COVER LETTER

Details of related papers already published

Taylor A, French T, Lennox J, Keen J. Developing a design brief for a virtual hospice using design tools and methods: a preliminary exploration. *Visible Language* 2015;49:96–109.

KEYWORDS

Virtual hospice; hospice; end-of-life care; palliative care; health; design methods; design principles; experience labs.

TITLE PAGE

Title of the article

Developing Design Principles For a Virtual Hospice: Improving Access to Care

Corresponding author

Andrea Taylor

GSA Highlands & Islands Creative Campus, Blairs Farm Steading, Altyre Estate, Forres, Moray IV36 2SH, UK

A.Taylor@gsa.ac.uk

07704 911756

Co-authors

Andrea Taylor, School of Design, Glasgow School of Art, Moray, UK

Tara French, Institute of Design Innovation, Glasgow School of Art, Moray, UK

Sneha Raman, Institute of Design Innovation, Glasgow School of Art, Moray, UK

Word count

1500 words

ABSTRACT

Objectives

Providing access to hospice services will become increasingly difficult due to the pressures of an ageing population and limited resources. To help address this challenge, a small number of services called Virtual Hospice have been established. This paper presents early-stage design work on a Virtual Hospice to improve access to services provided by a hospice (Highland Hospice) serving a largely remote and rural population in Scotland, UK.

Methods

The study was structured as a series of Experience Labs with Highland Hospice staff, healthcare professionals and patients. Experience Labs employ a participatory design approach where participants are placed at the centre of the design process, helping to ensure that the resultant service meets their needs. Data from the Labs was analysed using qualitative thematic analysis and design analysis.

Results

A number of themes and barriers to accessing Highland Hospice services were identified. In response, an initial set of seven design principles was developed. Design principles are high-

level guidelines that are used to improve prioritisation and decision-making during the design process by ensuring alignment with research insights. The design principles were piloted with a group of stakeholders and gained positive feedback.

Conclusions
The design principles are intended to guide the on-going development of the Highland Hospice Virtual Hospice. However, the challenges faced by Highland Hospice in delivering services in a largely remote and rural setting are not unique. The design principles, encompassing digital and non-digital guidelines, or the design approach could be applied by other hospices in the UK or overseas.

INTRODUCTION

Hospice care provides physical, social, emotional and spiritual support for people with life shortening illness. The number of people seeking specialist palliative care is expected to increase considerably as more people are living longer with life shortening illnesses. To help address this challenge, a small number of services called Virtual Hospice have been developed around the world. For example, the Canadian Virtual Hospice is a well-established web-based platform that allows Canadians to email questions to a palliative care team.[1] In Australia, the Virtual Hospice provided by Maitland Palliative Care Service is a community-based service supported by online resources that is founded upon collaborative relationships between people involved in end-of-life care.[2]

This paper describes the development of design principles for a Virtual Hospice in collaboration with Highland Hospice, which provides specialist palliative care in the Highlands of Scotland, the largest and most sparsely populated part of the UK. Highland Hospice provides an inpatient unit and a range of services at its main building in the city of Inverness, and a day therapy centre in outlying areas. A specialist palliative care team supports healthcare professionals to provide palliative care in individual's homes, care homes and hospitals. However, most patients access services based in Inverness and tend to live within a 30-mile radius. Also, if not inpatients, most patients have contact only within office hours. The vision of Highland Hospice is to create a Virtual Hospice to improve access to its services.

This paper contributes an initial set of design principles for a Virtual Hospice, developed based on the experiences and priorities of key stakeholders. Design principles are concise, high-level guidelines that are used to improve prioritisation and decision-making during the design process by ensuring alignment with research insights.

METHOD

The research involved three Experience Labs. Experience Labs is a participatory design approach developed by Glasgow School of Art to co-create sustainable solutions in response to health and care challenges.[3] Experience Labs facilitate collaboration among academic, business and civic partners, and end-users, to generate solutions that are user-driven and meet the needs of those who will receive or deliver care. Employing participatory design can lead to enhanced results in terms of efficiency and usability when designing services[4], and there has been increased use of design approaches within health and care service improvement.[5,6] The Experience Lab results were captured by the research team using audio recordings, photographs and field notes, and analysed using thematic analysis.[7] The results of Lab 1 were additionally analysed using analysis on the wall[8] and affinity diagraming[9] design methods.

Prior to the Experience Labs, the research team worked with staff at Highland Hospice to succinctly document its services. These were visualised as a deck of 24 cards, one card per

service, grouped into four types of service: telephone advice, inpatient services, outpatient services and education services.

Lab 1

Lab 1 explored professionals' awareness, use, and barriers to use, of Highland Hospice services. It was delivered in four locations across the Highlands. Nineteen professionals participated: general practitioners, nurses, care home carers and a community pharmacist. Participants were tasked to draw the illness trajectory of their last deceased patient on a graph with two axes: time (starting with recognition of life shortening illness) and health. The deck of service cards was then presented and discussed. Next, participants were asked to reflect back on selected trajectories and consider which services might have been helpful, and where services were used, whether they might have been helpful at an earlier stage. Fourteen trajectories were produced, reflecting the different experiences of participants. Following Lab 1, the research team developed seven design principles.

Lab 2

Prior to trialling all seven design principles, Lab 2 gathered preliminary feedback on a single principle, 'Show and Tell', of particular relevance to patients (described later). Five Highland Hospice patients and one carer participated. Participants formed two groups to explore opportunities for promoting Highland Hospice services. Guided by a facilitator, one group role-played the creation of a promotional video describing their experiences. The other group discussed important characteristics of promotional videos and their feelings about sharing their stories. Lab 2 also explored patients' awareness, use, and barriers to use, of Highland Hospice services. The deck of service cards was presented and discussed, and participants were asked to consider other services they might now use.

Lab 3

Lab 3 trialled all seven design principles. Fifteen stakeholders participated, most of who had participated in a prior Lab: Highland Hospice staff, healthcare professionals, patients and a carer. Working in two mixed groups, participants were tasked to choose a location in the Highlands and ideate a Virtual Hospice 'hub' by applying the design principles. Two tools were provided: a template with seven columns and headers—one per design principle—for transcribing design ideas; and Lego for visualising design ideas. At the end of Lab 3, each group presented their Virtual Hospice hub and gave feedback on the design principles.

RESULTS AND DISCUSSION

The research team identified four themes and a number of barriers to accessing Highland Hospice services. Based primarily on the barriers, seven design principles were developed for the Virtual Hospice, which are aligned with and supported by the themes:

Themes and Design Principles

<u>Awareness and Perception (increase communication and change attitudes)</u>

1. Create a physical presence: establish an element of Highland Hospice in communities across the Highlands that people can recognise and draw reassurance from.
2. Show and tell: produce and promote case study videos explaining Highland Hospice services that will inspire local trials of future services.

<u>Education and Training (empower professionals and volunteers)</u>

3. Collate and curate: provide and maintain information and education resources that different groups of people can access online.

<u>Embedding Trust and Familiarity (increase local connections and networks)</u>

4. Gather the people: build and maintain a network of people including local collaborators and volunteers.

5. Put in the technology: as needed, ensure robust and reliable equipment and Internet connectivity is in place.

Enriching Life (provide everyday support for all)

6. Open the door wider: remove the requirement for referral to suitable Highland Hospice services and promote direct access.
7. Offer practical services: provide practical care and support services for professionals, patients and their families.

Table 1 outlines the identified barriers and shows the connection with the design principles. Figure 1 is an example patient trajectory and illustrates the Awareness and Perception theme. The participant who charted this trajectory commented there was 'nothing untoward that needed managing', highlighting the misperception of 'hospice'. They later identified nine services that might have been beneficial earlier on in the patient's illness had they been aware of Highland Hospice's full service offer. The results suggest that a Virtual Hospice should extend beyond a purely web-based platform, to include a network of people across the Highlands to support community-based care, and similarly a network of places (hubs) for people to connect and experience hospice-style care.

Themes	**Barriers**	**Design Principles**						
		Create a physical presence	Put in the technology	Gather the people	Offer practical services	Open the door wider	Show and tell	Collate and curate
Awareness and Perception	Low awareness among some professionals of the services and support that Highland Hospice can offer, reflected in a limited uptake of services.	■					■	
	Limited understanding among some professionals of the benefits of hospice care, reflected in the trend for referrals at a late stage in the course of an illness.						■	
	A 'we can manage' attitude among some professionals in more sparsely populated communities, resulting in a disinclination to ask for support if/when needed.		■					■
	Some resistance by some GPs, who are largely the gatekeepers to hospice care, to refer patients or to refer without conditions.					■		
Education and Training	General practice nurses need to obtain permission from GPs to refer patients, but can lack training and resources to support their decision to refer.					■		
Embedding Trust and Familiarity	Existence of similar services locally. Or perceived existence, given that some professionals do not fully understand the specialist nature of a hospice team.			■			■	
	The importance for some patients to receive support from local people they know rather than a hospice team that they don't know.			■				
	Too long travelling distances for some people to inpatient and education services provided in the main Highland Hospice building or outreach centres.		■					
Enriching Life	Identifying the key point in a patient's illness at which to refer for hospice care, which can delay access to services that would be beneficial earlier on.				■			

Trialing the Design Principles

During Lab 2, feedback was gathered on the 'Show and Tell' design principle. Overall, feedback was positive. Participants agreed that videos could be a valuable method to raise awareness of Highland Hospice services, and could help change the perception of hospice as a 'place to die'. Some participants suggested that the video could be shown as part of a school education programme. They felt that the content of the videos should include sharing stories, but that people should have the flexibility to tell their story in their own way.

During Lab 3, participants prototyped two potential Virtual Hospice hubs using the design principles: a Men's Shed and a hub within a care home—described here. The team, which included a senior care home nurse, discussed each design principle in turn and recorded their ideas. Ideas included:

- For 'Create a physical presence', participants proposed a plaque (mark of recognition) above the entranceway to the care home inscribed with 'Supported by Highland Hospice';
- For 'Put in the technology', participants proposed a video conferencing system for round-the-clock access to specialist advice from Highland Hospice staff in Inverness;
- For 'Gather the people', participants proposed offering school leavers the opportunity to volunteer.

Overall, feedback on the design principles was positive, and participants reported that the principles helped them create a shared vision for high-level design.

CONCLUSION

The number of people seeking specialist palliative care is expected to increase significantly in the near future. By encompassing networks of people and places supported by digital technologies, a Virtual Hospice could maximise access to Highland Hospice services and enable a higher quality of community-based care and support. The challenges faced by Highland Hospice in delivering services over a wide geographical area are not unique to the Highlands of Scotland. Potentially, the design principles or the participatory approach to develop the design principles could be explored by other hospices in the UK or overseas. A limitation of this study is that the design principles have been piloted with a small number of stakeholders in two possible community settings. However, they are derived from considerable user research data, including findings from the authors' previous work,[10] and preliminary feedback has been positive.

ACKNOWLEDGEMENTS

We thank all those who were involved for their time and support, with special thanks to Jeni Lennox who was part of the research team and Dr. Jeremy Keen, Consultant Physician in Palliative Care at Highland Hospice. The Digital Health & Care Institute, supported by the Scottish Funding Council, funded the project.

Competing Interest

Competing Interest: None declared.

ETHICS

Study approval was obtained from the National Research Ethics Service, Research Ethics Committee reference: 15/LO/0744.

REFERENCES

1. Chochinov H, Harlos M, Cory S, et al. Canadian Virtual Hospice: A Template for Online Communication and Support. In: Holland J, Breitbart W, Butow P, Jacobsen P, Loscalzo M, McCorkle R, eds. Psycho-Oncology (3 ed.) 2015;doi:10.1093/med/9780199363315.001.0001 [published Online First: March 2015].
2. Virtual Hospice. http://www.virtualhospice.com.au (accessed 16 Aug 2016).
3. French T, Teal G, Raman S. Experience Labs: co-creating health and care innovations using design tools and artefacts. In: Lloyd P, Bohemia E, eds. *Proceedings of DRS2016: Design + Research + Society - Future-Focused Thinking* 2016;7:2965–2979.
4. Schuler D, Namioka A. Participatory Design: Principles and Practices. USA: L. Erlbaum Assoc. Inc.1993.
5. Robert G, Cornwell J, Locock L, Purushotham A, Sturmey G, Gager M. Patients and staff as codesigners of healthcare services, *BMJ* 2015; 350: 7714.
6. Bowen S, McSeveny K, Lockley E, Wolstenholme D, Cobb M, Dearden A. How was it for you? Experiences of participatory design in the UK health service, *CoDesign* 2013;9:230-246.
7. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3:77-101.
8. Sanders E, Stappers P. Convivial Toolbox: Generative Research for the Front End of Design. Amsterdam: BIS Publishers 2012: 212–215.
9. Martin B, Hanington B. Universal Methods of Design. USA: Rockport Publishers 2012:12–13.
10. Taylor A, French T, Lennox J, Keen J. Developing a design brief for a virtual hospice using design tools and methods: a preliminary exploration. *Visible Language* 2015;49:96–109.

LEGENDS

Table 1. Identified barriers to accessing hospice care in relation to the design principles.

Figure 1. An example of an illness trajectory and where Highland Hospice services may have been beneficial.