

Impact case study (REF3)

Institution: Sheffield Hallam University		
Unit of Assessment: UOA32 – Art and Design: History, Practice and Theory		
Title of case study: Lab4Living: design to promote quality of life and wellbeing		
Period when the underpinning research was undertaken: 2007 - 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Paul Chamberlain	Director Lab4Living	September 1991 - present
Claire Craig	Professor of Design & Health	May 2004 - present
Heath Reed	Principal Researcher	January 200 - present
Joseph Langley	Principal Researcher	May 2007 – present
Period when the claimed impact occurred: 2014 - 2020		
Is this case study continued from a case study submitted in 2014? No		

1. Summary of the impact

Research undertaken by Lab4Living has developed products that have **enhanced dignity and quality of life for individuals with long-term conditions**. The Head-Up neck orthosis has **delivered ‘life-changing’ improvements for people living with Motor-Neurone Disease (MND)** and is now **in use at 25 NHS Trusts in the UK and available worldwide**. Lab4Living’s Support4All garment has **improved modesty and dignity for women undergoing treatment for breast cancer whilst increasing the accuracy of radiotherapy procedures**.

The research-informed product Life Café has **enabled people to engage in open conversations about the care of the dying**. Life Cafés have been **adopted by terminal cancer charity, Marie Curie, for their national programme** of work on enhancing end of life care. Lab4Living’s Journeying through Dementia intervention has **shaped national policy and provision of care for people living with dementia** across Scotland and Wales.

2. Underpinning research

Medicine is a material science and is enacted through instruments, objects, furniture and products. Dominant medical discourses can neglect to understand this materiality and the meaning of these products in the context of patients’ lives. This disconnect is most apparent during major health transitions, for instance in the diagnosis of chronic conditions such as dementia or in the experience of invasive treatments such as those for cancer.

A programme of funded research (British Council, NIHR i4i, Marie Curie, NES, Alliance Scotland) has used design methodologies to understand the challenges that individuals experiencing these transitions face and developed informed responses through the creation of products and tools that challenge existing medical discourses, placing emphasis on dignity and quality of life. Central to this research has been overarching methodological principles that bring together diverse communities of stakeholders from the outset, foregrounding the experiences of the end-users and a thinking-through-things methodology (**R1**) drawing on exhibition and collective making as knowing. In doing so, an overly dominant discourse and reliance on written and verbal methods of data collection is challenged and knowledge is situated within and across the communities where it is generated. (**R2**)

A methodology centred on collective making creates the right conditions for research knowledge to be mobilised by addressing issues relating to stakeholder relationships and enabling the discovery, sharing and blending of different forms of knowledge from different perspectives. This can be applied across different contexts, enabling stakeholders from diverse methodological

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paradigms in design and health to learn about the practical implications of knowledge use and to collectively create actionable products (R2).

Reed and Langley led a series of collaborative workshops with neurologists clinicians, industry, people with MND and their carers and identified a need to increase usage of traditional neck orthoses by people living with MND (R3). Research revealed a number of factors leading to non-use including restrictiveness, levels of support and stigma. Funding through the NIHR i4i programme was secured with partners and through an iterative practice-led method of co-designing and testing with the research partners led to the design of a new customisable collar named **Head-Up** (R3).

A similar collaborative methodology was adopted by Reed et al. for the research programme **Support for All**, (R4) which sought to improve the experience of woman undergoing radiation treatment for breast cancer. Research focused on an area of unmet need - the development of a bra providing a more dignified, stabilising and positioning garment for use during post-operative breast cancer radiotherapy. (R4).

Medical advancements have resulted in an extended 'end of life' where people live with and die from multimorbidities that has placed more pressure on palliative care services. In 2017 cancer charity Marie Curie commissioned a programme of research to inform the development of new models of end of life-care. 141 older people were recruited from community and third sector organisations to participate in the study which utilised a thinking through things methodology named exhibition in a box (R1). A key finding of the research was that people did not have the opportunity to talk about what was important to them and how they gave and received care (R5). It was found that the curated creative activities named **Life Café**, developed as a methodology through collective making within the research, offered a vehicle through which individuals could articulate the values, meanings and motivations that individuals regarded as a priority (R5).

Dementia impacts on the quality of life of 850,000 individuals in the UK. Craig's (2017) enquiry (R6) brought together people living with dementia and their families to gain insight into what would promote wellbeing following diagnosis. This led to the co-designed intervention **Journeying through Dementia**, equipping individuals with the skills required to redesign their life-style to accommodate the challenges that living with dementia brings. This research then brought together policy makers and lead clinicians to understand what was required to operationalise the intervention across health services and collectively co-create tools with them (R6).

These outputs form part of Lab4Living's portfolio of research that supported the success in gaining the Expanding Excellence in England (E3) Award from Research England in 2019. As one of only 13 recipients nationally, the award was a recognition of the quality of the research undertaken. This quality has been endorsed through a number of awards (ROMPA Quality of Life Award 2010, Innovations Award, 2010). Research Councils cite Lab4Living research as examples of excellence in applied research (e.g. NIHR 2018) and methodologies as best practice in co-design (NIHR INVOLVE 2019).

Lab4Living has established wide reaching pathways to the dissemination of research in this field. These mechanisms include (but are not limited to) the International Design4Health conference, which attracts world leading design and healthcare researchers the Design for Health Journal and the Design4Health Global Network.

3. References to the research

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- R1.** Chamberlain P., Craig C. (2013) Engagingdesign – Methods for Collective Creativity. In: Kurosu M. (eds) Human-Computer Interaction. Human-Centred Design Approaches, Methods, Tools, and Environments. HCI 2013. *Lecture Notes in Computer Science*, vol 8004. Springer, Berlin, Heidelberg. https://doi.org/10.1007/978-3-642-39232-0_3
- R2.** Langley, J. Wolstenholme, D and Cooke J. (2018) Collective making as knowledge mobilisation; the contribution of participatory design in the co-creation of knowledge in healthcare. *BMC Health Services Research*, 18, p.585. <https://doi.org/10.1186/s12913-018-3397-y>
- R3.** Reed, H et.al. (2015) Head-Up; An interdisciplinary, participatory and co-design process informing the development of a novel head and neck support for people living with progressive

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neck muscle weakness, *Journal of Medical Engineering & Technology*, 39 (7): 404-410. <https://doi.org/10.3109/03091902.2015.1088092>

R4. Reed, H. (2017). Proving the proof of concept; developing new methods and knowledge to evaluate products supporting cancer therapy in *Design for Health* 1(1) p105-114. . <https://doi.org/10.1080/24735132.2017.1295660>

R5. Fisher, Helen, Craig, Claire and Chamberlain, Paul (2019). Life Cafe - A co-designed method of engagement. *The design journal: Proceedings of the 13th EAD conference* University of Dundee, 10-12 April 2019, 22 (sup1), 445-461 <https://doi.org/10.1080/14606925.2019.1595431>

R6. Craig, Claire and Fisher, Helen (2020). Journeying through Dementia: the story of a 14 year design-led research enquiry. In: Christer, K, Craig, C and Chamberlain, P, (eds.) *Proceedings of the 6th International Conference on Design4Health*. Lab4Living, Sheffield Hallam University: 105-117 <https://research.shu.ac.uk/design4health/wp-content/uploads/2020/06/D4H-Proceedings-2020-Vol-1-Final.pdf>

All outputs were rigorously reviewed prior to publication.

4. Details of the impact

Products developed by Lab4Living have improved quality of life and wellbeing for individuals living with MND, cancer and dementia, promoting dignity and independence. Lab4Living's methodology, which strategically engages stakeholders throughout research programmes, has established pathways to impact and has led to shaping government policy, the commissioning of interventions within health and in the extension of commercial markets.

Head-Up: Head Up was selected as one of four case studies from a total of 170 funded projects for a report by RAND on the NIHR Invention for innovation (i4i) programme to evaluate outputs and impacts emerging from the programme. The report identified that common enablers included the multidisciplinary skill mix of the Lab4Living team as well as consultation and access to patients (users) and proactive efforts to understand the regulatory landscape. Insights generated through the Head-Up research (**R3**) resulted in a product distinct from any existing orthosis (**E1**) offering support whilst also providing freedom of movement. Head-Up has enabled ongoing participation in meaningful activity including, driving, work and interacting with others. Patients have described the 'life changing' impact the collar has had on their **quality of life (E1)** and carers also affirmed benefits on their own **wellbeing**.

I could not contemplate life without my husband having the collar (UK customer, E1)

'Her life has been transformed by the use of the head collar. She is able to sit more upright...it has been life enhancing in that she can sit in her wheelchair and spend more time outdoors' (French carer, E2)

Head-Up wearers have noted the non-stigmatising appearance of the collar which promotes **dignity** as '*it looks like a piece of clothing rather than a medical device*' (**E1**) and its unique design allows it to be customised to the exact needs of the individual so that as their needs change the collar can provide additional support with demonstrable outcomes. In a study of 140 patients Head Up scored significantly better ($p < 0.005$) than previous collars used by patients in terms of satisfaction, level of support offered, residual head movement possible, appearance, and lack of interference with eating and drinking. **Patient health outcomes have been improved**. In a trial of 100 patients in 10 sites across the UK, key **functional improvements** were seen and Head Up was found to be more effective than previous collars in enabling patients to eat, drink and swallow (**E3**). Correspondingly, care practices have changed and by 2018 the collar was **offered by 25 hospital trusts in the UK (E4)**.

Head-Up has been licenced to, and manufactured by leading medical device supplier, Talarmade. This has opened up a **new market** for the company [Text removed for publication]. Patents have been granted in the UK and the USA. Head-up is CE marked, complies with US standards and has been granted the 'L0170' code (pre-requisite for clinical prescription in US) (**E2**). Head-Up is currently distributed across all mainland EU countries, Nordic countries, Australia, New Zealand, Canada and Ireland. It has three distributors in the US including the two largest in the sector (**E5**).

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Support4All: Research (R4) led to the design of the Support4All garment (S4A) which stabilizes and positions the breast during radiotherapy treatment. This has improved the **accuracy** of the procedure, preserved the **dignity** of the patient, who is not required to fully undress or undergo as many permanent tattoos to guide treatment. A randomised feasibility trial involving 50 patients showed improvement in mean ipsilateral lung breast irradiation dose when using the garment (E6). User experience was improved with evidence of increased **patient wellbeing, modesty, dignity** and **empowerment** (E6). The research was named in the top 100 university discoveries (E7).

'This is exciting and innovative research with the potential to improve both the accuracy and experience of radiotherapy.' (Nicola Blackwood, Public Health Minister)

A **patent** for S4A has been granted with national validations in Austria, Belgium, Germany, Denmark, Spain, France, GB, Ireland, Italy, Lithuania, Netherlands, Switzerland and Sweden. A US patent application is pending, and **licencing** discussions are underway with www.macromedics.com (E5).

Life Café: The outcome of the Design to Care research programme (R5), the Life Café is a product comprising a set of curated creative activities which has enabled individuals to engage in conversation about end of life and, where appropriate, has informed treatment planning. Over 200 Life Cafes have been purchased by the 3rd sector terminal cancer charity, Marie Curie, who have **adopted the product** to support a national programme of work to promote **wellbeing** by engendering conversations about end of life care:

'Lab4Living's Life Cafes stood out as a truly innovative method of community consultation and development. The Life Cafes proved much more useful than interviews, because we heard answers to questions that had not necessarily occurred to us, as service deliverers' (Clinical Director, Marie Curie, E10)

Since 2018, over 50 Life Cafés have been held in communities, care homes, hospitals and hospices where it has supported conversations about care requirements promoting **dignity** and **quality of life** in the context of care. (E10) A study evaluating the Life Café on a national scale has been delayed due to COVID-19, however data collected to date shows that **participants value the Life Café** in promoting conversation and in sharing hopes and fears around the taboo subject of death **promoting mental wellbeing**(E8, E10):

'It's been wonderful to communicate with people on this level and think about the moments that are not very far for some of us...what would we like when we're in that position', (Life Café participant, E8)

'Wherever Life Cafes are held, they generate a tremendous amount of enthusiasm; also a kind of relief that it is possible to be open, spontaneous and creative about such a difficult subject as the death of ourselves, and those we love', (Clinical Director, Marie Curie, E10)

In Higher Education settings, including in Sheffield and Lincoln, it has been recognised as a 'powerful and innovative tool ... to cultivate significant connection and conversation' around end of life care for students of Occupational Therapy.

Journeying through dementia: The *Journeying through Dementia* programme has been a **key component in the delivery of the dementia strategy for Allied Health Professionals (AHP) in Scotland**. The programme has **been adopted by Alzheimer Scotland**. It has also formed the basis of a Royal College of Occupational Therapists **AHP career Fellowship Scheme** (E9). *Journeying through Dementia* is cited as a **central element of the AHP Scottish policy, Connecting People, Connecting Support** (E9) and, as part of a national roll-out, has been **successfully implemented by health services** in Fife and Aberdeenshire. AHP consultant, and lead for Policy Research in Scotland, has secured Alliance self-management funding for roll out across a further 7 Boards in Scotland. She reports that:

'Data captured following its implementation across Fife and Aberdeenshire showed that 71% of participants reported improved quality of life as measured using QoL-AD. People with dementia described feeling more confident and more able to engage in meaningful activities'. (E9, E10)

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The original programme developed by Craig has been the focus of an RCT in England (Mountain et al 2015) involving 480 people living with dementia and 50 staff and is now **part of the West Wales dementia wellbeing pathway (E9,E10)**. The focus on individuals at an early point of their dementia journey was **a complete departure from existing approaches to practice** and one which they embraced (<https://youtu.be/RtooHE3hNYk>). Facilitators using the resource reported **'increased confidence, self-efficacy and engagement in new and previous activities, leading to increased social contact'** for their patients (E9). Reflecting on the adoption of *Journeying through Dementia*, an occupational therapist in West Wales noted that the programme *'enables patients to face the future with hope that life can be lived well. It aligns with our occupational therapy philosophy, looking for strengths, concentrating on the person and what is important for them and the importance of occupation in all our lives'* (E9).

Materials from programme are hosted on the web-platform *Connecting People, Connecting Support* which has been **accessed over 56,000 times** in the ten months since it was established. Alzheimer Scotland reported that *'People with dementia and their families have described this as a life-line'* (E10). The materials are cited in the NHS England (2020) response to COVID-19 and endorsed by the Royal College of Occupational Therapists (E9,E10).

5. Sources to corroborate the impact

E1. NIHR video: 'HeadUp Collar: A new cervical orthosis for neck weakness' corroborates life-changing quality of life for patients <https://www.youtube.com/watch?v=Db7yrIDNszs>

E2. TalarMade product website and fitting video. Corroborates licence and manufacture of HeadUp in UK. <https://www.talarmade.com/products/headup-collar/>

E3. Publication corroborating improved effectiveness for patients' eating, drinking and swallowing with HeadUp, World Federation of Neurology Research Group on Motor Neurone Diseases. Sproson, L et al. (2020) Fit for purpose? A cross sectional study to evaluate the adaptability and usability of HeadUp, a novel support collar for neurological neck weakness. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, Sep 10; 1-8. <https://doi.org/10.1080/21678421.2020.1813308>

E4. NIHR website corroborates use of HeadUp in 25 NHS trusts <https://www.nihr.ac.uk/news/revolutionary-neck-support-collar-now-available-on-the-nhs-for-people-with-motor-neurone-disease/10903>

E5. Copies of UK and US Patents for HeadUp and SuPPORT 4 All.

E6. Material corroborates improved irradiation dose and patient experience with SuPPORT 4 All. Probst, H (2020). A randomised clinical feasibility trial of a breast immobilisation device: The SuPPORT 4 All (S4A) Project. In: *UK Imaging and Oncology Conference*, Virtual, 1 Jun - 31 Jul 2020.

E7. MadeAtUni website corroborates SuPPORT 4 All in top 100 university discoveries. <https://madeatuni.org.uk/sheffield-hallam-university/bras-aid-breast-cancer-patients>

E8. Marie Curie: The Life Café website. Corroborates improvements in dignity and quality of life as part of end of life care <https://www.lifecafe.org.uk>

E9. Journeying Through Dementia website (<https://www.jtd.org.uk>) and online resources. Corroborates improvements in quality of life for people living with dementia, as well as adoption across Scotland <https://dementiatogether.online>; [Connecting People, Connecting Support – Scottish Government](#), West Wales (OTnews, October 2020) and England <https://youtu.be/RtooHE3hNYk>

E10. Written testimonials corroborating impacts of HeadUp, Journeying Through Dementia and The Life Café from Alzheimer Scotland, Sheffcare, Sheffield Teaching Hospitals NHS Foundation Trust, Marie Curie.