A patient-led approach to product innovation in patient education and wound management

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ABSTRACT

This paper reports results from a multi-disciplinary industry-academia research partnership whose goal was to conceive, design and prototype solutions for older adults with chronic wounds.

Aim: The aim of the project was to explore the potential enhanced benefits of extended patient involvement in an entire live product development process, from understanding the wound care environment, through needs identification, to solution generation and iteration.

Methods: An action-design research methodology was used to engage with 47 target users and develop design ideas and prototypes. The research was built around a theoretical framework that integrates aspirations and needs of target users with socio-technical systems thinking and innovation management processes.

Results: The design component of the research methodology resulted in the concept design of a wound management education and information system for use by patients and their caregivers. This concept was developed based on observations of and interaction with patients and caregivers. A prototype solution was built and used as a vehicle to gain an understanding of opportunities, issues, and challenges to be addressed in supporting older adults with chronic wounds and enabling them to maintain and improve their personal wellbeing. This led to the identification of the need for readily available, current wound care information, advice, and support for older people and caregivers. The design concept was a response to this need. From early evaluations of a prototype implementation, age was identified as not necessarily being a barrier to the use of a technology-based solution; IT skills, confidence, and access to the internet were identified as more important factors.

Outcomes: A prototypical wound care information system was developed that has been evaluated with target users using deliberative panels and home-based evaluations of a prototype implemented on a tablet platform. Wound care solutions focussed on the need to support people in maintaining their personal wellbeing lead to different requirements from those that support wound treatment. By considering wider perspectives, solution providers have opportunities to utilise fewer or re-allocate resources whilst improving user wellbeing by creating user-focussed outcomes that are effective, efficient, and valued by both patient and provider.

INTRODUCTION

Policy developments in the UK resulting from the Health & Social Care Act[1] prioritise the adoption of a proactive approach to patient involvement in service and product innovation in healthcare. The "user pull" this creates aligns with innovation theories[2] that emphasise the importance of understanding user and market needs in addition to technologies that could be used to create solutions. Within industry, the importance of customer insight is increasingly recognised, and growing numbers of companies in the medical technology sector are looking to open innovation as a key approach to drive future growth[3]. However, currently less than one third of medical technology-based solutions have been co-created with customers or external partners[4]. ▶

In addition to achieving user pull, a further challenge in creating such solutions lies in understanding the organisational context in which solutions are to be introduced. This is especially the case when introducing information and communications technology (ICT)-based solutions, where failure is often associated with social dimensions of the environment in which they are introduced and with interactions between social and technical dimensions[5,6]. With solutions intended for use in patients' homes, the importance of close interaction with patients and of integrating solutions within the broader patient experience and home environment is even higher. This research used a socio-technical systems framework[7] as a means of gaining these insights both in the early stages of the design process and in the evaluation of prototype solutions.

The problem of older adults living with chronic wounds was selected as a case study because of the challenges involved in supporting this population to allow them to live independently, thereby improving their quality of life and wellbeing. Solutions were conceived, designed, and prototyped. The specific focus on development of innovative internet/e-technology-based solutions was identified early in the process, during which patients highlighted the importance of being able to manage, rather than cure, their wounds. The approach used both educated researchers and clinical experts, and addressed issues of both personal wellbeing and clinical health, driven by a philosophy of patient-identified need.

BACKGROUND

There is a tension between the primary focus of clinicians, industry, and healthcare organisations with regards to cure and compliance, and the importance to patients of the everyday impact of living with a wound and the requirements of innovations that will address their sense of wellbeing[8]. At the same time, there is increased recognition within the NHS in the UK, for example, of public and patient involvement both in research and in the design and delivery of services[9]. This creates a challenge in identifying, hearing, and maintaining the voice of the patient amongst the plethora of multi-professional voices. These competing commitments informed the rationale for beginning with the patient perspective, thereby ensuring that this perspective was the inspiration for the innovation process, and that it would continue to be involved and influence at critical stages of development.

The importance of user pull in successful innovation processes is increasingly recognised[10]. ICT-based systems and solutions can provide the "pull" from patients and caregivers for greater innovation by enabling patients and caregivers to make informed choices about which interventions they would like to receive and take responsibility for

in managing their own care. Patient and caregiver demand is an important driver for the adoption of technology as they become more empowered and more demanding about the kinds of treatment they want. Patients may not be able to specifically articulate an innovation, but they can describe their basic needs and their basic expectations of wound care management solutions. The aim of this project was to explore the potential enhanced benefits of extended patient involvement in an entire live product-development process, from understanding the wound care environment, through needs identification, to solution generation and iteration.

METHOD & RESEARCH PROCESS

An action-design research methodology was used[11]. Core aspects of the methodology were engagement with users through the whole process (before any solutions were proposed) and the use of design sketching and prototyping as a means of quickly exploring and evaluating potential solutions, broadly illustrated in Figure 1.
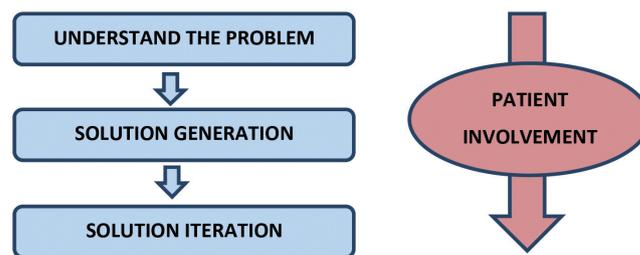

Figure 1. The design and development process

As preparation for the cycle, a desk-based analysis of patient and other stakeholder needs, informed by a socio-technical systems thinking approach to innovation and management processes[5] , was carried out. This was combined with the concept of using design to create self-perpetuating Virtuous Cycles of Wellbeing[12]. The research team engaged with 47 older people with a focus on the key experience of "living with" a chronic wound.

The more detailed research process, illustrated in Figure 2, began with a study of the problem domain, which included a desk-based study and discussions with wound care professionals, and a literature review of innovation systems in the wound management domain. This ensured that all academic participants had a basic awareness of issues and current practices in the management of wounds.

Two series of half-day workshops were then carried out. These workshops involved 15 selected urban, community-based, ambulatory, and wheel-chair bound patients and caregivers with a history of wound care, and an ability to articulate their stories, experiences, and needs gained from

training they had previously received from the University of Leeds. The results of this preliminary work, in terms of how meaningful it was for patients and their caregivers, were evaluated at the beginning of the first action design research workshops. This led to a shared understanding of patient and caregiver perspectives on living with a chronic wound and highlighted differences in priorities of different stakeholders within chronic wound care systems where patients and caregivers place more value on living well (e.g., no discomfort related to compression stockings and being able to wear shoes that are comfortable, aesthetically pleasing, and odour free[13]) rather than healing the wound. Outputs from these workshops were in the form of low-fidelity prototypes of possible solutions and their pros and cons. Results from the initial study and the workshops were passed to a professional design team to inform the development of five concept designs with an IT interface but with no functionality. These concepts were evaluated in a second series of patient-led workshops held in both an urban and a rural environment with ambulatory and wheelchair-bound community-based patients and caregivers less familiar with articulating their needs.
Based upon the qualitative and quantitative feedback from the workshops, specified concept selection criteria were used to select the final concept for further development.

Feedback on both the product solutions and their involvement in the development process was obtained from the participating patients and caregivers.

The final result from this phase of the research was the definition of a concept that was then implemented as a prototype that could be evaluated with a wider range of community-based patients and caregivers, again, from both urban and rural settings. The prototype was implemented as semi-functional software on a hand-held device, in order to allow the patient and caregiver to develop a better feel for a potential live solution. The research took the form of one-to-one or one-to-two interviews, conducted by a project team member, either in the patient's home or a neutral health-related environment.

With the exception of the Design team (ex-students), all activity was conducted by project team members and associates drawn from the initial academic, health provider, and industry participants. Feedback on the process was obtained from the team members.

RESULTS

The key results of the project are split into two areas of focus:
1. The benefits of extended patient and caregiver involvement in the product development process.
2. The final design concept definition as shown in Figure 3.

It can be seen that the final concept was an education and wound management information system informed by issues that patients and caregivers said were important to them. Appropriate expert advice on relevant topic-related issues was included along with advice on management, support and personal goal setting, self-monitoring and reporting of wound profile (self-assessment) capabilities, ▶
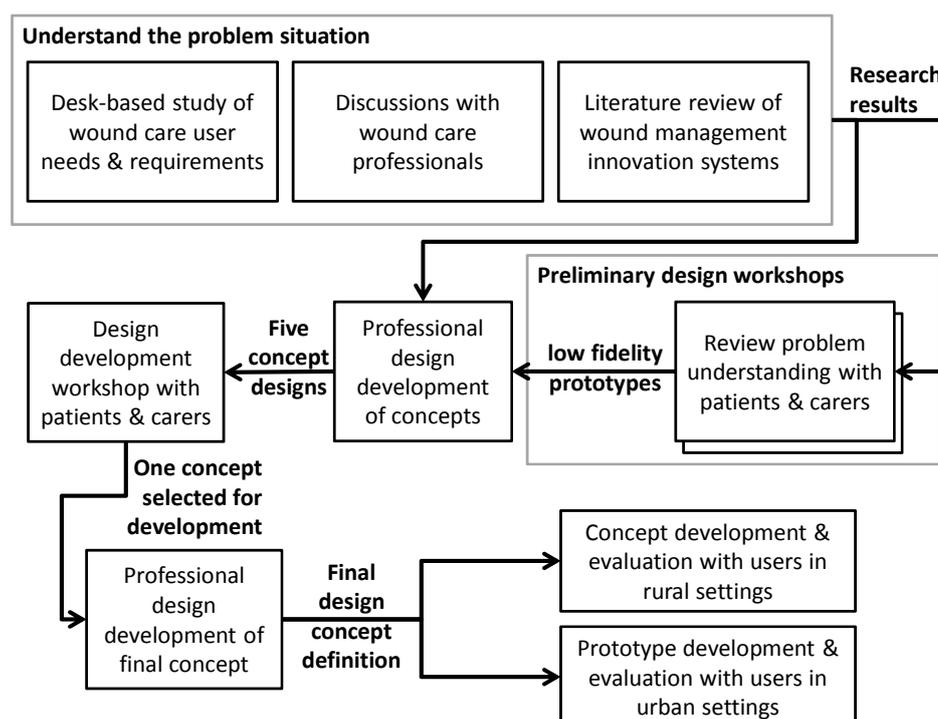

Figure 2. Flow chart of the research process

Figure 3. Design concept

information on and suggestions for exercise and diet, and links to other potentially useful resources. This addressed a number of issues that patients and caregivers identified and other key stakeholders recognised.

LACK OF READILY AVAILABLE CURRENT WOUND CARE INFORMATION, ADVICE, AND SUPPORT

A key benefit to patients and caregivers was that the design overcame a problem described by one patient as "There is not a lot of care information available other than a simple leaflet and basic information from district nurses." Patient focus groups emphasized that information and advice were not readily available or understandable, and that they were unable to determine if the advice was appropriate for themselves and the care they required. The approach to wound management embedded within the design enables patients to access information when required, as opposed to having to remember it from when it was provided, and allows caregivers and family members to easily access this information.

USING TECHNOLOGY

IT skills, confidence, and issues of access were all pertinent to the potential value and impact of the system and were addressed by creating an easy-to-use system that could be deployed on multiple platforms.

ISSUES IDENTIFIED AS IMPORTANT BY PATIENTS INCLUDED:

- Trust in the confidentiality of the system, that is, that they could access information as and when they wanted to as well as record information specific to their wound that would only be accessible to themselves and to the healthcare professional. A real fear existed with patients that technology-enhanced care meant that their details could be "hacked."

- Ease of access to expert information and personal wound history as and when needed was seen as empowering and enabling individuals to make decisions and live their lives more independently, an important component of "wellbeing." However, there was some concern that the technology might mean less input and support from the clinicians and by default more work and responsibility for the management of the wound by the patient. The importance of practitioner contact was emphasised by participants and seen as an enabler for technology adoption. This tension is not limited to wound management; it is also reflected in the wider self-management literature[14,15].

- The recognition that age need not be a barrier to the use of technology. More important was that the technology was described as easy to use, and because it had followed the KISS 'keep it short and simple' principle, that it overcame any anxieties individuals may have had due to either a lack of familiarity with IT technology or to lack of physical dexterity.

Among practitioners, views differed between social care and healthcare professionals; social care professional tended to feel that the solution increased empowerment and independence, whereas healthcare professionals tended to hold the view that many older people want to be cared for rather than empowered, and raised concerns that additional monitoring may increase their workloads and that changes in patient and practitioner roles reduced the need for their professional expertise. In discussions considering how these concerns might be addressed, the use of the solution as a "safety net" and a "red flag" system was positively received.

The design was generally regarded as strong, however, in developing it further, a number of technical issues would need to be addressed. For example, methods for caregivers and patients to measure wounds would be needed, as would easy-to-use means of capturing lifestyle-related information, such as nutrition, exercise, and rest. Patients and caregivers recognised the importance of a good diet and exercise, but also identified that the impact of the wound was that "exercise can often be difficult and painful. Anything to help with and monitor exercise would be very beneficial." (Patient quotation).

DISCUSSION AND FUTURE OPPORTUNITIES

The research reported in this paper is part of a wider research initiative with a long-term goal of creating effective and efficient ways of engaging with the users of health and social care systems and with a goal of generating meaningful "user pull" to inform the programmes of change that are being introduced in response to challenges arising from the ageing population. The methodology and process used are outlined in Section 2; a more detailed paper on the

methodology is currently in preparation. However, key features of the process are engagement with users through the entire process and the use of design prototypes to help build a shared understanding of both the problem and the proposed solution, and to identify further development opportunities.

A key feature of the action design research methodology is that it benefits both the researcher, by generating new knowledge, and the system users (patients and caregivers), through the resulting solutions. The solution reported in this paper has the potential to lead to a reduction in treatment costs through more appropriate use of clinical appointments. The on-line tool would help inform decision making about whether to request an appointment with a clinician, thereby reducing potentially unnecessary appointments and saving patients time and resources by their not having to either stay at home waiting for a visit or travelling to a clinic. By capturing more holistic information, such as diet, exercise, support, and broader well-being issues, in addition to wound-specific issues, individually-designed treatment plans can be created.

From a process perspective, patient-led identification of needs requiring solutions may identify different priorities to the professionals. Ensuring innovations are fit for purpose and acceptable (i.e., usable, affordable, and wanted) to the patient/caregiver makes them more likely to be adopted, thus speeding up the adoption process of appropriate innovation. Innovations are tailored with patients and caregivers to meet their needs, recognising their unique insights and embedding the inclusion of their perspective throughout the development process to ensure that the end product delivers on the initial identified need.

A "patient-led" approach moves beyond the principle of "patient involvement."[16] It demonstrates a commitment to the concept that the patient has a different but equally valid expertise that should be heard and inform service and treatment innovation. The inclusion of the patient voice at all stages of the innovation process fosters an "on-going" relationship and helps to address the issue of tokenistic involvement. In this instance, the context has been wound care, but the principle and practice of a patient-led approach to product and service innovation is transferable to other health conditions and contexts.

CONCLUSIONS

The aim of the project was to explore the potential enhanced benefits of extended patient involvement in an entire live product development process.

It is clear from the findings that patient and caregiver participation in the product development process brings benefits to understanding the issues that are important to patients' health and well-being, co-creating potential solutions that address those issues and thereby potentially improve clinical outcomes and use of clinical resources, and tailoring technical requirements to ensure product innovations are fit for purpose in the lived world of the patient as well as in the laboratory.

Involving patients and caregivers in selecting product concepts is not new, but rigorously involving them all the way through the product development process from concept through prototyping and ultimately to marketing is not common and is a practice that this project suggests is advantageous.

Recommendations for practice:
- Recognise the patient and caregiver's expertise of lived experience and respond to it with the same respect as to a clinician's or technologist's expertise.
- Invest time in understanding the patient and caregiver experience of wounds and innovating new products and services in response to that insight.
- Involve patients and caregivers at the beginning and through all key stages of innovation development to ensure a good idea becomes a good product or service.

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