MyHealth - Developing accessible health materials with men with intellectual disability: A co-created Proof of Concept

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Title: Myhealth-Developing accessible health materials with men with intellectual disability: A co-created Proof of Concept

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Co-creation, human centred design, intellectual disability, health information, male health, communication
Abstract

This paper describes the development of user focused health materials for men, in the form of a tactile set of health post cards and a digital web-based platform- Myhealth. Health experts with Intellectual Disability (ID) co-created Myhealth over the two phases of work reported in the paper. Men with ID experience more health concerns when compared with the non-disabled population and themselves require user sensitive health promotion materials to effectively access health provision. Following the successful co-creation of Men’s health postcards, Co-creation also underpinned the method adopted to create the digital version of Myhealth. Through a series of prototyping workshops, we co-created the content, key health messages and navigation of information for a web-based version. Human centred engagement with this able, but marginalised group of men enabled the production of user accessible health materials relevant for all men.

Introduction

This paper describes the Co-creation (CC) of user-focused men’s health information, designed in partnership with male experts by experience who have Intellectual Disability (ID). We discuss how working with a marginalised group of men, with a range of communication difficulties and autism, sharpened the linguistic clarity necessary to design user-focused health information. The paper demonstrates how adopting a CC methodology enabled the initial development of tactile health postcards and then secondly the development of a digital platform. Both versions are called Myhealth. Integral to Myhealth is the way in which health messages are communicated, devoid of any stigma and relevant to all men. Through learning more about how male health messages should be communicated from this group of men with (ID), could inform a method of communication that relates to
communicating other health topics affecting different population groups with communication difficulties.

Intellectual Disability (ID) is a contentious term. Often ID is described as Global Developmental Delay (GDD), a condition that occurs between birth and the age of 18 which prevents a child from reaching key milestones of development like learning to communicate, processing information, remembering things and organising their thoughts (Mental Health Foundation 2014). People with ID also have poorer physical health than non-disabled people (Taggart & Cousins 2014). This population is more likely to develop epilepsy, mental health conditions and coronary heart disease which they experience at a higher rate compared with the non-disabled population (Emerson & Hatton 2014). They also have an increased risk of physical health conditions associated with specific genetic and biological causes of ID, such as congenital heart disease among people with Down’s syndrome (Roizen & Patterson 2003).

Two phases of Myhealth occurred over approximately 16 months. Phase one was funded by internal University seed funding and phase two by a European Regional Development Fund managed by Coventry University as a Proof of Concept (POC). The overall aim was to develop user–accessible health information for men in partnership with a local third sector advocacy organisation called Grapevine. Men who are members of Grapevine acted as experts by experience. Experts by experience are people who have personal and lived experience of using health and/or social care services (NHS Mental Health Improvement 2018). The men from Grapevine not only had lived experience from their own health concerns, such as depression and anxiety related disorders, but also experience from sharing that experience with others, such as health professionals and health professional undergraduate students. Two of the men also had autism in addition to ID.
Background

Health literacy is essential for patient safety, self-management and effective health and social care relationships with patients, family carers and is a key determinant of health (Rowlands et al. 2017). For marginalised groups of people, such as those with (ID), equitable access to health resources can be a challenge (Taggart and Cousins 2017). ID is typically understood to affect an individual’s ability to learn and socially adapt (Emerson and Hatton 2014). A range of communication difficulties, such as dysphasia is also associated with (ID) and people with ID are more likely to have poor literacy levels (Baur 2007). The need therefore for user focused accessible health materials becomes a necessary requirement. In addition to this, it is widely acknowledged that men do not access or act on health information as well as women (Payne 2006). While health information specifically tailored to men does exist, it is often presented in such an over-masculine format, that many find themselves excluded from it.

For clarity, the Myhealth project did not begin as a linear academic study. Indeed, the non-linear process has been used as the basis for conference dissemination (Magee and Bollard 2018) as a metaphor for the importance of working at user focused level, for whom, in the instance of ID, the process of engagement is typically non-linear.

Co-creation not consultation

Co-creation (CC) is not consultation. It is a philosophy that seeks to involve the widest range of users at the outset of a project or task. Collaborative creation tools have been developed from the qualitative research approach of Participatory Action Research (PAR) to meaningfully involve participants in as many of the aspects of the research process as possible (Baum et al. 2006). As a methodology, CC has roots in mid-20th century post-war research (Lewin et al. 1946) and subsequent evolution into social change methodologies. Co-creation has become a method to engage citizens more effectively in design and research,
recognising the advantage of real user insight, rather than development based upon exclusive assumptions.

The philosophy has variations in terminology including Co-design, Co-creation and Co-Production. We have found that Co-creation tends to be used in the UK, whilst EU research tends towards Co-Production. For the purpose of this paper, we refer to Co-creation as the overall methodology and to Co-Design as involvement from the advocacy group involved (H Team at Grapevine), since they did not produce the outcomes, but did contribute, guide and inform the system design with us.

Collective creativity is at the core of CC – which essentially refers to creativity shared by two or more people (Sanders and Stappers 2008). Our aim when using CC, is to gather rich qualitative data, using a variety of methods to understand the user journey from beginning to end. Influenced by previous CC with experts with experience with ID, specifically related to research communication design (Magee et al. and c2u 2016), Myhealth is led by men with ID’s need for health information communicated in a format that aims to make sense to them (see table 1). There is a shortage of accessible men’s health material (Bollard and Magee 2018). Being intentionally biased towards men’ health, it is envisaged that Myhealth content remains relevant to the whole male population.

In the world of technology development, CC practice is seldom published. There is some logic to methodological secrecy in protection of valuable intellectual property concerning development, but this prevents evaluation of the substance of the CC methods employed. Ineffective user interaction risks tokenism, not truly representative of the widest user base that may stem from an issue of informed engagement and the difficulty this poses. For instance, working with ID can require knowledge of empathic communication techniques, requiring specific training. Establishing a working partnership about ID is not the same as
arranging a focus group, for example. The greater level of time investment required to meaningfully engage with users with communication needs, may be considered indulgent, and prohibitively expensive. A reluctance to invest resource time is exacerbated by the lack of mass-economic drive to address marginalised-user needs over requirements of the general market. We disagree with this exclusive paradigm, and prefer the notion that if it is possible to design a system for people with ID, that system can work well for the wider population. In terms of adopting co-production methods, Roberts et al. (2013) involved people with ID to co-produce a board game to help others understand the principles of human rights. Brookes et al. (2012) used a co-production approach to understand issues associated with adult protection (safeguarding). These examples point to the value of co-creation with people with ID using basic technology. However the breadth of technology now available seldom suits the whole disabled population. Indeed many are excluded from the overall benefit that modern technology can provide resulting in inequitable access to health and learning information. This inaccessibility has wider implications for marginalised groups such as people with ID, impacting on employment opportunities for example and continues to compound marginalised socio-economic status (Bollard 2009).

Across the broad health and social care field of Intellectual Disability, skilled democratic collaboration enabling the co-creation of different products is limited, not widely disseminated or performed amongst a wider product development phase (Magee et al. 2016). The second author’s experience (PM) has highlighted limited understanding of communication-need in technology development, and a lack of empathy from a young-designer’s perspective as a barrier to gaining insight from the widest audience, including disabled people. (Woodcock et al. 2019). Given this understanding, we aimed to develop user focused CC methods that underpinned the two design phases reported next.
Design Process Phase 1

Ethical approval from Coventry University Ethics Committee was granted for this project. The method adopted by Myhealth started with two workshops with men with ID (n=6) and a co-worker at Grapevine, a local advocacy organisation in the West Midlands. Working with Grapevine, Myhealth sought collaborators not consultants, shifting the working approach from a consultative focus group to engagement with co-creators. The purpose of the workshops was to identify what the group wanted to talk about related to men’s health and how this could be made accessible. Our understanding of communication around ID suggested a need for clarity in lay language. Consequently, starting a discussion based upon a typical University style Participant Information Sheet (PIS) may cause confusion; we could not therefore have been certain of comprehension. We elected to explain the following 11 points before discussing the possibilities for information communication:

1. What is the purpose of the project?
2. Why we need your help.
3. Do I have to take part?
4. What do I have to?
5. Are there any risks to me being involved?
6. What are the benefits of taking part?
7. Can I stop at any time?
8. Data protection & confidentiality
9. Can I complain if things go wrong?
10. What happens to the results of the study?
11. Who reviews the study?

We used large printed sheets containing each title; during the discussion the men added notes, questions or additional details. To begin workshop 1, the refined PIS was first discussed and
agreed. To help make sense of the above questions, a co-worker who knew the co-creators well helped explain the PIS with each individual. We were present to assist where required. Visual representation was not required as all parties agreed to comprehending the information provided. In this way the men were co-creating the principles of how they wished to be included at the outset and determining what would help facilitate that. A series of guidelines resulted from the workshop and consequently, Myhealth prototype literature adopted the principles shown in table 1 (Magee et al. 2017):

Table 1: Design principles applied to Phase 1 of Myhealth

<table>
<thead>
<tr>
<th>Principle</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper based (offering tactile material and discrete ownership)</td>
<td></td>
</tr>
<tr>
<td>Clarity of content with useful detail written in lay language</td>
<td></td>
</tr>
<tr>
<td>Short sentence structure (i.e. no more than 2 lines of text)</td>
<td></td>
</tr>
<tr>
<td>Minimal typographic distraction (for example, no punctuation)</td>
<td></td>
</tr>
<tr>
<td>Small, easy to handle format (A5 booklet size as a guide)</td>
<td></td>
</tr>
<tr>
<td>A reply consent card, written in participant’s own words</td>
<td></td>
</tr>
</tbody>
</table>

An example A5 postcard was shared with a first group of men with ID to identify their preferred health content, each noting ideas directly on mock-up postcards (figure 1 Mocked up cards for co-create content near here). The language shown on the postcards presents a positive message, it is not personally critical; instead gently highlighting sensitive health issues. The information selected for the postcards is brief; typically, a single sentence as a prompt to seek more detail. As new evidence emerges on Men’s Health, or different health concerns become apparent, the content of MyHealth can be easily updated and further postcards produced. Based on Workshop 1’s specification, a revised set of postcards was shared with co-creators from Grapevine. The men’s input as experts by experience was valuable here, to review and refine
the printed language and visual impact, see how co-creators may engage, thus ensuring suitability for these co-creators with ID and therefore intentionally replicability to other men. (figure 2 near here Developed Format)

At the same time, we asked co-creators to consider this format and how the information could be used with the non-ID male population. The Myhealth postcards are used with the ID community as a sharing tool for health information, offering men the support and inclusion of a community that needs health education (Taggart and Cousins 2014). However, there is no mention of ID as a health concern, enabling the postcards to be accessible by the whole population without stigma.

There are intrinsic advantages to a printed postcard in this communication space. Firstly, they are hand held and do not require any technological ability. The format has a familiar, nostalgic quality that is comforting, yet design variation can ensure contemporary relevance. The tactile qualities include the ability to feel and hold an individual physical copy, not dependant on internet accessibility nor manipulation of a device. Limited dexterity is required to flick through the A5 size sheets and browse the accessible health information (figure 3 Tactile version of Myhealth). Finally, the postcard itself is low value, so does not need to be handled as a precious item, thus improving the prospect of actually being used.

Table 2 Co-Design Process
Reflection of phase 1. Once the postcards were produced and the co-creators confirmed they were satisfied with the result so far we started talking about what they would like to do next – given that the postcards could be adapted to other health messages. What struck us was how they would take a card, scan the content and gesture as though selecting with a touchscreen to select content. This then prompted the need for a digital version for phase 2.

Phase 2

This phase involved translating the Myhealth cards into digital specification though a number of prototype workshops. Securing further Proof of Concept (POC) funding enabled us to engage the services of a local web design company whom were commissioned to replicate the card design in digital form, based upon a Co-created UX specification. Three separate co-creation workshops were held to develop the different iterations and the final digital version. A co-worker from Grapevine accompanied the co-creators for each workshop. An online discussion platform–sketchpad, enabled the authors and the co-creators to share feedback comments to the web designers without any interpretation bias. Given the volume of comments generated by the co-creators, the web designer requested additional face-to-face
meetings with the authors in between each iteration, to ensure authenticity of the co-design process. The web designer was not part of the CC process.

A key feature of translating a handheld version of Myhealth from phase one into a digital version was deciding on how the users wished to navigate content. This was discussed with the co-creators at the first workshop of phase 2. (Figure 4 near here Moving from hand held to digital illustrates in part how the animation that replicates the physical representation of flipping a card over was decided. In this way the co-creators explicitly determined how MyHealth shifted from a set of post cards to a digital platform.

The second workshop enabled the authors to co-create the position and layout of the content. The Co-creation team clearly demonstrated their health expertise by making suggestions to other sources of health information they felt should be signposted within the digital version (figure 5 near here Digital Content Process). After the second workshop, more comments were posted onto sketchpad for the web designers to develop the finalised version. Workshop 3 enabled all participants to interact with the digital version on iPads and to make final recommendations for its usability and functionality. We were pleased with this level of engagement and input from the co-creators and were satisfied our efforts to understand, sympathise and operationalise their design needs on this topic had been taken into account as best we could (figure 6 near here Testing final Myhealth version

Discussion

Human centred design is based on the use of techniques which communicate, interact, empathize and stimulate the people involved obtaining an understanding of their needs, desires and experiences (Giocomin 2014:610). This underpinned the approach to developing the two phases described in this paper, but also resonates with the widely promoted person centred approach associated with the field of ID (Walmsley 2004).
However, acknowledging the need to be human centred and then be able to achieve it effectively when working with adults with communication needs are two different things.

This case example demonstrates how attempts were made to overcome this challenge in phase 1 and 2 of this Co-creation case example.

Engaging meaningfully involved co-designing a communication process alongside this group of men. A specific workshop was run in phase one to devise the Participant Information Sheet (PIS). This was useful in establishing and coming to an agreement on the constituent parts of the co-creation process. Moreover, it enabled the principles of the prototype health content to be developed with deliberate positive health message content. The specification of the postcards were based on the health topics highlighted by the co-creators and ones understood to represent the wider community of men. There are two benefits to initially producing a set of hand held ‘tactile’ cards. Firstly accessing them does not require knowledge of technology and secondly limited dexterity is required to flick through the A5 size sheets and browse the accessible health information (Magee and Bollard 2018). This enabled the creativity of designers and people not trained in design working together in the design development process, by drawing in those with little experience of design and providing them with the tools to contribute to design processes (Reay et al. 2017).

Phase two of Myhealth developed on from the hand held set of post cards into a digital format. This was based on the co-creators desire for more information demonstrated by deliberate pointing gestures, representative of using a smart phone or LCD device. Three separate workshops developed the different iterations of the digital format. Volumes of comments at the workshops were posted up onto sketch pad. This enabled the user perspective to be fed directly back to the web designers. The web designers requested the authors meet face to face to authenticate posted comments before making any changes to the next iteration. In this way we could show how the desires and experiences of the co-creators
were being fed back into the Myhealth digital iterations. Although the users did not
determine the outcome of Myhealth, we believe the co-design process we adopted enabled
the users to be actively involved in the system design.

**Conclusion**

There is limited evidence of meaningful involvement of adults with ID in the system design
of co-created products. The tactile version of Myhealth (Phase 1) paid particular attention to
the linguistic clarity required to provide simple and positive health promotion messages on
aspects of men’s health. The co-creators had diverse communication needs, including
Autism. The techniques we adopted enabled the accessibility of such needs to be understood
and presented a platform for the men to indicate the digital development of Myhealth (Phase
2) on their terms. The communication lessons learned in co-creating Myhealth provide a case
example that can be adopted to co-create different accessible health materials, on different
topics, with other population groups with communication needs.
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