address	Head of Research Quality and Policy Research and Enterprise Services Lancaster University
Post Code	LA1 4YW
E-mail	sponsorship@lancaster.ac.uk
Telephone	+44 (0)1524 592981
Fax	0

**A5-1. Research reference numbers. Please give any relevant references for your study:**

Applicant's/organisation's own reference number, e.g. R & D (if available):	FHM REC18113
Sponsor's/protocol number:	N/A
Protocol Version:	0.1
Protocol Date:	06/09/2019
Funder's reference number (enter the reference number or state not applicable):	N/A
Project website:	N/A

**Additional reference number(s):**

Ref.Number	Description	Reference Number
	Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.	

**A5-2. Is this application linked to a previous study or another current application?**

☒ Yes ☐ No

Please give brief details and reference numbers.

This is a qualitative exploration related to a neurologists' survey (application 262063)

**2. OVERVIEW OF THE RESEARCH**

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

**A6-1. Summary of the study.** Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.

Breaking medical bad news is a challenging aspect of healthcare communication which can cause distress to both the bearer and the receiver of the news. How healthcare professionals break bad news can have a detrimental effect on patients' both immediate response to the news, but also on their long-term adjustment to their condition. Most studies have been conducted within the field of oncology, however breaking bad news is a critical issue for other specialties, such as neurology and particularly motor neurodegenerative diseases (MNDDs), which are incurable and progressive in nature and can have a severe impact in patients' quality of life. Studies with people with Parkinson's disease (PD), multiple sclerosis (MS) and motor neurone disease (MND) have indicated that patients are often dissatisfied with how they received their diagnosis and referred to inadequate information provision, lack of empathy and limited consultation duration as the main factors for this negative experience. Studies on professionals' perspectives are limited and have focused on their practice and attitudes towards diagnosis delivery. These studies have shown that neurologists meet basic standards of good practice, but find it difficult to spend enough time and respond to patients' emotions. However, there are no qualitative studies on neurologists' lived experiences in delivering a diagnosis for MNDDs. There are also no studies about the involvement and experiences of other healthcare professionals, such as nursing staff, in breaking bad news for MNDDs. This study will adopt a qualitative methodology to explore the experience of breaking bad news for MNDDs (PD, MS, MND and Huntington's disease) for neurologists and other healthcare professionals in the UK. Developing an understanding on their experiences in the process of breaking bad news for MNDDs can be a first step to reveal potential barriers to optimal practice and assess their needs for training and support.

**A6-2. Summary of main issues.** Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

There are no major ethical considerations which have not been addressed elsewhere in this application form, the research protocol or the supporting documents to be reported here. This study presents minimal risk for the participants and requires minimal resources from the participating sites involved. The research protocol and the interview schedule have been developed by the research team after careful study of the relevant literature and after receiving consultation by healthcare professionals experienced in breaking bad news for MNDDs.

## 3. PURPOSE AND DESIGN OF THE RESEARCH

**A7. Select the appropriate methodology description for this research. Please tick all that apply:**

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☒ Qualitative research
- ☐ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

**A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.**

This study's broad aim is to explore healthcare professionals' perspectives and experiences in breaking bad news and supporting newly diagnosed patients with motor neurodegenerative diseases.

**A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.**

In particular, for the group of neurologists we are looking to focus on their practice and lived experiences on delivering the diagnosis, addressing their emotions and thoughts, identify potential challenges that they face and communication training needs. For the group of other healthcare professionals, we aim to explore their experiences and range of involvement in breaking bad news and supporting newly diagnosed patients with MNDDs.

**A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.**

Research has shown that breaking bad news is a challenging aspect of healthcare professionals' work which can induce stress and negative emotions. Although they can provide useful information about professionals' perspectives so that they can be more effectively trained and supported, qualitative studies on the topic are few and almost non-existent for the case of neurology. In addition, research on lived experiences has focused on the receivers of bad news and research in general has ignored other healthcare professionals' perspectives on breaking bad news, reflecting a definition of bad news breaking as being a single event. Our research is employing a qualitative methodology and uses both an interpretative phenomenological analysis and a thematic analysis approach to explore neurologists' lived experiences of delivering a diagnosis.

**A13. Please summarise your design and methodology. It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.**

Participants recruited via collaborations with participating NHS sites and via online advertisements of the study will be asked to attend an interview at a time and place of their preference, which could include the interview taking place through the telephone or Skype. We chose to provide flexibility via including these options because it is sometimes particularly challenging to recruit healthcare professionals. Also, we do not anticipate that telephone interviews would pose a significant threat to the study's overall quality. Information about the proposed sample sizes and their justification can be found in the relevant question later in this form.



Potential participants in participating sites will be informed about the study either via the attendance of EA to their professional meetings or by a member of staff (for example a research nurse) who will have received the advertising material and will have been previously informed about the study by the research team. Participants who indicate interest to participate will be given out a copy or a link to the participant information sheet which they can read carefully and decide to contact the research team via phone or email should they wish to participate.

Should they want to review it, the participant information can will also be handed to them before the interview begins. Participants will be then asked to provide informed consent by completing the consent form. Those attending the interview via Skype or over the phone will be sent a link to the consent form and the interview will start once they have given consent online by providing their initials after every consent statement, their name and date.

The interviews will be semi-structured, in-depth and audio recorded. The research team has received consultation by healthcare professionals and has developed two interview schedules for this study, one for the group of neurologists and one for the other healthcare professionals group. These will make sure that significant aspects of the study topic will be covered, however the conversation will be mainly guided by the participants and new questions tailored to their narratives will be asked. After every interview, reflective notes will be taken which will help with the subsequent analysis of the data.

Interviews then will be transcribed manually and the transcripts will be printed in order to be coded and analysed. More details on the analysis methods can be found in later questions in this form.

Although focus groups will not be considered for the sample of neurologists due to potential recruiting challenges, it might be possible to conduct one or two focus groups with other healthcare professionals (for example PD specialist nurses), building on the current schedule of their meetings. This will not only help to the co-construction of valuable data, bringing the different experiences and views of different professionals together and creating an open dialogue, but it will also serve as an educational experience for EA's doctoral training, who will be trained and supervised in focus group research by experienced members of the research team. These focus groups will also be audio-recorded and transcribed for analysis in the same way as the data from the other healthcare professionals group.

**A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?**

- ☐ Design of the research
- ☐ Management of the research
- ☐ Undertaking the research
- ☐ Analysis of results
- ☐ Dissemination of findings
- ☒ None of the above

*Give details of involvement, or if none please justify the absence of involvement.*

This is a project focusing on healthcare professionals' perspectives and the patients' perspectives have been addressed through previous research. In addition, the research team has received consultation from healthcare professionals for the design of this study.

**4. RISKS AND ETHICAL ISSUES**

**RESEARCH PARTICIPANTS**

**A15. What is the sample group or cohort to be studied in this research?**

Select all that apply:

- ☐ Blood
- ☐ Cancer
- ☐ Cardiovascular
- ☐ Congenital Disorders

<input type="checkbox"/> Dementias and Neurodegenerative Diseases
<input type="checkbox"/> Diabetes
<input type="checkbox"/> Ear
<input type="checkbox"/> Eye
<input checked="" type="checkbox"/> Generic Health Relevance
<input type="checkbox"/> Infection
<input type="checkbox"/> Inflammatory and Immune System
<input type="checkbox"/> Injuries and Accidents
<input type="checkbox"/> Mental Health
<input type="checkbox"/> Metabolic and Endocrine
<input type="checkbox"/> Musculoskeletal
<input type="checkbox"/> Neurological
<input type="checkbox"/> Oral and Gastrointestinal
<input type="checkbox"/> Paediatrics
<input type="checkbox"/> Renal and Urogenital
<input type="checkbox"/> Reproductive Health and Childbirth
<input type="checkbox"/> Respiratory
<input type="checkbox"/> Skin
<input type="checkbox"/> Stroke
Gender: Male and female participants
Lower age limit: 21 Years
Upper age limit: 120 Years

**A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).**

Consultant neurologists and neurology registrars with experience in delivering the diagnosis of at least one of the MNDDs we focus on (PD/MND/MS/HD). Experience is not defined by years of experience because we would like recruit both inexperienced and experienced professionals, but we expect that participants (especially for the case of neurology registrars) will have communicated at least 5 diagnoses of MNDDs, upper limit was set to 120 because a number had to be provided in the form).

Also, other healthcare professionals, such as specialist nurses, who are involved in breaking bad news and/or supporting newly diagnosed people with MNDDs will be included in this study.

Participants can be working in the NHS or in the private sector, but they must be practising within the UK and speak English. No age or gender restrictions will be applied, lower age limit has been set as 21, the age when someone can work as a qualified healthcare professional.

**A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).**

No experience in delivering at least one MNDD diagnosis for the neurologists and neurology registrars group  
No involvement in breaking bad news or supporting newly diagnosed people with MNDDs

**RESEARCH PROCEDURES, RISKS AND BENEFITS****A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.**

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Reading participant information sheet and approach the research team if they want to participate	2	0	15'-30'	The participants themselves
Provide written consent	1	0	5'-15'	The participants themselves
Interview	1	0	30'-90'	Eleftherios Anestis, at a place or via a medium selected by the participant

**A21. How long do you expect each participant to be in the study in total?**

Seeking informed consent will take about 10-15 minutes if the participant has to read the PIS at the time of the interview.  
In-depth interviews usually last at least 30 to 90 minutes.

**A22. What are the potential risks and burdens for research participants and how will you minimise them?**

*For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.*

Although this study will not include any participants from risk-sensitive populations and not major risks are anticipated, we have to address some risks and burdens associated with qualitative studies using interviews in general.

To begin with, participants might feel burdened by the time they invest in taking part in an in-depth interview. However, we have made sure that the interview schedule is strictly focusing on the subject of the study, we, therefore, did not include too broad questions that would make the interviews unnecessarily lengthy, apart from a warming up question. In addition, participants will guide the pace of the interview and we will not push participants to talk more than they want to. Furthermore, participants will decide on the place (or medium, e.g. via telephone) where the interview will be conducted so that they will not be burdened by travel inconveniences.

Qualitative studies collecting data through interviews can also raise anonymity and confidentiality issues. Participants will be anonymised with the use of pseudonyms and sensitive personal information, such as the name of the hospital they practice in, will also be anonymised at the stage of transcription. All information provided by the participants will be treated as confidential and only the research team will have access to the raw data which will be securely stored in box, the cloud service recommended by Lancaster University. However, quotes from the interviews will be used in the presentation of the results of the study in subsequent publications or conference presentations. However, any information included in the quote that could lead to the identification of the participant will be anonymised.

Participants might find the topic of this study to be sensitive, especially since they have to recall experiences that might have been distressing for them. However, the anticipated risks related to the topic of the study are minimum and the participant information sheet will provide participants with a list of contacts should they need support after the interview. In addition, participants might find audio recording to be intrusive, but its necessity will be discussed with the participants should they raise any concerns. EA has a background in psychology, has received training and has experience in conducting interviews and will try to make participants feel relaxed. He will also be supervised by the research team which has significant experience in conducting qualitative research.

Finally, participants will give consent to take part in the study after having read the PIS which will inform them about all the issues raised above. Their participation will be voluntary and they will be able to withdraw at any time during the interview and within two weeks from the day of the interview.

**A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?**

☒ Yes ☐ No

*If Yes, please give details of procedures in place to deal with these issues:*

Participants will be asked to talk about their practice of breaking bad news and will potentially recall distressing experiences. However, being healthcare professionals, we do not anticipate that this would cause significant distress to them. In case they feel severely distressed, they will be offered to have a break, end the interview or talk about this with the researcher who has a background in Psychology. Should they need further support, participants can get in touch with one of the contacts for support, which will be included in the PIS.

In the case that participants disclose information that may refer to unprofessional practice, EA will discuss this with his supervisors, who will decide if any form of action needs to be taken.

**A24. What is the potential for benefit to research participants?**

There will be no direct benefit to research participants, however we believe that taking part will be a good opportunity for them to reflect on this sensitive part of their practice and express their emotions. In addition, this study aims to generate results which will indicate implications for clinical practice and suggest ways to better support healthcare professionals carrying out this task.

**A26. What are the potential risks for the researchers themselves? (if any)**

There is no direct anticipated risks for the researchers themselves other than those associated with lone researching work. EA who is conducting the interviews will follow Lancaster University's, Department of Health Research Lone Researching Policy to minimise the risks by taking specific actions such as having a 'safety partner' who he will share the details of the interview site and time and he will call once the interview is concluded. It is also possible that a professional lone working system (e.g. skyguard) may be used, especially in case the researcher is conducting the interview at a participant's house.

**RECRUITMENT AND INFORMED CONSENT**

*In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.*

**A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?** *For example, identification may involve a disease register, computerised search of social care or GP records, or review of medical records. Indicate whether this will be done by the direct care team or by researchers acting under arrangements with the responsible care organisation(s).*

Participants will be recruited through collaborations with neurology departments and centres for motor neurodegenerative diseases within the NHS. After ethical approval is granted, the research team will be in touch with these sites and a person from the staff team will be asked to inform potential participants about the study (for example by distributing study advertising material via email), who can then send an email or call someone from the research team to indicate their interest to participate. EA will also visit participating sites to inform potential participants about the nature and aim of the study and give out copies of the participant information sheet to those that indicate interest to participate. The study will also be advertised by the Association of British Neurologists website and websites or twitter pages related to neurology/neurological conditions and potential participants will be able to contact the research team via email should they wish to take part. We are also expecting to recruit participants via snowball sampling.

**A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?**

☐ Yes ☒ No

*Please give details below:*

**A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?**

☒ Yes ☐ No

*If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).*

The study will be advertised through the website of the Association of British Neurologists and neurology-related pages websites or profiles on twitter (see advertising material document).

**A29. How and by whom will potential participants first be approached?**

Participants who find out about the survey online will contact the research team should they wish to participate.

Participants through the collaborations with NHS sites will be approached through either visits from the research team to the sites or the involvement of staff which could for example distribute information about the study via email or talk about it in staff meetings.

**A30-1. Will you obtain informed consent from or on behalf of research participants?**

☒ Yes ☐ No

*If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.*

*If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.*

*If you are not obtaining consent, please explain why not.*

Please enclose a copy of the information sheet(s) and consent form(s).

**A30-2. Will you record informed consent (or advice from consultees) in writing?**

☒ Yes ☐ No

**A31. How long will you allow potential participants to decide whether or not to take part?**

Participants who indicate interest to take part will be handed/sent the participant information sheet and there will be no time limit for them to decide if they want to participate or not, given that they do so before the data collection phase of the study has concluded. The participant information sheet will also be provided to participants just before the interview, in case some participants did not have time to read it beforehand. They will be given 15' to read the participant information sheet and decide if they want to participate.

**A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)**

No translation or use of interpretation arrangements have been made. Since participants will be practising in the NHS they are most likely expected to be fluent in English.

**A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.**

- ☐ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ☐ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ☐ The participant would continue to be included in the study.

- ☐ Not applicable – informed consent will not be sought from any participants in this research.
- ☒ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

*Further details:*

#### CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

#### Storage and use of personal data during the study

**A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)**

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Access to social care records by those outside the direct social care team
- ☒ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☒ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☒ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☒ Use of audio/visual recording devices
- ☒ Storage of personal data on any of the following:
- ☐ Manual files (includes paper or film)
- ☐ NHS computers
- ☐ Social Care Service computers
- ☐ Home or other personal computers
- ☒ University computers
- ☐ Private company computers
- ☐ Laptop computers

*Further details:*

After every interview the digital audio recordings of both the interview and the recorded consent will be uploaded onto Box, a password secured cloud service recommended by Lancaster University, and will then be deleted from the recording device. These two files will be stored in separate folders. A second audio recorder will be used as a back-up in case the first stops working.

The research team will sometimes have access to participants' email addresses in case these have contacted the research team to indicate their interest to take part in the study. In addition, some participants might want to discuss potential participation and schedule the interview via the phone (or participate in a telephone interview), therefore sharing their telephone number with the research team. In all cases, only the research team will have access to these information which will be treated as confidential. Telephone numbers will not be saved as contacts in the researchers' personal phones, instead they will be listed in a document which will be securely stored in Box.

Potentially identifying data from participants will be anonymised during transcription so they will not lead to participant identification if they are going to be used as direct quotations in the publication of the research, but the interviewers will

also not ask participants to share personal information during the interview (such as the name of the clinic in which they practise).

For this study the research team will borrow an audio recorder from Lancaster University (plus one to be used as a back-up).

All data related to the study such as the raw audio data, transcripts, participants' telephone numbers, will be stored in Box.

**A37. Please describe the physical security arrangements for storage of personal data during the study?**

Participants personal data will only be stored in digital form. Data from the recorder will be deleted as quickly as possible, once they have been transferred to a password protected PC and in the meantime the recorder will be stored securely.

**A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.**

Personal data such as participants' email addresses and phone numbers will be stored in Box, which is a password protected cloud service and only the research team will have access to it. Other personal data, such as participants' names, the name of the hospital/trust in which they practice or any other obviously identifying information which participants might mention during the interview will be anonymised through the use of pseudonyms during transcription. The transcription will be performed by EA, but the anonymised transcripts will be available for all the research team. Particular attention will be paid in the publication of direct quotes, where we will make sure that no participant identifying information are used.

**A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.**

Only the research team will have access to participants' personal data during the study.

**Storage and use of data after the end of the study**

**A41. Where will the data generated by the study be analysed and by whom?**

Audio recordings will be transcribed and these transcripts will be printed and analysed by EA in his office at Lancaster University or his house. These transcripts will not be linked to participants personal data such as email addresses and telephone numbers and any identifiable information will have been anonymised during transcription. After the completion of the analysis, the printed transcripts will be scanned in PDF form, uploaded onto Box. The printed transcripts will then be destroyed using an appropriate machine at Lancaster University.

**A42. Who will have control of and act as the custodian for the data generated by the study?**

	Title Forename/Initials Surname
	Prof Jane Simpson
Post	Professor in Psychology of neurodegenerative conditions and Director of Education, Division of Health Research, Lancaster University Assistant Dean, Faculty of Health and Medicine, Lancaster University
Qualifications	PhD in Psychology DClinPsy
Work Address	Division of Health Research, Furness College, Lancaster University, Lancaster Lancaster United Kingdom
Post Code	LA1 4YG
Work Email	j.simpson2@lancaster.ac.uk
Work Telephone	+441524593301

Fax	0000000000
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**A43. How long will personal data be stored or accessed after the study has ended?**

- ☒ Less than 3 months  
☐ 3 – 6 months  
☐ 6 – 12 months  
☐ 12 months – 3 years  
☐ Over 3 years

**A44. For how long will you store research data generated by the study?**

Years: 10  
Months: 0

**A45. Please give details of the long term arrangements for storage of research data after the study has ended. Say where data will be stored, who will have access and the arrangements to ensure security.**

Data will be stored in a password protected file on the university's secure server for ten years and if the work is published, data will be stored for five additional years from the date of publication. Jane Simpson will be responsible for the protection of the data after the student has finished with his studies in Lancaster University.

**INCENTIVES AND PAYMENTS****A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?**

- ☐ Yes ☒ No

**A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?**

- ☐ Yes ☒ No

**A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?**

- ☐ Yes ☒ No

**NOTIFICATION OF OTHER PROFESSIONALS****A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?**

- ☐ Yes ☒ No

*If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.*



## PUBLICATION AND DISSEMINATION

**A50-1. Will the research be registered on a public database?**

☐ Yes ☒ No

*Please give details, or justify if not registering the research.*  
No suitable register exists.

*Registration of research studies is encouraged wherever possible.*  
*You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.*

**A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:**

- ☒ Peer reviewed scientific journals  
☐ Internal report  
☒ Conference presentation  
☒ Publication on website  
☐ Other publication  
☐ Submission to regulatory authorities  
☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators  
☐ No plans to report or disseminate the results  
☒ Other (please specify)  
 Part of EA's PhD Thesis

**A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?**

Pseudonyms will be used instead of participants' real names, no details about their location will be published and any direct quotations which could lead to their identification will be anonymised.

**A53. How and when will you inform participants of the study results?**

*If there will be no arrangements in place to inform participants please justify this.*  
Participants will be asked to provide their email should they wish to be provided with a summary of the results once the study has concluded.

## 5. Scientific and Statistical Review

**A54-1. How has the scientific quality of the research been assessed? Tick as appropriate:**

- ☐ Independent external review  
☐ Review within a company  
☐ Review within a multi-centre research group  
☒ Review within the Chief Investigator's institution or host organisation  
☒ Review within the research team

☒ Review by educational supervisor

☐ Other

*Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:*

The study has been designed under the supervision of Eleftherios' Anestis work by the rest of the research team (Prof Jane Simpson, Dr Ian Fletcher and Dr Fiona Eccles) and it has also received ethical approval by Lancaster University, Faculty of Health and Medicine Ethics Committee (approval letter enclosed).

*For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.*

*For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.*

**A59. What is the sample size for the research?** *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 30

Total international sample size (including UK): 30

Total in European Economic Area: 30

*Further details:*

For the group of neurologists' we are aiming to include a minimum of 6 and a maximum of 12 and we expect to include a bigger number (approximately up to 24) of participants for the group of other healthcare professionals. Justification of the proposed sample size is provided below.

**A60. How was the sample size decided upon?** *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

IPA is idiographic in nature, which means that it mostly aims to achieve rich phenomenological insight and therefore bring out the uniqueness of the experiences of the individuals. We believe that the sample size proposed for the neurologists group will help us reach this aim but it will also allow us to highlight contrasts and differences in the experiences of neurologists delivering a diagnosis for a MNDD. In addition, the small number of participants can also be justified by the fact that we expect the group of neurologists to be a fairly homogenous group.

For the group of other healthcare professionals, we propose a slightly bigger sample size since this group is expected to be more heterogenous and we are interested to explore professionals' range of involvement in breaking bad news. Participants' roles and experiences are expected to vary and data saturation, in this case, will be an indicator that we can stop recruiting new participants.

In addition, conducting this amount of in-depth individual interviews and potentially a focus group, is expected to generate a rich amount of data which translates to hundreds of pages. It would be, therefore, pragmatically challenging to consider a bigger sample size taking into account the resources available for and time restrictions of this project.

**A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.**

Data collected will be analysed according to published IPA (Smith, 2009) and thematic analysis (Braun & Clarke, 2006) staged procedures and recommendations. After transcription, EA will read and reread all interviews until familiarisation with the data is reached and he will then proceed to the appropriate coding phase for each analytical method. All transcripts will be printed and analyzed on paper. Following the coding phase, the research team as a whole will move on to a 'clustering themes' phase and a cross-case analysis (comparison of individual interview transcripts).

## 6. MANAGEMENT OF THE RESEARCH

**A63. Other key investigators/collaborators.** *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title Forename/Initials Surname
	Prof Sofia Triliva
Post	Professor of Clinical Psychology
Qualifications	Psy. D. Doctor of Psychology
Employer	University of Crete
Work Address	University of Crete School of Social Sciences, Department of Psychology Rethymnon, Crete, Greece
Post Code	74100
Telephone	28310-77542
Fax	0
Mobile	0
Work Email	triliva@uoc.gr

## A64. Details of research sponsor(s)

## A64-1. Sponsor

## Lead Sponsor

Status: ☐ NHS or HSC care organisation☒ Academic☐ Pharmaceutical industry☐ Medical device industry☐ Local Authority☐ Other social care provider (including voluntary sector or private organisation)☐ Other*If Other, please specify:*

Commercial status: Non-Commercial

## Contact person

Name of organisation Lancaster University

Given name Becky

Family name Gordon

Address Lancaster University

Town/city Lancaster

Post code LA1 4YW

Country United Kingdom

Telephone +441524592981

Fax 0

E-mail sponsorship@lancaster.ac.uk

**Legal representative for clinical investigation of medical device (studies involving Northern Ireland only)**

*Clinical Investigations of Medical Devices that take place in Northern Ireland must have a legal representative of the sponsor that is based in Northern Ireland or the EU*

**Contact person**

Name of organisation

Given name

Family name

Address

Town/city

Post code

Country

Telephone

Fax

E-mail

**A65. Has external funding for the research been secured?**

*Please tick at least one check box.*

- ☐ Funding secured from one or more funders
- ☐ External funding application to one or more funders in progress
- ☒ No application for external funding will be made

What type of research project is this?

- ☐ Standalone project
- ☐ Project that is part of a programme grant
- ☐ Project that is part of a Centre grant
- ☐ Project that is part of a fellowship/ personal award/ research training award
- ☒ Other

Other – please state:

Project as a part of a PhD thesis

**A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? Please give details of subcontractors if applicable.**

- ☐ Yes ☒ No

**A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?**

- ☐ Yes ☒ No

*Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.*

**A68-1. Give details of the lead NHS R&D contact for this research:**

	Title Forename/Initials Surname
	Mrs Gill Hamblin
Organisation	The Walton Centre NHS Foundation Trust,
Address	The Walton Centre NHS Foundation Trust
	Lower Lane
	Liverpool
Post Code	L9 7LJ
Work Email	gillian.hamblin@thewaltoncentre.nhs.uk
Telephone	0151 556 3389
Fax	00000000000
Mobile	07842052673

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

**A68-2. Select Local Clinical Research Network for NHS Organisation identified in A68-1:**

North West Coast

For more information, please refer to the question specific guidance.

**A69-1. How long do you expect the study to last in the UK?**

Planned start date: 15/08/2019

Planned end date: 15/07/2020

Total duration:

Years: 0 Months: 10 Days: 1

**A71-1. Is this study?**

- ☐ Single centre
- ☒ Multicentre

**A71-2. Where will the research take place? (Tick as appropriate)**

- ☒ England
- ☒ Scotland
- ☐ Wales
- ☒ Northern Ireland
- ☐ Other countries in European Economic Area

Total UK sites in study n/a

**Does this trial involve countries outside the EU?**

- ☐ Yes ☒ No

**A72. Which organisations in the UK will host the research?** Please indicate the type of organisation by ticking the box and give approximate numbers if known:

- ☒ NHS organisations in England
- ☐ NHS organisations in Wales
- ☒ NHS organisations in Scotland
- ☒ HSC organisations in Northern Ireland
- ☐ GP practices in England
- ☐ GP practices in Wales
- ☐ GP practices in Scotland
- ☐ GP practices in Northern Ireland
- ☐ Joint health and social care agencies (eg community mental health teams)
- ☐ Local authorities
- ☐ Phase 1 trial units
- ☐ Prison establishments
- ☐ Probation areas
- ☒ Independent (private or voluntary sector) organisations
- ☐ Educational establishments
- ☐ Independent research units
- ☒ Other (give details)

Total number currently unknown, other organisations e.g the association of British neurologists

Total UK sites in study: 0

**A73-1. Will potential participants be identified through any organisations other than the research sites listed above?**

☒ Yes ☐ No

**A73-2. If yes, will any of these organisations be NHS organisations?**

☐ Yes ☒ No

If yes, details should be given in Part C.

**A74. What arrangements are in place for monitoring and auditing the conduct of the research?**

EA's academic supervisors (JS, IF & FE) and Prof Sofia Triliva will be monitoring and auditing the conduct of the research via weekly supervision meetings.

**A76. Insurance/ indemnity to meet potential legal liabilities**

*Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

**A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.**

*Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.*

- ☐ NHS indemnity scheme will apply (NHS sponsors only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

**A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research?** Please tick box(es) as applicable.

*Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.*

- ☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

**A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?**

*Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.*

- ☐ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- ☒ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

**A78. Could the research lead to the development of a new product/process or the generation of intellectual property?**

- ☐ Yes ☒ No ☐ Not sure

**A79. Please select the level of commercial participation in this project.**

- ☒ None
- ☐ Industry funding, but not industry sponsored
- ☐ Industry funding and industry sponsored
- ☐ Industry sponsored, but not industry funded

**A80. Please select the main subject area of research. Additional sub-topics may be selected, if required**

- ☐ Age and Ageing

- ☐ Anaesthetics
- ☐ Cancer (includes malignant haematology)
- ☐ Cardiovascular
- ☐ Clinical
- ☐ Critical Care
- ☒ Dementias and Neurodegenerative Diseases
- ☐ Dermatology
- ☐ Diabetes
- ☐ Ear, Nose and Throat
- ☐ Gastrointestinal
- ☐ Genetics
- ☒ Health Services Research
- ☐ Hepatology
- ☐ Immunology and Inflammation
- ☐ Infectious Disease and Microbiology
- ☐ Injuries and Accidents
- ☐ Medicines for Children (does not include Paediatrics)
- ☐ Mental Health
- ☐ Metabolic and Endocrine
- ☐ Musculoskeletal (Rheumatoid Arthritis is a separate category)
- ☐ Nervous System Disorders
- ☐ Non-malignant Haematology
- ☐ Ophthalmology
- ☐ Oral and Dental
- ☐ Paediatrics (does not include Medicines for Children)
- ☐ Primary Care
- ☐ Public Health Research
- ☐ Renal
- ☐ Reproductive Health and Childbirth
- ☐ Respiratory
- ☐ Rheumatoid Arthritis
- ☐ Stroke
- ☐ Surgery
- ☐ Urogenital

**9. Has the study been the subject of a scientific review/opinion (Expert Panel)?**

☐ Yes ☐ No

*If yes, please provide a copy of the review as part of your application.*

**PART C: Overview of research sites**



Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For further information please refer to guidance.

Investigator identifier	Research site	Investigator Name
IN1	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site  Organisation name THE WALTON CENTRE NHS FOUNDATION TRUST Address LOWER LANE  LIVERPOOL MERSEYSIDE Post Code L9 7LJ Country ENGLAND	Forename Eleftherios Middle name n/a Family name Anestis Email e.anestis@lancaster.ac.uk Qualification BSc in Psychology (MD...) MSc in Health Psychology Country United Kingdom
IN2	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site  Organisation name SALFORD ROYAL NHS FOUNDATION TRUST Address SALFORD ROYAL STOTT LANE SALFORD GREATER MANCHESTER Post Code M6 8HD Country ENGLAND	Forename Eleftherios Middle name n/a Family name Anestis Email e.anestis@lancaster.ac.uk Qualification BSc in Psychology (MD...) MSc in Health Psychology Country United Kingdom
IN3	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site  Organisation name SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST Address NORTHERN GENERAL HOSPITAL HERRIES ROAD SHEFFIELD SOUTH YORKSHIRE Post Code S5 7AU Country ENGLAND	Forename Eleftherios Middle name n/a Family name Anestis Email e.anestis@lancaster.ac.uk Qualification BSc in Psychology (MD...) MSc in Health Psychology Country United Kingdom

IN4	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site	Forename Eleftherios Middle name n/a Family name Anestis Email e.anestis@lancaster.ac.uk Qualification BSc in Psychology (MD...) MSc in Health Psychology Country United Kingdom
	Organisation name KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST Address DENMARK HILL LONDON GREATER LONDON Post Code SE5 9RS Country ENGLAND	
IN5	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site	Forename Eleftherios Middle name N/A Family name Anestis Email e.anestis@lancaster.ac.uk Qualification BSc in Psychology (MD...) MSc in Health Psychology Country United Kingdom
	Organisation name UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST Address 250 EUSTON ROAD LONDON Post Code NW1 2PG Country United Kingdom	
IN6	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site	Forename Eleftherios Middle name n/a Family name Anestis Email e.anestis@lancaster.ac.uk Qualification BSc in Psychology (MD...) MSc in Health Psychology Country United Kingdom
	Organisation name ROYAL CORNWALL HOSPITALS NHS TRUST Address ROYAL CORNWALL HOSPITAL TRELISKE TRURO Post Code TR1 3LJ Country ENGLAND	

IN7	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site		Forename Eleftherios Middle name n/a Family name Anestis Email e.anestis@lancaster.ac.uk Qualification BSc in Psychology (MD...) MSc in Health Psychology Country United Kingdom
	Organisation name LEICESTERSHIRE PARTNERSHIP NHS TRUST Address RIVERSIDE HOUSE BRIDGE PARK PLAZA BRIDGE PARK ROAD LEICESTER LEICESTERSHIRE Post Code LE4 8PQ Country ENGLAND		
IN8	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site		Forename Eleftherios Middle name N/A Family name Anestis Email e.anestis@lancaster.ac.uk Qualification BSc in Psychology (MD...) MSc in Health Psychology Country United Kingdom
	Organisation name UNITED LINCOLNSHIRE HOSPITALS NHS TRUST Address LINCOLN COUNTY HOSPITAL GREETWELL ROAD LINCOLN Post Code LN2 5QY Country ENGLAND		

## Participant Information Sheet

### Healthcare professionals' perspectives and experiences of breaking bad news and supporting patients newly diagnosed with motor neurodegenerative conditions

My name is Eleftherios Anestis and I am conducting this research as a part of my PhD in Health Research thesis at Lancaster University.

#### What is the study about?

The purpose of this study is to explore healthcare professionals' experiences, roles and range of involvement in relation to breaking bad news and supporting newly diagnosed patients with motor neurodegenerative diseases (MNDDs), such as Parkinson's disease, multiple sclerosis, Huntington's disease and motor neurone disease.

#### Why have I been approached?

You have been approached because the study requires information from healthcare professionals who work with patients with MNDDs and practice in the UK.

#### Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

#### What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to attend an interview at a time and place (or medium, for example, telephone or Skype) of your convenience. The interview will be audio recorded and you will be asked questions about your practice, your experiences and your thoughts on breaking bad news and supporting newly diagnosed patients with MNDDs.

#### Will my data be identifiable?

The information you provide is confidential. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data.

- Printed transcripts of the interviews will be analysed and will then be destroyed after they have been converted in digital form and securely stored online.
- Audio recordings will be deleted once the project has been submitted for publication and examined.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your

interview may be used in the reports or publications from the study, so your name or any other identifying information will not be attached to them.

- All your personal data will be confidential and will be kept separately from your interview responses.
- Data will be stored in a password protected file on the university's secure server for ten years and if the work is published, data will be stored for five additional years from the date of publication.
- There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.
- Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researcher on your particular study.
- For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: [www.lancaster.ac.uk/research/data-protection](http://www.lancaster.ac.uk/research/data-protection)

#### **What will happen to the results?**

The results will be summarised and reported in my PhD thesis and may be submitted for publications in an academic or professional journal and for presentations in academic conferences. A summary of the results can also be sent to you should you request it.

#### **Are there any risks?**

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet. In addition, you can withdraw your data within two weeks from participation.

#### **Are there any benefits to taking part?**

Although you may find participating interesting, there are no direct benefits in taking part.

#### **Who has reviewed the project?**

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University. The study has also received approval from the Health Research Authority.

#### **Where can I obtain further information about the study if I need it?**

If you have any questions about the study, please contact the main researcher:

**Eleftherios Anestis**

VO.1 (3/6/2019) | IRAS ID: 266719 | Healthcare professionals' perspectives and experiences of breaking bad news and supporting patients newly diagnosed with motor neurodegenerative conditions

PhD in Health Research student  
Division of Health Research, Faculty of Health and Medicine  
Address: Furness College, Lancaster University, Bailrigg, LA1 4YG. United Kingdom  
Email: [e.anestis@lancaster.ac.uk](mailto:e.anestis@lancaster.ac.uk)

*Alternatively, you can contact one of the supervisors of this project:*

**Prof Jane Simpson**

Director of Education, Professor of the Psychology of Neurodegenerative Conditions  
Division of Health Research, Faculty of Health and Medicine  
Address: Furness College, Lancaster University, Bailrigg, LA1 4YG. United Kingdom  
Telephone: +44 (0) 1524 592858  
Email: [simpson2@lancaster.ac.uk](mailto:simpson2@lancaster.ac.uk)

**Dr Ian Fletcher**

Senior Lecturer  
Division of Health Research, Faculty of Health and Medicine  
Address: Furness College, Lancaster University, Bailrigg, LA1 4YG. United Kingdom  
Telephone: +44 (0) 1524 593301  
Email: [i.j.fletcher@lancaster.ac.uk](mailto:i.j.fletcher@lancaster.ac.uk)

**Dr Fiona Eccles**

Lecturer  
Division of Health Research, Faculty of Health and Medicine  
Address: Furness College, Lancaster University, Bailrigg, LA1 4YG. United Kingdom  
Telephone: +44 (0)1524 592807  
Email: [f.eccles@lancaster.ac.uk](mailto:f.eccles@lancaster.ac.uk)

**Complaints**

If you wish to speak to someone outside of the [name of] Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746  
Associate Dean for Research Email: [r.pickup@lancaster.ac.uk](mailto:r.pickup@lancaster.ac.uk)  
Faculty of Health and Medicine  
(Division of Biomedical and Life Sciences)  
Lancaster University  
Lancaster  
LA1 4YG

Thank you for taking the time to read this information sheet.

**Resources in the event of distress**

Should you feel distressed either as a result of taking part, or in the future, you could either contact your professional organisation, talk to your occupational health department or

VO.1 (3/6/2019) | IRAS ID: 266719 | Healthcare professionals' perspectives and experiences of breaking bad news and supporting patients newly diagnosed with motor neurodegenerative conditions

contact one of the helplines provided by the NHS: <https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/>

### Consent Form

Healthcare professionals' perspectives and experiences of breaking bad news and supporting patients newly diagnosed with motor neurodegenerative conditions

We are asking if you would like to take part in a research project about healthcare professionals experiences in breaking bad news and supporting newly diagnosed patients with motor neurodegenerative conditions. Before you consent to participate in the study, we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak or send an email to the principal investigator, Eleftherios Anestis (e.anestis@lancaster.ac.uk).

**Strikethrough**

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be kept until the research project has been examined. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time during the interview or within two weeks from the interview without giving any reason. ☐
6. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published. ☐
7. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
8. I understand that the researcher will discuss data with their supervisor as needed. ☐
9. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with their research supervisor. ☐
10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished and an additional of 5 years if the study is published. ☐
11. I consent to take part in the above study. ☐

Name of Participant \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Name of Researcher \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_



Applicant: Eleftherios Anestis  
Supervisors: Jane Simpson, Ian Fletcher, Fiona Eccles  
Department: Health Research  
FHMREC Reference: FHMREC18

13 August 2019

Dear Eleftherios

**Re: Healthcare professionals' perspectives and experiences of breaking bad news and supporting newly diagnosed patients with motor neurodegenerative conditions**

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987

Email:- [fhmresearchsupport@lancaster.ac.uk](mailto:fhmresearchsupport@lancaster.ac.uk)

Yours sincerely,



Becky Case  
Research Ethics Officer, Secretary to FHMREC.





Prof Jane Simpson  
Furness College, Lancaster University, Bailrigg  
Lancaster  
United Kingdom  
LA1 4YW

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)  
[HCRW.approvals@wales.nhs.uk](mailto:HCRW.approvals@wales.nhs.uk)

26 November 2019

Dear Prof Simpson

**HRA and Health and Care  
Research Wales (HCRW)  
Approval Letter**

<b>Study title:</b>	<b>Healthcare professionals' perspectives and experiences of breaking bad news and supporting newly diagnosed patients with motor neurodegenerative conditions</b>
<b>IRAS project ID:</b>	<b>266719</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>Sponsor</b>	<b>Lancaster University</b>

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

**What are my notification responsibilities during the study?**

The "[After HRA Approval – guidance for sponsors and investigators](#)" document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **266719**. Please quote this on all correspondence.

Yours sincerely,

Kevin Ahmed  
Approvals Manager

Telephone: 0207 104 8171  
Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: *Mrs Becky Gordon*

## **Appendix 2**

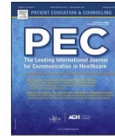
### **Publications**



Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: [www.elsevier.com/locate/pateducou](http://www.elsevier.com/locate/pateducou)



Review Article

## Giving and receiving a diagnosis of a progressive neurological condition: A scoping review of doctors' and patients' perspectives

Eleftherios Anestis\*, Fiona Eccles, Ian Fletcher, Maddy French, Jane Simpson

Division of Health Research, Lancaster University, Lancaster, LA1, UK

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Parkinson's disease  
Scoping review

### ABSTRACT

**Objective:** Delivering a life changing diagnosis can be a distressing experience for patients and a challenging task for professionals. Diagnosis delivery can be especially difficult for individuals with neurodegenerative diseases such as motor neurone disease (MND), multiple sclerosis (MS) and Parkinson's disease (PD). This review aims to scope the literature on doctors' and patients' perspectives on diagnosis delivery for these conditions in order to enhance our understanding in this area and identify potential research gaps.

**Methods:** A scoping review methodology was used, and data were summarised using content analysis. **Results:** 47 studies fulfilled the inclusion criteria. Studies showed that although patients were generally satisfied with diagnosis delivery, a considerable proportion was still dissatisfied with aspects of the consultation, especially the information and time provided and the doctor's approach. Only six studies addressed doctors' perspectives, which focused more on doctors' practice.

**Conclusion:** There was a significant research gap in professionals' perspectives. The review also found that although basic standards of good practice were being met, a significant proportion of patients were dissatisfied with diagnosis communication.

**Practice implications:** Professionals delivering such diagnoses need to assess and respond to patients' information needs, provide time for questions and maintain an empathic attitude.

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Footnote	00
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## 1. Introduction

Diagnosis delivery for a significant health condition is a particularly challenging aspect of doctor-patient communication and most commonly described as 'breaking bad news' [1]. Bad news is usually described as 'any information likely to drastically alter a patient's view of his or her future' [p. 1597] [2]. How such news is delivered can have a long-term impact on the patient's satisfaction with care [3], understanding of the disease [4], involvement in decision-making, psychological adjustment [5], prolonged distress, confusion and treatment adherence [6]. At the same time, delivering a serious diagnosis can also be an emotionally challenging task for healthcare professionals. This aspect of their clinical work can induce moderate but lasting stress reactions [7] and emotions of anger and guilt, and distressing thoughts around their powerlessness to make a positive difference and their own personal fear of death [8].

Studies in this area have been conducted predominantly within fields such as oncology, obstetrics and emergency medicine [6], however bad news delivery can be a critical issue in other medical specialties such as neurology. Progressive neurological conditions such as Parkinson's disease (PD), multiple sclerosis (MS) and motor neurone disease (MND) are incurable and result in a gradual decline in physical and cognitive functioning, restricting individuals' daily activities and affecting their quality of life and psychological functioning [9]. Before receiving their diagnosis, patients often experience a stressful pre-diagnostic period [10], are often misdiagnosed and may experience significant diagnostic delay [11–13]. Reaching a diagnosis for such motor neurodegenerative diseases (MNDDs) can be a demanding task for health professionals due to the similarities in and overlap between symptoms of different conditions [14,15] and the need for specialised testing. Communicating the diagnosis can also be challenging for doctors since such 'bad news' might elicit reactions of different types of distress from the patients [16].

Given the progressive, often life-threatening nature of these conditions and the likely stressful pre-diagnostic experience, receiving the diagnosis will be a critical time for patients. A PD patient survey reported that 'satisfaction with the explanation of the condition at diagnosis' had a significant effect on future quality of life [17]. This review will focus on three neurological conditions which all include forms of neurodegeneration<sup>(1)</sup>. Neurologists commonly deliver these diagnoses which primarily affect movement and have a high 'burden of illness' i.e. impact on both human and economic dimensions [18]. A scoping review was undertaken to identify and summarise existing empirical studies which addressed doctors' current practice and perspectives on breaking bad news, and patients' experiences and perspectives on the process of diagnosis delivery. Other reviews in this area have not focused solely on receiving the diagnosis but more on the experience of services [19–21] or doctor-patient interactions in general [22] and have excluded studies on professionals' perspectives. Including both patient and doctor perspectives will achieve a better understanding on the

neurologist-patient interaction at this critical timepoint and will help identify areas of miscommunication, and gaps in the literature.

## 2. Method

A scoping review was adopted to incorporate patients' and doctors' perspectives that have been reported in qualitative and quantitative studies. Scoping reviews focus on mapping and summarising key concepts from a range of research activities and identifying potential gaps in a broad research topic [23]. They offer similar rigor to reviews using a systematic review methodology, and aim to understand complex topics and not simply summarise the best available evidence. Heterogeneous designs can be included and quality assessments are not usually conducted [24]. This review followed the 6-step framework developed by Arksey and O'Malley [23] and further recommendations by Levac and colleagues [24]. Five of six steps were completed, while the sixth optional step, consultation, was omitted. These steps are briefly outlined below:

### i) Identifying the research question

The research question was: What are patients' and doctors' perspectives on the delivery of the diagnosis for MND, MS and PD? The term 'perspectives' was intentionally broad in order to capture both a priori themes such as patient satisfaction and doctors' practice and to identify and map other key concepts addressed by the literature.

### ii) Identifying relevant studies

PubMed, CINAHL, PsycINFO and Scopus were accessed, using subject terms where available. The search strategies were developed with the help of a subject specialist librarian (see Appendix A). The citation lists of all the included papers were hand searched for additional studies, Google Scholar's 'cited by' service was also accessed.

### iii) Study selection

Table 1 summarises inclusion and exclusion criteria.

Empirical studies of any design were included in the review if they were published in a peer-reviewed journal and addressed patients' or doctors' perspectives on the delivery of diagnosis for MNDDs focusing on the consultation when the diagnosis was delivered. As a first step, titles were screened and all irrelevant papers were excluded. Then abstracts were screened, irrelevant studies were excluded, relevant studies were included and potentially relevant studies were read in full. The main reasons for excluding articles included: no data on diagnosis delivery, a focus on the pre-diagnosis journey, and only addressing patients' emotional reactions to diagnosis. The first author screened all retrieved citations and consulted the rest of the research team to resolve any ambiguity. Additionally, a random 10 % of all retrieved citations were reviewed by another author (MF) and any discrepancies were resolved. Fig. 1 features a PRISMA diagram which illustrates the study selection process.

Please cite this article in press as: E. Anestis, et al., Giving and receiving a diagnosis of a progressive neurological condition: A scoping review of doctors' and patients' perspectives, Patient Educ Couns (2020), <https://doi.org/10.1016/j.pec.2020.03.023>



**Table 1**  
Inclusion and Exclusion Criteria.

Inclusion criteria	Exclusion criteria
Empirical studies	Reviews, guideline or opinion papers
Written in English	Written in any other language
Published in peer-reviewed journals	Published in non-peer-reviewed journals
Adult patients' and doctors' perspectives	Child or adolescent patients, patients' families, carers or healthcare professionals' other than doctors' perspectives
Studies focusing on people with MND, PD or MS	Studies focusing on other conditions or studies which include MND, PD or MS but do not report separate data for these conditions
Studies reporting data on doctors' and patients' perspectives on the diagnostic delivery consultation (e.g patients' information needs and satisfaction with the consultation, doctors' practice and attitudes towards breaking the bad news and doctor-patient communication at the point of diagnosis in general)	Studies who focus on other aspects of diagnosis delivery such as the timing of the diagnosis, the pre-diagnostic period, or the long-term impact of diagnosis delivery. Also, studies which only report data on patients' emotional reactions or coping with the diagnosis.

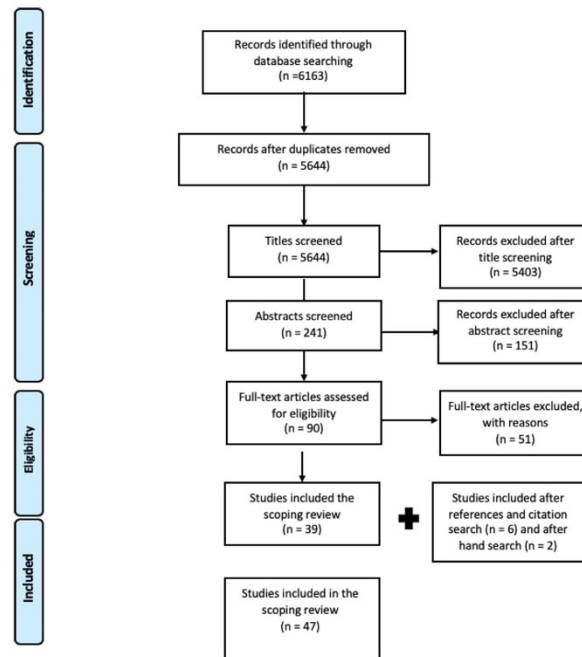


Fig. 1. PRISMA Diagram.

#### iv) Charting the data

Study information and results which addressed the research question were extracted (see Table 3).

#### v) Collating, summarising and reporting the results

Except for a few cases of basic numerical analysis of percentages, data answering our research question were analysed qualitatively through a conventional content analysis approach [25]. The content codes were organised into meaningful categories which summarised available evidence. Results regarding patients' perspectives were analysed and reported independently for each neurological condition, and doctors' perspectives were analysed together due to the limited number of relevant studies.

### 3. Results

#### 3.1. Overview of studies included in the scoping review

In total, 47 studies were included in the review. Table 2 summarises basic study characteristics and Table 3 presents characteristics for every study included in the review.

The majority of studies (n = 22) focused on MS; studies on doctors' perspectives were severely underrepresented in the literature with only six studies included in this review. Qualitative and quantitative methodologies were equally represented in the patient studies and all study designs were retrospective. Studies represented a range of countries, mainly from a western

**Table 2**

Characteristics of included studies.

Total number of studies included	47
Studies on patients' perspective	42 (MND = 15 [26,27,28,29,30,31,32,33,34,35,36,37,38,39,40], MS = 20 <sup>a</sup> [41,42,43,44,45,46,47,48,49,50,51,52,53,54,55,56,57,58,59,60], PD = 7 [61,62,63,64,65,66,67])
Studies on doctors' perspectives	6 (MND = 2 [70,71], MS = 3 [46,68,69] PD = 1 [72])
Quantitative studies	19
Qualitative studies	25
Mixed-methods studies	3
Countries	UK = 15, Australia = 6, USA = 4, Italy = 5, Germany = 3, Sweden = 3, Netherlands = 2, South Africa = 2, Canada = 1, Greece = 1, Iran = 1, New Zealand = 1, Norway = 1, 2 European, multi-country surveys

<sup>a</sup> One study [46] addressed both patient and professionals' perspectives.

perspective, however the similarity of themes across studies indicated that patients' experience of receiving a diagnosis shared common features.

### 3.2. Receiving the diagnosis of MND

#### 3.2.1. Satisfaction with diagnosis delivery

In general, patients with MND were satisfied with the way neurologists delivered the diagnosis, but this was not always the case. Patients in an Italian survey gave high ratings of satisfaction with bad news communication and felt that the doctors were encouraging and understood their feelings during the diagnosis [26]. Other quantitative studies [27,28] reported mixed results; although the majority of patients were satisfied with how the diagnosis was delivered, 32%–35% of patients felt dissatisfied. In particular, patients were mostly satisfied with the privacy provided and the absence of interruptions during the consultation, with only a few exceptions reported. Satisfaction was also positively associated with patients' perceived ability of their neurologist, although it is unclear whether the term ability specifically referred to their communication skills or their general medical competence [28]. However, 36%–56% of patients rated their doctor's ability as average or below average [28,29]. Similarly, qualitative studies also revealed mixed results with patients sharing both positive and negative experiences [30,31] although a study of a single centre which was following international guidelines for MND care received only positive feedback [32].

#### 3.2.2. Information provision

Given the rarity and life-threatening nature of MND, patients often required detailed information about their diagnosis. Patients wanted to know about current research on MND, disease-modifying therapies, their prognosis [26], their entitlements to services [32], the treatment plan and information sources [28,30]. However, it was sometimes felt that the doctor shared insufficient information about these topics [29,30]. Patients also reported their dissatisfaction with doctors, indicating that the information given was not always adequate and that the doctors did not always check they had clearly understood the information [34] or provide the opportunity for questions [35]. This elicited a 'feeling of abandonment' with patients feeling responsible for seeking information about their condition themselves. However, some patients felt that there was limited potential for further information due to the poor prognosis [36] and a qualitative study highlighted that patients' receptivity to information differed dramatically [37].

#### 3.2.3. Consultation duration

Survey studies reported a mean consultation of approximately half an hour [28,29]. Patients who had received longer consultations were more satisfied and considered their doctor more skilled [28]. On the contrary, doctors who were judged to possess poor skills only spent an average of 13.4 min on the

consultation [29]. Patients were often frustrated with a very short consultation as they did not have the opportunity for discussion [31]. At the same time, they knew the clinicians were in high demand and it could take months for the next appointment [34]. Receiving such a complex diagnosis required time for them to digest the information provided, express their feelings and ask questions. The evaluation of a fast-track diagnostic service based on principles of good practice in breaking bad news showed positive patient satisfaction regarding the communication of the diagnosis and the time taken [37]. Similarly, a qualitative study which assessed patients' perspectives on diagnosis delivery in a 2-tiered approach reported positive outcomes. Patients viewed the second appointment - which they received only 10–14 days after the first - as an opportunity to prepare questions, clear misunderstandings and make informed decisions regarding their treatment [36].

#### 3.2.4. Doctors' empathy

Qualitative studies and qualitative comments in quantitative studies sometimes highlighted the need for doctors to show more empathy. Patients often felt that their doctors did not approach such a serious diagnosis in a caring and sensitive way and were described as 'detached', 'very clinical' and 'insensitive' [31,38]. Similarly, Pavey et al. [34] described that patients considered that doctors were unwilling to be personally involved and offer emotional support; a participant in the Hughes et al. [33] study also reported feeling 'dehumanised'. However, most studies that addressed the issue reported mixed experiences [30,31,33,35,39] or even exclusively positive experiences [37]. Patients valued being listened to when they expressed their anxieties and fears regarding the future [36] and those who were satisfied with their doctor's approach [31] described them as a 'fantastic, caring person' and 'kind and empathetic'. Interestingly, the older study reported that patients often found a straightforward and even blunt disclosure style acceptable [40].

### 3.3. Receiving the diagnosis of MS

#### 3.3.1. Satisfaction with diagnosis delivery

Regarding general satisfaction with the way doctors broke the bad news for a MS diagnosis, studies presented mixed results. A quantitative survey showed that 67% of patients were completely and 24% were partially satisfied with the diagnosis delivery, 64% thought the medical staff were kind, 30% thought they were attentive and only 6% thought they were unfriendly or hasty [41]. It is noteworthy though, that this survey was conducted in a single MS centre. Additionally, two studies from Norway which used the same questionnaire found that there was definitely room for improvement as only 33%–55% of patients were satisfied with the circumstances in which their diagnosis was communicated [42,43]. Qualitative studies, on the other hand, indicated that although some positive experiences were reported by patients, these were the exceptions [44,45].

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**Table 3**  
Characteristics of studies included in the review.

No.	Paper	Was diagnosis delivery the main focus of the study?	Methodology	Participants <sup>a</sup>	Country	Main results <sup>a</sup>
<b>Studies on patients' perspectives</b>						
1	Abdulla et al., 2014 [27]	No	Quantitative	106 people with MND	Germany	68 % were satisfied with how the diagnosis was delivered, 69 % were satisfied with the amount and 77 % with the comprehensibility of information provision. Qualitative comments about impersonal/too short consultation.
2	Aoun et al., 2016b [28]	Yes	Quantitative	248 people with MND	Australia	65 % were satisfied with diagnosis delivery and 35 % were not satisfied. Higher satisfaction was associated with longer consultation times.
3	Aoun et al., 2018 [31]	Yes	Qualitative	248 people with MND	Australia	Mixed results regarding neurologist's empathy and emotional support provision as well as time provided for the consultation. Information preferences differed among participants but signposting to the MND Association was viewed positively. Patients shared their experiences with doctors' 'overly medical or formal approach'.
4	Barker-Collo & Read, 2006 [56]	No	Qualitative	16 people with MS	New Zealand	All participants wanted information about MS at the time of the diagnosis but were aware that shock at that point did not help assimilate it.
5	Beisecker et al. 1988 [40]	No	Quantitative	41 people with MND, but only 35 were asked about diagnosis disclosure	United States	Of the 35 patients who responded to questions about diagnosis delivery, 24 described a straightforward or even blunt disclosure style. Out of these 24 patients, 19 found this an acceptable disclosure style but others thought the physician seemed upset for having to give such a diagnosis or talking about the fatality of the disease took away all hope.
6	Bloem & Stocchi, 2012 [62]	No	Quantitative	2068 people with PD	35 countries in Europe	52.5 % of patients rated their experience with the diagnosis delivery as 'good or very good' and 45.3 % as 'poor or very poor'. 62.2 % of patients reported having received general information about their condition, 22.1 % received detailed information, 14 % received information about medication at diagnosis and less than 2.8 % received information about PD support organisations. 66 % found information provided to be 'helpful or very helpful'
7	Callagher et al., 2009 [37]	Yes	Quantitative (Clinical audit of patient satisfaction)	23 people with MND	United Kingdom	Patients receiving their diagnosis through a 'fast-track' service which utilised knowledge from the 'breaking bad news' literature and limited waiting times shared their positive experiences with the consultation they received at the time of diagnosis and were content with the privacy, time and sensitivity provided and having a relative present.
8	Ceuninck van Capelle et al., 2015 [57]	Yes	Qualitative	10 people with MS	Netherlands	Patients could vividly remember the physician delivering the diagnosis and reported mixed experiences. Some were satisfied with how the doctor handled the consultation and the way they explained the diagnosis, while some others reported receiving the diagnosis in an abrupt manner, not having their questions answered and their emotions attended.
9	Chiò et al., 2008 [26]	No	Quantitative	60 people with MS	Italy	Patients gave high ratings about their overall satisfaction with diagnosis delivery and how encouraging and understanding of their emotions their physician was. Higher satisfaction was associated with the feeling that the physician has understood their feelings. Most patients wanted to receive information about current research on MND (65 %), therapies that could slow disease progression (56.7 %) and MND outcome (43.3 %)
10	Dennison et al., 2016 [59]	No	Qualitative	15 people with MS	United Kingdom	Patients reported negative experiences about how their diagnosis was communicated and the lack of support they received at that time which left them feel distressed and upset. Neurologists were viewed as 'diagnosers' with no interest in patients' perspectives. All patients reported diagnosis as an unsuitable point for receiving prognostic information.
11	Edwards et al., 2008 [49]	Yes	Qualitative	24 people with MS	United Kingdom	Many participants were not satisfied with how they received their diagnosis, especially with physicians' often casual and unsympathetic approach. One participant reported being given the diagnosis over the phone and another one at Christmas Eve. Such negative experiences elicited emotions of disappointment and anger. The majority felt they had not received adequate amount of information (n = 20)

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Table 3 (Continued)

No.	Paper	Was diagnosis delivery the main focus of the study?	Methodology	Participants <sup>a</sup>	Country	Main results <sup>a</sup>
12	Gottberg et al., 2008 [42]	No	Quantitative	166 people with MS	Sweden	55 % of patients were dissatisfied with the situation in which they first received the diagnosis
13	Habermann, 1996 [64]	No	Qualitative	16 people with PD	United States	Reactions of shock when receiving the diagnosis did not allow some participants to process the information provided at that point, but others clearly recalled being given very little information about their diagnosis. A participant who received inadequate information at the point of the diagnosis shared his experience with an unsympathetic professional who only saw him for 12 min and did not give him any hope. Living and coping with the disease were not discussed with their physician at the point of diagnosis.
14	Hepworth & Harrison, 2004 [51]	No	Mixed (questionnaires and focus groups)	2030 questionnaire respondents and 103 participated in the focus groups (people with MS)	United Kingdom	Out of the 103 patients who participated in the focus groups, 49 % mentioned negative experiences they had when they received their diagnosis and only 8 participants were happy with how they were given the diagnosis. The most often negative experiences were related to the physicians' attitude and inadequate provision of information and support. Data from the questionnaires showed that at the point of diagnosis over 50 % of participants would like to receive information on symptoms and management, drug treatments, disease course, exercise, diet and information for the family. The study also showed that whereas only 20 % of patients diagnosed in 1980 received information about their diagnosis, the majority of patients (70 %) diagnosed after 2000 had received information at diagnosis.
15	Hogden et al., 2012 [38]	No	Qualitative	14 people with MND	Australia	Two participants reported having limited understanding of the implications of MND at the time of diagnosis which implied inadequate information provision, but also several participants were frustrated that professionals did not share information on survival times and disease trajectories. Patients considered insensitive communication of the diagnosis by neurologists as one of the negative experiences they had had with interacting with healthcare professionals.
16	Hugel et al., 2006 [32]	Yes	Qualitative	13 people with MND	United Kingdom	Patients in this single-centre study were satisfied with how their diagnosis was communicated and particularly valued being given the diagnosis in a private setting, with a relative or carer involved in the consultation, in an empathic way tailored to their needs.
17	Hughes et al., 2005 [33]	No	Qualitative	9 people with MND	United Kingdom	Patients needed information about their entitlements to services at the point of diagnosis. Some patients felt that the physicians delivering the diagnosis were distant.
18	Isaksson & Ahlström, 2006 [58]	No	Qualitative	61 people with MS	Sweden	Some patients reported having received the diagnosis through the telephone and felt angry about the way they were informed.
19	Johnson, 2003 [45]	Yes	Qualitative	24 people with MS	United Kingdom	Patients shared a variety of experiences related to how they had received their diagnosis, but most of them shared their dissatisfaction with how this had been approached by the professionals. Some patients felt the neurologists were only concerned with reaching the diagnosis and had no further interest in them as patients, leaving them feeling 'cut-off' post diagnosis. More positive experiences were reported by a patient who was given the news by their GP and five participants who were told of an MS nurse.
20	Johnston et al., 1996 [35]	Yes	Quantitative	50 people with MND	United Kingdom	29 patients understood what they told at diagnosis, 15 did not and 5 were unsure. 24 patients asked the questions they wanted to ask but 22 did not and understanding was associated with being able to ask questions. Half of the patients were given the diagnosis with no one else included in the consultation and only 8 had been asked to bring someone. Four patients were given the diagnosis in a non-private setting. 23 patients reported some good points about how they received the diagnosis, such as the doctor telling the truth, being honest and direct and showing kindness/empathy. 26 patients reported some bad points such as being told the diagnosis in a vague or indirect way, not being able to ask questions or the lack of privacy. Patients suggested improvements for better diagnosis communication such as giving more information and providing clearer explanations.

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**Table 3** (Continued)

No.	Paper	Was diagnosis delivery the main focus of the study?	Methodology	Participants <sup>a</sup>	Country	Main results <sup>a</sup>
21	Lode et al., 2007 [55]	No	Quantitative	86 people with MS	Norway	56.8 % of patients were satisfied and 43.2 % were dissatisfied or very dissatisfied with the information they received at diagnosis (satisfaction with information was associated with future coping with the condition and the employment of problem-solving strategies).
22	Lorefice et al., 2013 [41]	No	Quantitative	497 people with MS	Italy	67 % of patients were completely satisfied with their diagnosis, 24 % thought the process to be lacking in some respects and 9% were dissatisfied, while 64 % thought the medical staff were kind and 30 % thought they were attentive. Information on MS therapies and therapeutic choice were considered exhaustive by the majority of patients (79 % and 83 %) and 53 % of patients were satisfied with information about future therapy options.
23	Macht et al., 2003 [65]	No	Qualitative	33 people with PD	Germany	At diagnosis, patients needed information on the causes, symptoms and treatment choices. Patients shared a variety of experiences regarding the communication of their diagnosis. Those who shared positive experiences had been immediately given diagnosis and disease-related information tailored to their needs and felt they could cope with their condition. On the other hand, patients were not always provided with information or answers to their questions about their diagnosis in a timely manner. A patient also reported that they were given the diagnosis within 5–10 minutes without any further explanation.
24	Malcomson et al., 2008 [44]	No	Qualitative	13 people with MS, 2 focus groups	United Kingdom	7 patients shared their experiences with the physicians' often abrupt and insensitive approach to diagnosis delivery, which lacked empathy and understanding. 10 participants also thought that professionals were vague when giving the diagnosis. 11 participants reported that they received no information about coping with the diagnosis and the symptoms and daily living with the condition. These negative experiences caused confusion and worry to these participants, whose questions about their condition remained unanswered and felt the physicians could not understand how they feel. In contrast, one participant shared a positive experience with how she received the diagnosis by a GP who provided her support and information and was also offered counselling and help from nurses.
25	McCluskey et al., 2004 [29]	Yes	Quantitative	144 people with MND	United States	Patients reported that physicians spent an average of 32 min to deliver the diagnosis, 36% spend less than 20 min, 27% spent less than 15 min, 17% spend less than 10 min and 5% less than 5 min. Patients rated the physician's performance as poor (16.4 %), below average (8.6 %), average (31 %), good (19 %), or excellent (25 %). Less than half of physicians informed patients about MND-related association and about half gave information on specialised centres. 65 % of physicians identified MND as terminal, but according to patients only a few (11 %) discussed end of life options, hospice (9%) and tracheostomy and ventilation (17 %). Rating of physician's performance was associated with time spend to deliver the news.
26	O'Brien et al., 2011 [30]	Yes	Qualitative	24 people with MND	United Kingdom	Patients reported mixed experiences regarding diagnosis delivery. Some reported positive experiences, where bad news was adequately explained in a sensitive manner. Others had unsatisfactory experiences, reporting blunt interactions with physicians with poor communication skills and empathy. Some patients also talked about the very short consultation that lacked privacy and information provision. Patients with such negative experiences felt anger but could also feel sympathy and understood the difficulty that physicians faced when breaking bad news.
27	Pavey et al., 2013 [34]	Yes	Qualitative	41 people with MND	United Kingdom	It was common in participants' accounts to feel that diagnosis delivery was carried out in a way that avoided personal involvement and lacked emotional support and empathy. Limited consultation duration and inadequate information provision and explanation of the diagnosis was also a common issue for patients. Some reported being informed about the MND Association but this was not the case for everyone. Finally, some patients reported that they had not been asked to bring someone with them.

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Table 3 (Continued)

No.	Paper	Was diagnosis delivery the main focus of the study?	Methodology	Participants <sup>a</sup>	Country	Main results <sup>a</sup>
28	Peek, 2017 [63]	Yes	Qualitative	37 people with PD	United Kingdom	Most patients talked about their negative experiences of being diagnosed. They felt their interaction with the doctor was 'business-like' and 'swift', the physicians did not seem to understand the emotional impact of the diagnosis and often offered a very short appointment, providing little or no explanation of the diagnosis. On the contrary, patients appreciated an approach that showed that the significance of this moment was respected by the doctor, who provided reassurance and a sense of hope.
29	Pretorius & Joubert, 2014 [53]	No	Qualitative	10 people with MS	South Africa	Most participants were dissatisfied with their doctors' often unsympathetic or 'rushed' approach, reporting very short consultation times and little or no information provision about how to cope with MS and adjust their lifestyle.
30	Remm, 2019. [39]	Yes	Qualitative	6 people with MND	Australia	Patients reported mixed experiences regarding the physician's approach to diagnosis delivery. Patients valued being cared for and treated as a person rather than a diagnosis and felt anger when this was not the case. Patients with positive experiences felt their physician was genuinely interested in them, someone who they could speak openly and trust.
31	Schrag et al., 2018 [61]	Yes	Quantitative	1775 people with PD	11 European countries	50 % thought they were given the diagnosis quite or very sensitively and 50 % felt they were told not very or not at all sensitively. 38 % reported being given enough time to ask questions and discuss concerns, while 17 % would have liked more time to ask questions, 12 % reported not having been given any time to ask questions and 28 % felt they were not able to ask question at that time anyway. 2% reported not being given any information at all, patients received mostly information on symptoms, diagnosis, causes and medication and almost half of the respondents did not receive information on non-drug treatments. Information was perceived as helpful by 64 % of respondents, but 36 % did not find the information helpful. 49 % were satisfied, 29 % were neutral and 22 % were dissatisfied with the consultation at diagnosis. Patient satisfaction was associated with more sensitively diagnosis delivery, time provided to ask questions and quantity of information provided.
32	Seeber et al., 2016 [36]	No	Qualitative	10 appointments observed, 21 people with MND were interviewed	Netherlands	Some patients wanted to obtain as much information as possible while others were more reserved at diagnosis, however everyone wanted to know about prognosis and available therapies. Patients valued when the physicians were straightforward and had asked them to bring someone with them and being offered a second appointment to further explain the diagnosis was generally viewed positively. Patients valued this quick follow-up appointment since it gave them the opportunity and time to ask questions, clear misunderstandings, but also express their stressed, wishes and expectations about the future.
33	Shaw et al., 2017 [67]	No	Qualitative	12 people with PD	United Kingdom	While some participants were satisfied with how they were given their diagnosis, others had negative experiences, such as being told in a non-private environment or being told in an abrupt, impersonal manner. Patients' information preferences at diagnosis also differed, with some patients wanting as much information possible, while others felt that too much information was not helpful for them.
34	Solari et al., 2007 [50]	Yes	Qualitative	23 people with MS in two focus groups	Italy	Patients reported mixed experiences regarding how they received their diagnosis, but it was generally agreed that patients diagnosed more recently had more positive experiences. All participants agreed that physicians should invest adequate time for diagnosis delivery, however not all had enough time to discuss the diagnosis in-depth and ask questions. Patients also required a private setting without interruptions when receiving the bad news and when this was not the case, they felt helplessness. Patients had different preferences regarding the presence of significant others or other healthcare professionals in the consultation at the point of diagnosis but agreed that the presence of staff not involved in the consultation impaired the

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Table 3 (Continued)

No.	Paper	Was diagnosis delivery the main focus of the study?	Methodology	Participants <sup>a</sup>	Country	Main results <sup>a</sup>
35	Thorne et al., 2004 [48]	No	Qualitative	12 people with MS	Canada	confidentiality of the meeting. Regarding information provision, patients agreed that it should be tailored to the situation and the needs of the individual, but explanations should be kept simple, using direct language and avoiding medical jargon. Patients valued bilateral communication and being offered a quick follow-up appointment with the same physician to further discuss the diagnosis and ask questions. Participants talked about the value of timely and direct information provision and their disapproval of being patronised by physicians who did not want to give too much information, avoided to talk about worst-case scenarios and were evasive and general rather than direct and specific. However, a participant felt disempowered by learning about the chronic and degenerative nature of MS.
36	Thornton & Lea, 1992 [52]	No	Mixed	40 people with MS	South Africa	70 % felt they did not receive sufficient information at the time of diagnosis and out of 30 % who did so, most believed it was because they had pushed for it and others felt they would not be able to cope with additional information. Although most participants felt their consultants would be able to answer their questions, some thought they were to ignorant to know what questions to ask.
37	Warren et al., 2016 [66]	Yes	Qualitative	6 people with PD	United Kingdom	Patients shared negative experiences they had with diagnosis delivery, particularly a lack of compassion or sensitivity from the diagnosing physician. Patients also had the sense that professionals did not have sufficient time for the consultation.
38	White et al., 2007 [60]	No	Quantitative	145 people with MS	United States	44 % of patients reported that a medical provider discussed their emotional well-being with them at the time of diagnosis. Patients who reported talking about their emotional well-being at diagnosis had significant higher levels of acceptance and positive outcomes illness Cognition Questionnaire.
39	Wollin et al., 2000 [54]	No	Mixed	34 people with MS completed the questionnaire and 7 were interviewed	Australia	73 % of patients believed patients should be informed about how MS affect patients at diagnosis (the need for information on MS symptoms was also a common theme for the patients interviewed). Information on managing (57 %) and treatment (50 %) of MS was also favoured. Regarding information about services at the point of diagnosis, patients reported that information about counseling (62 %), support groups (59 %), and physiotherapy and exercise (58 %) would have been useful. From the 29 patients who answered the open-ended questions of the survey, 20 % had been advised to contact MS society and 17 % indicated they had received no useful information at diagnosis.
40	Yazdannik et al., 2015 [47]	No	Qualitative	20 people with MS	Iran	Some patients were not satisfied with how the diagnosis was communicated, especially when they were only provided with a brief description of the diagnosis and the consultation was rushed or they felt the professional did not pay attention to their mental needs.
41	Ytterberg et al., 2008 [43]	No	Quantitative	219 people with MS	Sweden	57 % of patient were satisfied with the circumstances under which the diagnosis was delivered
<b>Studies on doctors' perspectives</b>						
42	Aoun et al., 2016a [71]	Yes	Quantitative	73 neurologists	Australia	68 % reported requiring two consultations to convey the diagnosis. Mean consultation time was 23 min and 45 min for neurologists practicing in MND multidisciplinary clinics. 70 % found delivering the diagnosis "very to somewhat difficult", 43 % found responding to patient/family emotional reactions to be difficult and 65 % experienced "high to moderate" stress and anxiety. Being honest but not taking away hope (80 %); dealing with the patient's emotion (38 %) and spending the right amount of time (28 %) were found to be the most challenging aspects of diagnosis delivery. 74 % were 'somewhat to very interested' to receive training in responding to patient's emotions.

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Table 3 (Continued)

No.	Paper	Was diagnosis delivery the main focus of the study?	Methodology	Participants <sup>a</sup>	Country	Main results <sup>a</sup>
43	Chiò et al., 2001 [70]	No	Quantitative	36 centres with an interest in MND (questionnaires filled by neurologists)	Italy	Mean consultation time for diagnosis delivery was 32.7 min in large centres and 27 min in small centres. Written information at diagnosis was given by 8 (36 %) small and 5 (36 %) large centres.
44	Martinelli et al., 2012 [69]	Yes	Quantitative	172 neurologists	Italy	96 % of neurologists communicated the diagnosis in a private setting 52 % required less than half an hour, 38 % require 30–60 minutes and 10 % require more than an hour to deliver the diagnosis. 61 % answered patients' questions and doubts and try to offer comfort and support, suggesting a disease-modifying therapy 26 % provided written information 88 % preferred to involve patients' relatives in the consultation 32 % straightforwardly used the term multiple sclerosis from the beginning of the consultation, 11 % avoided using it and 57 % only used it at the end of the consultation or in subsequent visits. 87 % used language aimed at obtaining cooperation and bidirectional communication, 79 % would like to tailor their communication on patient's psychological profile but only 3 % thought this is possible, mostly because of limited time resources 64 % felt emotionally involved in the relationship with the patient 79 % rated their communication as adequate or competent, but only 14 % thought they could manage all patients' needs and expectations
45	Papathanasopoulos et al., 2008 [68]	Yes	Quantitative	217 neurologists	Greece	41.7 % of neurologists used the term multiple sclerosis when delivering the diagnosis and preferred other terms such as demyelination or nervous system infection. 78.7 % included patients' relatives in the consultation Most physicians felt that the information they provided helped the patient understand the meaning of the diagnosis. When a patient does not fully understand the meaning of the diagnosis, 72 % of physicians thought this was mainly because of their education level and also their emotional response to the news (51.9 %). 52 % reported investing more than 30 min, 22 % more than an hour and at least two sessions to deliver the diagnosis.
46	Pinder, 1992 [72]	Yes	Qualitative	18 GPs (the study also reports data from 15 people with PD, however these were not included in the analysis since they mostly on emotional reaction and coping with the diagnosis)	United Kingdom	GPs approached diagnosis delivery based on their theoretical knowledge and felt content having 'solved the puzzle' and being able to manage the condition via medication. Most of them felt the diagnosis of PD is not as emotionally loaded, comparing it to other more severe neurological conditions and considered it a somehow natural outcome of the ageing process, ideas which they try to incorporate in the diagnosis delivery consultation. However, some GPs also acknowledged the 'horrifying' impact the diagnosis might have on the patients and tailored their consultations accordingly.
<b>Studies on both patients' and doctors' perspectives</b>						
47	Heesen et al., 2003 [46]	Yes	Quantitative	434 people with MS, 80 neurologists	Germany	90 % of patients reported receiving the diagnosis from a neurologist and 50 % considered them the major aid helping to understand the disease and up to 50 % reported that the time invested by the physician for the diagnosis delivery was too short. 30 % reported that information was given too cautiously and 52 % were not informed about available therapies at the point of diagnosis, 71 % of those who received such information rated the extent as sufficient. 28 % of neurologists do not use the term multiple sclerosis when explaining the diagnosis, 84 % try include patients' relatives to the consultation, most of them believe that 80 %–100 % of their patients are fully informed about their diagnosis but 70 % thought their patients are well-informed about therapeutic options

<sup>a</sup> The table only addresses study participants and results that relate to the research question of this review.



### 3.3.2. Information provision

Beyond sharing their preference to be told their diagnosis in an honest and clear way, patients in most studies also shared their views on the amount and nature of the information they received during the diagnostic consultation. A survey showed that although 90 % of MS diagnoses were given by neurologists, only 50 % of patients considered them their major support regarding the meaning of the diagnosis [46]. In general, data from both quantitative and qualitative studies showed that patients felt they were not provided with adequate information about their condition [44–53] or they had to push to receive the information they wanted [53].

At the time of diagnosis patients seemed to need general information about MS, information on treatment options and managing their symptoms [46,48,52], information on counselling services [51,54] and lifestyle changes [44,53]. A survey [46] showed that 52 % of patients were not informed about MS therapies when the diagnosis was made, however in a more recent study [41], 79 % of patients considered their doctor's information on treatment choices to be exhaustive. Patients preferred information to be communicated in a simple and direct way [48,50], without the use of medical jargon [50] and reference to worst case scenarios [48]. However, a few studies made it clear that the type of information provided at diagnosis should be tailored to the individual [50] and some patients might not want any additional information at that point when the diagnosis itself is 'enough to handle' [52]. In addition, patients often felt that accessing reliable information sources was not facilitated by healthcare professionals [45] who sometimes failed to signpost patients to organisations or specialised MS centres which could have been useful [44,49,55].

Patients explained that effective information provision at the time of the diagnosis would help mitigate the fear elicited by the diagnosis it [44,48]. Moreover, in a study in which 43.2 % of patients were dissatisfied or very dissatisfied with the information they received at diagnosis, satisfaction with information was associated with more adaptive coping with the condition [55]. Nonetheless, some patients expressed the view that even though the doctor might have provided them with information about their diagnosis, their state of shock might have not allowed them to assimilate it [49,56].

### 3.3.3. Consultation duration

Time dedicated to the consultation was an important variable which shaped patients' experiences of diagnosis delivery. A survey showed that 50 % of patients thought that time taken by the doctor to deliver the diagnosis was too short [49] and patients in qualitative studies [50,53,57] also reported that their appointment felt 'rushed'. Doctors were perceived to be in a hurry to see the next patient, with not enough time to ask questions and receive answers.

### 3.3.4. Doctors' empathy

Patients in several studies reported that sometimes their doctors did not show any empathy, did not provide emotional support and delivered the diagnosis in a casual and overly medical way [44,56,49,51,53,57]. In a UK study with focus groups, out of 103 patients with MS, only 8 reported being happy with the communication of their diagnosis [51]. Some qualitative studies captured some extreme scenarios, for example, patients who were told their diagnosis over the telephone [49,58], on Christmas Eve [49] or via mail [50]. Neurologists were sometimes viewed as 'diagnosers' with little or no interest in the patients [45,59], unable to understand fully the patients' perspective [44]. Patients who had negative experiences reported anger, disappointment and bitterness towards the medical profession [49,59]. Furthermore, a

quantitative study associated discussion of patients' emotional well-being with the professional at the time of diagnosis with positive post-diagnostic outcomes [60]. In this study, 44 % of patients reported having such a discussion with their doctor which was associated with significantly higher levels of acceptance of their condition as well as other benefits.

## 3.4. Receiving the diagnosis of PD

### 3.4.1. Satisfaction with diagnosis delivery

Data on overall satisfaction with the delivery of PD diagnosis indicated that there was room for improvement with 49 % of patients being satisfied with their consultation, 29 % being neutral and 22 % being dissatisfied [61]. A more negative image was drawn in another study where 52.5 % of patients rated their experience with the diagnosis delivery as good or very good and 45.3 % as poor or very poor [62]. However, this difference can potentially be explained by differences in culture and healthcare systems since, although both were European surveys, the second study gathered data from 35 countries whereas the first one did so from 11.

### 3.4.2. Information provision

In Bloem's and Stocchi's [62] European survey, 62.2 % of patients reported having received general information about their condition and although less than 1 % reported not having received any information, only 22.1 % said they received detailed information. Around 14 % received information about medication at diagnosis and less than 2.8 % received information regarding PD support organisations. In the same study, the information provided at diagnosis was considered helpful or very helpful by 64 % of respondents, with a more recent European survey reporting the same percentage (64 %) [61]. In this survey, although respondents reported having received general information about the causes, symptoms and medication, nearly half stated they had not received any information on non-drug treatments at diagnosis. Qualitative studies often reported patients' negative experiences with information provision at diagnosis. Patients often felt that they left the consulting room with very little information about their condition [63–65]. There were instances when patients' questions were not answered in a satisfactory manner [65] or patients reported receiving no information at all from their doctors but were encouraged to buy a book about PD or search information on the internet instead [63].

### 3.4.3. Consultation duration

Inadequate information provision could be associated with limited consultation duration since only 38 % of patients in the most recent European patient survey reported being given enough time to ask questions, while 17 % would have liked more than the time they were given and 12 % were not given any time at all [61]. Other studies also reported short consultation times (even 5–10 min in extreme cases [65]) which did not allow time for a detailed explanation of the diagnosis [63,64,66]. On the other hand, some patients were satisfied with the information they were provided [65] and it should be noted that being given too much information was also at times considered problematic [67].

### 3.4.4. Doctors' empathy

European surveys presented mixed patient experiences regarding the doctor's approach to delivering the diagnosis. Bloem and Stocchi [62] used a 10-point Likert scale to measure clinicians' attitude, ranging from abrupt to kind, in which 58.9 % of patients gave positive scores (6–10) and 36.4 % gave negative scores (1–5) with 16.9 % choosing the best possible and 11.3 % the worst possible score. Percentages differed in a more recent survey where 50 % of patients reported that their PD diagnosis was communicated quite

or very sensitively and 50 % felt it was given not very or not at all sensitively [61]. Qualitative studies were consistent with these findings and provided vivid accounts of patients who felt that receiving the diagnosis was an important moment for them which was not always handled appropriately by the doctors. The diagnosis was often communicated abruptly, in a casual way, without any sensitivity or compassion [63,66,67].

Patients often shared similar stories in which their diagnosis was handled 'routinely' in a 'business-like' way, in an appointment so 'swift' that they did not have space to consider their reaction [63]. On the contrary, an account from a patient who had a positive experience with her doctor indicated that patients value doctors who show an understanding of the emotional impact of the diagnosis, adopt a positive attitude and provide reassurance that their condition can be managed with professional help. Indeed, a more sensitive delivery of the diagnosis was associated with higher patient satisfaction, having a stronger relationship with satisfaction than the helpfulness of the information provided, and the time provided to ask questions [61].

### 3.5. Doctors' perspectives on communicating the diagnosis for MNDDs

Studies on doctors' perspectives on communicating a diagnosis for MNDDs were limited and reported little data on the actual consultation. Instead, these studies focused on other issues such as when the diagnosis should be disclosed. Data relevant to our review question were mostly associated with neurologists' practice.

For the case of MS, doctors often [46,68] (28 %–58.3 %) avoided using the term 'multiple sclerosis' when communicating the diagnosis or did so only at the end of the consultation or in subsequent visits (57 %) [69]. Instead, other terms such as 'demyelination' or 'nervous system infection' were used [68], possibly because they were considered less 'negatively charged' and less associated with the stigma associated with the term MS. Overall, neurologists in these surveys seemed to be sensitive to the emotional impact of the diagnostic process and reported being willing to support patients through information provision. The vast majority reported delivering the diagnosis of MS in a private setting [68], involving patients' relatives [68,69] and approximately 50 % took more than half an hour (and sometimes more than an hour) for the consultation [46,69]. Most neurologists felt emotionally involved in the relationship with the patient (64 %) and used the shared decision-making model (87 %). They aimed to initiate bidirectional communication, answered patients' questions (61 %) and tried to 'offer comfort and support suggesting a disease-modifying therapy' [69]. Around 77 % believed the way they communicated the diagnosis assisted the patient in understanding the meaning of the diagnosis [68] and although 79 % considered their communication practice as competent, only 14 % believed they had managed all patient needs and expectations [69].

Apart from a survey assessing MND care in Italy, which found that the time taken to explain the diagnosis was around 30 min [70], the only survey focusing solely on the communication of MND diagnosis was conducted in Australia and assessed neurologists' current practice and experiences of breaking bad news [71]. Most neurologists (68 %) used two consultations to deliver the diagnosis with the mean duration of each consultation being 23 min. The duration was double (45 min) for neurologists who practised in multidisciplinary MND clinics. Almost all (98 %) of neurologists reported having a patient's relative involved in the consultation, 73 % referred to an MND association and 78 % gave the diagnosis in a private space but only 41 % were always able to avoid interruptions. Regarding the content of the consultation, the degree of certainty, how the diagnosis was reached and the course of the disease were

the most discussed aspects, while being honest without taking away hope, dealing with a patient's emotions and spending enough time were the most challenging aspects. About 70 % of neurologists reported that delivering the diagnosis was a 'very to somewhat difficult' task and believed that difficulties were due to the lack of effective treatment for MND, the fear of causing distress or not having all the answers. Moreover, communicating the diagnosis induced 'high to moderate' stress and anxiety for 65 % of neurologists.

Finally, Pinder's study conducted in the UK [72] explored general practitioners' (GPs) perspectives on the diagnosis of PD. This qualitative study focused on professionals' experience of reaching the diagnosis and the beliefs that informed their practice. Diagnosing was often a 'eureka moment', a moment of theoretical 'coherence' that gave satisfaction to the doctors. The diagnosis was viewed positively since it did not only validate their role as 'diagnosticians' but also enabled them to initiate treatment, help patients manage their condition and prove their symptoms credible. A PD diagnosis was not viewed as so 'emotionally loaded' by GPs especially when it was diagnosed in older people and it was often compared with other 'more serious' conditions. Doctors tried to incorporate these views into the communication of the diagnosis to help patients come to terms with the disease. In addition, several doctors were more empathetic and tried to deliver the diagnosis in a way which showed consideration for how PD might affect patients' relationship with their bodies and their daily lives.

## 4. Discussion and conclusion

### 4.1. Discussion

Although the topic of breaking bad news has been studied more extensively within other fields of medicine [6], a considerable number of studies were identified that addressed this issue for MNDDs. This scoping review revealed a significant research gap in doctors' perspectives of delivering a MNDD diagnosis. Moreover, the small number of doctor-studies included in this review made it difficult to compare and contrast patients' and professionals' views on the delivery of the diagnosis of an MNDD. Overall, patients across conditions were fairly satisfied with the way they were told their diagnosis and more recent papers drew a more positive image than older ones, potentially due to the growing emphasis on the importance of communication in healthcare and the patient-centred care 'movement' [73,74]. Most doctors also reported relatively high standards of practice in delivering this task. However, survey studies reported considerable percentages of patients who were dissatisfied with the process and, with the qualitative studies, illustrated several aspects of the diagnosis delivery consultation which could be improved.

Effective information provision and patient education are considered two of the pillars of patient-centred care, a model of care considered appropriate for individuals with chronic conditions and complex health care needs such as MND [75], MS [76] and PD [77]. However, patients in the studies included in this review often expressed their dissatisfaction with both the amount and nature of information they received (or did not receive) during the delivery of their diagnosis. Studies with newly diagnosed cancer patients have shown that information provision can lead to several positive outcomes such as gaining a sense of control, reducing anxiety, promoting compliance, realistic expectations, self-care and feelings of safety [78]. Increasing patients' knowledge of their condition can tackle stereotypical disease representations that do not apply for all cases (e.g., equating having MS with being wheelchair-bound and dependent). Providing adequate and timely information at diagnosis is also vital for shared-decision making,



especially for conditions such as multiple sclerosis when long-term treatment decisions have to be taken early on [79,80]. Additionally, some patients reported that their doctor did not signpost them to relevant organisations or reliable information sources which raised feelings of abandonment. This was a missed opportunity to connect with community-based organisations which have been shown to generate a feeling of relief while offering a holistic approach to supporting patients and their carers [81]. Being left alone to seek information for their condition themselves, patients often turned to the internet, where information sources varied in reliability and could be misleading, especially regarding treatment options [82,83].

On the other hand, studies on neurologists' practice illustrated a willingness to support patients via information provision. Although, as stated above, the limited volume of data on doctors' perspectives does not allow for robust comparisons, this discrepancy between patients' experiences and doctors' reported practice could be attributed to doctors' often not assessing accurately patients' information needs [79]. The preferred amount of information differed significantly among patients, but in general it seemed that doctors tended to underestimate patients' information needs [84].

Whether health care professionals showed compassion while delivering the diagnosis was another major topic addressed. Patient studies across conditions reported mixed results regarding the doctor's manner of managing the consultation. While this was not the case for everyone, it was often felt that they did not receive emotional support at the time of diagnosis and described unsympathetic, detached, insensitive professionals with an overly medical and casual approach. In other words, as Habermann [64] noted: 'The human significance was passed over and objectified by what is known about the disease and treatment'. [p.404]. Patients' negative experiences highlighted a contrast between their strong emotional reaction to the news of the diagnosis and the often-emotionless practice of their doctors, which left them feeling angry, disappointed, bitter or even dehumanised.

A factor that could partially explain why individuals felt they did not receive adequate information and emotional support from their doctors were time constraints. Individuals across conditions often reported receiving short consultations, which caused frustration and a sense of being 'rushed' [65].

#### 4.2. Practice and research implications

This scoping review showed that several aspects of the diagnosis delivery process could be improved. Although the difficulties inherent in effect doctor-patient communication are significant, efforts must be made to promote a culture of continuous professional development and learning in this important area [85]. Adopting a truly patient-centred approach to communication needs to be the overarching framework for development and improvement. As part of this, healthcare professionals delivering such diagnoses need to assess patients' information needs by being sensitive to patient cues, checking their understanding of the information provided and providing time for questions. However, given that many professionals are restricted by time, it is suggested that they at least provide basic information about the condition, an overview of treatment options and effects of the condition on daily life and then signpost patients to reliable information sources such as specialist nurses and disease associations which will further support them. Delivering the diagnosis in two consultations has also been found to be beneficial to patients. Moreover, professionals need to maintain a caring and empathic attitude, avoid an overly medical and detached approach and provide support especially to patients who show the need to share their concerns and emotions.

Beyond practice implications, future research should incorporate doctors' views, encourage experiential and emotional explorations and, therefore, create a deeper and more holistic understanding of the doctor-patient communication at the time of diagnosis. The aim of this would be to shed light on the challenges and facilitators of effective communication at this time, inform best practice guidelines and appropriately support professionals.

#### 4.3. Limitations

This scoping review's main limitations are the inclusion of only studies written in English due to funding and time constraints, and the potential inclusion of low-quality studies due to the absence of a quality appraisal tool. However, this is usual practice in scoping reviews [86]. In addition, the screening of the titles/abstracts and the eligibility assessment of the papers were made by only one person and only 10 % of the citations were reviewed by a second person.

#### 4.4. Conclusion

This scoping review found that diagnosis communication is a crucial moment for patients with MNDDs which requires a careful approach from doctors. Although some basic standards of good practice were being met and patients were generally satisfied, a significant proportion of patients were dissatisfied with the way they were given their diagnosis and reported issues related to inadequate information provision, lack of empathy and insufficient consultation duration. The review also found an important research gap on professionals' perspectives of giving bad news to individuals with these conditions. More research involving both the bearer and the receiver of bad news for MNDDs is needed for the development of evidence-based training programmes and guidelines for diagnosis communication, all informed by a patient-centred approach.

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#### Footnote

(1): MS's neurological nature has been a matter of controversy in medicine. We signpost to this review of data that supports neurodegeneration as the major cause of irreversible neurological damage: Trapp, B. D., & Nave, K. A. (2008). Multiple sclerosis: an immune or neurodegenerative disorder?. *Annu. Rev. Neurosci.*, 31, 247–269.

#### Appendix A.

##### Search strategies (Databases searched on July 29th 2019)

##### PubMed

(((((("Multiple Sclerosis/diagnosis"[Mesh] OR "Multiple Sclerosis/physiology"[Mesh]) OR ("Motor Neuron Disease/diagnosis"[Mesh] OR "Motor Neuron Disease/physiology"[Mesh])) OR ("Amyotrophic Lateral Sclerosis/diagnosis"[Mesh] OR "Amyotrophic Lateral Sclerosis/physiology"[Mesh])) OR ("Parkinson Disease/diagnosis"[Mesh] OR "Parkinson Disease/physiology"[Mesh])) AND (((((((("Patient Satisfaction"[Mesh] OR "Referral and Consultation"[Mesh]) OR ("Physicians/ethics"[Mesh] OR "Physicians/psychology"[Mesh])) OR "Communication"[Mesh]) OR "Truth Disclosure"[Mesh]) OR "Attitude to Health"[Mesh]) OR "Physician-Patient Relations"[Mesh]) OR "Attitude of Health

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Personnel"[Mesh]) OR "Professional-Patient Relations"[Mesh]) OR "Health Personnel/psychology"[Mesh])

Scopus  
(TITLE-ABS-KEY("parkinson" disease" OR "motor neuron" disease" OR "amyotrophic lateral sclerosis" OR "Lou Gehrig" OR "multiple sclerosis")) AND (TITLE-ABS-KEY("bad news" OR (communicat\* W/4 diagnos\*) OR (deliver\* W/4 diagnos\*) OR "being diagnos\*" OR (receiv\* W/4 diagnos\*) OR (giv\* W/4 diagnos\*))

CINAHL:  
(MH "Parkinson Disease/DI/ED/EI/NU/PF") OR (MH "Amyotrophic Lateral Sclerosis/DI/ED/EI/NU/PF") OR (MH "Multiple Sclerosis/DI/ED/EI/NU/PF") OR (MH "Motor Neuron Diseases/DI/ED/EI/NU/PF")

AND  
(MH "Parkinson Disease/DI/ED/EI/NU/PF") OR (MH "Amyotrophic Lateral Sclerosis/DI/ED/EI/NU/PF") OR (MH "Multiple Sclerosis/DI/ED/EI/NU/PF") OR (MH "Motor Neuron Diseases/DI/ED/EI/NU/PF")

PsycINFO  
(DE "Parkinson's Disease") OR (DE "Amyotrophic Lateral Sclerosis") OR (DE "Multiple Sclerosis") OR (DE "Neurodegenerative Diseases")

AND  
(DE "Diagnosis") OR (DE "Medical Diagnosis") OR (DE "Preferences") OR (DE "Information Seeking") OR (DE "Health Personnel Attitudes") OR (DE "Therapeutic Processes") OR (DE "Neurologists") OR (DE "Client Satisfaction") OR (DE "Health Service Needs") OR (DE "Neurodegeneration") (DE "Quality of Care") OR (DE "Quality of Services") OR (DE "Client Attitudes").

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RESEARCH ARTICLE

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# Neurologists' current practice and perspectives on communicating the diagnosis of a motor neurodegenerative condition: a UK survey

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## Abstract

**Background:** The communication of a life-changing diagnosis can be a difficult task for doctors with potential long-term effects on patient outcomes. Although several studies have addressed the experiences of individuals with motor neurodegenerative diseases in receiving this diagnosis, a significant research gap exists regarding professionals' perspectives, especially in the UK. This study aimed to assess UK neurologists' current practice and perspectives on delivering the diagnosis of a motor neurodegenerative disease, explore different aspects of the process and detail the potential challenges professionals might face.

**Methods:** We conducted an anonymised online survey with 44 questions, grouped into four sections; basic demographic information, current practice, the experience of breaking bad news and education and training needs.

**Results:** Forty-nine professionals completed the survey. Overall, participants seemed to meet the setting-related standards of good practice; however, they also acknowledged the difficulty of this aspect of their clinical work, with about half of participants (46.5%) reporting moderate levels of stress while breaking bad news. Patients' relatives were not always included in diagnostic consultations and participants were more reluctant to promote a sense of optimism to patients with poorer prognosis. Although professionals reported spending a mean of around 30–40 min for the communication of these diagnoses, a significant proportion of participants (21–39%) reported significantly shorter consultation times, highlighting organisational issues related to lack of capacity. Finally, the majority of participants (75.5%) reported not following any specific guidelines or protocols but indicated their interest in receiving further training in breaking bad news (78.5%).

**Conclusions:** This was the first UK survey to address neurologists' practice and experiences in communicating these diagnoses. Although meeting basic standards of good practice was reported by most professionals, we identified several areas of improvement. These included spending enough time to deliver the diagnosis appropriately, including patients' relatives as a standard, promoting a sense of hope and responding to professionals' training needs regarding breaking bad news.

**Keywords:** Breaking bad news, Diagnosis communication, Patient-provider communication, Neurodegenerative, Motor neurone disease, Multiple sclerosis, Parkinson's disease, Huntington's disease

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## Background

Breaking bad news is a critical and distressing process for patients but also an often stressful and challenging task for clinicians [1, 2]. Bad news in medicine refers to 'any information likely to alter drastically a patient's view of his or her future' (p. 1597) [3] such as the communication of the diagnosis of a potentially life-changing condition. How a diagnosis is delivered can have a long-term impact on patient outcomes such as treatment adherence [1], psychological adjustment and involvement in treatment decision making [4], understanding of the condition [5] and satisfaction with care [6]. From the doctor's perspective, breaking bad news can be an emotionally burdensome and intrinsically difficult task, with factors such as time constraints, intercultural differences in relation to diagnosis disclosure and lack of private space making it even more challenging [7].

Most studies on the delivery of bad news have been conducted within the field of oncology. However, the delivery of bad news can be a critical issue in other medical specialties such as neurology. Storstein [8] argues that when breaking bad news, neurologists deal with specific challenges that relate to particular medical considerations and the emotional aspects of neurological diseases. In particular, several chronic neurological conditions, such as Parkinson's disease (PD), multiple sclerosis (MS) and Huntington's disease (HD), are incurable, have a progressive nature and impact both physical and cognitive functions [8], while others, such as motor neurone disease (MND), can also be more immediately life threatening [9]. A scoping review of doctors' and patients' perspectives on giving and receiving the diagnosis of MND, MS or PD [10] revealed mixed results regarding patients' experiences and satisfaction with how diagnosis delivery was handled. The main factors which contributed to negative patient experiences were the often-limited duration of the consultation, inadequate information provision and a perceived insensitive approach by the professional breaking the news. Moreover, the review found a significant research gap on studies addressing the physicians' perspectives, which could offer a better understanding of the doctor-patient interactions at the time of the diagnosis.

The aim of this study was to assess UK neurologists' current practice when delivering the diagnosis of a motor neurodegenerative disease (MNDD), in particular PD, MS, HD and MND. Currently, there are no UK studies on this topic, the aim of the study was to explore different aspects of the process, such as the setting, duration and challenges of communicating a diagnosis of this nature. In addition, potential factors affecting practice and differences between delivering the diagnosis for different conditions were also explored. As the results are descriptive, no hypotheses were made.

## Method

The study was approved by both the authors' host institution's research ethics committee and the Health Research Authority, a unified system for the governance of health research in the UK.

The questionnaire used for this study was constructed after a comprehensive review of the relevant literature on breaking bad news and guidelines such as SPIKES, the Six-Step Protocol for Delivering Bad News [11] and the National Institute for Health and Care Excellence (NICE) guidelines for the management of MND [12], MS [13] and PD [14]. It was also largely based on the questionnaire used by Aoun et al. [15] for a similar study on neurologists' experiences on delivering the diagnosis of MND in Australia. The first draft of the survey was reviewed by two practising neurologists for clarity and relevance and adjustments were made based on their comments.

The survey was hosted online on the Qualtrics platform and was open for 2 years (from September 2018 to September 2020). Eligible participants were medical professionals, including specialist registrars, practising in the UK who had experience in delivering the diagnosis for at least one of the conditions included in the survey. The survey comprised 44 questions grouped into four sections; demographic information, current practice, the experience of breaking bad news and education and training needs (Additional File 1). It was completed anonymously, and questions were mainly closed with several open-ended questions where participants were asked to elaborate on their answers or provide any further comments. Participants were recruited through the Association of British Neurologists (ABN), other associations related to neurology or MNDDs and through collaborations with National Health Service (NHS) trusts.

Data from the closed questions were imported and analysed in IBM SPSS 26 software package [16], using descriptive statistics; means, standard deviations, range and frequencies. In addition, qualitative data from the open-ended questions of the survey were used to enhance, explain and expand the findings from the analysis of the quantitative data. Respondents who completed less than 50% of the survey ( $N < 5$ ) were excluded from the study.

## Results

### Participants profile

Forty-nine professionals responded to the survey; 43 consultant neurologists, 4 neurology specialist registrars, one consultant neuropsychiatrist and one clinical fellow. Participants were mainly male (67%), almost half of them were in the 41–50 age group (48%) and had a mean of 10 years of experience (ranging from less than one to 23;  $SD = 6.8$ ). Almost all participants mainly

**Table 1** Participants' characteristics

Participants' role:	Number of participants (%)
Consultant neurologist	43 (88%)
Neurology specialist registrar	4 (8%)
Consultant neuropsychiatrist	1 (2%)
Clinical fellow	1 (2%)
<b>Gender</b> ( <i>one response missing</i> )	
Male	32 (67%)
Female	16 (33%)
<b>Age</b> ( <i>one response missing</i> )	
31–40	13 (27%)
41–50	23 (48%)
51–60	11 (23%)
61 or older	1 (2%)
<b>Experience in delivering the diagnosis</b>	
Parkinson's disease	44 (90%)
Multiple sclerosis	41 (84%)
Motor neurone disease	43 (88%)
Huntington's disease	33 (67%)

practised in England, 5 participants mainly practised in Wales and although all participants practised in the NHS, 12 participants were also practising privately. See Table 1 for a summary of participants' demographics.

#### Diagnosis disclosure

Most participants had experience in communicating all four diagnoses under review; 90% of professionals had experience in breaking bad news for PD, 88% for MND, 84% for MS and 67% for HD. Most of the professionals who had experience in delivering the diagnosis of HD (73%) had only communicated 1–20 diagnoses, which can be explained by the rarity of the condition and the diagnosis of onset<sup>1</sup> of HD potentially being given mostly in specialist clinics.

The vast majority of professionals (87%) reported always disclosing the diagnosis for these conditions to the patients. Text comments highlighted that it would be 'fundamentally unethical' not to inform a patient of their diagnosis. Participants believed that being honest and transparent about the diagnosis helped with the management of the condition and building a relationship with the patient. However, some comments indicated that professionals would not disclose the diagnosis only when patients had clearly stated that they did not wish to know or when the diagnosis was not definite and further investigation was required. Moreover, 30% of participants reported

that they would sometimes refer patients to other medical professionals who would then deliver the diagnosis. Qualitative comments indicated that they would follow this approach when they were uncertain about a diagnosis or they could refer to a specialist clinic.

#### Setting, time and people involved in the consultation

When asked about the setting of the consultation, 74% of participants reported 'always' delivering the diagnosis in a private space and 96% stated that 'most of the time' or 'always' the diagnosis was communicated without any interruptions. In addition, 75% of professionals reported always maintaining eye contact with the patient and 75% arranged to have suitable seating at the same level as the patient without a desk or barrier.

On average, professionals reported investing around 30 min for the delivery of the diagnosis for PD ( $M = 30$ ,  $SD = 9.3$ ), MS ( $M = 28.7$ ,  $SD = 10.4$ ) and HD ( $M = 29.9$ ,  $SD = 16.5$ ) and 41 min ( $SD = 26$ ) for MND. However, a considerable proportion of participants (21% for PD, 32% for MS, 39% for HD and 20% for MND) reported spending 15 to 20 min for the diagnosis consultation and 30% of participants reported spending over an hour to communicate the diagnosis of MND. More than half of professionals (64%) believed patients were given enough time to ask questions and express their emotions. However, across conditions, 58–69% of professionals 'sometimes' needed more than one consultation to explain these diagnoses and 23–35% 'always' needed more consultations. One participant explained that diagnosis communication was a more dynamic process, beyond the diagnostic consultation:

*'I do not think that breaking the diagnosis is really a one-off event (even if you had all the time in the world), but rather a process that continues throughout much of the time that you look after an individual as the disease and the patient's relationship with it often change as time goes on.'*

Furthermore, 72% of professionals did not refrain from giving a diagnosis at any specific time or day, and those who did so explained that they avoided giving bad news at a late appointment or before the weekend if the patient was not accompanied by someone and also before patients' birthdays or before holidays such as Christmas.

Regarding the involvement of other people in the consultation, 60% of professionals stated that 'most of the time' or 'always', patients were asked to bring someone to the consultation, however 15% reported that patients were not asked to bring someone. In addition, 53% of participants 'sometimes' included other healthcare professionals in the consultation and 19% 'never' did so.

<sup>1</sup>In this study we focused on the diagnosis of the onset of HD, the start of the symptomatic stages of the condition, which can often be years after confirmation of gene positive status

#### Content of the consultation / information giving

Almost all participants agreed that how the diagnosis was reached (96%), treatment options (96%), the degree of certainty of the diagnosis (92%) and the course/prognosis of the disease (90%) were topics that should be discussed with the patient at diagnosis. Causes of the disease (76%) and current research (63%) were also considered important topics to be covered. Additional comments showed that neurologists also chose to discuss other important topics, such as the family, hereditary and legal implications of the diagnosis (e.g. driving), information on the support plan and other healthcare professionals who would be involved in their care and signposting to related charities and reputable sources of information. In addition to oral information, 28% of professionals 'always' provided patient-tailored information in written form and 43% did so 'most of the time'. Information on local support groups and national charities was 'always' shared by about half of the participants for PD, MS and HD and by 67% of participants for MND. When asked whether they promoted a feeling of optimism when delivering a diagnosis, more respondents reported 'probably' or 'definitely' promoting hope in PD (91%) and MS (90%) than HD (39%) and MND (31%).

#### Personal experiences and challenges in breaking bad news for MNDDs

Regarding the perceived difficulty of diagnosis communication for these conditions, 54% of participants believed that it was 'definitely' and 23% that it was 'probably' a difficult task for the physician. Most professionals (74%) agreed that being honest without taking away hope was the most challenging part of communicating the diagnosis of MNDDs, followed by spending the right amount of time (47%). Dealing with the patient's emotional reaction (25%), involving the family of the patient (14%) and involving the patient or family in decision making (12%) were considered difficult by fewer participants. When asked about how often they faced several potential barriers during a breaking bad news consultation, professionals reported that fear of causing distress (32.5%), excessive workload (32.5%) and perceived lack of time (30%), were among the most often experienced barriers, which they faced 'most of the time' or 'always'. Conversely, fear of the 'messenger getting blamed for bad news' and lack or insufficient training in breaking bad news were not often experienced as barriers. In addition, 46.5% of respondents reported experiencing moderate and 9% reported high to very high levels feelings of stress and anxiety during the delivery of these diagnoses, while only 12% reported not experiencing such feelings at all.

Overall, most professionals (61%) believed they were 'good' at communicating the diagnosis of a MNDD, 23%

assessed themselves as 'very good' and none thought they were 'poor' at it. For PD and MS, more than half of the respondents were confident to very confident (63%) that patients left the consultation having taken in all the information relevant to them at that point. However, for the case of HD and MND, 61 and 58% of professionals respectively were 'not sure' to 'really not confident' that patients had taken in all the relevant information. In general, 81% believed patients were 'somewhat satisfied' to 'very satisfied' with how the diagnosis was delivered.

#### Strategies and training on breaking bad news

In the last part of the survey, participants were asked to report on the strategies they employed and the training they had received in breaking bad news. Most professionals (75.5%) reported not following any specific strategy or best practice guidelines when delivering an MNDD diagnosis. Those who did explained that they followed NICE guidelines and were familiar with research on best practice and breaking bad news. Most professionals (83%) had received some kind of training on breaking bad news, either as a part of their formal education, clinical training or by sitting in with other clinicians who broke bad news. Qualitative comments also showed that respondents had learnt how to break bad news through experience, advanced communication skills training and generic training on breaking bad news, although the latter had focused on cancer. Around 31% had received no training in techniques of responding to patients' emotions and, for those who had, they reported having received such training as a part of their degree or developed these skills through experience and observing others breaking bad news. Finally, most participants (78.5%) were somewhat to very interested in receiving further education on breaking bad news and on techniques for how to respond best to patients' emotional needs.

#### Qualitative comments

Most qualitative comments given by participants were related to the challenges of communicating the diagnosis of an MNDD. Two common issues for professionals were related to limited consultation times and the lack of capacity to schedule a follow-up with the patient soon after diagnosis with some follow-up appointments booked for even 15 months post-diagnosis. Therefore, especially in general neurology clinics, participants had to cover many different topics in one single consultation, although the official time slot allocated for the appointment was not long enough:

*'Given current waiting lists for some of my movement disorders clinics, it may be 9 months before I next see a newly diagnosed PD patient. I therefore not*



*only have to explain the diagnosis, pathogenesis, and treatment options but also explain the treatment plan and contingencies for possible hiccups to cover a ridiculously large period of time in (officially) fifteen minutes. Is it any surprise my clinics (overruns) by several hours.'*

*'Insufficient time for vast amount of information to be usefully imparted. Pregnancy discussions alone merit a full consultation.'*

Conversely, a participant who was also practising privately reported that they could 'see patients again within a week to go over questions and discuss treatment plans once dust has settled'.

Several professionals talked about this lack of capacity as 'a service delivery issue', which, apart from limited consultation time, involved insufficient access to nurses and administrative staff who could coordinate these appointments: 'Someone (is needed) to coordinate (the) pathway so everything (is) available at consultation: relative, nurse, info etc.'. Specialist clinics seemed to be able to offer a better service, however one participant commented that referrals were not always possible when there were no specialist services locally.

Apart from organisational factors which affected their practice, professionals addressed how various illness and patient-related factors could affect their diagnostic practice. Diagnostic and prognostic uncertainty were common issues for participants delivering MNDD diagnoses. One person highlighted feeling 'pressured' by patients to give a diagnosis, even though they had not reached diagnostic certainty. Similarly, it was not always possible to share prognostic information, for example regarding the rate of progression and the potential level of future impairment. In addition, it was often commented that the lack of curative treatments made breaking bad news more difficult, especially when patients were initially unaware of the incurable nature of their condition. However, being able to offer symptom management for PD and disease modifying treatments for MS made the process of diagnosis delivery more positive.

On an emotional level, professionals reported several patient-related factors that made breaking bad news more challenging:

*'At times a patient's situation particularly resonates and this can be emotionally draining on the clinician.'*

Participants mentioned several cases that were particularly challenging, such as delivering a PD diagnosis to young people, delivering an MS diagnosis to young women who wanted to have children ('shattering hopes'), delivering an HD diagnosis to people with children or

delivering the diagnosis of MND to a patient who was presenting rapid progression or with already advanced symptoms at diagnosis. One professional used the word 'despondency' to describe how they felt when delivering such diagnoses.

## Discussion

This is the first UK survey study to address doctors' practice and experiences in communicating the diagnosis of an MNDD.

Generally, participants seemed to meet the setting-related standards of good practice [11] in breaking bad news by communicating the diagnosis in a private space, avoiding interruptions, arranging suitable seating and maintaining eye contact with patients. Regarding involving other people in the consultation, there was room for improvement since only 21.3% of professionals always asked patients to bring someone in consultation, 38.3% did so most of the time and 15% never did. One participant highlighted the fact that asking a patient to bring someone with them might act as a warning and could also increase their distress prior to the consultation and affect how much information they could absorb. However, although involving patients' relatives in a diagnostic consultation can be a challenge for healthcare professionals, they can offer emotional support, serve as the patient's advocate and receive important information they will need if they act as the patient's primary caregivers [17, 18]. Moreover, several MNDDs guidelines specifically recommend or imply that, with the patient's agreement, their support network should be present at diagnosis [12–14, 19].

Consultation duration reported by professionals in this survey was not always optimal and qualitative comments showed that organisational factors affected how much time they could invest for diagnostic consultations. Participants reported spending a mean of around 30 min to deliver the diagnosis of PD, MS and HD and 41 min for MND, however there was a considerable percentage of professionals (20–39%) who reported spending 15–20 min. The latter falls short compared to the European Federation of Neurological Societies (EFNS) recommended guideline of 45 to 60 min for the diagnosis of MND [19], however there are no published guidelines on consultation times for the other MNDDs. These findings correspond with both UK [20–22] and international [23–27] MNDD patient studies which have reported short consultation times that often led to patient dissatisfaction. Even though participants in this study reported sharing information on how the diagnosis was reached, the impact of the condition on patients' lives and their care plan, they still believed patients left the consultation not having taken in all information relevant to them at the point of diagnosis, especially for the case of MND

and HD. This is possibly linked to limited consultation times or, as one participant noted, due to patients' state of shock which affects how much information they can absorb. Professionals reported that they would often need more than one consultation to fully deliver the diagnosis. However, this is challenging since, particularly for PD, qualitative comments highlighted issues related to lack of capacity to book early follow-ups with some consultations being booked even 15 months post-diagnosis.

Most professionals agreed that diagnosis communication for MNDDs was a difficult task and being honest without taking away hope was the most challenging aspect of the consultation, a challenge which has also been reported by Aoun's survey of neurologists in Australia [15] and professionals working in other medical specialties such as oncology [7]. Participants in this study reported being particularly reluctant to promote a feeling of optimism when delivering the diagnosis of HD and MND. As some qualitative comments suggest, this could be associated with the poor prognosis for these conditions, however EFNS guidelines for MND [19] encourage professionals to discuss reasons for hope, such as ongoing research, drug trials and the variability of the disease and specifically advise against not providing hope during diagnosis. It should also be noted that providing hope is not always analogous to indicating the possibility of a cure. Hope can be generated for the optimal management of the condition, in whatever form that has to take. Instilling hope therefore can take many forms and is an important aspect of the patient's rehabilitation [28]. Feelings of hopelessness in people with MND have been reported to be more strongly correlated to quality of life than their physical functioning [29] and dissatisfaction with information delivery can negatively influence patient's sense of hope [30]. Moreover, a review by Clayton et al. [31] showed that although most patients approaching end of life prefer honest and accurate information, they are also able to maintain a sense of hope. The review suggested that healthcare professionals should recognise and foster different and realistic forms of hope relevant to the particular patient and their family by carefully assessing patients' information preferences and emphasising on what can be done for them.

Participants in this survey were also asked about the emotional aspects of delivering the diagnoses of MNDDs. More than half of professionals reported that they experienced moderate to high levels of stress during diagnosis delivery. This finding is supported by a review of studies that used self-report and psychophysiological measures and showed that during the communication of bad news, doctors experienced moderate levels of stress, with stress reactions lasting for hours or even days after the diagnosis [32]. The experience of stress could

potentially be linked to participants reporting 'perceived lack of time' and 'fear of causing distress' as the barriers they often experienced while breaking bad news and qualitative comments indicating that diagnosis delivery could sometimes be emotionally '*draining*'. Despite the emotional toll of breaking bad news, dealing with patients' emotional reactions did not seem to present a particular challenge for the participants of this survey. However, studies of patients with MNDDs have shown that patients are often dissatisfied with the lack of empathy shown by doctors during diagnosis delivery [10]. The seemingly contradictory finding here in that participants in this survey reported strong competency in this domain could either be attributed to participation bias (see limitations below) or different views and expectations between patients and professionals regarding the emotional aspects of the consultation.

Finally, most participants in this study reported not following any specific strategy or guidelines when delivering an MNDD diagnosis. Although step-wise protocols for breaking bad news have been criticized for potentially focusing more on the process than the people involved, their contribution to the medical practice and their emphasis on empathy and individualised information provision is acknowledged [33]. Despite their usefulness, these protocols, such as SPIKES [11], have been developed and have mostly been used within oncology settings. In addition, when it comes to MNDDs, only EFNS [19] and NICE MND [12] guidelines adequately addressed the topic of diagnosis delivery, while, for the other conditions, guidance was mostly limited to what kind of information to impart at diagnosis and we found no guidelines for HD. This could partially explain why most participants did not follow any specific strategies when breaking bad news for MNDDs. However, most participants in the survey indicated their interest in receiving further training on breaking bad news and responding to patients' emotions.

#### Implications for research and practice

This exploratory survey highlighted several aspects of diagnosis delivery for MNDDs which could be improved. Limited consultation times and inability to offer early follow-ups were often reported by participants as factors that hampered optimal diagnostic communication. This is potentially linked to staff shortages in neurology, services constraints and the NHS in general being under strain but highlights the need for organisational changes which acknowledge the importance of diagnosis delivery consultations for MNDDs. Beyond longer consultations, there is also a need for early follow-ups so the professional can provide all the relevant information and the reassurance that patients and their families need at diagnosis and will also provide the opportunity for patients



to express their emotions, prepare questions and make informed decisions regarding their care [34]. When faced with limited consultation times at diagnosis, professionals should make sure that they provide tailored information to each patient, written information about their condition, discuss their plan of care, reliable sources of information and support and ensure an early follow-up, usually with a specialist nurse. Data from our survey also showed that, despite recommendations, patients were not routinely advised to bring someone to the consultation. It would be worth exploring whether this varies among conditions and what factors influence this policy. However, we suggest that for the diagnosis of all MNDDs, patients are always given the option to be accompanied by someone. Moreover, it is recommended that, when it would not cause serious diagnostic delay, doctors should avoid delivering the diagnosis before national holidays or important events for the patient, building on the good practice reported by the majority in this survey.

Regarding professionals' manner of delivering these diagnoses, our findings suggest that participants were reluctant to provide a sense of hope to patients with MND or HD. Despite the severe life-limiting and threatening nature of these conditions, professionals should still try to explore and enhance patients' own concepts of hope and share information which could be deemed as positive [31], such as providing reassurance for effective symptom management and long-term support by a multi-disciplinary team. This is a topic where more research and development of training would be particularly useful in order to explore professionals' working in neurology concepts of hope and how these affect their practice of breaking bad news. Professionals in this survey reported moderate levels of stress when communicating an MNDD diagnosis, they acknowledged the difficulty of the task and briefly discussed the emotional aspect of being the bearer of such bad news. Further qualitative research on professionals' lived experience of communicating these diagnoses would help develop a deeper understanding on their perspectives and how they cope with giving these diagnoses on an emotional level. Exploring the opportunity for psychological input and the involvement of a multidisciplinary team in the process of breaking bad news would also be beneficial. This knowledge would be useful for developments in the design of medical education in neurology, adequately supporting professionals with this challenging task and eventually improving the patient experience. In addition, although diagnosis delivery is a critical milestone in patients' care, future research could also address other forms of breaking bad news in MNDDs such as the initiation of discussions around advanced directives.

Finally, most participants in this study indicated an interest in receiving further training in breaking bad news and reported low familiarity with published protocols of best practice. Professionals are encouraged to familiarise themselves with such protocols and best practice guidelines for breaking bad news which could be incorporated as a part of their training. Even though the SPIKES protocol [11] was initially developed for use within oncology, some data indicate its relevance for use within neurology. In particular, MND patients were more likely to judge neurologists' skills as 'above average' when they delivered the news in a way that resembled the steps described in SPIKES [35]. Nevertheless, further research incorporating both professionals' and patients' and families' needs and perspectives could help develop more tailored guidelines for neurology.

#### Limitations

The survey's relatively small sample size ( $N = 49$ ) could be considered one of the study's limitations. However, the recent ABN's Neurology Workforce Survey [36] identified a serious lack of UK neurologists within the UK, with the second lowest number of neurologists per head of population in Europe. It is estimated that 958 are practising in the UK [37] and although 84% of them run general neurology clinics [36], not all of them will deliver the diagnosis for the conditions included here. In addition, recruiting NHS healthcare staff in health research has been increasingly difficult due to often severe staff shortages and pressure being placed on clinicians [38]. Ultimately, this is a descriptive survey which gave the opportunity to these professionals to report on a significant aspect of their clinical practice and, through qualitative comments, discuss how it has been affected by the current NHS climate. Moreover, the results of this survey could be affected by participation bias. In particular, it is likely that most people who completed the survey were interested in the topic [39], and thus potentially better at breaking bad news and acknowledging the complexity of the task, and thus the findings may not be entirely representative of all neurology professionals.

#### Conclusion

Medical professionals delivering the diagnosis of MNDDs are faced with the challenge of communicating effectively, but also sensitively, being honest, but also providing a sense of hope. This was the first survey in the UK to address neurologists' practice and experiences in communicating these diagnoses. It was clear that for participants of this survey giving such bad news was an intrinsically challenging and stressful task which became even harder due to long waiting times for appointments in neurology and limited consultation times. Participants

reported often spending a sub-optimal amount of time for these diagnostic consultations and discussed how the incurable nature of MNDDs, the uncertainty about the rate of disease progression and the, occasionally, young disease onset made such diagnostic consultations more challenging. Nevertheless, participants in this study showed signs of good practice regarding the setting of the consultation and providing appropriate and honest information at diagnosis. Apart from time restrictions and issues related to capacity, this study highlights other areas of improvement such as including patient's family routinely in the appointments and providing some sense of hope even for conditions with a poor prognosis. Participants also reported low familiarity with breaking bad news protocols and best practice guidelines but also indicated an interest for further training in this domain.

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12883-021-02062-6>.

#### Additional file 1.

### Abbreviations

ABN: Association of British Neurologists; ENFS: European Federation of Neurological Societies; HD: Huntington's disease; HRA: Health Research Authority; MND: Motor neurone disease; MNDD: Motor neurodegenerative condition; MS: Multiple sclerosis; NHS: National Health Service; NICE: National Institute for Health and Care Excellence; PD: Parkinson's disease

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Not applicable.

### Authors' contributions

EA, JS, FE and IA designed the study, EA collected the data, carried out the analysis and wrote the paper, with assistance from JS and FE. All authors read and approved the final manuscript.

### Authors' information

EA has a BSc in Psychology and an MSc in Health Psychology. He is currently studying for a PhD in Health Research at Lancaster University. FE is a Lecturer in Health Research at Lancaster University UK with research interests in the psychological wellbeing of people with neurodegenerative conditions. JS is Professor of the Psychology of Neurodegenerative Conditions at Lancaster University, UK, and is the lead author of the British Psychological Society's guidance on working psychologically with people with neurodegenerative conditions. IF has an MSc in Applied Psychology and a PhD in Psychiatry; he is currently a senior lecturer in Health Research.

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### Availability of data and materials

The datasets used and analysed during the current study are not publicly available because participants have not given consent for public availability of their data. Data are available from the corresponding author on reasonable request.

### Ethics approval and consent to participate

The study adhered to relevant guidelines and regulations. It received ethics approval by the Faculty of Health and Medicine Research Committee of Lancaster University (FHMREC17106) and the HRA (19/HRA/5761). Participants had to give informed consent online prior to proceeding to the survey by confirming that they have read the participant information sheet and understand their rights as research participants and what is expected from them.

### Consent for publication

We obtained informed consent for publications by participants of this study.

### Competing interests

The authors declare that they have no competing interests.

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## Appendix 3

### Survey questionnaire

#### Survey questions

##### Sociodemographic information

**Q1** What is your gender?

- ☐ Male
- ☐ Female
- ☐ Other

**Q2** Please indicate your age

- ☐ Under 30
- ☐ 31-40
- ☐ 41-50
- ☐ 51-60
- ☐ 61 or older

**Q3** Are you a consultant neurologist or a specialist registrar?

- ☐ Consultant neurologist
- ☐ Neurology specialist registrar
- ☐ Other (please specify) \_\_\_\_\_

**Q4** If you are a consultant neurologist, how many years have you been practising?

\_\_\_\_\_

**Q5** In which part of the UK are you mainly currently practising? (tick all that apply)

- ☐ England
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland

**Q6** Practice sector (select both if both apply)

- ☐ NHS
- ☐ Private practice

**General questions about giving a diagnosis for motor neurodegenerative diseases**

**Q7** For which of the following conditions have you given a diagnosis before? Tick all that apply

- ☐ Parkinson's disease (PD)
- ☐ Multiple sclerosis (MS)
- ☐ Huntington's disease (HD)
- ☐ Motor neurone disease (MND)

**Q8** Approximately how many diagnoses for these neurological conditions have you communicated so far?

	1 - 20	21 - 50	51 - 100	more than 100
PD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MND	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q9** Do you tell someone with a neurological condition their diagnosis?

	Always	In most cases	In some cases	Just in part	Never
PD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MND	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q10** Please state the reason(s) for your answer above

---

**Q11** What would be the average length of time between your first clinical consultation with the patient and the delivery of the diagnosis?

	Months OR	Weeks
PD		
MS		
HD (when genetic status was unknown)		
MND		

**Q12** On average, how long is the consultation when you deliver a diagnosis?

	Minutes
PD	
MS	
HD	
MND	

**Q13** Do you ever require more than one consultation to fully explain the diagnosis?

	Always	Sometimes	Never
PD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MND	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q14** If you do, please indicate the reasons you would require more consultations.

\_\_\_\_\_

**Q15** Do you ever refer patients to a different physician or service, who will then deliver the diagnosis of a neurological condition (e.g., the patient's GP)

- ☐ Yes (please indicate on which occasions and for which of the conditions we are focusing on) \_\_\_\_\_
- ☐ No

**Q16** Is it your service's policy to ask the patient to bring someone to the consultation?

- ☐ Always
- ☐ Most of the time
- ☐ About half the time
- ☐ Sometimes
- ☐ Never



**Q17** How often do you include a nurse or another health care professional in the consultation?

- ☐ Always
  - ☐ Most of the time
  - ☐ About half the time
  - ☐ Sometimes
  - ☐ Never
- 

**Q18** Do you refrain from giving a diagnosis at any specific time or day?

- ☐ Yes (please specify) \_\_\_\_\_
- ☐ No

**Q19** When you first give the diagnosis, which of these clinical aspects do you consider should be discussed with the patient? (Tick all that apply)

- ☐ How the diagnosis was reached
- ☐ The degree of certainty of the diagnosis
- ☐ The course/prognosis of the disease
- ☐ Possible causes of the disease
- ☐ Treatment options
- ☐ Current research
- ☐ Other (please specify) \_\_\_\_\_

**Q20** How often do you deliver the diagnosis in a private space? (e.g in a consulting room)

- ☐ Always
- ☐ Most of the time
- ☐ About half the time
- ☐ Sometimes
- ☐ Never

**Q21** How often do you communicate a diagnosis without any interruptions?

- ☐ Always
- ☐ Most of the time
- ☐ About half the time
- ☐ Sometimes
- ☐ Never

**Q22** Do you maintain eye contact with the patient?

- ☐ Always
- ☐ Most of the time
- ☐ About half the time
- ☐ Sometimes
- ☐ Never

**Q23** Do you arrange to have suitable seating at the same level as the patient and without a desk or barrier?

- ☐ Always
- ☐ Most of the time
- ☐ About half the time
- ☐ Sometimes
- ☐ Never

**Q24** Do you promote a feeling of optimism when delivering a diagnosis?

	Definitely yes	Probably yes	Might or might not	Probably not	Definitely not
PD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MND	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q25** When talking about treatment, do you enable the patient to express their personal needs and preferences?

- ☐ Always
- ☐ Most of the time
- ☐ About half the time
- ☐ Sometimes
- ☐ Never

**Q26** Do you believe patients are given enough time to ask questions and express their emotions?

- ☐ Definitely yes
- ☐ Probably yes
- ☐ Might or might not
- ☐ Probably not
- ☐ Definitely not

**Q27** In addition to copying the patient to the standard mails that are sent to their GP, do you provide any other information tailored to their case in written form?

- ☐ Always
- ☐ Most of the time
- ☐ Occasionally
- ☐ Seldom
- ☐ Never

**Q28** How often do you share information about local support groups and national charities?

	Always	Most of the time	About half the time	Sometimes	Never
PD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MND	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q29** Do you initiate a follow up communication and support plan following giving the diagnosis?

- ☐ Always
- ☐ Most of the time
- ☐ Occasionally
- ☐ Seldom
- ☐ Never

**Q30** On average, how soon after giving the diagnosis would you follow up the patient?

	WEEKS OR	MONTHS
PD		
MS		
HD		
MND		

#### **Experiences of breaking bad news**

**Q31** Do you think delivering the diagnosis for the conditions discussed is a difficult task for the physician?

- ☐ Definitely yes
- ☐ Probably yes
- ☐ Might or might not
- ☐ Probably not
- ☐ Definitely not

**Q32** What is the most difficult part of communicating the diagnosis for these neurological conditions? (Please tick all that apply)

- ☐ Being honest but not taking away hope
- ☐ Dealing with the patient's emotion (e.g. crying, anger)
- ☐ Spending the right amount of time
- ☐ Involving the family of the patient
- ☐ Involving patient or family in decision-making
- ☐ Other (please specify):

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**Q33** How would you assess the stress and anxiety you experience during the delivery of a diagnosis of this nature?

- ☐ None
- ☐ Slight
- ☐ Moderate
- ☐ High
- ☐ Very high

**Q34** Research has shown that there are several potential barriers a physician might face during a breaking bad news consultation. Based on your experiences,

please indicate how often, if ever, the factors listed below affect the way you deliver the diagnosis for a neurological condition.

	Never	Sometimes	About half the time	Most of the time	Always
Fear of the messenger getting blamed for bad news	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fear of causing distress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fear of not having all the answers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fear of being asked difficult questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patients/relatives being non- receptive or challenging	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of/insufficient training in breaking bad news	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Perceived lack of time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Excessive workload	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information flaws within the service (e.g not having all patient's files/tests available)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q35** Please outline any specific challenges when communicating the diagnosis, associated with the particular clinical nature of these conditions (e.g. lack of an effective treatment, different types of MS etc.)

	Challenges
PD	
MS	
HD	
MND	

**Q36** Please rate the level of difficulty in the different aspects of delivering the diagnosis below

	Not at all difficult	A little bit difficult	Somewhat difficult	Difficult	Very difficult
Finding enough time to deliver the diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Responding to patient's emotions (crying, anger, disbelief)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Evaluate the patient's preferences about the amount and nature of information they want	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



**Q37** In general, how would you self-assess how well you communicate the news for a motor neurodegenerative condition?

- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Very poor

**Q38** How confident are you that patients leave the consultation having taken in all the information relevant to them at that point?

	Very confident	Confident	Not sure	Not confident	Really not confident
PD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MS	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MND	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q39** In general, how satisfied do you think your patients are with the way the diagnosis is delivered?

- ☐ Very satisfied
- ☐ Somewhat satisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Very dissatisfied

**Education and Training needs**

**Q40** Have you had any specific education or practical training for giving a motor neurodegenerative disease diagnosis?

- ☐ No training
- ☐ Part of degree/formal education
- ☐ Clinical training post qualification
- ☐ Sat in with clinicians in breaking bad news interviews
- ☐ Other (please specify): \_\_\_\_\_

**Q41** Have you had any training in the techniques of responding to patients' emotions?

- ☐ No training
- ☐ Part of degree/formal education
- ☐ Clinical training post qualification
- ☐ Sat in with clinicians in breaking bad news interviews
- ☐ Other (please specify): \_\_\_\_\_

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**Q42** Do you follow any specific strategy or best practice guidelines when delivering a motor neurodegenerative disease diagnosis?

- ☐ Yes (please specify) \_\_\_\_\_
- ☐ No

**Q43** Would you be interested in receiving further training/education in breaking bad news and techniques of responding to patients' emotions to this news?

- ☐ Very interested
- ☐ Somewhat interested
- ☐ Not interested

**Q44** Are there any other comments you would like to make regarding the topic in general or the survey questions?

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## Appendix 4

### Supplementary Material for PP3

#### Interview Guide

Question	Prompts
Can you tell me how you have come to work in this context and this line of work?	How long are you in practice? How old are you? Where were you trained?
What are your experiences with communicating with patients in this context in general?	How important do you think communication with the patient is?
How long after the patient receives their diagnosis will they usually get an appointment with you?	At this point, how have patients usually dealt with the bad news they received?
At this initial appointment you have with the patient post-diagnosis, are you involved into tasks that could be considered bad news breaking? If yes, can you talk to me about it.	Have patients fully understood their diagnosis and treatment options at this point? If not, do you provide them relevant information?  What kind of conversations with patients do you consider to be <i>difficult conversations</i> ?  How do you feel when you have to provide information that could be perceived as bad news or cause distress?
How do you provide support to newly diagnosed patients with motor neurodegenerative conditions?	How do you help patients cope with their diagnosis?  How do you respond to patients' emotional reactions?  Are patients willing to receive support at that time?
How do you feel about this aspect of your clinical work? (I mean breaking bad news and supporting newly diagnosed patients with motor neurodegenerative conditions)	What are your views on the difficulty of this task?  What are some positive aspects of this task?  How do you manage your own emotions when conversations are difficult?
What are the most challenging aspects of working with newly diagnosed patients with motor neurodegenerative diseases and engaging in breaking bad news tasks?	Do you always have enough time and a private space for your appointment with these patients?  How do organisational factors affect how you provide support at this point? (either helpful or obstructive)

	What do you do when you feel that you cannot answer some of the patients' questions?
What kind of education and training have you received on communication with patients?	Have you received training specifically for breaking bad news?  Would be interested to receive further training on breaking bad news and supporting newly diagnosed patients?

## Additional participant quotations

### Theme 1

*'Especially, as someone who has passed from pillar to post and took a long time to get into any support at all or there's been...problems with getting from the GP to the neurologists, so there's been a long...people can come in very "bristly" [...] and I might be the first health professional they are seeing when they 've had the opportunity to just go, you know, let off some steam. [...] – Often, I am the first opportunity for them to say, to express dissatisfaction with how long things have taken.'* (Participant 6)

*'They normally come in afraid, withdrawn, scared and I think 90% of the patients that come in, you know, the main, I'm not being nasty or... but sometimes doctors can be, you know, more kind of blunt, if that makes sense, and give the diagnosis more matter of fact.'* (Participant 14)

*'I do come across clients that come to the centre who are very angry with the way that the news has been delivered. And sometimes that's for good reason, for*

*people that were told when they were on their own, for people upset because a GP has told them over the phone or they 've opened up a letter.'* (Participant 5)

*'A difficult aspect is dealing with the 'aftermath' when the bad news of the diagnosis has not been broken well.'* (Participant 7)

*'You're trying to hold a neutral ground, if that makes sense. You want to give the person some space to talk about what they've been through and you want to empathise with that, but you also want to hold, hold some neutral territory, because they might need to go back to see that clinician again in the future.'* (Participant 13)

*'Talk to that person, take that time, answer their questions, try to use the right communication skills to de-escalate, re-assure them.'* (Participant 6)

*'So, some consultants, one in particular doesn't even tell his patients that there is a Parkinson's nurse...Or tells some of them, I get intermittent referrals from him. [...] So, some people say they've been told, you 've got Parkinson's go...and try and do what you can, the medication is worse than the symptoms...I 've had people actually said have that said to them... people terrified then of going on medication.'* (Participant 6)

*'So, when you come to see them, you know, they've had a good rapport with the consultant that they're gonna see [...] they ask you questions, it makes quite an easy sort of visit that you can ask them things as well.'* (Participant 7)

## Theme 2

*'What patient questions can lead to difficult conversations?' (Interviewer)*

*'When people ask what to expect in the future, or maybe 'when people's expectations of their degenerative conditions, maybe they don't have realistic expectations'. Some people don't process the fact that they are going to get worse and think that they will always stay independent even when that is not realistic.'*

*(Participant 16)*

*'It's a bit, like, imagine like a seed, you know they're given the seed by the genetic counsellor but then the seed unpacks, you know, it starts to grow and it takes, out of that seed, grows a plant, you know, a huge, huge plant and there's so much in that seed. So, the point where we get involved initially, usually they're trying to cope with the initial news and an awful lot of what they've been told might be forgotten, not going in, they might be scared to ask questions about it, they might be burying their head in the sand about it. [...] It's just a process of helping them through absorbing the magnitude of what's in that seed, so in that sense that's what we do, we unpack the bad news I suppose and it's, it's practical implications for their lives.'*

*(Participant 9)*

*'Depending on how we're talking about bad news, because we wouldn't be involved in giving any diagnostics, but we may be involved in actually helping the person to understand the implications of their diagnosis.'* (Participant 11)

*'I think we have to say you 're always gonna be, you 're never gonna be as if you never got this condition, you 're always going to be a bit more stiff, more slow, not everyone responds as well to the medication.'* (Participant 6)

*'You know, people have just had this horrible diagnosis and have physical symptoms or speech problems to then think, that I might be discovering another problem, I think it's quite hard for some people.'* (Participant 8)

*'And I think it's also introducing where appropriate, direction for the future, so we will, I will be opening up conversations about gastrostomy and I will be opening up conversations about non-invasive ventilation, I will be opening up conversations about linking-up with palliative care and, you know, possibly end of life conversations as well. There's so much misinformation available so, I have to provide some direction, but breaching that initial palliative discussion, I think yes, that can be quite, quite hard. I suppose I have quite long experience of working with people and, and perhaps passing difficult information across to them, but I don't, you never get used to this, it can be really tough.'* (Participant 10)

### Theme 3

*'I think it's really important to be honest, because if a patient asks you a question and you give them a fake, you know, an answer that's not clear and honest,*



*they will not trust you to come back in the future and give them the right answers.'*

(Participant 4)

*'they (patients) might forget the news itself, but they will never forget the way they were told the news' (Participant 19).*

*'So, you have to be able to... phrase your answers in a way that, won't scare them but is honest.'* (Participant 4)

*'I suppose whatever bad news that we deliver, about the illness, about the future, we try and wrap it up with hope and there's things like, with this illness (MND), it's almost always a very slow development, so there's not gonna be a sudden change of symptoms overnight, they won't deteriorate in one area really, really quickly, that's, that's likely and when you do deteriorate, we've got treatments, we got things, we can't stop the illness but we can, you know, help with the symptoms and we got medications, we've got things that physiotherapists and speech and language therapists and dieticians can do to make life easier. Erm and there's research going on, you can tell them about the research and the hope that that's providing. (Participant 9)*

*'There's this kind of line between giving hope, but not giving too much hope.'*

(Participant 9)

*'It is difficult because you don't know them, yes it easier when you 've formed a bit more of a relationship with some of the, because you know how to read them. So, the question you think they 're asking, might not necessarily be what they are asking. So, I mean that's where a lot of counselling skills come in, kind of reflecting back. Right you 're saying this...is this what you need? In which case I will give you this bit of information. But, it's, it's double-checking that they do want the bare facts and not just, you know a quick reply.'* (Participant 3)

*'It's difficult because if you get it wrong in the early stages, it can affect, you're trying to establish engagement and a relationship with somebody to build upon. So, if you get it wrong in the early stages it can backfire.'* (Participant 9)

*'I suppose it's a part of our job, finding ways to give back that feedback in a way that people can leave the room still feeling like there's a plan and there's something that we can do, even if the results are not what they wanted or hope. You know, they can still feel like there's something we can be working on, there's some sort of plan around that and I suppose you just want to get it right for them, really, you don't want them to be in any more risk.'* (Participant 13)

#### Theme 4

*'It depends on the medication, but I am explaining all their options depending on their MRI and I'm helping them make an informed choice on when to plan to make a family.'* (Participant 14)

*'You know, having met people who have just been given a diagnosis, you have to support people to make some really difficult decisions around giving up work, giving up driving, being able to manage, you know, personal care, before their condition progresses even more.'* (Participant 11)

*'We're trying to give them as much control as possible, cause a lot of them obviously have lost a lot of control, so we say to them, you know, 'it's... nobody's going to force our service on you, we will give you as much or as little as you want, you can nip in and out.'* (Participant 9)

*'And holding on to something, whether it's the way they dress or the music they listen to or what they're interested in, trying to enable them to keep those things going is so important. [...] I try to make their lives have some meaning and for it not to be just about the death because I try to encourage them to try...try to make them live the rest of their lives, try to help them live the rest of their lives.'* (Participant 4)

## Coding example

Transcript excerpt	Codes
<p>I: So, at this initial appointment, you have with the patient, are you involved into tasks that could be considered bad news breaking?</p> <p>P: Well...yes, sort of, because often, I may be asked, so 'why am I no eligible for a disease-modifying drug?', you know. And it may be because, 'well these disease-modifying drugs tackle relapse and you have a form of MS that doesn't have relapse, therefore, that drug is of no use to you'. And sometimes that is accepted as alright, 'well I understand now, that makes sense' and other times that's taken as, you know, the final blow, 'really, I 'm not ever gonna get that drug?', you know. And it takes away that little bit of hope that someone once somewhere along the line had made the mistake and they are going to get this drug, that's difficult.</p> <p>I: How do you react when this happens? When they get devastated by this...</p> <p>P: So, erm what we have to do then is let that sink in and then see, so for the part of the disease that everybody has, the progressive part, here's where we come in, 'whether you 've got relapse and remitting or secondary progressive, primary progressive, what we are looking at here is getting you involved in the strength and balance class, in the mindfulness class, in the fatigue management class,</p>	<p>Clarifying patients' misconceptions regarding their eligibility for DMTs</p> <p>Explaining the nature of a diagnosis</p> <p>Explaining ineligibility for DMTs could be accepted by patients or completely shatter their hope</p> <p>Dealing with patients' expectations who have been misinformed</p> <p>Giving patients time for the bad news to 'sink in'</p> <p>Providing information on what can be done for the patient to help manage both the physical and psychological impact of MS</p> <p>Explain the importance of self-management despite the incurable nature of MS</p>

<p>then', you know, 'yoga, pilates'. We explain that whilst there's not a drug, there are other ways to self-manage this disease.</p> <p>I: So, you tell me that not all patients, when they come to see you, have fully understood their diagnosis and treatment options?</p> <p>P: Oh yeah, that's the case, yeah. And sometimes people come and they don't actually know what type of MS they have.</p> <p>I: Do they share their experiences of how they received the news with you?</p> <p>P: Yeah... I think there are different categories. So, I do come across clients that come to the centre who are very angry with the way that the news has been delivered. And sometimes that's for good reason, for people that were told when they were on their own, people might be upset because a GP has told them over the phone, they 've opened up a letter... I would say by far, the vast majority have had an inkling that there's something significantly wrong and that the news they get is news that they don't want to hear but they're not that surprised, they are devastated but they are not shocked. But there is a lot of anger, a lot of grief, a lot of frustration, particularly if, erm, you know I had one.... I had one young woman who's been saying for years there's been something radically wrong with her and she was then transferred to, erm, psychology, erm, for, health anxiety, and her husband - now bear in mind this is a young couple-, erm, her husband, was saying look, there's nothing wrong, you've had all the tests... And then there was a significant incident, and she was rushed into hospital</p>	<p>Newly diagnosed patients might lack a basic understanding of their diagnosis</p> <p>Patients might express their anger towards an insensitive diagnostic experience</p> <p>Although devastated, most patients are not shocked because they knew there was something wrong with their health</p> <p>Listening to patients' illness journeys even before receiving their diagnosis</p>
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and it turned out that she had multiple lesions and that she was right, there was something wrong. And, so therefore, she was very mistrustful then.	Patient mistrust caused by diagnostic delay and not having her symptoms validated for years
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## Themes and relevant codes

Theme	Codes
<b>Dealing with the diagnostic aftermath</b>	<p>Listening to patient stories of bad diagnosis delivery</p> <p>Allowing patients to express their anger or frustration caused by the diagnostic delay</p> <p>Allowing patients to express their anger or frustration caused by sub-optimal diagnostic experiences</p> <p>Empathising with patients who had negative pre-diagnostic/diagnostic experiences</p> <p>De-escalating the situation - holding a middle ground between patients and doctors</p> <p>Acknowledging the time restrictions faced by neurologists</p>
<b>Unpacking the diagnosis</b>	<p>Newly diagnosed patients have not always understood their diagnosis</p> <p>Re-iterating diagnostic information</p> <p>Managing patient expectations regarding the goal of treatment and rehabilitation</p> <p>Clearing misconceptions about the nature of MNDDs</p> <p>Helping patients understand the impact of their diagnosis</p> <p>Discussing prognosis</p> <p>Having enough time to offer long consultations and provide adequate information</p>
<b>Breaking bad news as a balancing act</b>	Being honest and realistic

	Being sensitive
	Providing positive information/Promoting a sense of hope
	Avoid providing false hope
	Assessing patients' information needs and preferences
	Providing potentially distressing information regardless of patients' readiness to receive it
<b>Empowering patients to regain control over their health and lives</b>	Breaking bad news to prepare patients for the future
	Discussing treatment options
	Supporting patients to made decisions and plan for the future
	Providing holistic assessments
	Signposting to other professionals/sources of support
	Encouraging self-management
	Providing emotional support

## Appendix 5

### Supplementary Material for PP4

#### Interview guide

Question	Prompts
Can you tell me how you have come to work in this context and this line of work?	How long are you in practice? How old are you? Where were you trained? What kind of diagnoses do you give?
So, let's say that you have to deliver a diagnosis for a MNDD. How do you prepare yourself before the consultation?	What kind of goals do you set for the consultation? What do you think the main goal of diagnosis delivery is? How do you feel and what are your emotions at this point?
What is the usual practice in your organisation regarding the setting where diagnosis delivery takes place?	Is privacy always guaranteed? Did you ever have to deliver the diagnosis through the phone?
Are there any other people usually involved in the consultation?	...such as patients' family or a nurse Do you think it is helpful for you or the patient to include others in the consultation?
How much time do you usually dedicate to a diagnosis delivery consultation for an MNDD?	Do you dedicate a different amount of time for different MNDDs? Do you think this is enough for patients to get all the information needed at that point?



How do you start the consultation? What would you usually say? Can you narrate for me how a typical consultation would go?	Do patients usually know they are about to receive bad news?  Do you try to give some warning signs that you are going to break bad news?
What is your emotional state like when you are giving the name of the condition and you see the patient's reaction?	
What are patients' usual reactions to the news?	How do you respond to their reactions?  Do you give them time to express their emotions?  Do you remember any occasions when the patient had a very strong reaction when they received the diagnosis?  How do you react if a patient starts crying?  Has anyone ever got an angry reaction to the news? How did you manage this?  What are usually the reactions of the family?  How do you manage them?
Have any experiences of breaking bad news particularly memorable for you?	Either positive or upsetting  Can you talk to me about it?
How do you check patients' information preferences?	Do you withhold any kind of information when you are delivering a diagnosis for a MNDD?  How do you decide what kind of information to provide?  When talking about treatment, do you enable the patient to express their personal needs and preferences?
Let's say that you have to deliver the diagnosis of MS to a woman in her 30s with 2 children, how does this make you feel?	How do you go about doing this? How would you describe your experience in taking on such a task?  Can you describe any somatic feelings?

	Do patient factors such as their age affect your emotions and how you deliver the diagnosis?
Have you ever been emotionally affected after a breaking bad news consultation?	How did you feel?
How is a breaking bad news consultation different than other consultations?	Do you experience it in a different way? Do you think it is a difficult task? Why? Do you think it is a stressful task? Why?
How does diagnosis delivery differ among MNDDs?	Any illness-related factors that you take into account when delivering the diagnosis?
What are the most challenging aspects of delivering a diagnosis for an MNDD?	In case they do not provide enough information to the open-ended question, examples will be given by the interviewer on which the participant can elaborate on (e.g. incurable nature of the conditions, responding to patients' emotions)
Can you give me an example of a consultation that went particularly well?	How do you feel after diagnosis delivery has been particularly effective?
Do organisational/healthcare system factors affect the way you deliver a diagnosis for an MNDD?	In case they do not provide enough information to the open-ended question, examples will be given by the interviewer on which the participant can elaborate on (e.g. time constraints)
In general, how would you self-assess how well you communicate the news for a motor neurodegenerative condition?	How confident are you that patients leave the consultation having taken in all the information relevant to them at that point?  In general, how satisfied do you think your patients are with the way the diagnosis is delivered?
What kind of education and training have you received on communication with patients?	Have you received training specifically for breaking bad news?

	<p>Do you follow any specific guidelines for breaking bad news? If no, do you think it would be valuable for your organisation to follow a specific set of guidelines?</p> <p>Would be interested to receive further training on breaking bad news?</p> <p>How has your practice on breaking bad news changed over the years?</p>
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## Coding example

Reflection – Initial ideas	Transcript excerpts	Coding Descriptive/interpretative/linguistic
<p><i>Maybe there isn't a perfect way to deliver such diagnoses that's where support, empathic and compassionate practice could be fundamental?</i></p>	<p>I: So, what are the most challenging aspects of delivering a diagnosis of MND?</p> <p>P: Is knowing how to do it right, that's the most challenging. How do you, how do you best give terrible news to somebody in a way that allows them to absorb the information without shutting down emotionally and without it being such a traumatic experience that they can't, they just re-live it it or they can't even think about it? It's that, how do you give that information in a gentle way. Because that's in the end what you have to be you have to be gentle, you're giving someone a massive blow. It's like trying to punch someone so hard to knock them out but you have to do it very, very gently.</p> <p>I: So ideally, how do you want the patient to leave the room?</p> <p>P: I want them to leave, having absorbed the information in a state of mind where they can deal with it. I want them to leave feeling positive. So, a lot of what I do is, after giving the terrible diagnosis, tell them what we can do, and telling them that there's an army of researchers trying to support them, and, you know, I don't know how long it'll be before we find a cure, but everyday we're closer, obviously. And I try to give them hope and I help them with things like alternative therapies, you could go here. And there's these clinical trials, and we do this research...</p> <p>I: So, you give them some treatment and management options...</p>	<p>Knowing how to give 'terrible' news without hampering patient's information absorption, shutting them down emotionally and contributing to a traumatic experience is the most challenging aspect of BBN – places the challenge of BBN on 'knowing' rather than the 'doing', implies BBN is a process that can be approached in different ways and primarily requires knowledge and potentially experience - he's sensitive to the immediate impact the diagnosis can have on patients.</p> <p>Uses metaphors to describe the paradox of having to give such bad ('terrible') news in a gentle way: 'being gentle when giving someone a massive blow' &amp; 'punching someone so hard to knock them out but doing it gently'. The use of these verbs and metaphors illustrates the potentially destructive nature of an MND diagnosis and also imply a sense of responsibility for the diagnosis, personal agency – it sounds like BBN for MND is a lose-lose situation, where neurologists will inevitably distress patients through diagnosis communication – however, the need to be gentle and sensitive is emphasised</p> <p>Wants people to leave the consultation having absorbed information, being able to cope with it and feel positive. After giving the diagnosis he tries to instil hope by informing patients about current research on cures, current trials and alternative therapies they can try</p> <p>Balancing bad news by also promoting some sense of hope for potential research advances regarding therapy. Being well-informed but still feeling a bit positive as ideal outcomes of an effective BBN consultation.</p>

<p><i>The participant has been reluctant to discuss the emotional aspect of delivering these diagnoses up to this point – what he says here might explain why (see coding) – I should have asked why he believed that.</i></p>	<p>P: Yes, yeah. The other thing, as I say, we have a multidisciplinary team, so they know they're supported. And I make it explicit that we don't want them to feel abandoned. And that the purpose of our clinic is that they can ring or contact us at any time for any support they need.</p> <p>[...]</p> <p>Have you ever been emotionally affected after consultations when you had broken bad news?</p> <p>Yes.</p> <p>How did you feel?</p> <p>Well, sad. Yeah. I mean, I don't know what more I can say. You know, I could give you a sort of florid series of metaphors about my emotional status, but I don't think it would help very much.</p> <p>Oh, why not? You can just give me one.</p> <p>Okay. Well, maybe I can't, but let me just think. I suppose it's a bit like going to funerals. I don't know if you've been to many. But you know, whenever you go to a funeral, it reminds you of all the others that you've ever been to, including those of your nearest relatives. And, whenever you break bad news, it sort of reminds you of all the others. And it reminds you of your own predicament in life and of life, fragility.</p> <p>See? That's not a metaphor. That's really interesting!</p> <p>It's not, it's not! That's true. That's true.</p>	<p>Informing patients about the MDT support available to them and the availability of the clinic for whatever support patients might need – Another positive message he includes during BBN consultation: providing reassurance about the availability of long-term support, acknowledges the potential feelings of isolation and helplessness that receiving an MND diagnosis might trigger</p> <p>Feeling sad after breaking bad news – says he doesn't know what more to say other than feeling sad. – reluctance to elaborate on the emotional impact of BBN</p> <p>He can elaborate on his emotional state after BBN using metaphors but does not believe this would be helpful – potentially views his own emotional experience of BBN as being insignificant or he wants to avoid elaborating on experiences that might have been distressing for him. Throughout the interview he has focussed on the information that needs to be imparted and has viewed emotional aspects of these consultations as secondary to the information exchange.</p> <p>Breaking bad news is a sad process that feels like going to funerals, it reminds him of all the times he's broken bad news and reminds him of his own predicament in life, his fragility – The funeral metaphor might imply a general feeling of sorrow surrounding the process of giving bad news. Breaking bad news triggers memories from all similar past consultations and also acts as a reminder of his own fragility - these add to the sadness experienced when conducting this task but also make it personal for the doctor as well, exposing his own vulnerability and mortality.</p>
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	<p>So it's kind... there's this sense of sorrow, kind of.</p> <p>Sorrow. Yes, that's true. You know, is it existential angst in a sort of way? Yeah.</p>	<p>The sorrow experienced when delivering these diagnoses could trigger existential angst – beyond the experience of distressing emotions, being the bearer of such bad news can trigger philosophical questions about life</p>
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## Printing and grouping codes and interpretative comments from each individual interview to create interpretative summaries



## Example of an interpretative summary from an individual interview

### Interpretation both at coding level and also when writing these narrative summaries

#### Example 1. *Hierarchy of neurological conditions*

Narrative summary	Codes	Examples of supporting quotes
When she was asked about her general experience in communicating the MNDD diagnosis, the participant presented a hierarchical ordering of neurological conditions, based on how manageable and directly life-threatening they are. The perceived severity of an MNDD seemed to influence her perceived difficulty of diagnosis delivery, her emotional experience of breaking bad news and some parameters of her practice (such as the amount of time invested for the consultation). At the bottom of her hierarchy of neurological conditions was MS. Due to advances in available disease-modifying treatments the participant could offer a better prognosis to patients which made it one of the 'easier diagnosis to give'. She reported telling patients that an MS diagnosis is ' <i>actually good news</i> ', implying that it could be something worse than MS. Her professional knowledge and clinical perspective allow her to contrast and compare MS to	<p>Because of advances in available treatments, BBN in MS has changed massively for the better since she feels she can discuss a better prognosis</p> <p>Views MS as 'good news' which she might also mention to patients</p> <p>She tells MS patients that the chance of being in a wheelchair 5 years post-diagnosis, has gone from 50 to 5%</p> <p>Giving an MS diagnosis can be a positive discussion that includes treatment options</p> <p>MS is now one of the easier diagnoses she gives - 'Easier' not 'easy' might imply that it's still difficult nevertheless</p> <p>People know about PD but dread it coming with a preconception that it is incurable, and nothing can be done about it, although she states this is not entirely true as PD for her is 'nowhere near the worst</p>	<p><i>'Communicating with patients with a diagnosis of MS has changed massively in the last 15 years. And that's probably because we're able to offer a much better prognosis.'</i></p> <p><i>'I say show them the scans, I say, "There are multiple, these are called scleroses and this is MS, had you thought about that?", and they say "yes" or "no" and then I'll say, "This is what this means, actually this is quite good news", etc.'</i></p> <p><i>'So, actually, I find the diagnosis of MS is much easier, it's positive, we can talk to them about treatment.'</i></p> <p><i>'A Parkinson's disease diagnosis is still nowhere near the worst thing that I have to do, I can often say to people, "We can't cure this, but we often can manage it really well and there are lots of</i></p>



<p>other, more severe conditions, [yet from the patient's perspective MS could still be a disruptive diagnosis which they do not necessarily compare with other more severe ones]. Similarly, she found PD to be <i>'nowhere near the worst thing'</i> she has to diagnose, mostly because of its chronic nature (versus conditions with limited life expectancy) and the variety of options she could offer patients (medications, physiotherapy, rehabilitation etc.) to help manage their condition. However, she found diagnosing young onset Parkinson's difficult because of how upsetting and life-changing the diagnosis can be for young people. Moving up the 'hierarchy', she believes that HD is one of the worst conditions to diagnose because of the 'often-huge implications' on a family level and the fears regarding the hereditary nature of the condition. On a more positive note, unlike the rest of MNDDs, an HD diagnosis does not usually come out of the blue, patients might have known for years, so breaking bad news is more challenging when the patient and their family did not know about a positive gene testing for HD. According to the participant, MND was the diagnosis she struggled with the most due to its <i>'bleak'</i> nature associated with a</p>	<p>thing she has to diagnose'. [mismatch between her and patients' experiences]</p> <p>Discussing ways to manage PD make it an 'easier' diagnosis.</p> <p>She presents a 'hierarchy' of neurological conditions based on their severity which affects how difficult diagnosis giving is for her – based on her clinical knowledge and experience, potential divergence to the patient's experiences?</p> <p>More difficult to deliver a young onset diagnosis for PD as it can be life-changing and upsetting</p> <p>The often-huge implications of a HD diagnosis on a family level makes it one of the worst conditions to diagnose</p> <p>Struggles the most with giving an MND diagnosis because it is bleak – associated with the lack of positive aspects of it, a diagnosis is difficult when she feels she can't offer much to the patient – 'bleak' emphasises the hopeless and destructive nature of this diagnosis</p> <p>MND diagnosis as 'awful news' - Besides giving an MND diagnosis, she has to make people think about making decisions about the future, even their end-of-</p>	<p><i>things that we can try to help you get better".'</i></p> <p><i>'The big different for Huntington's disease is usually then the family will come to the diagnostic interview and, erm, everybody's invested interest in it. And I once diagnosed somebody with Huntington's disease at the age of 82. And she had a lot of children and grandchildren so, the implications were huge, really. So, Huntington's disease tends to be one of the worst because of the wider view.'</i></p> <p><i>'But, of all the things I diagnose, MND is the thing that I find hardest to discuss because it is so bleak and erm... I can't find many positives to offer at all.'</i></p> <p><i>'If we're dealing with MND, first of all, I'll give myself a double slot to break that bad news.'</i></p>
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complete lack of positive aspects she could discuss with patients. When breaking the bad news of MND, she feels that she cannot offer much for patients, but at the same time she had to deliver a significant amount of distressing information. The hierarchy that she presented can also explain why the participant reported spending 1-1.5 hours to BBN for MND and HD, but half of that for PD and MS.	<p>life care – bad news beyond just naming the condition</p> <p>Books double slots to deliver an MND diagnosis – more serious diagnosis, more info to be shared</p> <p>For most BBN consultations she spends 1-1.5 hours and half of that for PD and MS</p>	
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### **Theme titles of all interpretative summaries develop from each interview**

#### **P1:**

- I have a way of doing it: a gradual approach to breaking bad news
- Punching someone but gently: the paradox of imparting distressing information in a sensitive way
- After giving the name – assessing patient's info needs and dealing with patients' reactions
- Being part of a specialist MND clinic makes everything easier

#### **P2:**

- Leave a piece of you in the room or be a robot
- Clock watching
- Softening the blow

#### **P3:**

- Hierarchy of neurological conditions
- *'I'm still human'*
- Assessing information needs and tailoring information giving

- Providing a supportive consultation

**P4:**

- It's sad but you have to be strong
- Acknowledging patients' need for support during and after the consultation – 'Hope would be unfair but live for today'

**P5:**

- Focusing on aiding patient understanding
- 'The most central thing I do' – what makes it emotional and difficult

**P6:**

- The importance of providing a tailored consultation when breaking bad news
- 'You're only human' / 'Welcome to the human race': the emotional toll and emotional triggers of being the bearer of bad news

**P7:**

- A patient-centred approach to information giving
- Reluctancy in talking about the emotional experience of breaking bad news

**P8:**

- Sharing the silence: allowing people to express their emotions
- 'You're telling a fellow human being they have a horrible disease' – the emotional experience and impact of breaking bad news.
- Beyond giving a name: the challenges of knowing how far to go with information giving at diagnosis in the context of MNDDs