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White, Hazel; Nevay, Sara; McNicoll, Joanne; Press, Mike; MacKinnon, Paul; Zhou, Yumeng

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Praxis and Poetics: Research Through Design Fabric Fobs and Family Ties

Hazel White

Dundee University
Dundee
DD1 4HT

h.white@dundee.ac.uk

Sara Nevay

Dundee University
Dundee
DD1 4HT
s.z.nevay@dundee.ac.uk

Joanne Hodge

Dundee University
Dundee
DD1 4HT
joanne@joannehodge.co.uk

Mike Press

Dundee University Dundee DD1 4HT m.press@dundee.ac.uk

Paul Mackinnon

Dundee University
Dundee
DD1 4HT
p.d.mackinnon@dundee.ac.uk

Yumeng Zhou

Dundee University
Dundee
DD1 4HT
ymingzhou@gmail.com

Abstract

How can the co-creation of bespoke, handmade playful objects support children who have complex communication needs? 'Fabric Fobs' are prototypes of digitally tagged objects that comprise key touchpoints of a service system that enables independent access to online communication in a demanding family-centred healthcare context.

In a project funded by the Scottish Funding Council through its Spirit Innovation Voucher Scheme, the research team used a co-design method: grounded in the understanding of the real life experiences, ideas and skills of the people, who use, need and run services. Design and craft methods were used to create an environment in which new digitally tagged objects could be created by parents, children and health professionals to explore relationships and observation, participation, conversation, prototyping and manufacturing could happen in the same space.

The collaborative workshops uncovered a latent need which the team are currently working on – designing a service system to enable the parents and carers of children with complex communication needs to share information about their child's personality, likes and environmental needs.

Working with children, their families and carers in 'craft cocreation' workshops enabled conversations about family relationships, home, music, films, sounds and other activities which paint a picture of the life of a child who cannot communicate be shared and documented. The families and carers of children with complex communication needs became designers of their own interactions. This paper discusses the staff and parents' responses to the process and recommendations for the next stage of the process.

Author Keywords

design, collaboration, craft, co-design, healthcare, public services, service design



Figure 1. Mother, daughter and carer engaged with a 'Fabric Fobs' making activity within a co-design workshop

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Research Imperatives

The aim of the project was to explore the value of working with children with life-shortening conditions and complex communication needs, together with their families and carers, to design bespoke handmade playful objects that enable independent access to online communication.



Figure 2. RFID tagged textile fob

A central research question is how can craft-based co-design processes provide innovative solutions to accessing secure social networks that enhance the quality of care for such children and their families? This builds on two previous projects by members of the research team exploring the value of communication systems integrating bespoke handcrafted components: Hamefarers' Kist (White, 2009) is a system developed to connect older people in the remote Shetland Islands with their far-flung relatives, using networked knitted objects to link people and events; Pigeon Post (Hodge, 2011) is a doctoral research project exploring communication between parents and children who are separated through illness or family breakdown, demonstrating the use of digitally tagged toys and accessories which enable very young children to

activate Skype calls or send texts to family and relatives from whom they are separated.

The Fabric Fobs project applied these methods and practices to a new and highly challenging research context. Children's Hospice Association Scotland (CHAS) is the only charity that provides hospice services in Scotland for children and young people with life-shortening conditions, supporting over 300 children and families, as well as providing a significant number of families with bereavement support (CHAS, 2012). The relationship between the design research team and CHAS was facilitated by Nora Kearney, Professor of Cancer Care at the University of Dundee who had seen a demonstration of the Hamefarers' Kist and recognised its potential application in a new care environment.

The research team from the University of Dundee brought together a range of expertise: Hazel White and Mike Press: codesign, craft research and service design research, Paul MacKinnon, technology expertise in programming and app development, Jo Hodge and Sarah Nevay textile and design research research and practice and Yumeng Zhou service design and UX testing. The team from CHAS' Rachel House Hospice supported us at all levels, from children and their families, activities and care staff, particularly Alison Blair and Carla Halkett to CEO Maria McGill .

The project explores how technology can be humanised by using handcrafted, often lo-fidelity artifacts created by users to give meaning and purpose to interactions with secure online social networks. The lo-fi approach enables non-designers to participate in the creation and development of the system. In this process, young people and families at CHAS were invited to design bespoke communication systems that specifically met and complimented their needs, allowing those with conditions that may affect their motor skills or mobility or their ability to verbalise or sign to begin to independently build and maintain new bonds and relationships and share their changing likes and dislikes. This "opens up a world of 'can do'" (Carer, CHAS

2013) and aids in self efficacy for young people and their families. Furthermore, as Wallace (2010) states, the co-creation of personalised artifacts linked to these such experiences allow objects to "act as anchor points to events in our lives and consequently our sense of who we are". For CHAS's young people these objects as communicators and signifiers may communicate, not only a basic need, phrase or like, but a sense of a person.

Research Process

We began by exploring how tagged textile objects could enable young people with muscular dystrophy to continue to access their favourite online content independently.

Two one day, co-design workshops running 4 weeks apart were designed by the research team to create a natural and safe environment in which families and staff could comfortably work over a sustained period. Children, their families and staff explored their needs and abilities, and the requirements for the system. With backgrounds in design, programming and craft, the design team used their knowledge and experience of visualisation and making objects to facilitate participating families and staff in becoming designers themselves within the co-design process, imagining how they might use the system in the future and making their ideas tangible.

Demonstrator 'fabric fobs' were prepared in advance: small RFID (Radio Frequency Identification) tagged padded pockets that can be customised by painting with fabric paint, or embroidery or embellishing with buttons, eyes, and bells, or applying transfers of drawings and photographs. We used RFID technology to assign each tag a unique identification number, which is read wirelessly when in close proximity to a reader. This allows for activation without the object needing to be accurately placed, meeting the needs of young people whose gross motor skills may be diminishing. A new iPad version of the app, which powered Hamefarers' Kist, was programmed so that online content could be shown on tablet technology, which

is familiar and readily in use by children and staff at CHAS. In the workshops, participants – children, siblings, parents and CHAS carers and activity staff - could try out the demonstrators with various handmade, tagged fabric fobs that connected to online content on the iPad. The participants were enchanted; finding this interaction 'magical', expressing delight and wonder, that such a simple, handmade object could control the iPad's online content. We observed a heightened level of engagement from some children when linking their customized fobs to their favoured online content and parents commented on the power of these simple interactions in "giving (their child) a voice" in directing even day to day tasks and activities. As Wallace et al. state "Enchantment does not necessarily imply that the object of enchantment must be novel or extraordinary, rather that the person sees how rich and extraordinary the everyday and familiar can be..." (Wallace et al. 2005)

We interacted with around six children, seven parents and nine staff over the course of these two workshops. The first uncovered a range of design opportunities, including validating the original premise of enabling independent access to online content with some of the children, but suggesting other needs for children with more complex communication requirements.

The research team made a prototype sensor mat to present to new children and families: a multi-pocket felt construction, designed so that each individual coloured pocket contained sensors for different functions. This was trialed at the second workshop with the caveat that it had not taken a long time to make and we work to the principle of 'prototype like you're right, listen like you're wrong' (Moon, 2011). Over the next two hours a system of handmade objects was prototyped that could connect to an online interface enabling both staff at CHAS and the grandparents of one child to easily access music, images and video associated with him. The discussion and evaluation of this rapidly constructed hand crafted demonstrator with the family and CHAS staff led to the development of the key requirements for the next iteration of the system.

Research Outcomes

Conversations with families and staff, facilitated by the making activities within this research, led us to uncover an unanticipated latent need: for products and services to help the parent and carers of children with complex communication needs to share information about their child/s personality, likes and home life.

CHAS staff commented that they had 'got to know well' the family in Workshop 1 in a relatively short time, whereas they might have expected to have built that relationship over a number of visits. The co-design environment therefore had unanticipated therapeutic and healthcare benefits as families and staff had the opportunity to share their stories, learn from and afford one another a deeper understanding of their needs and personal circumstance in a safe space, without pressure as the making activities took focus.

This project demonstrates the value of craft-based collaborative making in a healthcare context in ways rarely explored by previous research. Corkhill (2007), Argyle and Bolton (2005) and Fratiglioni et al (2004) variously attribute benefits to craft's role in healthcare. Wallace has explored the value of creating jewellery objects for use in clinical contexts. But as Yair (2011) observes, "Craft's contribution to wellbeing is not limited to clinical and therapeutic settings. In the wider community, there are very specific ways in which craft can bring us together and strengthen our sense of connectedness."

Research has thus demonstrated (i) the therapeutic value of making both in itself and as a consequence of its social dynamics, (ii) the value of handmade objects in some clinical contexts and (iii) the community based value of craft that has indirect health and wellbeing benefits. However, there has been less attention paid to studying the processes of creative making as a mediator between providers and recipients of healthcare. The value of this study is in demonstrating the potential value of this, not only as a means of enhancing communication per se,

but very specifically as a process by which families and carers can be encouraged and enabled to become designers of their own interactions.

The outcome of the project has been the development of design requirements for a system which will enable staff at CHAS and the families and relatives of children with complex communication needs to share the personality of a child through bespoke handcrafted objects which link to private social networks.

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