Digital Mental Health for Older Adults: Privacy Considerations from an Implementation Perspective

Abstract
Older adults with depression face a number of barriers to accessing treatment. However, the introduction of computerised Cognitive Behavioural Therapy is a promising salutation to a number of obstacles that older adults encounter. Despite this, older adults are underrepresented in the current literature. Older adults do not engage with technology in the same way as other demographics and have privacy concerns about sharing mental health information which may deter older adults from engaging with interventions and hinder implementation. This paper draws on privacy literature to highlight the need for a greater focus on privacy considerations that older adults may face when engaging with online treatment in order to achieve successful dissemination amongst older adults and to inform policy and design of online mental health interventions.

Author Keywords
Privacy; Depression; Older adults; cCBT; Policy; Implementation.

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Introduction
Depression is the most prevalent and debilitating mental health condition among older adults, affecting roughly 22% of women and 28% of men in the United Kingdom (UK). Yet, 85% of older adults in the UK fail to receive assistance from the National Health Service (NHS) for depression related symptoms [17]. This problem of access has prompted the emergence of an array of therapies – such as Computerized Cognitive Behavioural Therapy (cCBT) delivered through ubiquitous digital technologies like mobile applications. Issues of user identity information, stigma and confidentiality of data associated with mental health conditions, mean that the widespread institutionalization and adoption of these innovations will be influenced by an understanding of privacy considerations.

The purpose of this paper is to synthesize evidence from related literatures in online mental health interventions and online health information seeking by older adults to demonstrate the urgent need for research that sheds light on the question of interest: What are the privacy concerns of older adults utilizing cCBT services and how can these considerations be incorporated into the design, evaluation and scaling-up of cCBT interventions?

The Problem of Depression
Clinical and subthreshold depression are the biggest cost to mental health services in the UK. However, due to limited number of trained psychotherapists, a lack of help seeking behaviours, stigma and long waiting times, depression is not always treated [9,22]. For example, in England, one in ten people wait more than a year for a mental health assessment [1] with 85% of older people receiving no assistance from the NHS for mental health conditions. These trends are significant given that depression is associated with reduced quality of life, increased disability and increased risk of suicide in the elderly [25]. Even relatively minor levels of depression can lead to a significant decrease in quality of life and negative attitudes towards ageing [3]. It is clearly of great importance to increase older adult’s access to mental health treatment.

Online Mental Health Interventions (OMHI) for Older Adults
Older adults face numerous barriers to accessing therapy for depression such as stigma, mobility, and limited number of trained therapists [26]. Over the last decade OMHI have received a great deal of attention due to their potential to tackle barriers to traditional face to face therapy. Literature in this field repeatedly lists accessibility and reach of online mental health interventions to be one of the main advantages [19,23], which seems particularly pertinent to older adults who may be suffering with pain, poor mobility or other chronic illnesses which are barriers to them receiving face to face therapy.

Computerised Cognitive Behavioural Therapy (cCBT) is one type of OMHI and is based on the CBT principles utilised in common treatment for mild and moderate depression. cCBT can be delivered through mobile applications (apps) and online internet sites. Currently the National Health Service (NHS) in England have attempted to introduce a small number of cCBT apps into their stepped care model. There are currently five apps available that utilise CBT principles however there are only two that specifically address mild to moderate depression.

Much of the research supporting the evidence base for cCBT to allow its integration within the NHS has been conducted predominately on adults between 18 and 50
years of age and therefore older adults are dramatically underrepresented in cCBT research. In the limited number of studies conducted for older adults and OMHI, the results have been somewhat positive, suggesting that older adults may respond well to cCBT. For example, a number of Randomised Control Trials (RCT) specifically targeting the older adult demographic have found positive effects for symptom reduction (and at 3 and 12 months follow up), acceptability, satisfaction and adherence, measured by completion rate [6,7,24].

However, outside of a research environment, older adults do not respond to technologies in the same way as other age demographics. Older adults tend to adopt new technologies much later, which may predict greater reluctance to engage with cCBT [5]. Furthermore, older adults are much more cautious about disclosing information while online, particularly in the context of physical and mental health, as they seek to maintain a positive self-image and avoid negative stigma [16]. This presents challenges that need to be overcome for the successful implementation of online interventions for use by older adults.

Privacy for OMHI among Older Adults

Privacy is a factor that features very little in the literature for online CBT. Given the paucity of literature and policy surrounding privacy in OMHI there is a need to draw upon evidence from other domains to inform design and implementation decisions. Previous privacy literature suggests when using online interventions older adults undergo a cost-benefit trade off whereby they may disclose information in order to receive the benefits of reduced symptom severity and not being subject to stigma [15]. Therefore, older adults must perceive cCBT to be more beneficial to them than not receiving therapy/going in person, in order to share their mental health information.

One way cCBT may achieve this is by allowing older adults to access therapy in their own home where they are free from stigmatisation, which has been identified as a key barrier for older adults accessing therapy [4]. This creates a relationship between physical privacy and online privacy worth examining. On the one hand, users may physically isolate themselves in order to engage with the online material, but by doing so are having to share personal, and often sensitive, information about themselves through the digital online application. Physical solitude and isolation have been well documented in privacy literature as types and functions of privacy [20,28,29], so it is perhaps unsurprising that online mental health interventions can help users avoid the stigma of face to face therapy. This trade-off between physical privacy and online privacy may in fact act as a facilitator for older adults wishing to engage in therapy without being subject of stigmatisation.

On the other hand, a recent paper has found that older adults are very cautious when it comes to sharing health information using technology – particularly information specifically relating to mental health as they classify mental health information as sensitive [16]. This may present a barrier for older adults when participating with online mental health technologies in the UK as some of the NHS endorsed apps encourage sharing of mental health information. For example, the ‘Catch it’ app, encourages users to rate their mood, reflect on thoughts and feelings and collects data about mood and location. Similarly, ‘Big White Wall’, uses online tests to measure anxiety and depression levels to set goals and track progress. Older adults may be cautious about engaging with these specific apps because for older adults, symptoms of depression are perceived to be associated with cognitive impairment and decline. It is also common for older adults to perceive depression as a natural part of ageing (Law, Laidlaw, & Peck, 2010) instead of a mental health condition, which contributes to the misconceptions older adults have about mental health [2]. Therefore, in order for older adults to engage with this technology and participate in the sharing of sensitive
information, it relies on the fact that they trust their information is stored correctly and confidentially [10], and they feel as though they are free from risk of stigmatisation to maintain a positive self-image.

Although there are arguments for privacy to be a facilitator and a barrier for older adults when engaging with OMHI, the arguments are speculative at this point in time as there is a large gap in the literature when addressing privacy concerns for OMHI in general, but more specifically for older adults. While some OMHI have considered privacy concerns by providing anonymity to encourage free and open expression (e.g. Big White Wall), there is no evaluation of how older adults engage with this facility given their cautiousness when sharing health information online. Therefore, this paper calls for future research to study how older adults engage with OMHI to address privacy concerns.

**Privacy as a key Implementation Construct**

Privacy as an implementation barrier should also be considered by researchers, practitioners and policy makers. In the translation of CBT from face to face to online applications, privacy has not been considered to the same extent. A qualitative study with key stakeholders, policy and information technology informants found that there is insufficient privacy protection around personal health information and there is a lack of knowledge and expertise around cybersecurity in online mental health care [30]. This finding has been supported by interviews with therapists, who raised concerns over data protection and data security [27]. Although the clients did not share this concern in this particular study, it still poses an implementation issue as therapists will be the ones administering and recommending cCBT in primary care, and if they have negative attitudes towards its use then they are unlikely to recommend it to their patients.

Clearly there is a need to ensure that the privacy policies surrounding online mental health are legally fit for purpose, and adhere to the same standard of confidentiality that face to face therapy offers [12]. There is also a need for this to be portrayed to older adults in a way that they can easily understand. Further advances in the field of OMHI will refine privacy policy to ensure users’ information is protected. However these developments may present an avoidable barrier to use given the preconceptions older adults have towards mental health, privacy and technology, unless communicated effectively to the older adult demographic using strategies that are accessible and easily understood.

Failure to consider privacy concerns can cripple the scalability of OMHI and its potential to reach older adults who fear stigmatisation. This is evidenced by the fact that privacy concerns have been identified as a reason for discontinuation of an intervention by participants [8]. However qualitative data detailing the participant’s specific privacy concerns have not been gathered by researchers so it is difficult to provide meaningful design implications from the studies conducted to date. Qualitative research validates quantitative findings by providing a rich insights into participant’s thoughts, attitudes and feelings which drive behaviour decisions. Therefore, the value of qualitative data in privacy considerations for OMHI cannot be understated as researchers have called for future research to gather qualitative information to explain specifically why participants drop out [12]. Until privacy concerns of both, the therapist and user have been addressed it is difficult to speculate how successful the diffusion and uptake of OMHI’s ‘in the wild’ will be.

One way in which scalability and implementation challenges of OMHI interventions can be improved is to apply an implementation framework. RE-AIM (reach, effectiveness, adoption, implementation, maintenance) is a framework commonly referred to within the field of
implementation science to evaluate dimensions most relevant to real-world implementation [11,13]. Briefly, reach refers to the percentage and characteristics of people receiving the treatment; effectiveness is the impact of the intervention; adoption concerns the percentage and representativeness of services that adopt the intervention; implementation refers to the consistency and cost of delivering the intervention and maintenance refers to long-term sustainability [13].

For the successful implementation of OMHI for older adults, privacy concerns should be considered at each stage of the implementation process - particularly in the reach, implementation and maintenance dimensions. These are key dimensions in the RE-AIM framework to tackle privacy concerns as the appropriateness of an intervention can be hindered if privacy concerns of older adults are not considered, given that they have a number of different characteristics in the way they approach technology and mental health. Similarly, if an intervention is well maintained and has long term use, users should be informed what will happen to their information if they choose to disengage with the intervention. Utilising the RE-AIM framework may also encourage interdisciplinary collaboration between researchers, designers, policy makers and end users to ensure a holistic approach is taken when designing OMHI with the consideration of privacy.

**Research and Policy Recommendations**

cCBT represents a major advance in how therapy is delivered and shows promising potential to overcome barriers to treatment that face to face therapy has encountered. In order to ensure the privacy needs of older adults are considered, and to ensure older adults are properly represented in cCBT literature, a participatory approach to design should be encouraged. While qualitative research is starting to emerge describing user experience and attitudes towards online CBT [14,21], these do not specifically account for older adults, or their privacy preferences. Mohr, Weingardt, Reddy, & Schueller [18] have specifically called for a user-centred design approach to be employed from the earliest exploratory design stages to understand the needs, goals, limitations and capabilities of stakeholders. This is particularly pertinent to older adults as they are already underrepresented in the literature to date.

While older adults are cautious about sharing mental health information, research suggests they are more likely to engage and share information if company endorsements are clearly visible as this increases trust [31]. It would therefore be valuable for future research to investigate whether privacy concerns are present even if a mobile mental health app is endorsed by the NHS, or other health service, as this has not yet been investigated within the area of online CBT for older adults.

As this area of research develops, findings may well suggest that older adults do not engage with the types of online interventions that have already been released onto the NHS apps library. This would then raise questions about whether online mental health interventions can take a ‘one size fits all’ approach or whether designers of OMHI should design specifically for older adults.

**Conclusions**

This paper has argued that although privacy may represent both a barrier and facilitator for older adults accessing OMHI, there is still a large gap in the literature, with many questions relating to older adult’s privacy preferences remaining unanswered. As a result, there is a need for future research to focus on qualitative methods to understand and address privacy considerations older adults may face when engaging with OMHI. To address the gap in research and in order to implement OMHI’s into ‘the wild’ there should be a focus on interdisciplinary and inter-sectoral research
approaches between all key stakeholders to foresee and overcome barriers to successful engagement for older adults.

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