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User-Designed Dementia Care Pathways. A disruptive approach to mapping dementia support services

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Abstract:

This paper reports on the first author's ongoing Arts and Humanities Research Council (AHRC) funded PhD research exploring the potential for disruptive design interventions within the context of health and social care. This paper describes an ongoing project to map the services available to people with dementia and their carers, with a specific emphasis on the services available before the patient receives a formal diagnosis of dementia.

Many service users are simply unaware of the support available to them, and are left to navigate their own paths through the unfamiliar and intimidating landscape of dementia services. This paper reports on the development of two tools for use by carers, patients, and dementia service providers. These tools offer innovative ways of enabling service users to visualise the pathway of their current and future care, whilst also allowing service providers to identify the strengths and weaknesses in the type of support they provide.

Keywords: disruption, dementia, innovation, mapping, service design

1. Introduction

Around 850,000 people in the UK experience from some form of dementia (Judd & Alzheimer's Society, 2007) - a complex and unpredictable brain disorder associated with progressive cognitive and physical degeneration. Dementia manifests in many different ways - there are more than 200 different types of dementia - and its symptoms can have a wide-ranging impact on peoples' health, independence, and their relationships with friends and family members. Typical symptoms include "communication and language problems and changes in personality" (*Unforgettable Foundation*, 2015). Dementia can also bring about, or exacerbate, physical problems, such as frailty and poor self-

care. In 2015, dementia (and physical conditions arising directly because of dementia) became the leading cause of death in the UK (Office for National Statistics, 2016). There is no known cure for dementia.

The UK spends £14.7bn on dementia care services each year, with a further £11.6bn value of unpaid care provided by “informal carers” (Alzheimer’s Society, 2015). There are 670,000 informal carers in the UK who provide unpaid care for friends and family members with dementia. Informal carers often feel marginalized as they are left to cope alone as their loved one undergoes a significant deterioration in physical state and/or personality changes. This leads to a “biographical disruption” (Bury, 1982) as patients and carers struggle to come to terms with the new life circumstances forced upon them. This can leave both parties disorientated and upset as “a gradual, terrible, horrible progression” (Newkirk & Lui, 2016) unfolds before them. Carers for people with dementia report higher than normal levels of stress and depression than those who care for older people who do not have dementia (Wills and Soliman, 2001; Moise et al, 2004).

Informal carers play a vital role in supporting people with dementia. Because of the nature of the condition, many patients (particularly those in the advanced stages of dementia) are unable to understand information put to them, and in some cases, lack the mental or physical capacity to express even basic wishes. Informal carers – many of whom have spent a lifetime with the patient – are uniquely positioned to bridge the communication gap between service providers and service users.

This paper will describe an ongoing Arts and Humanities Research Council (AHRC) funded collaboration with Newcastle Carers, an independent charity that provides expert and impartial assistance to informal carers. This assistance includes practical advice, emotional support and counselling, and complementary therapy. The authors’ previous research in this area explored the experiences of informal dementia carers and their interactions with a complex web of health and social care services, as well how they designed their own methods of meeting the challenges they faced.

Our earlier projects (Carey et al, 2015) highlighted a lack of clarity in what are collectively referred to as “dementia support services”. These services are spread across the National Health Service (NHS), which provides “health care” (i.e. clinical treatment), and local authorities and charities which provide “social care” – although in practice these services overlap in numerous ways. Collectively, dementia support services include respite care, medication, hospital in-patient treatment, and many other forms of intervention for both patients and carers. Carers universally expressed the view that they required more assistance in identifying the most suitable path through what is, from their perspective, a new and obscure landscape. Furthermore, they informed us that such assistance would be most valuable in the early stages of their caring role – prior to, or immediately after, dementia is diagnosed. They also complained of a lack of guidance as to which specific interventions might assist (or hinder) their caring role – leading some to miss these services altogether.

The ongoing project described in this paper seeks to address this lack of clarity through the development of mapping tools which propose a physical topography of dementia services across two locations in North East England. The physical artefacts designed in these workshops are the first steps towards establishing a new approach for engaging with carers and people with dementia. In accepting that “social innovation involves — indeed, requires — redistributing power” (Westley, Zimmerman, & Patton, 2007), these innovative methods of visualising dementia support services seek to place greater power in the hands of carers and people with dementia who know little if

anything about what challenges await them and which services are best positioned to assist them on their individual journeys.

2. Aims and Objectives

2.1 Design Disruption in Context

The aim of this research is to develop disruptive design interventions that challenge the status quo and provoke new responses to the challenges faced by informal carers. The work here adopts a largely interventionist approach, which is based on numerous theories emanating from research in economics, business, and design (Christensen, 1997; Christensen & Overdorf, 2000; Scharmer, 2011; Rodgers and Tennant, 2012). The term “Design Disruption” is well established across the commercial sector, where economic effects are often concrete and measurable (Druker, 1985). By contrast, public services operate within a more nuanced environment and a more complex remit. Yee and White (2015) extensively discuss the “goals and values [of public service design] that are more ambiguous and difficult to quantify”, and offer examples of barriers including “a risk averse...performance driven culture and lack of incentives” (Mulgan & Albury, 2003).

Christian Bason of the Danish Design Centre visualised the role of design in public service within a linear process of exploration, policy development, implementation, and assessment of intended and unintended outcomes. This approach, however, situates design within a complex and ever-changing political landscape of “disjointed incrementalism” (Design Commission, 2014) in which the urgent needs of service users clash with the glacial pace of institutional change. Design Disruption, by contrast, declines to follow traditional models of public service design. Instead, it places an emphasis on action and reflection, “trial and error, hunches and experiments” (Mulgan et al, 2007), embraces failure as a vital part of the learning process, and seeks to directly address a societal challenge through advocacy, provocation, and unearthing new insights that can lead to further innovative and dynamic interventions in peoples’ lives.

Design Disruption shares a conceptual space with Critical Design in that it is arguably “more of an attitude than anything else, a position rather than a methodology” (Dunne & Raby, 2014). The term has been criticised as a potential hindrance within the field of design, an “unnecessary” (Tonkinwise, 2015) or potentially “unhelpful” qualification (Green, Rodgers, & Tennant 2016). Throughout our research, however, it has offered a useful vocabulary to establish a theme of energetic activism and a specific focus on *action* and *impact*. Adopting the prefix of “disruption” has assisted us in helping non-designers to understand and buy into the experimental nature of the projects.

Disruption arises “via an intense journey, a formative event...[leading directly to a] discomfort or dissatisfaction with the everyday way of working” (Celaschi, 2013). However it is reached, the overall goal is to create a counter-narrative in favour of positive social and institutional change (Faud-Luke, 2009) whilst recognising the inherent risk that such a narrative can be marginalised, “reduced to exhibition material or used to maintain the status quo” (Green, Rodgers, & Tennant, 2016), when subsumed within complex organisations. The designer must tread carefully to engage productively with health and social care organisations whilst retaining the independence to constructively critique, provoke, and challenge established ways of doing (Costa and Kallick, 1993).

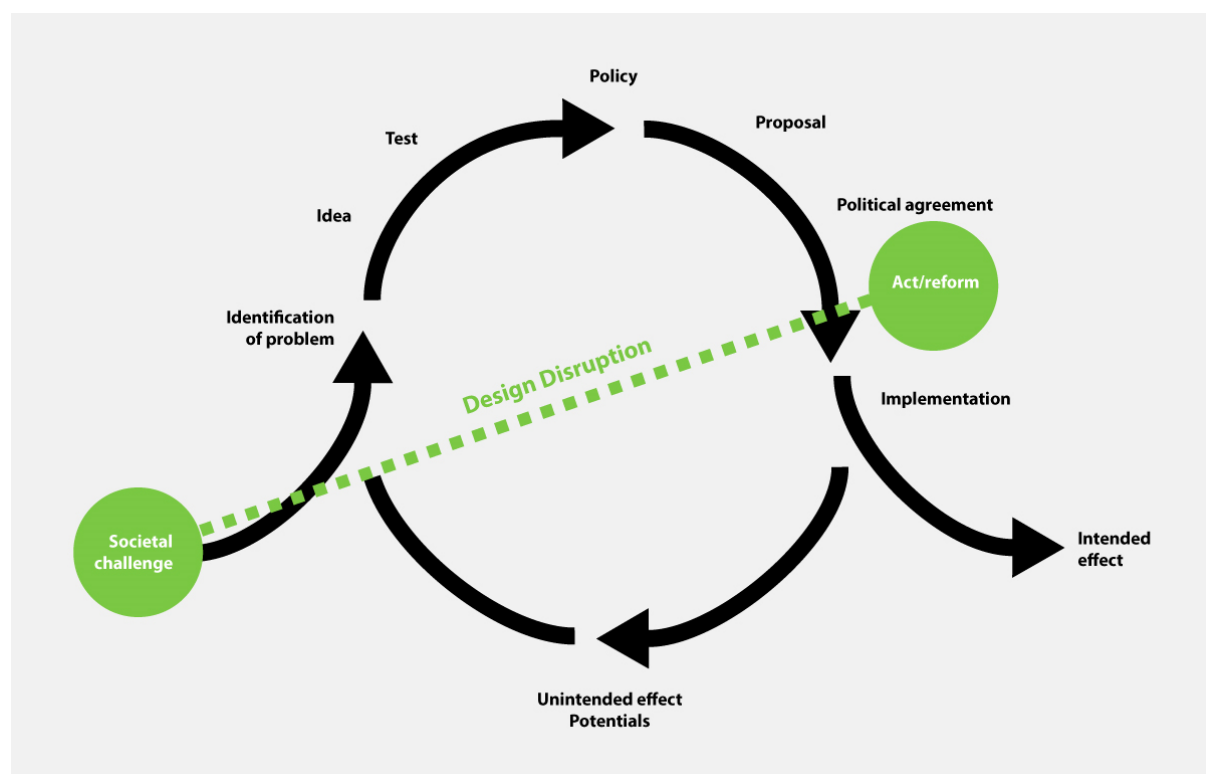


Figure 1. Christian Bason's visualisation of the process of service design (black) (adapted from his presentation at ServDes, 2016). By contrast, Design Disruption (green) eschews the drawn-out political process of policy development in favour of swift action to directly address social challenges.

This research aims to offer a space for “highlighting potential...transformative visions” (Jégou, 2010) within public services, where the ever-present pressures of expanding user bases and dwindling financial resources mean that “innovation has become nothing less than a survival strategy” (Brown, 2009). In Gui Bonsiepe's 1997 lecture “Design beyond Design”, presented at the Jan van Eyck Akademie, he proposed six virtues for design based on Italo Calvino's “Six Memos for the Next Millennium”. Bonsiepe's second virtue, “Intellectuality”, called for a more critical stance in design. That is, design must rock the boat, critique ‘what is’ and imagine ‘what could be’, and continually contest the legitimisation of established power bases. The work we present here strives to fulfil these ambitions.

2.2 Research Questions

- How can disruptive design interventions help ensure that carers and people with dementia develop a greater understanding of the options available to them as early as possible?
- How can these design interventions develop and remain useful to users as their circumstances change?
- Can these interventions be of use to, and be maintained by, dementia care support services?
- Can this approach affect positive change in how carers and people with dementia interact with dementia support services?

3. Dementia Service Mapping Project

3.1 Background

In 2015 we were approached by the National Health Service (NHS) England following the inception of its Northern England Dementia Advisory Group (NEDAG), a taskforce comprised of several NHS trusts, Public Health England, local authorities, and charitable services. We recognised this as an opportunity to work with a “suitable group of partners and [the opportunity to] build with them a set of shared values and converging interests” (Manzini, 2015) necessary for successful and sustainable collaborative design. We agreed to explore the overlap between social services - typically provided by charities and local authorities - and the clinical services of the NHS. In particular, we wanted to investigate methods of clarifying a pathway (or a multitude of pathways) for positive interventions with carers and people with dementia at the pre-diagnosis stage, when they typically receive little or no support.

The National Institute for Clinical Excellence (NICE) publish a “Dementia Overview” - a comprehensive and regularly updated online support tool for use by clinicians specialising in dementia care. It outlines best-practice treatment pathways and overarching guiding principles for NHS staff in providing care for people with dementia. The NICE Dementia Pathway does not, however, provide any assistance for the many people with dementia and their carers who deal with the condition for many years before a diagnosis is established. By taking steps to identify, intervene, and assist carers and patients earlier, the NEDAG aim to mitigate or entirely avoid crises in the future, and thereby relieve financial pressure on their services as well as the emotional toll on the service users.

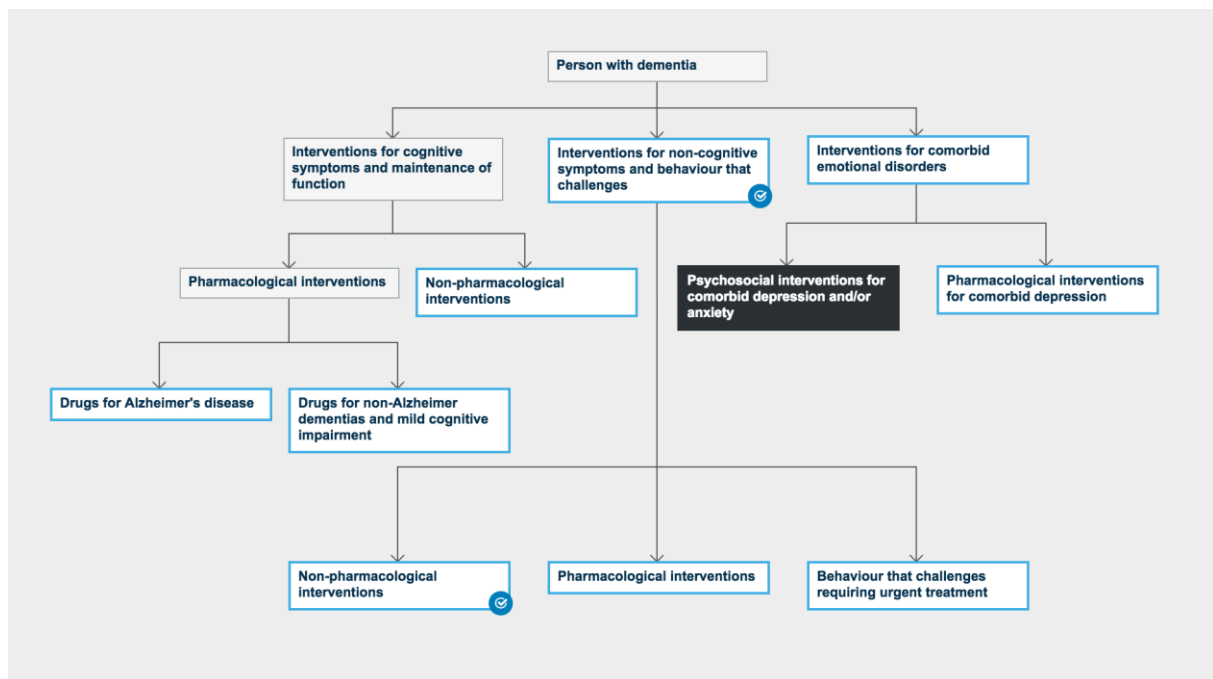


Figure 2. Detail of the National Institute for Clinical Excellence (NICE) Dementia Overview online support tool.

We proposed to explore the potential for creating artefacts that investigated the experiences of pre-diagnosis carers and patients and whether their goals are assisted by existing services. We agreed to pilot this project in two areas of the North East of England. The first is Stockton-on-Tees, which in 2014 won recognition for its work in developing a “Dementia Friendly Community” (Stockton Borough Council, 2014). The second is North Tyneside, a conurbation close to Newcastle upon Tyne,

which has comparatively little in the way of dementia support services. Separated geographically by around 35 miles, these two areas consist of broadly similar population size (each around 200,000 people) and age/race demographics (Office for National Statistics, 2012), which will allow for a valid comparison to be drawn between the services available in the two locations.

This paper reports on the development of the project in Stockton-on-Tees, with the North Tyneside project due to commence in early 2017.

4. Methodology

The methodology adopted for this project was that of a disruptive approach (see above) manifested via Action Research (Lewin, 1946), involving a sequence of planning, acting, observing, and reflecting on the intended and unintended outcomes. As the project is ongoing, this methodology is not a closed circle but a spiral (Carr and Kemis, 1986) where the process of reflection directly informs the next stage of planning, and so on. We organised two workshops to investigate the dementia service landscape in Stockton-on-Tees.

WORKSHOP 1, 19TH OCTOBER 2016

The participants in this first workshop were 15 carers and people with dementia. This was an informal session where we asked participants to respond to simple probes about their lives, their hopes for the future, and their experiences with dementia care services. Whipple's (1987) Community of Practice model espoused that "knowledge is created and not simply transferred and is considered to be located in the 'community' rather than the individual"; likewise, these accumulated responses provided us with insights into the individual experiences which were then used as the basis for a semi-structured group discussion about their experiences and concerns unique to the Stockton area.

This workshop generated numerous insights into the experiences of people in Stockton, including:

- A general satisfaction with the level of post-diagnosis support received, but frustration and uncertainty prior to this. Some participants explicitly stated that they felt "lost" when attempting to navigate services of which they had no prior knowledge;
- A consensus that the carers and patients feel overwhelmed and disorientated when the patient's needs require them to move out of their own homes and into staffed care homes. The process was described as "labyrinthine" and all parties who had experienced this transition felt they did not have a voice in this process;
- The experiences of some carers wildly differed from others, even though they accessed the same organisations;
- The vast majority of care takes place in a non-medical context (such as the family home) rather than a medical context (such as a hospital).
- When describing their experiences, participants used a vocabulary which echoed that of a physical journey. They felt "lost", they took "wrong turns" along a "long and difficult road", and at times felt "trapped".

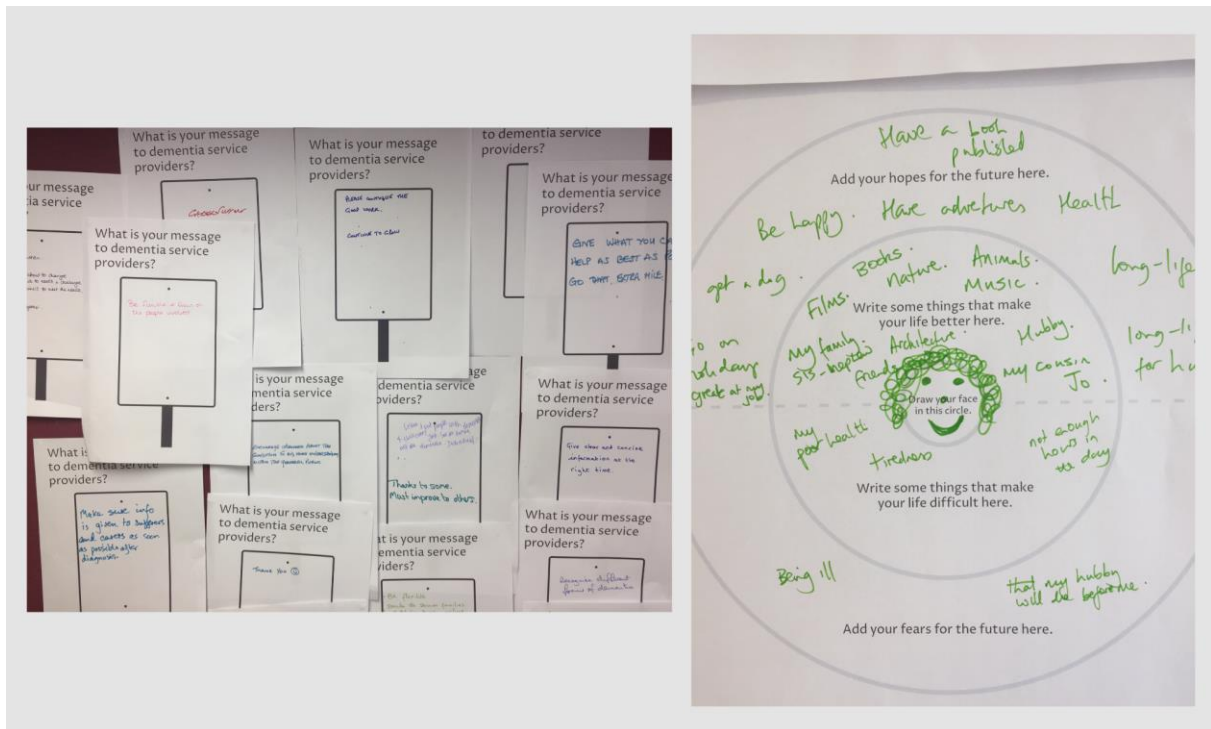


Figure 3. Images of the outcomes created at the first workshop. (right) One of the responses of a woman caring for her husband who has dementia. This gives some indication of the issues which are important to this carer – for example, the importance of strong family ties, balancing her own health the needs of her husband, and her desire enjoy life outside the “caring role”.

This workshop was followed by a reflection cycle (McNiff & Whitehead, 2006) during which the authors considered the outcomes of the workshop and how best to use them as the basis for the second workshop due to take place the following month. During this period of reflection, we distilled the outcomes into eight distinct goals shared by carers and people with dementia. The goals were:

- To be happy;
- To feel useful;
- To be able to plan ahead;
- To know what they are entitled to;
- To feel listened to;
- To choose to live the way they wished;
- To have assistance in coping with crises;
- To live healthy and active lives.

This led us to consider how dementia service providers, who typically have very narrow remits, help people to fulfil these abstract goals. We recognised an interesting tension between the service providers’ approach of focussing on very specific outcomes, and the comparatively abstract nature of the above goals. This tension was considered by Burns et al in their 2006 RED Paper:

“Here, emotional considerations are equal to practical ones, and this demands the ability to look at a problem from a perspective that may be fundamentally different from that of the business- owner or service-provider.”

To encourage this new perspective, we adopted the familiar visual device of a transit map with the service user placed firmly in the centre of the process.

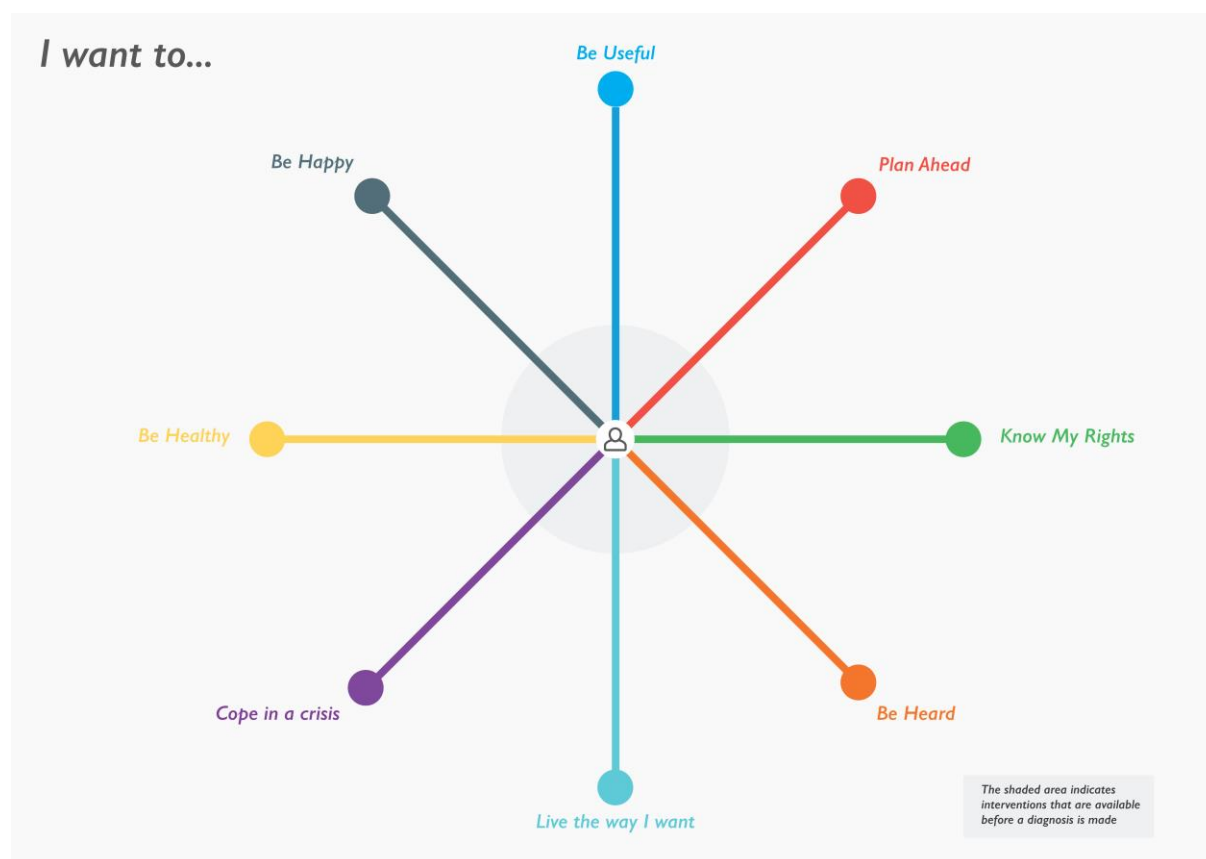


Figure 4. The goals of people with dementia and their carers, visualised as eight distinct paths they could take.

WORKSHOP 2, 23RD NOVEMBER 2016

This second workshop was attended by 18 participants, each of whom represented an organisation providing support for dementia patients and or carers. They were joined by husband and wife (who were also a patient and carer respectively), who also participated in the first workshop. They requested to continue to participate in the design process and give their views on the outcomes produced at the workshop.

We asked the participants to consider the many interventions each of their services provide - from information leaflets to dementia cafés, employment support to healthy living advice – and to place them on the map according to the goals they helped users fulfil. Each organisation found that their different interventions occupied numerous paths, and thus they could identify that several organisations overlapped significantly, with some pursuing similar interventions with identical goals. This highlighted space for potential collaboration between their services.



Figure 5. The completed "Interventions Map".

Pre-diagnosis services were highlighted at the centre of the map, allowing us to focus on these specific interventions within their wider context. It is clear that only a small proportion of dementia services provide any assistance at this stage, with the vast majority being 'passive' information gathering services such as factsheets, rather than providing 'active' planning and assistance. This highlights the untapped potential for providing assistance at an earlier stage.

This mapping technique generated a dense amount of information which we are in the process of decoding. Once this information is properly organised, we will offer it to service users who will be able to decide which intervention, or combination of interventions, is right for their specific needs. This stands in marked contrast to the current approach where this information is held within organisations and away from public view.

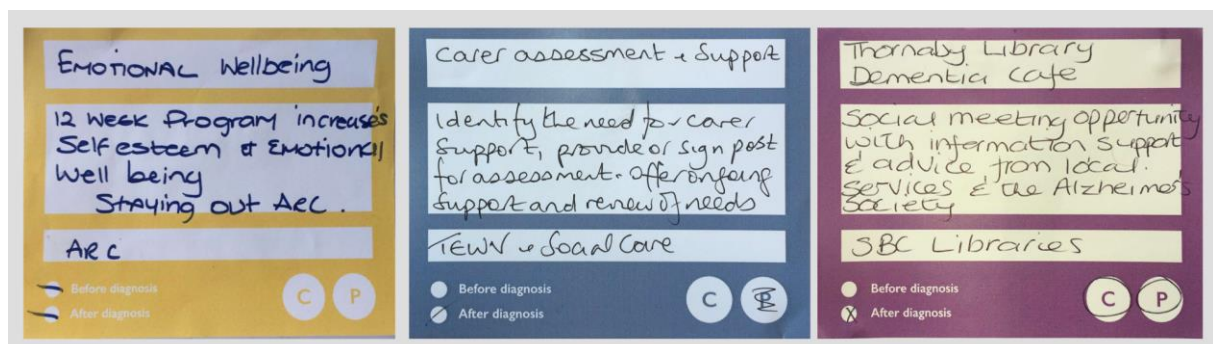


Figure 6. Samples of the specific interventions available to carers and people with dementia at different stages of their "journey" through dementia services.

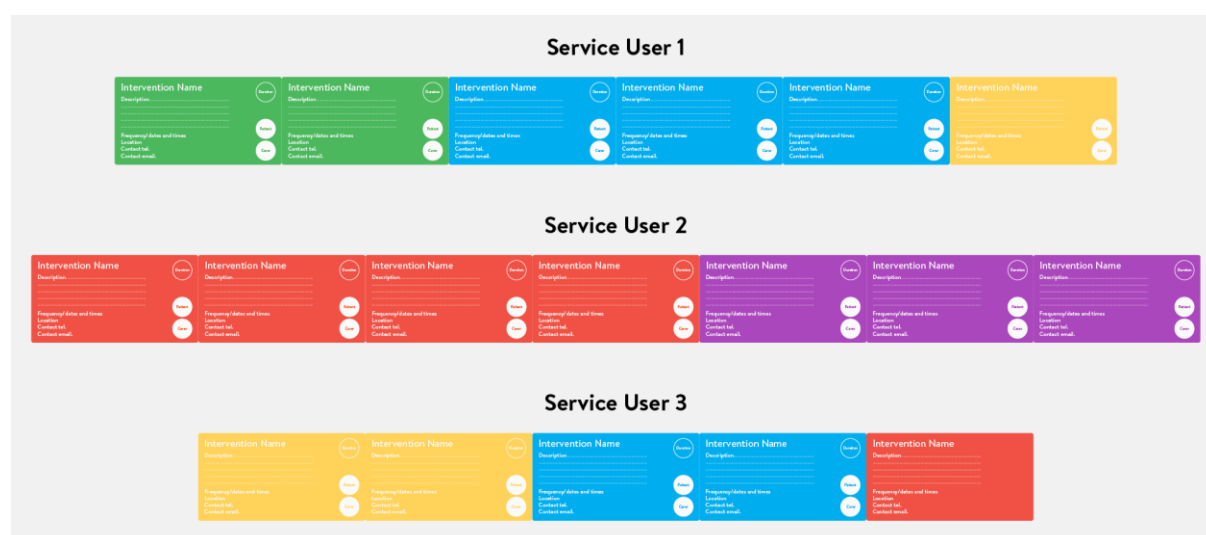


Figure 7. Potential uses for this mapping technique. Individual service users can see a comprehensive overview of the potential interventions available to them, identify the specific ones they wish to engage with, and create their own bespoke pathways through the various dementia services.

Following the production of this **Interventions Map**, we then asked the participants to consider dementia as a journey through a physical environment, with a mix of dangerous terrain and pleasant vistas. The participants populated this map according to where they felt their services should be situated. Some organisations operate in distinct areas, whilst others (most notably the NHS) drew multiple points of intervention covering large swathes of the landscape.

“Maps give their readers the simple and magical ability to see beyond the horizon” (Fawcett-Tang, 2008), and this cartography, based on a mental rather than literal environment, has the potential to help service users to see beyond the horizons of their own experience, to situate themselves within an existing framework, and to plan where they could go next and which services will be best positioned to provide them with assistance. We plan to produce numerous copies of this map and invite service users to draw their own paths through the landscape, allowing them to see where they have been and where they wish to go.

In designing the features of the **Stockton-on-Tees Dementia Landscape** (Figure 8) – such as *The Dreaded Financial Swamp* or the *Care Home Maze* – we sought to introduce some levity into an area of health and social care which is often characterised as an unwelcome burden. We were mindful of Bisson and Luckner’s (1996) view that “fun can have a positive effect on the learning process by inviting intrinsic motivation, suspending one’s social inhibitions, reducing stress, and creating a sense of relaxed alertness.” Approaching these difficult issues with a sense of playfulness may facilitate different outcomes than the ‘crisis management’ approach so often seen in health and social care. The top right corner of the map bears the slogan *Here be Dragons*, in recognition that any artefact we create cannot fully encompass the myriad experiences of all service users. This is a challenge common to all cartography, but it must be accepted that “a distorted mental model may be better than no mental model at all” (Roberts, Gray, & Lesnik, 2016). We invite future participants to edit the map to reflect their own realities.



5. Initial Findings / Contribution

In this project, we developed two very different methods of quickly gathering data to create physical maps of dementia services within a specific region. We collected significant amounts of raw data through a process of observation, reflection, and swift action. The outcomes can be interpreted in many ways and for different purposes, and we are in the process of refining the handmade artefacts into well-structured, understandable products which can be distributed widely.

For dementia service providers, the maps offer a novel way to visualise their interventions in peoples' lives, to see where there are gaps in the support they offer, and to highlight common ground and potential spaces for future collaboration. In doing so, this project is a step towards confronting "institutional and professional borders" (Ehn, Nilsson, & Topgaard, 2014) which may prevent service users from receiving the right support at the right time. By engaging them in a collaborative, co-design process, we offered them space to "jointly explore and articulate their latent needs and jointly explore and make solutions" (Steed, Manschot, & De Koning, 2011) to those needs. Now the topography of care has been made visible, there is a further challenge to explore whether this research can form part of a process of "continuous learning and redesigning" (Fuad-Luke, 2009), or whether it is a single snapshot of a landscape that will inevitably shift.

For carers and people with dementia, they offer new ways to interact with dementia services, help them to plan for the future, and to articulate their experiences in new ways. As with all maps, these "redescribe the world" (Harley, 2002) in ways which challenge the existing structures of power and practice. At this project's inception, we were asked to consider whether we could design a pathway for service users in the very early stages of dementia care. These maps reflect the lived reality – that there is no single pathway for everyone to follow – but invites them to create their own pathways to meet their specific challenges.

These workshops will be repeated in North Tyneside in January and February 2017. Once these maps are completed, we will be able to draw comparisons between the type of dementia care services available in each of these areas. This may further assist service providers in each location to consider the needs of their service users and the level of support they, in turn, provide.

"We think that we're in the artefact business, but we're not; we're in the consequence business" (Chocinov, n.d.) – and the true value of these design interventions comes in whether they result in outcomes which are valuable to all stakeholders. We do not propose that these maps should replace face-to-face discussions, but be used to add value to them as a tool to encourage new insights. We wish to empower dementia service providers and their service users to feel able to point to a map and ask, 'and what about this...?'

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