Technology Push without a Patient Pull: Examining Digital Unengagement (DU) with Online Health Services

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Purpose: Policymakers push online health services delivery, relying on consumers to independently engage with online services. Yet, a growing cluster of vulnerable patients do not engage with or disengage from these innovative services. We need to understand how to resolve the tension between the push of online health service provision and unengagement by a contingent of healthcare consumers. Thus, this study explores the issue of Digital Unengagement (DU) (i.e., the active or passive choice to engage or disengage) with online health services to better inform service design aligned to actual consumer need.

Methodology: Adopting a survey methodology, a group of 486 health services consumers with a self-declared (acute or chronic) condition were identified. Of this group, 110 consumers were classified as digitally unengaged and invited to write open-ended narratives about their unengagement with online health services. As a robustness check, these drivers were contrasted with the drivers identified by a group of digitally engaged consumers with a self-declared condition (n=376).

Findings: DU is conceptualized and four levels of DU drivers are identified. These levels represent families of interrelated drivers that in combination shape DU: Subjective Incompatibility (misalignment of online services with need, lifestyle and alternative services); Enactment Vulnerability (personal vulnerabilities around control, comprehension and emotional management of online services); Sharing Essentiality (centrality of face-to-face co-creation opportunities plus conflicting social dependencies); Strategic Scepticism (scepticism of the strategic value of online services). Identified challenges at each level are the mechanisms through which drivers impact on DU. These DU drivers are distinct from those of the digitally engaged group.

Research Implications: Adding to a nascent but growing literature on consumer unengagement, and complementing the engagement literature, we conceptualize DU, positioning it as distinct from, not simply a lack of, consumer engagement. We explore the drivers of DU to provide insight into how DU occurs. Encapsulating the dynamic nature of DU, these drivers map the building blocks that could help to address the issue of aligning the push of online service provision with the pull from consumers.

Practical Implications: We offer insights on how to encourage consumers to engage with online health services by uncovering the drivers of DU that, typically, are hidden from service designers and providers impacting provision and uptake.

Social Implications: Associated with the generic policy emphasis on pushing online services is concern over the unintentional disenfranchising of segments of society. We shed light on the unforeseen personal and social issues that lead to disenfranchisement by giving voice to digitally unengaged consumers with online health services.

Originality/Value: Offering a novel view from a hard-to-reach digitally unengaged group, the conceptualization of DU, identified drivers and challenges inform policymakers and practitioners on how to facilitate online health service (re)engagement and prevent marginalisation of segments of society.
Technology Push without a Patient Pull: Examining Digital Unengagement (DU) with Online Health Services

Introduction

Today consumers of healthcare face a plethora of online services across multiple platforms. Some health service providers offer online services to facilitate access to offline services, for example, the option to choose and book a buddy volunteer to accompany patients to consultations, access to Electronic Health Care Records, and 3D online tours of health institutions. Other service providers facilitate patient decision making through online services that, for example, help patients prepare for consultations or review options about chemotherapy treatments. Others use innovative service delivery, for example, Augmented Reality-based diagnoses and online mental health counselling. Rapid deployment of technological innovations and their associated efficiencies are largely driving this distinct push for expanding the delivery of online health services (Parasuraman and Colby, 2015; Patricio et al. 2018; Viswanathan et al., 2017). In a bid to enhance public service efficiency and reduce the growing cost of healthcare demands, policymakers increasingly resort to a broader set of touchpoints with patients (Pinho et al., 2014; Viswanathan et al., 2017). The underlying assumption of this technological push to offer online services is that it promotes more patient engagement in self-managing conditions and delivers greater opportunities for co-created value; hence, facilitating patient-centred care and better health outcomes (McColl-Kennedy et al., 2017).

Digital technologies can support a more active, engaged patient community (Pang et al., 2015; Viswanathan et al., 2017). Engagement is “a psychological state that occurs by virtue of interactive, co-creative customer experiences with a focal agent/object (e.g., a brand) in focal service relationships” (Brodie et al., 2011, p.260). The reported benefits of pushing patient engagement with online health services are
many. For patients, such services deliver quicker access to required services, facilitate self-care and decision-making, build trust and satisfaction with services, and so improve healthcare outcomes and quality of life. For care service providers and wider society, online services reduce personal and public costs of healthcare, lower healthcare disparities and achieve cost-effective service excellence by simultaneously improving service quality, customer experience and productivity (Wirtz and Zeithaml, 2018).

However a number of trends act as barriers. Whilst internet penetration and engagement with online service continues to grow (e.g., the UK has seen a 33% increase to 90% internet penetration since 2006; ONS, 2017), these figures mask a growing contingent of vulnerable groups (e.g., aged groups) who are not engaged with online services (Olphert and Damodaran, 2013). Recent research highlights that there is an observable specific reluctance to engage with online health services as a result of the perceived burden associated with these (MacGregor and Wathen, 2014). Further, it has been predicted that in the medium to long term the percentage of vulnerable groups not engaging with online services is likely to grow rather than decrease (Damodaran and Sandhu, 2016). In particular, recent studies have identified specific groups of unengaged patients, such as elderly patients with multiple conditions, patients with conditions affecting cognitive functioning, and perhaps less obviously vulnerable groups, including those on low incomes and the socially isolated (Damodaran and Sandhu, 2016). As a result, Pang et al. (2015) observe that there is a pertinent need to understand how the inherent tension between the push of online services and a decreased uptake by healthcare consumers can be resolved. Online service development tends to focus on those who ‘engage’ rather than those who ‘do not’, and this entails the inherent risk of perpetuating service design that is not aligned with need (Dietrich et al., 2017).

In addressing the aforementioned issues, we turn to an emerging body of literature on ‘digital unengagement’ (DU). Adapting O’Brien and Toms (2010)
definition, DU is when consumers make an active decision to not engage with or
disengage with a digital activity or when factors in the consumers’ external environment
cause them to not engage or cease being engaged. The notion of DU has gained traction
in the discourse on digital exclusion and studies on digital divides (Longley and
Singleton, 2009; Damodaran and Sandhu, 2016). However, the continuing scholarly
debate on DU centres on several important substantive and empirical issues. There is
general consensus that DU is not merely the absence of engagement; engagement and
unengagement are distinct, both being part of the dynamic longitudinal process of
interactions between consumers and services (O’Brien and Toms, 2010). Confusion has
risen as unengagement potentially covers multiple points in this process (figure 1),
specifically, both non-engagement (i.e., never been engaged) and disengagement (i.e.,
disruption of prior engagement). Further, Olphert and Damodaran (2013) argue that an
in-depth understanding of unengagement must be rooted in the social reality of actors
and recognize that this reality shapes a heterogeneous set of predictors unique to
unengagement. A further empirical issue is that digitally unengaged consumers are not
easily identified and/or reached and this hampers the development of our understanding
of DU. Whilst consumers may be unengaged due to known passive drivers, such as lack
of physical access to online services or digital fluency (Mims, 2012); there may be, as
yet undefined, active drivers to not engage with online health services (Parayil, 2005).
Thus, there is a need to understand the heterogeneity in drivers, not only to facilitate the
design of online services suitable for a wider audience, but also to help identify those at
risk of being unengaged in the future and how to support engagement with online
services over a lifetime.

This paper aims to address these issues by developing a framework of the
drivers of DU in online health services through the lens of the digitally unengaged,
which complements work on engagement. Given that the issues that shape
unengagement with online services over time often remain obscure (van Deursen and Helsper, 2015), in exploring the perspective of the unengaged we can identify those issues that typically would remain hidden from service providers. As such, we aim to make three substantive contributions. First, we conceptualize DU (incorporating non-engagement and disengagement) with online health services taking into account the three critical elements of: process, passivity versus proactivity, and significance to the individual (Kumar and Swaminathan, 2014; Parayil, 2005). Second, we identify and demonstrate the drivers of DU by overlaying recent theorizing on multiple resource drivers (e.g., van Deursen et al., 2017) with an understanding of individual perceptions of these resources in terms of accessibility and diagnosticity (Feldman and Lynch, 1988; Lynch, 2006). Thus, we recognize the potential scope of heterogeneity in DU. As a robustness check we contrast these drivers to those of the digitally engaged. Third, we identify the emergent challenges that need to be overcome to facilitate (re)engagement with online health services and provide insight into the potential design and delivery actions of online health services.

We seek to add to the wide and diverse corpus of knowledge within and beyond the engagement literature relevant to this area of study. Specifically, we complement the emerging body of knowledge on the complex antecedents of consumer engagement (e.g., Pansari and Kumar, 2017; Hollebeek et al., 2016b; Vivek et al., 2018). We demonstrate the complexity of the drivers of DU and argue and demonstrate that these drivers are distinct from those that drive engagement. Further, consistent with the body of scholarly knowledge on the intersection of services and technology, we also emphasise the need to provide consumer-relevant insights into the planning and offering of services and delivery of value to the consumer to facilitate adoption and use (e.g., Curran and Meuter, 2005; Lariviè re et al. 2017, Parasuraman and Colby, 2015; Scherer et al., 2015; Venkatesh et al., 2012). Typically, such research focuses on users of
technology, we expand this knowledge base by offering insights emerging from a different lens, that is, from unengaged consumers. Finally, researchers concerned with consumer channel switching behaviours emphasise the proactive role that consumers play in the success or otherwise of technology-based channels (e.g., Choudhury and Karahanna, 2008; Wang et al., 2016). We expand on this by offering insight into the proactive choices made by the unengaged consumer, including insight into disengagement with online services.

This paper proceeds as follows. First, we develop a conceptualization of DU with online health services and then advance a guiding theoretical framework for identifying the drivers of DU. Through gathering and analysing the accounts of those who are unengaged with online health services, we identify the drivers of DU. We subsequently contrast these with drivers of those who are digitally engaged. In our discussion, we identify emergent challenges and how these can inform policy and practice related to provision and design of online health services.

**Conceptualizing Digital Unengagement**

Contemporary theorizing argues for a distinction between unengagement and engagement (Longley and Singleton, 2009; O’Brien and Toms, 2010). A large and growing body of literature has contributed to strong conceptualisation of consumer engagement generally (e.g., Brodie et al., 2011; Hollebeek et al., 2016b) and in healthcare (e.g., Sudau et al., 2014; Xiao et al., 2014). To build a similar level of understanding of digital unengagement (DU) requires first establishing the nature of DU. We argue that DU is not simply the absence of engagement, rather it is conceptually related yet distinct.

**Figure 1 about here**
In conceptualizing DU we take into account three core elements. First, DU should be clearly located within a wider process that captures the dynamic interaction between consumers and services and positions DU against engagement (Longley and Singleton, 2009; O’Brien and Toms, 2010) – see figure 1. Whilst, DU has simply been defined as ‘non-use’ (Olpert and Damodaran, 2013), this simplicity does not capture the potential scope of DU. Others agree that (un)engagement is not “a single event of obtaining [or not] a particular technology” (van Dijk, 2006, p.22). Confusion has arisen as DU is multi-faceted encompassing those who have never been engaged (non-engaged) and those who have lost engagement (disengaged). Recent studies develop the concept of consumer disengagement as the process by which the relationship between the consumer and focal object (e.g., a brand) experiences a disruption leading to termination of the relationship (Bowden et al., 2015). Yet, this covers only one potential aspect of DU. Indeed, Longley and Singleton (2009) point to the need to understand the significant proportions of the population who have not engaged with Information and Communication Technologies.

O’Brien and Toms (2010) argue for a multi-stage process incorporating: point of engagement, engagement, (point of) disengagement, and reengagement. Adapting this framework we argue that DU is located both at the point of disengagement and (principally) at, what we identify as, an initial non-engaged period (figure 1). Our conceptualisation of DU, thus, includes the inexperienced with online services (non-engaged) and those who have experience and been engaged and due to some cause have disengaged from services. Further, based on this process view, we distinguish DU from the concepts of consumer acceptance and adoption, which we propose align with the point of engagement (figure 1), and typically describe intention to use or actual usage behaviour (Curran and Meuter 2005; Venkatesh et al., 2012). The point of engagement is a fuzzy point incorporating consumer trialling, acceptance, and use of technology,
which themselves are pre-requisites of engagement (Karahanna et al., 1999; Pansari and Kumar, 2017). There are important distinctions between point of engagement and both engagement and unengagement. On one hand, consumer acceptance and adoption do not incorporate the notion of longer-term interactivity between engagement subjects (e.g., a patient) and a focal object (e.g., online health resources) at the core of engagement (Hollebeek et al., 2016a). Indeed, behavioural manifestations of engagement have a much greater scope than simple ‘use’ or ‘purchase’, such as positive word-of-mouth and co-creation behaviours (van Doorn et al., 2010). On the other hand, consumer acceptance and adoption have the technology as their reference point and not the person, which limits our understanding of the wider personal and social context (and so the drivers) of DU. Thus, neglecting to account for (i) wider (alternative) options available to consumers (Antioco and Kleijnen 2010; Karahanna et al., 1999), and, (ii) possible changes in drivers for persons that become disengaged later in the process (Wood and Moreau, 2006).

Second, we acknowledge that DU has passive and active elements. DU does not equate with a ‘lack’ of motivation to engage (e.g., amotivation is often related to negative outcomes; Deci and Ryan 2000). Viewing unengagement as merely the absence of engagement, portrays the concept in too reductive terms (Parayil, 2005). Just as consumer engagement is a motivational state, the unengaged are not merely passively lacking motivation, resources and/or choice, rather unengagement can reflect active motivation and choice (Bunyan and Collins, 2013). Certainly the unengaged are often more disadvantaged in terms of resources (Bunyan and Collins, 2013). Indeed, Longley and Singelton (2009) further distinguish between the e-unengaged and the e-marginalised. The latter represents those with a wish to be digitally engaged but without the means to do so. However, reinforcing the need to use the person and not the technology as the reference point, unengagement could also stem from an active
distancing of the individual from online services. Translating services into the online environment can for some create an insurmountable distancing between their understanding of the offline service and its online form (Flanders, 2013), explaining such active unengagement.

Third, in parallel to the context-dependent nature of the concept of engagement (Hollebeek et al., 2016a), we incorporate the need to understand DU in terms of its significant meaning to the individual in the context of their daily living (Miller and Bartlett, 2012; van Deursen et al., 2017). To understand why consumers are unengaged with online health services in the first place (or become disengaged), particular reference should be paid to their levels of need and vulnerability (Kumar and Swaminathan, 2014). Whilst service policy celebrates the potential of online delivery, there is a disconnection with the embedded reality of that service for the individual (Nettleton et al., 2005). Recognising this discourse on the digital divide has expanded to include concerns over digital fluency, which highlights the importance of “not only knowledge of how to use digital technologies, but also knowing how to construct ideas of significance with digital technology” (Wang et al., 2012, p.571). That is, digital fluency incorporates the notion of personal agency, strategic expertise gained, identity representations used, and ownership adopted by individuals accessing online services (Miller and Bartlett, 2012). Thus any conceptualization of DU must incorporate the positioning of online services for developing significant individual meanings (Resnick, 2001). Adopting this stance helps us bridge our understanding of why people remain unengaged with online health services despite tangible outcomes of engagement (van Deursen et al., 2017).

We thus define DU as when consumers actively decide to or passively refrain from, or cease to engage with a digital service due to reasons that are personally significant to them or due to factors in the external environment. As such, we
understand DU, not simply as lack of engagement, but as an essential part of the process of the dynamic interaction between consumers and services, encompassing both the non-engagement and disengagement points within that process. Further, there is a higher degree of heterogeneity amongst those consumers who are in the DU group than those in the engagement group. This heterogeneity derives from the influence of both context-dependent elements, particularly driving passive DU (e.g., through ambivalence or circumstances), and person-dependent elements, particularly driving active DU (e.g., choice not to engage based on personal issues and preferences). That is, DU may be either a forced position or a choice position for the individual.

Drivers of Digital Unengagement with Online Health Services

Non-experienced and experienced consumers may have different perceptions and beliefs about a service (Bowden et al., 2015; Collier and Kimes, 2013). Indeed, early work on pre- and post-engagement with technological innovations, suggests that DU is likely based on a richer set of drivers than for the digitally engaged (Karahanna et al., 1999). Further, recent work reveals that less engaged groups may be further negatively affected by marketers’ tactics (Weiger et al., 2018). Yet, we lack knowledge of a defined set of drivers of DU. As such, we draw on two pertinent theoretical streams to inform our identification of the drivers of DU.

First, resource-based theories, founded on Bordieu’s original notions of capital, predominate in understanding the drivers of digital divisions. This view is useful as it recognizes the disparities, and hence the heterogeneity, between individuals’ relative available resources and the impact on their health-related behaviours (Oh and Cho, 2015). This also aligns with recent theorizing emphasising the importance of consumer resources for enabling or disabling consumer engagement (Hollebeek et al., 2016b). The resource-based view suggests that potential drivers of DU are far-ranging and operate at
different levels, for example, externally at the context level (e.g., material resources) or internally at the person level (e.g., motivation, knowledge and skills) (van Deursen et al., 2017; van Dijk, 2006). Further, drivers of DU may not act independently but through sequential or compound effects (Bunyan and Collins, 2013; van Deursen et al., 2017). Sequential effects imply that different levels of drivers are interrelated, such that internal person level drivers may precede external context level drivers. Compound effects imply that drivers have a cumulative effect. Further, drivers are dynamic and change over time. This is consistent with our inclusion of disengagement within DU, as perceptions, beliefs and emotions driving initial engagement may change and, hence, lead to disengagement (Karahanna et al., 1999; Wood and Moreau, 2006).

Second, we adapt this resource-based approach utilizing recent theorizing on accessibility and diagnosticity (e.g., Ludwig et al., 2013). The resource-based view, whilst acknowledging the internal/external distinction, has not sufficiently delineated the active versus passive drivers. When individuals engage with resources, accessibility-diagnosticity theory states that an input will be utilized depending on: input accessibility (in memory); input diagnosticity (relevance and usefulness); and relative accessibility/diagnosticity of alternative inputs (Li and He, 2013). Instead of inputs we can refer to resource-based drivers. We propose that accessibility-diagnosticity theory provides deeper insights into why individuals are unengaged with online health services by distinguishing between passive accessibility drivers and adding active decision-making (diagnosticity) drivers to the resource-based view. Furthermore, according to accessibility-diagnosticity theory, prior experience, learning and time will impact on which drivers become more or less dominant (Lund and Marinova, 2014), consistent with the dynamic nature of the process of interaction between consumers and services.

We develop our starting framework for understanding the drivers of DU in three parts. The passive drivers framed as accessibility resource-based drivers. The active
drivers framed as diagnosticity resource-based drivers. Finally, we consider the complexity added through alternative resource drivers.

**Accessibility Resource-Based Drivers of Digital Unengagement**

It is often assumed that DU is simply passively (externally) driven by a lack of physical resources (van Deursen et al. 2017). However, the concept of accessibility, defined as the cognitive “activation potential of available knowledge” (Aaker, 2000, p.342), helps us to broaden this understanding of the passive nature of resources as drivers of DU by offering a more (internal) person-focused lens. Applying this to DU drivers, we interpret accessibility as the (un)availability of diverse cognitive resources. For example, Ludwig et al. (2013) identify quality ratings and reviewer identity information as requisite aspects of the accessibility of online reviews. Vitally, the influence of these resources can be at multiple levels, incorporating but moving beyond the technology.

First, cognitive accessibility of a service may be (unknowingly) blocked by lack of awareness about availability and purpose of online health services (Dehzad et al., 2014), likely driving non-engagement. Second, accessibility of the online delivery mechanism may be reduced through low computer skills, low digital literacy, and navigational difficulties (van Dijk, 2006), driving either non-engagement or, after trailing, disengagement. Third, service accessibility can be hindered by over-technical language, lack of permanence and lack of peer review or regulation of online services (Xiao et al., 2014), driving non- or dis-engagement. Finally, there is evidence that the digitally unengaged and digitally engaged do differ on such accessibility resource-based drivers. For example, the unengaged have lower health literacy scores and lower perceived internet skills vis-à-vis electronic health records (van der Vaart et al., 2014).

**Diagnosticity Resource-Based Drivers of Digital Unengagement**

Diagnosticity refers to the degree to which an individual believes that an input would help them to accomplish their decision goals (Feldman and Lynch, 1988). Thus,
diagnosticity represents the perceived relevance, representativeness and validity of a potential input (Ludwig et al., 2013). If engaging with online health services is to be understood in broader terms as enabling an individual’s capability to achieve goals of significance with technology (Resnick, 2001), then we must extend our understanding of the drivers of DU similarly to incorporate diagnosticity. This is important as diagnosticity informs our understanding of the active drivers of DU because the diagnosticity of an input is defined subjectively (internally), not objectively (Feldman and Lynch, 1988). That is, (un)engagement with online health services is meaningful only within the psychosocial context of living with health conditions (Stanton et al., 2007), which, we argue, forms the foundation for an active rationale for choosing DU.

First, (un)engagement with online health services is embedded within and influenced by health needs relating to specific conditions. When confronted with poor health a person must adapt at emotional and physical levels, moderated by the nature and severity of the condition (van Deursen et al., 2017). Thus, diagnosticity drivers relate to how the individual adapts, and their adopted care pathway may mean that they view online self-management services, for example, as non-optimal (Choudhury and Karahanna, 2008; Keeling et al., 2015), driving non-engagement. Second, in conceptualizing health as a human condition, social and structural contexts impact resource availability, integration, choice and effectiveness (Hollebeek et al., 2016b; McColl-Kennedy et al., 2017). That is, the social context of diagnosticity drivers influences the consumer’s adaption and recovery process, influencing care pathways, and need and preferences for (online) services. Thus, consumers will make active, socially-influenced choices with regard to non-engagement with online services. Finally, the dynamic nature of the engagement process (figure 1) is such that experience with (and learning from) exposure to online health services directly relates to the
individual’s psychosocial context (Keeling et al., 2015). Lack of alignment likely drives disengagement with current, and non-engagement with future, online health services.

**Alternative Resource Drivers of Digital Unengagement**

An important element of accessibility-diagnosticity theory is the relative nature of inputs (Feldman and Lynch, 1988). That is, a resource must be relatively more accessible and more diagnostic than the alternative to be a genuine competitor used in decisions. An individual’s consideration of online health services ‘mixes’ with other available (offline) services (Nettleton et al., 2005; van Deursen et al., 2017). This mixing may, we argue, lead to DU as it impacts on accessibility as comparisons of services may result in perceived incompatibility of the online service (Antioco and Kleijnen, 2010). Further, we propose three pertinent elements that inform our understanding of the diagnosticity drivers of DU in relation to alternatives: preference, provision and proficiency. In DU terms, there may be an active choice to not engage with online health services because of a preference for the alternative. Straightforward factors, such as, preferring to see a doctor and other sources providing adequate guidance or being viewed as equally proficient, have obvious and immediate consequences for DU with online health services (Beck et al., 2014).

Yet, the relative balancing of online resources versus the alternative (offline) resources can be complex for consumers, particularly with regards to the emotional significance of health. Sensitivity of health-related topics, e.g., taboo subjects such as death, can shape (un)engagement with health services (von Roenn, 2013). Emotion is an important accessibility cue to understanding online content (Ludwig et al., 2013), but this equally applies to the accessibility of offline services. Indeed, some consumers do not engage with online services because of their anonymous and perceived impersonal nature. Additionally, emotion may shape diagnosticity drivers. In some cases, the diagnosticity of online health services may be stronger due to the emotional-laden
issues around health; consumers being more likely to seek out non-family sources of support, especially peer-to-peer, as part of their health management (Keeling et al., 2015). Further, consumers can engage with online services to develop new types of interactions with their family, friends, professionals and peers, which can help them manage their emotions (Lober and Flowers, 2011). Finally, the value of online health services has significance as it relates longitudinally to daily life (Porter, 2010). That is, the ongoing individual experience with health means that the perceived accessibility and diagnosticity of online health services and the relative accessibility/diagnosticity of alternative resources may change over time as people learn and develop.

**Methodology**

Adopting a survey methodology, data were collected using Computer Assisted Telephone Interviewing (CATI), using quota based on the population’s demographic profile. Survey informants were screened to ensure they had access to online services and asked to declare any current health condition. A total of 915 were surveyed, of which, 623 (68.1%) stated that they used online health services and 292 (31.9%) did not (table 1 provides a comparison by condition). Of the 292 in this unengaged group, 110 (37.7%) declared a current health condition. This paper focuses on the latter group (hereafter our DU group), as they were all internet users with an active rationale (a health condition) for engaging with health services, yet they were unengaged with those services (in contrast to the majority of people with a declared condition; table 1).

**Table 1 about here**

In the DU group the mean age of informants is 49 years (s.d.=15.88), with a male to female ratio of 58:52, 56.3% are living with a partner, with an average of 2 children per household. On average, informants have attained at least high school education and 55.4% are currently unemployed. To rule out demographics as an
explanation of differences in (un)engagement patterns between the groups, the
demographic profile of the engaged and DU groups were compared. No significant
differences between the two groups were discerned, except on educational attainment,
with the engaged group having higher levels of formal qualifications (median=A-levels
or equivalent, $\chi^2=59.437$, d.f.=6, $p<0.0001$). All informants completed a set of 8
screening items to assess their past and current use of online health services. Within our
DU group, we identified individuals who (i) have never used online health services
(n=91, 83%), and, (ii) have previously used (i.e., more than 12 months previously)
online health services but no longer do so (n=19, 17%). While relatively small, this
latter group provides key insights into why individuals disengage with online services.

Research Context

This study was located in the United Kingdom, dominated by a free-for-all at point-of-
care national health system, although private, paid-for, health services are available. The
Department of Health and Social Care’s policy-led initiatives aim to facilitate patient
choice, access to information, and active decision-making. There is a drive to develop
services through digital technologies (supported by funding initiatives, e.g., the Digital
Health Technology Catalyst Project). Yet, there is active concern from groups such as
Age UK that increasing use of online service delivery may leave some people without
adequate support (West, 2015). Indeed, the latest figures show that, despite a continued
increase in internet access and use (especially mobile access), a significant proportion of
the adult UK population (9.2%) have never used the internet (ONS, 2017). Those in
potentially more vulnerable groups are disproportionately represented in this group,
with 22.5% having a registered disability, and 51.9% aged 75 or above (ONS, 2017).

Capturing Narratives

Research focusing on hard-to-reach groups, such as, in our case, the unengaged,
presents challenges (Andrews et al., 2003). The specific characteristics of the
unengaged can make them hard to reach. For example, to unengaged individuals issues of engagement are often not salient, acting as a barrier to participation and increasing intolerance of question redundancy. Further, individuals often find it difficult to articulate why they do not engage with a service (Selwyn, 2004).

Following van Dijk’s (2006) call for more qualitative research in studies of the unengaged, still valid today, rather than completing a set of closed questions, our DU group were instead invited to provide an anonymous, unstructured narrative about their unengagement with online health services. We did not place minimum or maximum limits on the number of words per narrative, as such restrictions might impact on the richness of the narratives (e.g., forcing stories or limiting detail). The average word count was 49 words per narrative (total words = 5,390). Consistent with Selwyn (2004), some informants found it difficult to reflect on their unengagement (simply stating ‘no need’), yet we gained a rich set of insights from the narratives offered. As per the agreement made at the survey outset (required for ethics approval), narratives were not probed through further questioning or follow-up calls. This afforded freedom to our informants, but constrains our ability to elucidate on issues raised. This was viewed as a reasonable trade-off in order to gain insight from this important but hard-to-reach group.

**Interpretation Approach**

To gain insights from the narratives around the drivers of DU we adopt the interpretation approach developed by Gioia et al. (2013). An overall Data Structure is achieved progressively from the data through the following stepped procedure:

- **1st Order Issues** – The DU issues raised by informants through their narratives are identified and grouped according to commonality provided the first array.

- **2nd Order Challenges** – The corresponding challenges related to the issues raised by informants are then identified. We are guided by, but not limited to, the
active/passive and accessibility/diagnosticity elements of our initial framework in understanding these challenges as mechanisms of DU.

- 3rd Order Drivers – The next step develops a deeper structure in the array. The emergent themes are defined in terms of derived categories of drivers of DU. We utilize our initial framing of resource-based drivers as a referent point, whilst by no means limiting identification of themes to that framing.

- Aggregate Levels – The higher order theoretical concepts of the drivers of DU are identified based on the driver levels, working towards gaining a picture of the larger DU narrative. The aim was to represent the DU process appropriate to our informants by ordering a series of interrelated driver levels in terms of DU with online health services. This ordering was informed by our initial underpinning framework developed from prior research and was directly supported and by how informants described their situation.

Table 2 about here

The links between the first-order issues, second-order challenges, third-order driver categories and aggregate theoretical concepts are shown in table 2. The coding process was managed through NVivo (v11). The numbers of comments relating to each third-order driver category are represented as a percentage of the overall DU group. The percentages indicate the relative prevalence of the drivers but are not indicative of the importance of the drivers from an informant perspective (Braun and Clarke, 2006).

Robustness Check

Those participating in the survey who can be classified as digitally engaged consumers and also presented with a health condition (n=376) completed a similar narrative writing exercise to the DU group alongside a wider battery of questions (total words=18,048, average=48 words per narrative). This presented a means of providing a robustness check of the set of drivers of DU as they can be contrasted with the drivers for digital
engagement. A similar interpretation approach was adopted as for the main study. Table 4 presents the emergent thematic structure.

Drivers of Digital Unengagement with Online Health Services

We identified four main levels of DU drivers: Subjective Incompatibility; Enactment Vulnerability; Sharing Essentiality; Strategic Scepticism. These levels represent the families of interrelated drivers that work independently or in combination to drive DU with online health services. The four levels are ordered to reflect the underpinning framework and the flow of our informant narratives. We start with person-specific levels (Subjective Incompatibility and Enactment Vulnerability) through the social-specific level (Sharing Essentiality) to the application-specific level (Strategic Scepticism). We identify the drivers at level and discuss the challenges through which these drivers work to shape DU (table 2). Selected quotes exemplify the issues raised.

Level 1: Subjective Incompatibility

1a) Need Misalignment (non-engaged group and disengaged group)

Misalignment can first be understood in terms of an individual’s awareness of the potential accessibility of online health services. The narratives indicate a misalignment between perceived health needs and understanding the potential of online services to meet those needs. We interpret this perceived lack of need as a type of accessibility distancing. Some informants distance themselves from a condition, expressing they do not “bother about health” despite having a declared health condition. Others qualify their response by distancing themselves from online health services, stating that this reflects a lack of pressing health problems as they have “kept illness under control, so no need to [use online services].” The disengaged group, despite previous use and an existing condition, similarly distance themselves as they “do not suffer from any health
problem” or they “hope to remain in good health”. Implicit in these narratives is a lack of awareness or acknowledgement that online health services can serve preventative- and management-related needs alongside treatment- or illness-related needs.

In tandem with this, a lack of diagnostic relevance for the DU group is reflected by informants who state specifically that they perceived “no need” to look for health services online. We see this as evidence of diagnostic distancing. In all cases our informants highlight the significance of the alternative, that is, professional service provision, obviating the need to undertake self-directed service acquisition. Some informants go further and specifically distance through a perceived lack of diagnosticity of online services, exemplified by “I am not concerned with looking for potential problems.” As individuals in this sample have a self-declared health issue, these comments on accessibility and diagnosticity emphasize both individual differences in perceptions of health status and perceived need, including thresholds for coping with health issues, and a lack of awareness of the diagnostic scope of online health services.

1b) Lifestyle Disconnection (non-engaged group and disengaged group)

Lifestyle disconnection refers to the non-fit between online offerings and a consumer’s preferences for the medium of service delivery within their everyday activities. For some, online health services are not considered as part of their health toolkit as they have “never thought about going online for health reasons” despite using other online services. For others, online services in general are not a central feature of their lives. That is, it was not a default option; rather engaging with online services requires a particular effort. Some declare that they “just never got around to it – I keep thinking about it but have never done so.” Some explain that online health services do not fit with a “busy” lifestyle. There is a sense among such consumers that this “self-service” health activity is a burden and represents displacing professional service with consumer effort, stating that “I haven’t got the time or patience to look through everything”, or
“It’s too long and tedious.” We take this as a demonstration of peripheral accessibility of online health services within our informants’ daily lives.

This is accompanied by a tangential diagnosticity of online services. While all informants are internet users, internet experience varies, with utilization of online services related to familiarity with the internet. This is exemplified by informants who state that they have “only just got the Internet fitted and I’m just learning to use it properly.” There is a significant difference between the DE and DU groups in terms of internet experience ($\chi^2=33.451$, d.f.=6, p<0.0001); the DU group has a higher proportion of ‘novices’ (under 6 months) (12.7%:4.2%) and lower proportion of ‘most experienced’ (over 5 years) (53.8%:70.1%). Nevertheless, for some novice users, there is a perception that once they had gained the requisite knowledge and confidence they foresaw a time when they would access online health services: “I haven’t had the Internet long I am just learning how to use it but I will go into the health websites once I am more confident.” Others note that healthcare professionals do have boundaries and that once more familiar they “will use the internet … because doctors cannot possibly know all things about all illnesses.” What we observe here is naivety of the specific diagnostic relevance of online health services based on lack of understanding of the delivery medium. Yet, there is an awareness of potential diagnosticity. This is a good indication of the dynamic process of interaction between consumers and service. Yet, the disengaged also noted the disconnection with their lifestyle, highlighting that despite experience, online health services had not become embedded into their daily life.

1c) Professional Satisfaction (non-engaged group and disengaged group)

Satisfaction with current, alternative (to online) health services influenced DU, for both the non-engaged and disengaged groups. A clear alternative, or perhaps more accurately, the baseline health service for our informants are formal healthcare services.
factors: convenience and reliability (convincing accessibility), and fulfilment of needs (convincing diagnosticity). In terms of convincing accessibility, some are happy with their general practitioner (GP) because “I don’t need to arrange an appointment days in advance” or “I have a reliable GP easily available.” Further, “I have private health insurance, so go with that and trust it serves me well.” We note, however, that as service provision is not uniform, satisfaction based on convenience and reliability will be idiosyncratic to service provision in a particular geography. Other accessible alternative services cited are “I have a good medical book which is quicker” and “I can always pop in to see my pharmacist.” Conversely, convincing accessibility can be seen in a different light as some informants also express a sense of entitlement to professional service, exemplified by “that’s what the doctors for and why we pay our taxes.”

In terms of convincing diagnosticity, some informants (including disengaged) view online health services as simply “irrelevant” as they were happy with their healthcare professionals. For example, “I prefer to manage my diabetes through my GP and diabetic nurse.” Current healthcare providers fulfil two sets of needs, namely provision of information (and guidance), and delivery of tangible services. For example, “I get all information required from my GP”, “I have always been happy with my Dr’s advice” or “I go to see the hospital on regular appointments re my diabetes and they answer all my questions.” It is clear that satisfaction is based on a conception that going to see their GP would mean that they “get the right diagnosis and the right medicine.”

As a matter of simple practicality, a healthcare professional “can write a prescription if needed” or “would have to view [the problem] to state what the problem was.” The healthcare professional fulfils their health needs, answering their questions and has a proven track record of providing appropriate advice, leading to an underlying trust in the medical profession and no incentive to seek alternative services. Some individuals simply stating that “I trust my doctor/health providers” or more generally that “I trust
the recommendations of professionals.” These narratives have an embedded scepticism (occurring at later levels too) questioning the ‘professional’ status of online health services. This is despite many online services being provided by professional organisations. One disengaged person stated that engaging with online health services was a ‘desperate measure’ in cases where no alternative was available.

**Level 2: Enactment Vulnerability**

2a) **Mediation Vulnerability (non-engaged group only)**

Mediation vulnerability refers to the respective level of frailty felt by consumers relating to their degree of control over online access. We differentiate three levels of control over online access to health services (table 3). Personal ownership (n=93, 84.5%) is defined as having ownership of both device(s) and an Internet Service Provider (ISP). Mediated ownership (n=4, 3.6%) is defined as having an assured level of access to device(s) and an ISP through work or place of study, with some control over online access, although bounded by organizational regulations. No-ownership (n=13, 11.8%) is defined as having no assured level of access to technology or an ISP, that is, those who only have public access through, for example, libraries. Whilst the lack of ownership over online access does not by itself determine DU (Bunyan and Collins, 2013), it is the degree of control that matters (*controlled vs. mediated accessibility*). Ownership provides a level of individual control, without which barrier issues are raised in relation to the use of public access points. Controlled accessibility allows individuals to more readily integrate online services into their lives and fosters continuity of practice. Without personal ownership, physical accessibility to public facilities shapes DU. Through lack of health/mobility our informants are not physically able to visit public internet points as much as they would like: “I tend to use [the internet] at libraries and
hardly go out these days” and “I mainly use [the internet] in the library but ill health
does not allow me to go there anymore and I’m housebound virtually.”

Table 3 about here

Diagnostics of online resources through a public internet point is further
impacted by individuals being unable to get the desired amount of time online. They
also need to operate within the guidelines of whoever moderates internet access
(controlled vs. mediated diagnosticity). Without personal ownership, they have limited
control over the time spent online and the way it is used (i.e., content filtering and
restrictions). The inability to spontaneously revisit online services is particularly
important. Also, the constraint of not being able to store searches and the time limits
inhibit styles and depth of searching. Diagnosticity is further questioned by whether
public internet access points are suitable for sensitive issues such as health (exposure
diagnosticity). There is awkwardness at accessing perceived sensitive information from
a public access point: “Because I don’t have Internet at home & I access it in public
places and its awkward at times to use in public places for health matters.” As this is
their only option, privacy concerns effectively result in DU. The combined mediated
accessibility and diagnosticity of public internet facilities clearly disrupt practice in
engaging with online health services and its integration into consumers’ lives. Where
consumers had previously engaged with online health services, disability and
restrictions of using public facilities disrupt such practices and disengagement results.

2b) Comprehension Vulnerability (non-engaged group only)

For over a quarter of informants, a perceived lack of ability to comprehend the
information, guidance and other service offerings drives DU with online health services.
There is widespread recognition amongst our informants that it is critical to have the
technical health knowledge fluency to be able to exploit services effectively
(accessibility fluency). Such views mirror professionals’ concern over the lack of
consumer ‘discipline specific’ knowledge and the impact on consumer empowerment.

For some it is a case of “too much information that I don’t understand.” Others lack confidence because “At my age it is too complicated to understand.” For others, it is concern over the ability to exploit the diagnosticity of services (diagnosticity exploitation), that is, “it’s a minefield … to search for symptoms yourself could lead to a wrong diagnosis.” Informants felt they lack the knowledge to interpret information and guidance services, they are “not professional enough”, and to apply this to their circumstances, leading them to “steer clear” of online health services.

Health services are seen as unconstrained due to the reach of the internet, with the extent of choice paradoxically discouraging and disempowering consumers. A lack of knowledge of the range of available health services leaves some informants feeling a sense of bewilderment at where to start searching (bewildered accessibility). Some feel daunted at the perceived scale of available services, stating that they “would not know where to start as there’s just so much … out there” or simply that “I … don’t really know of any websites really.” Others are concerned that they lack the ability to evaluate the quality or origin of online services (padlocked diagnosticity). One informant states that “it’s impossible to know whether what you find is genuine or not” and another that “it might be dodgy, there’s no way of telling.” This reflects the challenges faced by consumers in an environment where many of the conventional social cues are absent. This brings into question whether consumers are aware of initiatives such as kite-marks, and, if so, to what degree they have confidence in such schemes. For some, this potential overload is a deterrent to engage, others are confused about the appropriateness of health services to their circumstances. The written format allowing presentation of multiple viewpoints is as an obstacle to engage: “[I’m] not sure if the information would be right for me, as things are contradictory in written information.”

2c) Emotional Vulnerability (non-engaged group and disengaged group)
Closely linked to comprehension vulnerability is the issue of emotional vulnerability, that is, the inability to engage with resources without distress or obsessive behaviours. The centrality of health to consumers, and the associated emotional vulnerability, is reflected in informants’ comments with it being important to have the ability to handle the emotions evoked by engaging with services (*emotional accessibility*). For example, “too much knowledge is sometimes worse to deal with and too disturbing” or “worried that it would frighten me more than I already am.” It emerges that DU with online health services protects informants from engaging with “scary” emotions. This applied to the disengaged too, who had through experience learnt their emotional vulnerability.

The combination of the volume of resources, perceived lack of relevant disciplinary knowledge and reduced emotional capability is a powerful combination generating the potential for consumers to become obsessed with engaging with health services. For example, one participant states that “too much information could have an adverse effect. The mind is a powerful tool for symptoms that don’t necessarily exist until you know about them.” Others agree that it is “too easy to become a hypochondriac with so much […] available” and that “too little information that I don’t understand would be bad for me […] as it would be more likely to make me very paranoid.” We interpret this as a type of *hyper-diagnosticity*, where consumers can come to overly rely on the diagnostic value of online services.

**Level 3 – Sharing Essentiality**

3a) *Sharing Centrality (non-engaged group only)*

Sharing centrality refers to the consumers’ perceived importance of shaping healthcare through interpersonal interactions. Individuals express preferences for interaction styles that facilitate exploitation of services. Some informants are actively unengaged with online health services in preference for interaction with healthcare professionals. At
times, this is expressed quite forcefully, “I’d rather speak to my doctor face to face rather than a machine.” This emphasis on sharing through personal interaction in preference to technologically-mediated interactions reflects the intersection of consumer attitudes towards professionals and integration of the internet into lifestyles. For consumers unengaged with online services, the preference for personalized services provision is driven by two factors: process factors around the opportunity for an interpretive dialogue, and; outcome factors around the exploitation of online services.

In terms of process factors, face-to-face personalized interaction with professionals affords an opportunity to discuss individual situations and access appropriate services. A strong undercurrent is the importance of engaging in a dialogue rather than a one-directional acquisition of resources, with awareness of the opportunity for emotional support inherent in such interactions. As one participant states “In my opinion you will never better the system of face to face consultation with the medical world.” Another states that “I prefer to be face to face with someone so I understand it fully.” Face-to-face interaction offers the opportunity for an interpretive dialogue that increases both accessibility and diagnosticity of the health service. From an outcome perspective, these process characteristics are important as a means of enhancing service diagnosticity for facilitating decision-making and anticipating better service outcomes. That is, “I prefer to go and see my GP face to face and get the right diagnosis & the right medicine” or “I’d rather go & see my GP and get a proper diagnosis.” We note here the re-emergence of the underlying scepticism around online health services.

At the core of such views is the personalization of services, both in process and outcome terms. Personalization of service provision occurs through healthcare professionals being ideally placed to ask questions in a dialogue that articulates the individual’s needs and identifies personally-relevant potential solutions. For our informants, this cannot be matched by online services (limitations of technologization).
This, however, reflects a specific perception of online services as a ‘resource library’ rather than as a social and interactive forum. Even consumers favouring technology-mediated interaction over personal interaction identify challenges in applying online services to individual circumstances. The potential for online communities to facilitate inter-consumer discussion and co-created service is not considered.

3b) Sharing Dependency (non-engaged group and disengaged group)

Sharing dependency refers to the often complex social reliances that consumers may have on their social networks. Some informants lack the self-assessed competence and confidence, to engage with online services, relating to basic computer and internet skills and, hence, perceived engagement as complex. Simply put, “I don’t know how to search for [services] online.” In such circumstances, DU is shaped by a lack of support to interact with online services. Informants have a dependent accessibility, exemplified by: “I’m not very good using the computer I usually get my sons to help me.” Reliance on others is not purely about the technical use of the internet, but also coupled with a dependent diagnosticity in terms of searching for appropriate services. Being reliant on others in these ways leads to a reduced ability to build capacity, that is, individuals are not learning the skills to search for health services effectively. This can be problematic if that source of support is lost. For example, one disengaged informant explains that “my marriage has broken down, so I have no-one to ask at present. My son would help me but he has a busy life.” Such dependence highlights the potential pitfalls of sharing that impacts on DU with online health services. For example, it emerges that sometimes the person providing ‘technical’ support advises against using online health services based on personal biases, which sometimes leads individuals to be too embarrassed to ask for support. There is also evidence that some healthcare professionals perpetuate DU through a dismissive manner, “My doctor advised that I don’t go digging about.”
There is also evidence of information sharing, particularly within families, and of family members, or others, completing searches. Thus, the DU group, are actually engaged through a third party (networked engagement). For example, one informant states that “my daughter does it for me mainly” (referring to using online health services) or that “I don’t have the Internet or a computer […] I ask a neighbour to get any [services] I need.” This engagement through others entails disclosure of personal information and reliance on others to locate, and initially evaluate, services. This is perceived as inconvenient and sub-optimal. There is also a sense of being a burden as they “would have to ask my husband all the time”, or their helper is “too busy.” Thus, reliance on others impedes informants’ engagement with online services when they most need it, heightened by lack of personal ownership as “don’t have a computer & need somebody to find out information for me which is not always convenient.”

**Level 4: Strategic Scepticism**

4a) **Strategic inferiority (non-engaged group and disengaged group)**

Strategic inferiority refers to a consumer’s perception that online health services have little or no added value in terms of benefitting their care. Reflecting on the personal relevance of online services, for some (including those in the disengaged group), the cost of searching is not perceived as proportional to the diagnostic value of potential online services. This is significant given that many online initiatives are directly aimed at reducing effort and facilitating engagement with services. However, in part this sense of proportionality may reflect satisfaction with professional provision and absence of a desire to substitute the professional. It further underlines the lack of centrality of online services in the lives of some of our informants. Both issues have been discussed above.

The underlying scepticism noted earlier crystallises into a concrete driver. Effective engagement demands that potential users perceive the available services as
credible, of suitable quality and appropriate to their needs if it is to warrant the cost commitment. They need to have confidence in the quality of the services available and that they are trustworthy. Whilst it is acknowledged that there are some quality online services available, there is a general sense that available services are “not consistently good enough” or that the quality is not guaranteed. For some there is a lack of trust in online service providers, “I don’t know if I could trust what I found so think it’s best to stay clear”, with a particular concern about information or guidance accuracy.

A number of individuals (including from the disengaged group) perceive that some online service providers might be deliberately misleading consumers into using unnecessary services, stating that “there may be a degree of scaremongering”. Our disengaged group describe having learnt not to trust “the axe grinders on the Internet.” It emerges that our informants find it difficult to identify ‘real’ professionals. For some, there is an unidentified ‘they’ (informant term) who could be deliberately ‘lying’. There is a sense of an unidentified group intentionally posting inaccurate or misleading material and ‘quack’ services; we interpret this as a disconnected diagnosticity. The disembodied ‘they’ providing online services are not as visible, and hence verifiable, as the healthcare professional consulted in person. Strikingly, the use of the ‘they’ term is not confined to non-practitioners but also encompassed professionals. This can partly be explained by the lack of face-to-face contact, echoing the challenges facing consumers in the absence of conventional social cues. One participant states that “If I cannot speak to a professional in person then I will feel I can’t trust them.”

4b) No voice, no choice (non-engaged group only)

For some the true value of online health services is measured in terms of influencing professionals (voice), and increases in service accessibility, for example, ability to switch service provider (choice). Where choice or voice were restricted there was frustration at the loss of opportunity for value.
Underpinning arguments around consumers’ voice is ensuring that consumers engage with services that inform their interaction with service providers. Yet an emergent challenge is that some consumers are sceptical of their ability to exercise voice effectively and influence professionals (voice diagnosticity). Encapsulated in comments such as “they’ll do what they want anyway”, there is a sense of powerlessness, and that the language of empowerment is simply rhetoric. For example, one informant stated that there is “little point [in accessing online health services] since GPs never have anytime to discuss anything with you they want you out the minute you are in.” The inability to influence service provision and the perception of professionals dismissing patient-generated resources and self-service activities inevitably influence DU with online services. Diagnostically relevant online health services are not seen as an automatic avenue to being able to exercise voice.

Although informants may be willing to engage with online health services, they recognise that the overarching organization of healthcare constrain their ability to utilize such services (choice inaccessibility). As such, formal healthcare services propagate DU with online health services. Specifically, there is little perceived opportunity to exercise real choice of provider, with initiatives to promote choice seen as creating only an illusion of choice. As exemplified by, “You can choose, but only if you are prepared to travel for miles, wait long periods of time and often the choice is between the unavailable and the unavailable!” Coupled to concerns over the ability to exercise effective voice, this is a further disincentive to engage with online health services. Some people feel that they must use formal healthcare services not as a baseline option but as the only option. Although the number of informants expressing this view is limited, possibly reflecting the demographic profile of the sample as well as their expressed satisfaction with professionals discussed earlier, the existence of this perspective illustrates the complex array of factors impacting on DU with online health services.
Robustness Check

We classify the drivers of Digital Engagement (DE) into 4 main themes (table 4): strategic self-management; forecasting; affirmation; play and exploration. Given space limitations and the large corpus of knowledge on consumer DE we briefly summarise the findings here and relate these to wider engagement literature.

Table 4 about here

1. Strategic Self-Management

This driver encompasses the effective self-management of care composed of several elements. The need to be prepared and manage expectations of a condition (e.g., long term prognosis) (Chan et al., 2014). To feel empowered (Keeling et al., 2018), have a sense of security (e.g., tangible resources) (Vivek et al., 2014) and to fully exploit health services (e.g., 24/7 services) (van Doorn et al., 2010).

2. Forecasting

Realising the potential of cumulative knowledge and knowledge sharing (Hollebeek et al., 2016b; Wirtz et al., 2013), this driver encompasses forecasting possible health pathways, incorporating future-proofing the self (e.g., integration of multiple conditions over time), expanding horizons (e.g., complementary therapies), and driving societal changes (e.g., reduction of taboo over conditions).

3. Affirmation

This driver embraces obtaining affirmation, through combatting isolation (e.g., opportunities for interaction), confirmation (e.g., sharing of similar experiences), and searching for meaning (e.g., coming to terms with what is happening). Similar drivers are noted by de Vries and Carlson (2014), Keeling et al. (2015), and Wirtz et al. (2013).

4. Play and Exploration
This driver, although the least cited, covers seeking out play and exploration
opportunities, specifically, entertainment (e.g., diversion from the condition) and
curiosity (e.g., general interest in health). Exploration and enjoyment are important
steps towards engagement (Mathwick and Mosteller, 2017; Pansari and Kumar, 2017).

Importantly, these four DE drivers do not significantly overlap with the DU
drivers. In particular, we note that (i) in contrast to the DU drivers there is strong
agreement on the core issue of strategic self-management and forecasting (including the
importance of the prevention and maintenance functions of online health services); (ii)
accessibility-related drivers are not explicitly mentioned by the DE group; (iii) online
health services were integral to everyday life, being viewed as interlinked with and/or
complementary to other health services; (iv) relatedly, the DE group also saw a role for
online services in terms of play and exploration; (v) the value of online sharing (e.g.,
within communities) plays an important affirmation role for the DE group.

Discussion

Adding to both the emerging literature on consumer unengagement and wider
engagement literature, this study offers insights into the nature and drivers of DU with
online health services. We posit that DU is distinct from, rather than simply a lack of,
consumer engagement. As our first contribution, we develop a conceptualization of DU
founded on three elements: (i) DU is an essential part of the dynamic process of
interaction between the consumer and a service, where DU incorporates both non-
engagement and disengagement; (ii) DU encompasses consumers’ passive and active
choices (iii) DU has meaningful significance to the consumer.

As a second contribution, we identify and explore the drivers of DU to provide
insight into how DU occurs by adapting resource-based models (van Deursen et al.,
2017) using accessibility-diagnosticity theory (Lynch, 2006). We empirically
demonstrate four levels of drivers that represent the psychosocial and contextual reality for consumers with respect to DU: Subjective Incompatibility; Enactment Vulnerability; Sharing Essentiality; Strategic Scepticism. At each of these levels, drivers shape DU either independently, sequentially or cumulatively (van Deursen et al., 2017). The existence of these drivers empirically establishes the wide sources of heterogeneity within DU in contrast to DE (Karahanna et al., 1999). We also evidence that DU drivers are distinct to DE drivers, complementing knowledge on the antecedents of engagement (Hollebeek et al., 2016b, Pansari and Kumar, 2017) by distinguishing those drivers that move consumers away from rather than towards engagement with services.

Adapting the approach taken by Wirtz et al. (2013), we categorise our drivers as person-, social- or application- focused. The two person-focused levels are Subjective Incompatibility and Enactment Vulnerability. Subjective Incompatibility represents the internal drivers of perceived misalignment of online services with personal needs, lifestyle and preferences. In particular, we see evidence consistent with the distancing hypothesis (Flanders, 2013), whereby consumers do not appreciate the translation of an offline service into the online environment. Online health services are viewed as inferior to formal offline health services with an underlying scepticism that online health services are ineffective (a thread that weaves through other drivers). This is coupled with, and compounded by, a possible naivety around the scope of online health services. Notably, the preventative and health management potential of such services is not openly acknowledged by the DU group in contrast to the prominence of this potential for the DE group. This informs our understanding of the specific issues that consumers lack awareness of in this important service context, and if addressed could help to drive engagement (Pansari and Kumar, 2017). Yet, we found that both the non-engaged and disengaged groups subscribed to this driver. This implies that there is a genuine incompatibility for some in the provision of online services that cannot simply be
attributed to a lack of knowledge or addressed by gaining experience. Indeed, experience and learning may be detrimental to online services (e.g., Lund and Marinova, 2014), relegating online services to a peripheral ineffective tool and impacting on a consumer’s readiness to further engage with such services (Parasuraman and Colby, 2015). Further, following the disengaged experience, it is not sufficient if service providers wish to promote online health services as only reactive. In fact, the strength of the relative advantage of such services (Choudhury and Karahanna, 2008) may lie in the pro-active contribution to illness prevention and health maintenance.

Enactment Vulnerability is also person-focused and represents consumers’ concerns over the inability to effectively use online health services due to combining external vulnerabilities around lack of control over access with internal vulnerabilities around reduced comprehension and emotional impact. This level provides insight in the nature of the disadvantages faced by the DU group (Bunyan and Collins, 2013). Consumers avoid online services to protect themselves, despite an underlying willingness to engage with online services. As such, choice not to use online services may result from a tension between positive and negative drivers (Wang et al., 2016).

We observe that emotional vulnerability shapes both non-engagement and disengagement with online health services. That is, through experience with online services, the disengaged have learnt about their emotional vulnerability, suggesting potential boundaries for the implementation of online services. The identified negative emotions are in contrast to the positive emotions that drive engagement (Pansari and Kumar, 2017). Further, there is an important distinction to be made; it is not the technology that is overwhelming (Parasuraman and Colby, 2015) but the services that technology gives consumers access to that they find potentially overwhelming.

The Sharing Essentiality level represents social-focused drivers. Sharing Centrality stresses the positive side of face-to-face interaction as this facilitates sharing
and co-creation between people and professionals. Thus, also representing a drive
towards engaging with alternative services through the perceived diagnostic co-creation
value (de Vries and Carlson, 2014, Feldman and Lynch 1988). This contrasts with the
drivers of the DE group where online sharing was viewed as important for affirmation.
On the negative side, the Sharing Dependency driver emphasises dependency on others
and social network complexities. We observe a distinct split whereby Sharing Centrality
drives pro-active non-engagement, whereas Sharing Dependency inhibits an underlying
willingness to engage and brings about disengagement. Indeed, consistent with the
compound effects hypothesis (van Deursen et al. 2017), the Sharing Dependency driver
leads to a reduction in capability (e.g., skills) building opportunities for those in the DU
group. The disengaged group experience a forced disconnection from online services
through this dependency. The Sharing Dependency driver operates in contrast to the
recognised cumulative social value of engaging with online services identified by the
DE group within this study, other studies of online health services (e.g., Keeling et al.
2015) and other contexts (e.g., Brand pages on Facebook, de Vries and Carlson, 2014).

The Strategic Scepticism level represents application-focused drivers regarding
the potential exploitation of online services for healthcare. Consumers sense that online
health services serve little purpose as they feel unable to exercise any level of
empowerment gained from such services. That is, the value barrier lies not purely with
the technology used to deliver the service (Antioco and Kleijnen, 2010), but in how
consumers can utilise the services accessed within the external context (and some note
the resistance of HCPs to their use of online services). Again, the preventative and
management scope of online health services is not acknowledged. This level also
impacts the disengaged, who, through experience learn to be sceptical of the value of
online health services. However, we see evidence of a genuine desire to take
responsibility for health matters, but consumers are disillusioned with the avenues for
achieving this, bringing uncertainty as to where to commit their efforts and resources, a
pre-requisite to initiating and maintaining engagement with services (Hollebeek et al.,
2016b). The levels of Sharing Essentiality and Strategic Scepticism are consistent with
our conceptualization of DU as being both passive and active (Parayil, 2005).

As a third contribution, we identify that the drivers at each level shape DU
through the mechanism of challenges (table 2). We ground these challenges in terms of
accessibility and diagnosticity. Accessibility challenges highlight the struggle between
independence and agency versus dependence and powerlessness. Diagnosticity
challenges highlight the wider debate on how individuals can engage with technology to
meet their needs successfully. For online health services this means that consumers need
to perceive them as central and offering true impact versus being peripheral and an
illusionary (or illusive) impact. Consistent with the distancing hypothesis (Flanders
2013), individuals will view online health services as a viable alternative to offline
health resources if they offer recognizable strategic value through a credible interactive
dialogue over a sustained period. Resolving these challenges could promote engagement
with online health services. For example, digital technologies may enable service
personalization. Yet, at the level of Sharing Essentiality there is a significant challenge
to overcome in convincing consumers that technologization of service can beat the
personalization offered by healthcare professionals within a dialogue that articulates
individual’s needs and identifies potential solutions.

Managerial Implications

Public service providers have great interest in online health services for the promotion
of empowerment, yet there is a lack of uptake across platforms (e.g., mobile - Dehzad et
al., 2014) and implementing service interventions across networked platforms, such as
social media, remains complex (Ma et al., 2018). This study offers essential insights on
how to encourage more consumers to engage with online health services by uncovering
the drivers of DU. Factors such as these drivers are often hidden to service designers and providers impacting on provision and uptake (van Deursen and Helsper, 2015). The DU driver levels can be a roadmap of the building blocks needed to align the push of online resource provision with the pull from consumers (Pang et al., 2015). Each level is a milestone at which DU with online health services could be tackled.

Specific online initiatives or applications for health rely on addressing the challenges of DU. In particular, we evidence that there may be a genuine incompatibility with online health services or specific personal vulnerabilities. Designers often consider the functionality of services without considering these wider personal or social aspects (Dietrich et al., 2017). In particular, a consumer’s emotional capacity to handle self-service health activities or the disruption of practice by events outside the control of service providers suggests possible boundaries to the reach and scope of online health services. Engagement also depends on the nature of the application. In the UK, the NHS Choices online service, for example, has immediate and transparent benefits for the individual. This makes the alignment between the service offering and individual need easier to evaluate. However, other online initiatives may need to be embedded over a longer period with consumers learning to understand, utilize and integrate the service into their everyday lives and service providers learning how delivery unfolds over diverse platforms (e.g., social media, Ma et al., 2018).

Further, we propose that engagement with online health services needs to be a socially supported practice. The wider marketing of online health services should raise community awareness levels, not just of online service provision, but also account for online realities, such as the fuzziness between professional and lay services. This understanding should permeate both professional and individual spheres; government policy, professional engagement and individual engagement with online health services should align. Overcoming challenges not only involves individual interventions, but
also policy, organizational, and professional interventions. Enhancing individual ability
to put online applications into practice is intricately connected with the alignment of
professional and individual viewpoints; where the professional needs to facilitate the
individual’s ‘choice’ and the individual needs to exercise their ‘voice’ (Keeling et al.,
2018). Health management is ultimately a balancing act between governmental
priorities, consumer preferences, alternative support provision, and infrastructure.

Finally, DU with online health services is set within the wider context of digital
inclusion and has application to a range of service settings. In working towards
inclusion we must consider the relative strengths and weaknesses of the internet
medium alongside individual preferences for (un)engagement and social complexities.
There is, thus, likely a ceiling on the uptake of online health services and other online
complex services (e.g., financial services, Laing et al., 2009). Also, experience is not an
inoculation against DU as evidenced by our disengaged group. There are potential risks,
such as hyper-diagnosticity, likely not limited to health services, and service developers
should take into account the necessary demand for capacity building (Hanson et al.,
2011). Further, this needs to be placed in the context of emerging formats of service
delivery (especially mobile and social media applications) that are already shaping
future online services (Parasuraman and Colby, 2015; Viswanathan et al., 2017).

**Future Research Directions**

This study was set within the context of one national healthcare system. Whilst our
informants are not restricted in access to online global services, they are inevitably
influenced by the country’s healthcare service and cultural attitudes to health. Future
research could explore the generalizability of our findings in cross-national settings.
First, the interaction between formal healthcare structures and DU with online health
services will be a rich starting point. Cultural issues to consider include norms regarding
caring roles, particularly expectations of family versus professional provision of care.
Second, the categorisation and detailed explanations of the DU drivers identified in this study provide the basis for scale development to quantitatively assess these drivers. Taking this approach would both enable a wider evaluation and corroboration of our results and facilitate differentiation of the drivers of non-engagement and disengagement, and more detailed comparative explorations of cross-national and cross-groups (e.g., different conditions) differences. Moreover, as drivers of DU may not act independently, quantitative research could aid identification of the interactions between drivers at different levels on non-engagement and disengagement.

Our study included people with a range of acute and chronic health conditions. Whilst health status will likely impact on DU/DE with online health services, our results (tables 2 and 4) indicate that within the DU and DE groups those with acute and chronic conditions largely share the same drivers. Yet, engagement with online health services is likely to be complex in situations where people have a severe condition. The intrusive impacts on their everyday life over the short or long term may inspire some people to engage with online services, whilst others may be too anxious to do so (Keeling et al., 2015). Future research could determine the relative levels of DU across different health conditions. Investigating how DU develops longitudinally, over the course of a condition, recognizing compound and sequential effects, would provide insight into significant touchpoints of DU and DE with online services as a condition progresses.

Our focus was on the drivers of patients’ DU with online health services. Of course, this could be influenced by active recommendations by healthcare professionals who have both the authority and opportunity to engage or re-engage patients with such services. Future research could focus on HCP-recommended services and develop detailed knowledge of patient preferences and trade-offs across a broad range of online healthcare services using conjoint designs. This is particularly pertinent as technology advances the emergent blended approach to healthcare, with an emphasis on mobile
applications, yet, unengagement persists in mobile online health services (Dehzad et al., 2014). Different blended pathways of (un)engagement may be defined according to health status or condition or depending on persona profiles developed through follow-up research. For example, those with chronic conditions may engage with mobile monitoring applications together with consultations with health professionals. Discerning identifiable pathways will inform the design of future online services.

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Table 1: Degree of Digital Un/Engagement by Condition Category (N=915)

<table>
<thead>
<tr>
<th>Condition category</th>
<th>Digital Unengaged Group (% of condition category)</th>
<th>Digital Engaged Group (% of condition category)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No declared condition</td>
<td>182 (42.5%)</td>
<td>247 (57.5%)</td>
</tr>
<tr>
<td>(n=429)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute condition</td>
<td>21 (35.0%)</td>
<td>39 (65.0%)</td>
</tr>
<tr>
<td>(n=60)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic condition</td>
<td>89 (20.9%)</td>
<td>337 (79.1%)</td>
</tr>
<tr>
<td>(n=426)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (N=915)</td>
<td>292 (31.9%)</td>
<td>623 (68.1%)</td>
</tr>
</tbody>
</table>
Table 2: Emergent thematic structure of drivers of Digital Unengagement

<table>
<thead>
<tr>
<th>Specific issues voiced by informants</th>
<th>Correspond to specific challenges</th>
<th>Lead to derived categories of DU drivers</th>
<th>Resulting in theoretical concepts of DU drivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not bother with health</td>
<td>Accessibility distancing</td>
<td><strong>Need Misalignment</strong> (14.5%)</td>
<td></td>
</tr>
<tr>
<td>Kept illness under control</td>
<td>Diagnostic distancing</td>
<td><strong>Need Misalignment</strong> (14.5%)</td>
<td></td>
</tr>
<tr>
<td>No need – professional services used</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not concerned with looking for problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never thought about going online</td>
<td>Peripheral accessibility</td>
<td><strong>Lifestyle Disconnection</strong> (21.8%)</td>
<td></td>
</tr>
<tr>
<td>Not a central feature of life</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thought about it but did not get round to it</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time effort, time poor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Burdensome self-service</td>
<td>Tangential diagnosticity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Just started to use the internet so not familiar with it</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Just learning to use the internet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Convenience and reliability of Professional</td>
<td>Convinced accessibility</td>
<td><strong>Professional Satisfaction</strong> (11.8%)</td>
<td></td>
</tr>
<tr>
<td>Irrelevant as happy with Professional</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Replacing professional service with consumer effort</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Entitlement to service</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional fulfils needs (guidance and tangible)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust Professional</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal ownership vs use of public facilities</td>
<td>Controlled vs mediated accessibility</td>
<td><strong>Mediation Vulnerability</strong> (13.6%)</td>
<td></td>
</tr>
<tr>
<td>Lack of access/time and convenience of public facilities</td>
<td>Controlled vs mediated diagnosticity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of physical mobility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controlled searches and storage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unsuitability of public access</td>
<td>Exposure diagnosticity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Privacy</td>
<td>Disrupted Practice vs Continuity of Practice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disrupted practice</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Technical health terminology</td>
<td>Accessibility fluency</td>
<td><strong>Comprehension Vulnerability</strong> (27.3%)</td>
<td></td>
</tr>
<tr>
<td>Misinterpretation leading in wrong conclusions</td>
<td>Diagnosticity exploitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of search skills</td>
<td>Padlocked diagnosticity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inability to evaluate</td>
<td>Bewildered accessibility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breadth disembpowerment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bewildenment library</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional distress, frightening</td>
<td>Emotional accessibility</td>
<td><strong>Emotional Vulnerability</strong> (6.4%)</td>
<td></td>
</tr>
<tr>
<td>Obsessive behaviours, lack of ability to cope</td>
<td>Hyper-diagnosticity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal interaction vs online interaction</td>
<td>Personalization and interpretive dialogue for accessibility and diagnosticity</td>
<td><strong>Sharing Centrality</strong> (20.0%)</td>
<td></td>
</tr>
<tr>
<td>Opportunity for dialogue/engagement</td>
<td>Limitations of technologization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resource library vs social forum</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Required support to access online and to search</td>
<td>Dependent accessibility</td>
<td><strong>Sharing Dependency</strong> (7.3%)</td>
<td></td>
</tr>
<tr>
<td>Discontinued support</td>
<td>Networked engagement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sharing health resources</td>
<td>Dependent diagnosticity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reliance on another to locate resources</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Effort disproportionate to strategic value</td>
<td>Diagnostic value</td>
<td><strong>Strategic Inferiority</strong> (10%)</td>
<td></td>
</tr>
<tr>
<td>Not consistently good enough</td>
<td>Disconnected diagnosticity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of trust of online service provider</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Little perceived real opportunity for choice</td>
<td>Choice inaccessibility</td>
<td><strong>No Voice, No Choice</strong> (6.4%)</td>
<td></td>
</tr>
<tr>
<td>They (Professionals) will do what they want</td>
<td>Voice diagnosticity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Powerlessness</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 These driver categories were also raised by the disengaged group
2 These drivers were also raised by those with acute conditions
Table 3: Ownership of online access

<table>
<thead>
<tr>
<th>Ownership Category</th>
<th>DU Group (n=292)</th>
<th>Engaged Group (n=623)</th>
<th>Total (N=915)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(% of n)</td>
<td>(% of n)</td>
<td>(% of n)</td>
</tr>
<tr>
<td>Personal Ownership</td>
<td>252 (86.3%)</td>
<td>591 (94.9%)</td>
<td>843 (92.1%)</td>
</tr>
<tr>
<td>Mediated Ownership</td>
<td>14 (4.8%)</td>
<td>25 (4.0%)</td>
<td>39 (4.3%)</td>
</tr>
<tr>
<td>No-Ownership</td>
<td>26 (8.9%)</td>
<td>7 (1.1%)</td>
<td>33 (3.6%)</td>
</tr>
</tbody>
</table>

1) personal ownership = having ownership of both device(s) and an Internet Service Provider (ISP).
2) mediated ownership = having an assured level of access to device(s) and an ISP through work or place of study
3) no-ownership = having no assured level of access to technology or an ISP
4) this group was excluded due to lack of a declared health condition
Table 4: Emergent thematic structure of drivers of Digital Engagement

<table>
<thead>
<tr>
<th>Specific issues voiced by informants</th>
<th>Lead to derived categories of DE drivers</th>
<th>Resulting in theoretical concepts of DE drivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Meaning of symptoms and severity of condition</td>
<td>1Preparedness and Expectation Management (48.1%)</td>
<td></td>
</tr>
<tr>
<td>• Understanding long term prognosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Understanding side-effects of treatments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Medications and interactions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Need to react to changes and how to do so</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Contribute to consultations through improved understanding</td>
<td>1Service Optimization (15.2%)</td>
<td></td>
</tr>
<tr>
<td>• Question development to optimize consultation time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Self-diagnosis to reduce visits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Second opinion seeking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• 24/7 service availability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Decision-making insights</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Facility and service provision information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Online services and resources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Explanation search for the unusual impacts</td>
<td>1Empowerment &amp; Security (21.0%)</td>
<td></td>
</tr>
<tr>
<td>• Sense of security in knowledge development</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Tangible resources to support necessary lifestyle changes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Complementing HCP advice with practical guidance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Reducing feelings of being lost without a plan</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Avenue for addressing embarrassing problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Longitudinal evolving nature of condition(s)</td>
<td>1Future-proofing the self (4.5%)</td>
<td></td>
</tr>
<tr>
<td>• Value from developing treatments and understanding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Integration of multiple conditions over time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Raising awareness of the unknown in relation to condition(s)</td>
<td>1Expanding horizons (4.0%)</td>
<td></td>
</tr>
<tr>
<td>• Complementary therapies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Holistic view of condition within everyday life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Engaging in new (replacement) activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Reduction of taboo over conditions</td>
<td>Driving Societal Change (1.6%)</td>
<td></td>
</tr>
<tr>
<td>• Crowdsourcing knowledge to drive change</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Collective memory to form new understandings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Accessible education and resources</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Consolidation tool (e.g., EHR)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Are there people like me?</td>
<td>1Combatting Isolation (5.6%)</td>
<td></td>
</tr>
<tr>
<td>• Scale of numbers affected by condition(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Opportunities for (controllable) interactions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Accessing support in time of need</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Sharing of similar experiences</td>
<td>1Confirmation (12.2%)</td>
<td></td>
</tr>
<tr>
<td>• Confirmation of own experiences and understandings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Sense of scale of condition (e.g., how many are affected)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Reduce feelings of wasting the HCPs time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Reassurance and positive feelings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Don’t understand what is happening to me</td>
<td>1Search for Meaning (3.2%)</td>
<td></td>
</tr>
<tr>
<td>• Reasons for illness or condition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Search for value of life despite condition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• How to carry on with life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Why do I have so many conditions?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Come to terms with what is happening to me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Achieve a balance in life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• ‘Light at the end of the tunnel’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Diversion from the condition</td>
<td>Entertainment (1.1%)</td>
<td></td>
</tr>
<tr>
<td>• Play around to find out what is there, without specific purpose</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Fun to play with some online services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Intrigued by lesser known condition(s) but not directly related to health management</td>
<td>Curiosity (4.0%)</td>
<td></td>
</tr>
<tr>
<td>• Following-up on issues raised with family and friends (everyday life related)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• General interest in health and seeing what is out there</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

¹these drivers were also raised by those with acute conditions
Figure 1: The process of (un-)engagement

Key to stages of the process:

- Unengaged
- Engaged