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Title: Meaningful Digital Health Interventions: bridging digital divides via tailored design

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Introduction

This UK study is part of on-going Economic and Social Research Council (ESRC) funded research seeking to better understand information behaviours in disadvantaged (socio-economic) and high risk (health and wellbeing) circumstances; that is working with young (<25) mothers from areas of multiple deprivation, to explore their information needs, behaviours, and challenges, and the factors influencing their selective engagement with supportive information services and resources in both the physical and digital space. Working closely with Public Health and Charity Sector partners, the project seeks to guide future health and wellbeing information policy (*what to provide and from whom*) and information process (*how to provide*), including cross-domain collaborative aspects.

Addressing issues of low digital literacy, access and use, this paper reports on an exploratory sub-project that sought to develop a prototype tailored digital portal to facilitate meaningful digital interventions between young mothers and their support workers. The research responds to calls for “person-based” and “persuasive” approaches to digital health interventions (e.g. Yardely et al, 2015) and recognition that “more work is needed to create successful [digital health] engagement strategies” (e.g. O’Conner et al, 2016, p1).

Background

The UK has one of the highest rates of teenage pregnancy in Western Europe, with associated conception rates correlated to multiple deprivation indexes. At risk groups are disadvantaged and disengaged, with significant health and wellbeing issues reported for mother and child. In a review of research studies, Trivedi et al (2007) highlights at risk groups as those: in care; homeless; school underperformers/truants; children of teenage mothers; and from deprived areas. Young mothers are more likely to be single parents, to have experienced family conflict/trauma, not to be in employment, education, or training, and to be at risk of short and long term mental health issues; infant mortality rates are 60% higher than those for older women (DfES, 2006), and babies are at greater risk of poor nutrition and childcare (Rowlands, 2010, Torvie, Callegari et al. 2015), and impaired development (UNICEF, 2007). Stress and anxiety are also heightened with young mothers three times more likely to experience post-natal depression (DfES, 2006, Kingston, Heaman et al. 2012). Low literacy levels are also reported (e.g. Bennett et al, 2013).

Beyond immediate parenting needs, on-going broader support is considered key to long-term success and social mobility (Trivedi et al, 2007; Smith and Roberts, 2011; Smith et al, 2012); however, a systematic review of the research evidence relating to teenage pregnancy, parenting and social exclusion (Harden et al, 2006, p.4), reports that mainstream services “have often failed to provide the holistic care required to support social inclusion or social re-integration for teenage parents” and in particular, to meet diverse needs and preferences. A key recommendation highlighted the need for *tailored* information, advice

and support for informed choices (Harden et al, 2006). A UK National Health Service (NHS) review of midwife services (Coltart, 2007) highlights similar issues, identifying a lack of age appropriate information, unmet social information needs, and issues of equity of access to information. There have been further follow-on calls for tailored health information (e.g. Berkule-Silberman et al., 2010; Hagell & Coleman, 2012) and increased digital provision (e.g. Joint Strategic Needs Assessment, 2012), reflecting wider concerns regarding limited provision of digital resources specifically for young people (The Reading Agency, 2011). However, our ongoing research (Louden et al, 2016, Buchanan et al, 2017, Ruthven et al, 2017) suggests limited progress in addressing such issues; and reports young mothers as having multiple, complex, interrelated, and at times competing information needs, often individually sourced via multiple agencies and information systems not always easily found or navigated; and in relation, an often critical dependency upon support workers as information intermediaries, particularly when seeking information from external (non-interpersonal and/or digital) sources. To compound such issues, our project advisory board reported that while several agencies have previously attempted to compile directories to aid (both mother and support worker) access to online services, none are in widespread use and that many directories are little more than selective lists of links to websites with limited guidance as to the content contained within linked websites.

In summary, a persistent digital divide is evident with a clear and immediate need for a digital bridge. This raised three research questions that formed the basis of an action-oriented sub-project as reported here:

1. What are the information needs of young disadvantaged mothers?
2. What are the appropriate digital sources to meet these needs?
3. Given literacy and access issues, what would be an appropriate digital design, and how might it be used?

Design/methodology/approach

Applying overarching principles of design thinking (i.e. human-centered, integrative, and collaborative (Brown, 2008)), which remind us that “social challenges require systematic solutions that are grounded in the clients or customer’s needs” (Brown and Wyatt, 2010, p32); our approach consisted of a mixed method design incorporating semi-structured interviews, digital services analysis, evolutionary prototyping and exploratory focus groups, designed to: identify information needs, appropriate digital sources, and develop a tailored digital portal in a collaborative and evolutionary manner.

A purposive approach to sampling defined the key participant inclusion criteria as being a mother aged 25 or under from an area of multiple deprivation as defined by the Scottish Index of Multiple Deprivation¹; and for support workers, as being public or third sector professionals directly engaged in providing support to those young mothers.

A typology of information needs (research question one (RQ1)) was developed from previous information behaviour research with first-time mothers (Louden et al, 2016) and refined via fieldwork with support workers (Buchanan et al, 2017) and further on-going fieldwork with young mothers. In all studies, needs were identified via semi-structured interviews and focus groups, with data disaggregated into meaningful categories via identification of patterns and regularities through a cyclical process of iterative pattern coding (Miles and Huberman, 1994).

¹ <http://www.gov.scot/Topics/Statistics/SIMD>

Appropriate digital sources (RQ2) were identified via existing directories, online searches and website content analysis, approached in a systematic and structured manner via selective identification and visual inspection of UK non-commercial public and charity sector national and local websites, beginning with respective home pages and content analysis of pages beneath. Such an approach has been previously employed by Buchanan & McMenemy (2010) to identify digital services and was tailorable to study search parameters. Redundant sites were removed with the remainder mapped via a matrix to identified information needs, and assigned one or more of the following codes as appropriate: 3. Provides parent tailored information, 2. Is a primary source of information (for one or more identified needs), 1. Is a secondary source of some information (for one or more needs). The best matches combined 3 & 2.

To explore the concept, design, and potential utility of the prototype (RQ3), individual and group field trials and presentations were held with young mothers variously attending charity sector parent support groups or part of the NHS Family Nurse Partnership (FNP) programme. We recognised that in purposive samples, six interviews can be “sufficient to develop meaningful theories and useful interpretations” (Guest et al., 2006, p78), and that saturation can be reached after twelve interviews (Guest et al., 2006), a view also held within the Human Computer Interaction community regarding usability tests (e.g. Neilson, 2000). In relation, it is also recognised within design thinking that, “prototyping doesn’t have to be complex and expensive” (Brown, 2008, p.87). We therefore sought between 6-12 initial participants (concluding at saturation). The prototype was described to volunteer participants as a digital resource intended to provide tailored access to trusted online information, with the sessions framed as open exploratory discussions to solicit valuable feedback and aid further design.

Ethical approval was obtained via Institutional Ethics Committee, with all experiments run in strict accordance with the guidelines set out by our Institutional Code of Practice on Investigations of Human Beings.

Findings

Previous interviews with 22 first time mothers (general population) exploring information behaviours identified the following information needs which formed the initial typology (Louden et al, 2016): sleeping, milk feeding, weaning, health and infant care, family, activities, products and recommendations. Further work with 49 support workers working with young mothers from areas of multiple deprivations supported our initial, largely childcare oriented categories, and added (Buchanan et al, 2017): finance, family relationships, education and employment, parent health, and housing. On-going fieldwork with young mothers from areas of multiple deprivations notably added several more information needs: stress, benefits, training (employment), legal advice, and domestic abuse. A repeat cycle of iterative pattern coding then arrived at the following categories of information needs: pregnancy; labour and birth; child development; child health; parent health; playtime activities; childcare; family relationships; housing; money; legal advice; work; education and training; domestic abuse; helplines; stress; and a glossary of terms.

In identifying appropriate websites to meet identified information needs, an initial list of 98 candidates was reduced to 36 when redundant sites were removed (the former a step that would also simplify design and the user experience (i.e. cognitive load)). Beyond identifying primary sources of tailored information for parents, this step also identified digital gaps; most notably to meet *housing* information needs, with the most appropriate primary source of information being identified as a charity rather than the responsible local (state) authority. Once primary online sources were identified for each information need this formed the initial architecture of the prototype portal. During this analysis and mapping initial child and parent health categories (i.e. pregnancy; labour and birth; child development; child health; parent

health) were noted to be logically grouped on existing websites separated by child age (i.e. baby or toddler), and this convention was adopted in our own model.

The graphical user interface (GUI) was designed to intentionally mirror ubiquitous tablet and smartphone design (see Figure 1). Each icon represents a category of identified information need and intentionally links directly to a single primary source of information, with 8 of the 15 underlying websites parent tailored. There are obvious strengths and weaknesses to single direct links, but cognisant to issues associated with literacy and cognitive load, we considered it beneficial to begin with an interface design that mitigated for issues of information overload common in the initial stages of information seeking (e.g. Kulthau, 2004), via simplified meaningful (needs based) search processes that expedited access to primary sources of trusted information (in psychology and cognitive science our categories of information need can be considered as schemas which “can be treated as a single element in working memory and thus heavily decrease cognitive load associated with the performance of later tasks” (Van Merriënboer and Sweller, 2009, p87). As a prototype all aspects of design are open to development with it envisaged that multiple resources could be gradually introduced under each category (and extending beyond websites to recommend YouTube videos and biblio-therapeutic eBooks etc., to provide additional demonstrative and experiential sources of information valued by mothers (Louden et al, 2016, Buchanan et al, 2017)).

12 young mothers (aged 15-23) variously attending third sector parent support groups or part of the NHS FNP programme volunteered to provide feedback on the GUI design and its potential utility. Comments regarding GUI design were mixed. Single direct links to trusted resources were positively commented on by several mothers, and felt to avoid unnecessary and tedious navigation, and providing valued “guarantees the information is reliable”. However, several mothers also described the design as “plain” and “boring”, and suggested that there could be “a more interesting background” and in relation, that it “could be a bit more colourful and not just white”. Positive pictures of parenthood were also suggested. Some mothers also suggested having a page beneath each icon providing more links for each topic and additional context and direction such as “general summaries” of the information available beneath.

Figure 1: Prototype Portal GUI (<http://yftm.cis.strath.ac.uk/mothers-digital-gateway/>)

Mothers Digital Gateway



The name (Mothers Digital Gateway) was disliked. It was suggested that “mother” needs to be replaced with a gender neutral term encompassing fathers and carers, and that “portal” might be replaced with “help book”, “helpful info for parents” or “survival guide”, although with the latter, when the researcher mentioned that there already exists a publication titled “The Young Parents Survival Guide”, another participant considered this insulting as she felt it suggests that young people cannot cope with parenthood, and in relation, another commented that, “when you get called a young mum or a young parent, it kind of makes you feel like you’re less... because of the way the generations seen as teenagers or whatever... or making you seem less valuable as a parent than older mums”. This is an important consideration as stigma is a known issue amongst young mothers (e.g. Ormiston et al, 2012), with stigma (and judgement) also known to influence information practices (Lingel & Boyd, 2013, Louden et al, 2016)).

With regard to utility, mothers appeared to intuitively understand the portals purpose and provided positive feedback regarding information topics, with none of the topics questioned and three further suggestions made: *sexual health*, *local information* and *useful phone numbers*. Several indicated that they might use this resource, with one commenting that it can “take forever” to find trusted sites, and another that it was “good to have all the trustworthy sites in one place”. Mothers also thought that there should be both a website and app to encourage widespread use and that it should have its own domain with visible links from NHS and public library sites.

The trial in itself also could be seen to increase awareness of online resources amongst participants, for example one mother while exploring the website link under family relationships commenting, “I quite like this one – family lives – I’ve never seen that one before”. However, the majority of participants as part of general discussions, also indicated a low use of online sources (favouring interpersonal sources such as family and health visitors instead), and infrequent use of online resources beyond Google. A preference for interpersonal sources has been previously reported amongst mothers (e.g. Berkule-Silberman et al., 2010, Louden et al, 2016) reflective of broader information behaviour findings, but our ongoing fieldwork suggests a low use of online sources (particularly State) in disadvantaged circumstances. For example, many of our participants in this study were unaware of *ReadySteadyBaby* (NHS Scotland’s main online guide to pregnancy and the first 12 months), and while all knew of *Young Scot* (Scotland’s national information and citizenship resource for young people aged 11-25), none used the website or knew of any peers who did, with the resource described by one as being “not really a thing that young people are actually interested in”. Consequently, notwithstanding ongoing evolutionary GUI design, our initial findings suggest that while the portal provides useful access to tailored and trusted online information for young mothers, usage is likely to be extremely low without systematic intermediary intervention, which given limited existing digital interactions, would for many most likely begin in the physical space (i.e. need to be viewed as a staged process of digital transition). With regard to the intermediary process, we know from our main study that support workers (health visitors etc.), beyond being a key source of information in themselves, play a key role in directing and linking young mothers to other information services, groups and resources; and dealing with misinformation (Buchanan et al, 2017); and we also know that it can be challenging for support workers to develop literacy skills and independent information seeking behaviours amongst adolescents in disadvantaged and dependent circumstances (Buchanan and Tuckerman, 2016). Support workers acting as human information intermediaries are therefore ideally placed to utilise this prototype in their interactions with young mothers, providing access to, and encouraging use of, meaningful and trusted sources of information; and providing opportunity to discuss and develop digital literacy skills in an interactive and meaningful manner, both of which might encourage independent usage of the portal over time. In combination (digital portal and human intermediary), a holistic systematic (transitional) approach can then applied to digital interventions, and this is the proposed next stage of this research.

Research limitations/implications

No claims are made to statistical power, significance, or generalizability of findings.

Practical implications

Provides a methodological framework and agenda for digital collaboration between Public Health Services and Charities to develop and implement digital health interventions that cannot be solely reliant on technology.

Originality/value

Highlights persistent digital divide issues amongst a high-risk group, and illustrates the role of focused information behaviour investigations in informing meaningful and systematic digital health interventions and transitions.

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