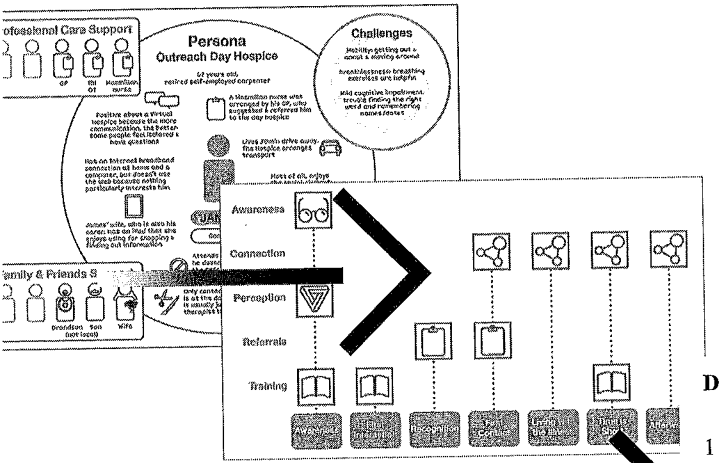

Design Brief:

1 Crafting the Message
2 Building the Virtual Hospice
3 Testing the Virtual Hospice
4 Look, Feel and How

6

Developing a Design Brief for a Virtual Hospice Using Design Tools and Methods:

a preliminary exploration

Andrea Taylor* Tara French*Jeni Lennox* Dr. Jeremy Keen**

*Glasgow School of Art, Forres Enterprise Park, Forres IV36 2AB
**Highland Hospice, Ness House, 1 Bishops Road, Inverness IV3 5SB

ABSTRACT:

Providing equitable access to specialist palliative care, regardless of diagnosis or geographical location, with relatively limited resources and an ageing population, will become increasing difficult for all hospice services. This paper describes the development of a Design Brief for a Virtual Hospice using design tools and methods. The main aim of the Virtual Hospice in this case is to improve access to services provided by the Highland Hospice in Inverness, Scotland. The project began by observing Hospice staff and their interactions with patients. Three User Personas were then created based on data gathered through interviews with a small number of patients and professionals. Each Persona's progress through the Highland Hospice service was visualised on a User Journey Map in the form of insights and opportunities, with five key themes emerging. The final step involved producing a Design Brief that synthesised the research findings in the form of a plan for creating, prototyping and testing the Virtual Hospice.

KEYWORDS

design methods; end-of-life care; health; hospice; palliative care; virtual hospice

INTRODUCTION

Hospice is a philosophy of care that focuses on providing physical, social, emotional, and spiritual support for people with life-shortening illness. The first hospices date from the Middle Ages, where hospice referred to a place of shelter for weary or sick travellers. The modern hospice movement began in the UK with the opening of St. Christopher's Hospice in 1967, which transformed the approach to death and dying from "there is nothing more that can be done" to "there is so much more that can be done." The hospice movement has since spread across the world. Services are provided within a definable building or are purely community based, can include art and complementary therapies, bereavement counselling, chaplaincy and spiritual care, occupational therapy and physiotherapy, as well as direct nursing and medical care.

In Scotland, Highland Hospice is contracted by the NHS (National Health Service) to provide specialist palliative care in Highland, Scotland. Highland Hospice serves a population of 220,000 people distributed over an area of 10,000 square miles comprising the largest and most sparsely populated part of the UK, with a mountainous terrain and limited transport and communication infrastructure. The Hospice provides a 10 bed In-Patient Unit, a Day Hospice, a Day Therapy Center, and a Bereavement Counselling Service at its base in the principal concentration of the population, the city of Inverness. It also provides a Day Hospice in outlying areas, currently Fort William and Thurso. A multi-professional team supports primary and secondary healthcare professionals to provide palliative care in individual's homes, care homes, and hospitals. The Hospice also works closely with two cancer charities: Macmillan Cancer Support and Marie Curie Cancer Care.

However, most clients access services based within the Hospice building in Inverness, tend to live within a 30-mile radius—given the difficulty of travel for a population who are often physically frail, have a diagnosis of cancer, and, if not inpatients, have contact only within office hours. Indeed, the total number of patients supported equates to 18% of the 2,500 people that die in the catchment area of the Hospice each year. In the near future, the number of people seeking specialist palliative care is expected to increase considerably because more people are living longer with long term and life-limiting conditions. The vision of the Hospice is to create a "Virtual Hospice" to improve access to its services for individuals and their families regardless of geographical location, diagnosis, or time of day. To this end, collaboration was forged with the Glasgow School of Art to develop a Design Brief for progression through the Digital Health Institute (DHI). The DHI is a Scottish Funding Council innovation center that aims to transform health and social care delivery in Scotland (Digital Health Institute).

This work contributes to the growing body of research within User Centered Design (UCD) on hospice care. The main contributions include new insights and opportunity areas for a Virtual Hospice that significantly extends the well-established and successful Canadian Virtual Hospice model (Canadian Virtual Hospice) gathered by directly engaging with potential end users, and three User Personas representing key types of users.

RESEARCH QUESTION

What are the opportunities for, and challenges to, improving access to hospice services for individuals and their families regardless of geographical location, diagnosis, or time of day?

RELATED WORK

This work builds upon existing approaches to improving access to hospice care, principally the well-established Canadian Virtual Hospice and the remote care of patients in their own homes using technology.

VIRTUAL HOSPICE

There are a small number of services entitled "Virtual Hospice" operating around the world, albeit in different forms. The Canadian Virtual Hospice is a website launched as the result of collaboration among Canadian palliative care clinicians, academics, and researchers that allows anyone in Canada to correspond via email with a palliative care nurse specialist or doctor (Canadian Virtual Hospice). However, the service is predominantly an information resource with limited interaction between professionals, patients, and caregivers. The Virtual Hospice being developed by Highland Hospice (Highland Virtual Hospice) will significantly extend the Canadian Virtual Hospice model by encompassing a broader package of services to facilitate the provision of a greater level of support at the time and in the place of an individual's choosing. Potentially, this could include all the current services provided by Highland Hospice—from clinical consultations and on-going symptom assessment to creative therapy and bereavement support, and from psychological counselling to practical, physical care advice for family caregivers.

In Australia, the Maitland Palliative Care Trust has developed a Virtual Hospice where the term refers to a network of supportive relationships connected in the desire to care for people at the end-of-life (Maitland Palliative Care Service). Support tools for patients, caregivers, and healthcare professionals are provided as part of the community based service. In the UK, several NHS organizations also offer such a Virtual Hospice enabled by collaborative work among community teams. Here, the term typically refers to caring for patients and their families in their own homes, rather than in an in-patient unit within a hospital or hospice, and/or providing beds in community settings such as a nursing home—programs that are set against a UK Government policy driver to shift care closer to home. However, while it is envisioned that the Highland Virtual Hospice will improve collaboration between the multiple organizations and individuals who provide palliative care by providing a platform to facilitate communication and learning, it differs in its focus on the use of digital technology to overcome time, geographic, and other barriers of access to hospice services.

ELEHEALTH (REMOTE CARE)

Telehealth is the remote care of patients in their own homes using technology. Examples include telephone advice lines, video consultations, and telemonitoring involving clinical review of data from equipment in the home that monitors vital signs and symptoms. The UK Government's Whole System Demonstrator Program, the largest randomised control trial of telehealth in the world, shows that at least three million people living in the UK with long-term conditions could benefit from telehealth (Department of Health, 2011). A systematic review that includes 26 articles published from 2000–2010 concludes that telehealth technologies hold promise to be useful and important tools for the delivery of hospice care, and that there are potential clinical outcomes and cost benefits (Oliver, Demiris, Wittenberg-Lyles, Washington, Day, & Novak, 2012).

A separate review of telehealth in palliative care in the UK included 21 published and unpublished research documents from 1999–2009 (Kidd, Cayless, Johnston, & Wengstrom, 2010), including a report of a pilot study involving Highland Hospice that demonstrates the feasibility and acceptability of using mobile phone technology to monitor symptoms reported by patients being cared for at home (McCall, et al., 2008). The review identifies a lack of evidence-based research and finds no evidence that telehealth is integrated into palliative care services in a systematic fashion. Both reviews conclude that telehealth technologies are acceptable to staff, patients, and family members.

ETHOD

The project employs a research method being developed by the Glasgow School of Art entitled "Three Cubed," which seeks to provide an exploratory and open approach to research through a process of extreme collaboration in short periods of time (cf. McHattie, Cumming, & French, 2014). "Three Cubed" comes from the word cubed or the power of three: the approach involves a core interdisciplinary team of three people working together in three stages of three days (3^3) with research participants. The stages of the Cube are entitled "Orientation," "Immersion," and "Validation." The core team members have disciplinary backgrounds in Service Design, Psychology, and Interaction Design, and worked in collaboration with the Consultant Physician in Palliative Care at Highland Hospice and other members of staff. The Three Cubed method was chosen as an appropriate method given the preliminary, exploratory nature of the project.

ORIENTATION

Stage 1 involved defining the research question through consultation with Highland Hospice staff and consideration and review of previous research conducted by the Hospice and other relevant literature.

IMMERSION

Stage 2 involved the researchers immersing themselves within the research context, starting with a tour of Highland Hospice facilities that included observing staff and their interactions with patients in the Day Hospice and In-Patient Unit in Inverness, and the Outreach Day Hospice in Fort William. Here, the purpose was to go "on location," to observe key stakeholders, and to record the experience by taking written notes and photographs in order to gain inspiration and a rich understanding of Hospice services and how they deliver value (see *Figure 1*). The visits included conversations with a range of specialist staff – doctors, nurses, an occupational therapist, a social worker, a chaplain and a bereavement counsellor – centered on the topic of their roles.

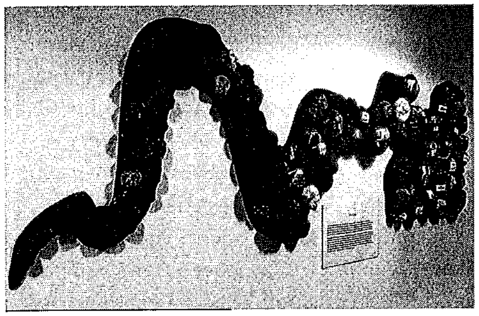

FIGURE 1.

A photograph of an artwork created by patients and staff at an Outreach Day Hospice depicting a journey that someone with a life-limiting illness might take. The dark cobblestones represent loss. However, there can also be profound gains progressing along the path, represented by the coloured cobbles and annotations, many of which refer to attending the Outreach groups with words such as 'advice' and 'fun and laughter'.

Each researcher then outlined a User Persona representing a key type of user: a middle-aged patient with a young family living in Inverness, an elderly patient living outside Inverness, and a healthcare professional living and working in a remote location. A User Persona is a fictional character that synthesises information about similar people and helps to maintain focus on the needs of users as services are developed. Individuals that matched the Personas were then invited to take part in an unstructured interview with the researchers. Interviews with healthcare professionals took place over the phone due to logistics of travel. Interviews with patients took place in Inverness and at the Outreach Day Hospice centers. The interviews focused on the topic of participants' experiences with Highland Hospice services and lasted up to one hour. Data gathered from the interviews and further discussion with Hospice staff informed the detailed development of the Personas.

The researchers then collectively created a User Journey Map, a visual representation of a user's journey through a service that allows for the identification of challenges and opportunities. The journey map was segmented into key stages of the care pathway. Insights revealed by each User Persona were succinctly written on post-it notes and affixed to the relevant key stage. These insights were translated into opportunities by imagining future possibilities concisely written on post-it notes and placed beneath the relevant insights. Different color post-it notes were used to visually separate the User Personas. Mapping each Persona's journey through the service in the form of insights and opportunities, on a single map, facilitated the identification of themes.

ALIDATION

Stage 3 involved validating the research findings. A Design Brief was produced that synthesised the findings. Then, the research findings and Design Brief were presented to an expert panel, including Highland Hospice staff, invited by the Glasgow School of Art for validation and final refinement.

ARTICIPANT RECRUITMENT

The intention was to recruit three individuals per Persona. Highland Hospice staff reviewed their patient administration system to identify potential patients, suggested appropriate healthcare professionals, and made the initial approach to potential participants. The staff also supplied an information sheet explaining the purpose of the research, the nature of their involvement, and a consent form. Six cancer and heart failure patients (4 females, 2 males) agreed to take part in the project. A single patient matched Persona 1, reflecting the much lower proportion of younger hospice patients; therefore, this Persona was created based on both patient and professional insights and experience. The other five patients matched Persona 2. Three healthcare professionals (2 females, 1 male) based over 60 miles from Inverness also agreed to participate: two nurses working part-time as a Macmillan nurse and part-time as a community nurse, and a GP (General Practitioner doctor). The North of Scotland Research Ethics Committee approved the project.

ESULTS AND DISCUSSION

The following section presents the User Personas, the key insights and opportunities arising from the User Journey Map, emerging themes, and the Design Brief.

SER PERSONAS

Three User Personas were created: Maria, James (see *Figure 2*), and Leesa. The Personas do not cover all types of users accessing Highland Hospice services as a consequence of the limited timeframe of the project; however, they do represent key user groups for a Virtual Hospice.

Persona 1 – Maria

"I was left to get on with it."

Maria, 42 years old and in remission from cancer, has always been aware of hospice through her employment in the healthcare sector. When she was first diagnosed, Maria was not initially referred to Highland Hospice. It was a difficult time as she was supporting her young family who struggled to come to terms with her treatment. It was not until Maria began experiencing feelings of low mood and anxiety that she was referred to the Day Therapy Center to take part in a 12-week activity program of her choice. Maria was not keen on attending at first, and the first session was upsetting because she was the youngest person there. Sometimes it was difficult for her to get to the sessions since she worked during the day.

Maria is comfortable with technology: she has an Internet Broadband connection at home, a computer, and a smartphone. She feels that a Virtual Hospice could be a convenient way for people with work and family commitments to access services, especially if they feel apprehensive about what to expect inside the Hospice buildings.

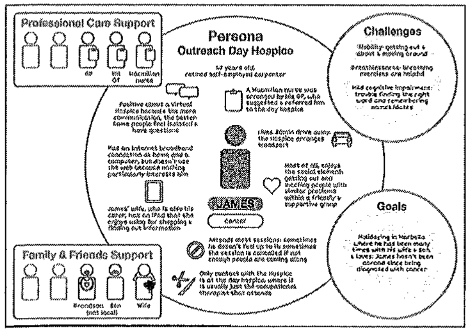

FIGURE 2.

One of three User Personas created based on user research, representing a key type of user accessing Highland Hospice services.

Persona 2 – James

"Talk to me; I'm still a person."

James is 76 years old and is living with cancer. A Macmillan Nurse, contacted by his GP, suggested and referred James to the nearest Highland Hospice Outreach Day Hospice service, which is a 30-minute drive away. The Hospice arranges community transport for James and other individuals. Most of all, James enjoys the social element – getting out and meeting people with similar problems within a friendly and supportive group. James attends most sessions: sometimes he doesn't feel up to it, and sometimes the session is cancelled. James has never been to the Hospice building in Inverness. His only contact with other patients and a very few staff members is through the Day Hospice.

James has an Internet Broadband connection at home and a computer, but he doesn't use the web because there is currently nothing of particular interest to him. However, his wife, who is also his caregiver, has an iPad that she enjoys using especially for shopping and finding out information. James is positive about a Virtual Hospice because he believes the more communication the better, and that some people feel very isolated and have questions they want to ask but are afraid to.

Persona 3 – Leesa

"If I had a magic wand, I would sprinkle the Hospice bed and environment to create that calm for the families."

Leesa is a nurse living and working on a remote Scottish island. Leesa is well connected to clinical staff in local GP surgeries, care homes, and hospitals. Her interactions with Highland Hospice are of a practical nature; she particularly values telephone advice on pain relief, symptom control, and domiciliary visits by Hospice staff. Unfortunately, it is often just too far for her patients and their families to travel to Inverness for care. Leesa supports around a dozen patients at any one time, most of whom have cancer, which involves extensive travelling time each week. Challenges of island life include patient privacy (as her car is recognised), little scope for drop-in visits due to travelling distances, and limited exposure to Hospice staff and their approach to care.

Leesa carries an Internet-enabled smartphone with her. She would love a "pocket Hospice clinician" for inspiration and knowledge and feels that a Virtual Hospice that reproduced the Hospice environment in community settings, especially the calmness, would be hugely beneficial to the islanders.

USER JOURNEY MAP

A User Journey Map was created with seven key stages based on a palliative care pathway provided by Highland Hospice: awareness (of Highland Hospice); first interaction (between healthcare professionals and Highland Hospice); recognition (of life-threatening nature of illness); first contact (between patients and Highland Hospice); living with the illness; time is short; and afterwards (see *Figure 3*). This section collectively describes the key insights and opportunities associated with each User Persona at each key stage of the map.

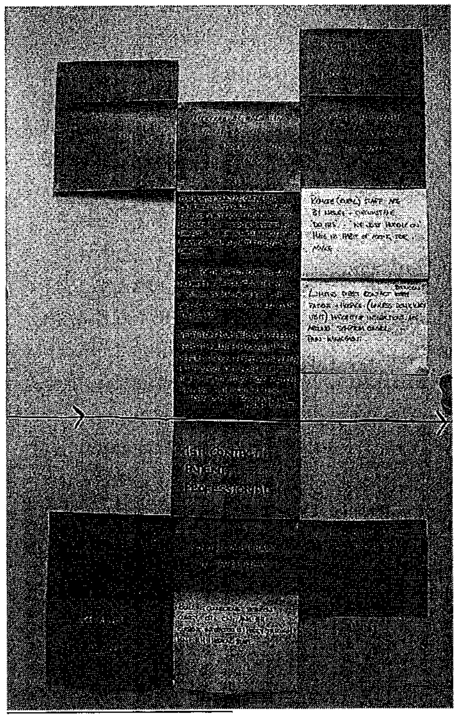

FIGURE 3.

Insights and opportunities relating to each User Persona were written on different coloured post-it notes (one colour per Persona) and affixed to the relevant key stage of the User Journey Map.

Awareness

Only those patients with previous knowledge of hospice, through their job or someone they knew having entered hospice, were aware of services prior to referral; other research also points to a limited understanding of end-of-life care among patients (Davidson, Whyte, & Richardson, 2012). Misperception of hospice among patients, e.g. hospice is only for people with cancer, and among professionals, e.g. hospice is only for pain and symptom control, was also revealed, although it was said to be changing among professionals. Finally, while the need to prepare for an ageing population is recognised among professionals, NHS staff training is viewed as ad hoc. The key opportunities identified included raising awareness of the services and support that hospice can offer, partly as a consequence, changing people's perceptions of hospice including fear, generating demand for support beyond clinical care, and providing online training programs for healthcare professionals.

First Interaction

Training sessions on palliative care at Highland Hospice are highly valued; however, those travelling long distances require a stopover in Inverness, which can be problematic for part-time staff. In addition, while Macmillan nurses are sent on an informal educational visit(s) to Highland Hospice as part of their training, they are not picking up the benefits of psychosocial support such as creative work and story telling. Funding for education and training on palliative care is also diminishing. The key opportunities identified included offering online learning programs and education resources for healthcare professionals, crafting a message that better communicates the psychosocial element of hospice care and the day hospice services available, and exploring alternative funding streams for delivering education.

Recognition

Healthcare professionals may not introduce the subject of hospice care in their early discussions with patients for reasons including that it is a sensitive and potentially upsetting topic to broach. Partly as a consequence, there can be a significant lapse of time before a referral to hospice, which can engender feelings in the individual of having been left unsupported. Interestingly, other research has identified key models of GP use of specialist palliative care services that includes seldom using such services (Shipman, et al., 2002) and has found large variation in GPs' knowledge about palliative care and available services (Higginson, 1999). The key opportunities identified included exploring why GPs do and do not refer patients to Highland Hospice services, building on the findings of Shipman, et al. (2002), using the feedback to improve referral rates at the earliest appropriate point, and allowing patients to self-refer (currently, patients must be referred by a healthcare professional).

First Contact

A relatively low number of individuals are referred to the Outreach Day Hospices, which, partly as a consequence, are run once fortnightly or even closed. Further, younger patients can find it problematic to attend Day Hospice services due to work and family commitments and upsetting to be put in a 'sick' role within a group that is typically much older. For patients not accessing Day Hospice services, direct contact with Highland Hospice is typically limited to domiciliary visits by clinical staff for pain and symptom control. The key opportunities identified included exploring why healthcare professionals do and do not refer patients to the Outreach Day Hospices, providing support for patients in the evenings outside normal office hours, and building connections between healthcare professionals and the full team of staff at Highland Hospice, as current interaction is mostly through Macmillan nurses and the Hospice clinical staff.

Living with the Illness

Patients attending the Outreach Day Hospices are consistent despite considerable travel time for some, with people particularly enjoying the social element. However, sessions are cancelled if numbers are too low, with patients additionally missing around one in four sessions for health reasons. Further, patients attending the Outreach Day Hospices generally only have contact with the few members of Hospice staff who facilitate or join the sessions. Healthcare professionals also find peer-to-peer support, e.g. sharing tips and experiences, extremely valuable. The key opportunities identified included video conferencing to improve the connection between patients attending the Outreach Day Hospices and Hospice staff in Inverness that do not regularly attend the sessions, using social media to support social interaction among patients, and online forums to support learning among professionals. Highland Hospice has no social media channels. However, research into new media usage within the hospice sector has identified a range of benefits using social networking sites as places for self-expression, finding out information, and feeling connected to friends and family—although usage is currently limited to patients and caregivers (Miller, 2013).

Time is Short

Hospital nurses deal with death and dying on a regular basis but have limited exposure to hospice staff in action compared to Macmillan nurses who liaise more closely with Highland Hospice staff. Domiciliary visits are appreciated, e.g. they confer value onto patients signed off by other consultants on a "there is nothing more we can do" basis; however, visits are by necessity planned around critical need due to time constraints and distance of travel. Travelling distance is also an issue for some patients living in remote areas far from Inverness who are reluctant to be admitted to the In-Patient Unit because the journey can be daunting for both them and their family. The key opportunities identified included improving access and training for nurses who work in hospitals on hospice care in action, connecting Highland Hospice staff with patients and their families in their own homes via videoconferencing when needed, and supporting enhanced caring for patients in their own homes through close collaboration with community teams.

Afterwards

Highland Hospice offers a range of bereavement support services. However, support groups for healthcare professionals are based in Inverness, which can be problematic for those travelling long distances. Nonetheless, Macmillan and community nurse teams do meet, sometimes to just cry together. While deriving great benefit from attending Day Hospice, including a real sense of comradeship, it can be upsetting each time a group member dies, partly due to missing the individual and partly fearing that they will be next. The key opportunities identified include establishing bereavement support groups across Highland, otherwise encouraging patients to talk about death and dying, and to plan for death to reduce the fear of dying, and to help caregivers return to living the life they led before becoming a caregiver.

THEMES

Five themes emerged from mapping each User Persona's journey through the Highland Hospice service experience, some of which were recurring (see *Figure 4*). Collectively, these themes frame the fundamental design challenge to the Hospice: raising public and professional awareness of Highland Hospice services, supporting connections between Highland Hospice and patients and healthcare professionals, changing perceptions of hospice to avoid delayed admission, increasing the number of referrals to Highland Hospice, and boosting training on palliative care.

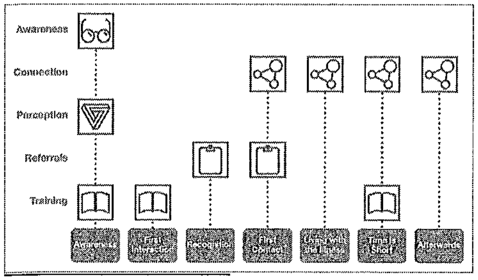

FIGURE 4.

DESIGN BRIEF

Lastly, a Design Brief was produced that synthesised the research findings in the form of a plan for creating, prototyping, and testing the Virtual Hospice through a series of Experience Laboratories. Experience Laboratories are at the core of the Digital Health Institute innovation model and are led and developed by the Institute of Design Innovation at the Glasgow School of Art. Experience Laboratories provide the opportunity to try new ideas and co-design solutions together with users in a realistic environment (Digital Health Institute). The Laboratories aim to bring together academics, business, and civic partners to collaborate in order to design sustainable solutions to health and social care challenges.

Four Laboratories were proposed, and the key aims are summarised here:

Lab 1

"Crafting the Message" aims to better understand health professionals' awareness and perception of Highland Hospice services and barriers to referral as the basis from which to move forward with the new Virtual Hospice service; if necessary, to more clearly define the current service offering ("message") potentially resolving the cause for some non-referrals.

Lab 2

"Building the Virtual Hospice" aims to co-design the Virtual Hospice with healthcare professionals through imagined removal of barriers to referral, to draft a Service Blueprint where the primary channel through which users will interact with the Virtual Hospice will be the web, and to identify areas to prototype. A

Service Blueprint is a design method that provides a visual and holistic view of a service and defines "front stage" (customer facing) and "back stage" (behind the scenes) activities.

Lab 3

"Testing the Virtual Hospice" aims to check that the proposed Virtual Hospice is acceptable and desirable to patients and their families by mocking up the home page of the Virtual Hospice website and navigation menu to show the full service offerings, making prototypes of parts of the service, and using established usability testing methods such as think aloud, where people say what they are thinking as they perform a task, and role playing, to gather feedback to iterate and improve the overall design of the Virtual Hospice.

Lab 4

"Look, Feel and How" aims to co-design initial concepts for the branding of the Virtual Hospice with stakeholders; to provide a consistent look and feel across services, focusing on key visual identity and user interface elements such as logotype, colour palette, fonts and widgets; to consolidate the learning and create a strategy for implementing the Virtual Hospice; and to identify creative and technical partners through the DHI Team Building service to assist with detailed service development, branding, and technology infrastructure set-up.

CONCLUSION

The number of people seeking specialist palliative care is expected to increase significantly in the near future. A Virtual Hospice would enable more equitable and convenient access to Highland Hospice services and a higher quality of community-based support. This is likely to increase the confidence of patients and their lay and professional caregivers, and improve the patient and family experience of palliative care. The challenges that face Highland Hospice in delivering services across a wide geographical area and around the clock are not unique to Highland; potentially, the Highland Virtual Hospice model could be reproduced by other hospices in the UK or overseas. Although this work involved a very small number of patients and healthcare professionals, the resulting Design Brief proposes engagement with a larger number of service users across Highland to build on and validate the research findings. The Design Brief has been accepted by the DHI and will be taken forward by the Experience Laboratory team.

ACKNOWLEDGEMENTS

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AUTHORS

Andrea Taylor

Andrea Taylor is a Research Fellow at the Glasgow School of Art. Andrea studied Interaction Design at the Royal College of Art. Research interests include user-centred design of health and care services.

Tara French

Tara French is a Research Fellow at the Glasgow School of Art. Tara studied Psychology at the University of Glasgow. Research interests include the use of digital technologies in health care and the role of music in health promotion.

Jeni Lennox

Jeni Lennox is an Associate of the Glasgow School of Art and a Consultant for Alzheimer Scotland. Jeni studied Product Design at the Glasgow School of Art. Research interests include service design for people living with dementia.

Dr. Jeremy Keen

Dr. Jeremy Keen is a Consultant Physician in Palliative Care at Highland Hospice. Jeremy has 25 years experience in cancer and palliative care. Research interests include the use of new technologies in palliative care.