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Co-designing with people living with dementia

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ABSTRACT

This paper presents research that illustrates how design thought and action has contributed to the co-design and development of a mass-produced product with people living with dementia. The research, undertaken in collaboration with Alzheimer Scotland, has adopted a range of disruptive design interventions for breaking the cycle of well-formed opinions, strategies, mindsets, and ways-of-doing, that tend to remain unchallenged in the health and social care of people living with dementia. The research has resulted in a number of co-designed interventions that will help change the perception of dementia by showing that people living with dementia can offer much to UK society after diagnosis. Moreover, it is envisaged that the co-designed activities and interventions will help reconnect people recently diagnosed with dementia to help build their self-esteem, identity and dignity and help keep the person with dementia connected to their community, thus delaying the need for formal support and avoid the need for crisis responses. The paper reports on an initial intervention where the author worked collaboratively with over 130 people diagnosed with dementia across Scotland in the co-design and development of a new tartan. The paper concludes with a number of recommendations for researchers when co-designing with people living with dementia.

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co-design; interventions

Introduction

As the UK moves to an increasingly older society where more than half of the UK's population will be aged 65 and over, and there will be 101% more people aged 85 and over, we have to face the reality of being woefully underprepared. By the year 2030, over 80% more people aged 65 and over will have some form of dementia (a moderate or severe cognitive impairment) compared to 2010. Globally, the World Health Organization (WHO) estimated there were 7.7 million new cases of dementia in the year 2010, or one new case every four seconds (WHO (World Health Organization) 2012). If the incidence increases in line with prevalence, since global ageing is driving both numbers, the incidence of new cases of dementia will have increased to 24.6 million new cases annually by 2050. This means 682 million people will live with dementia in the next 40 years, which is significantly more than the population of North America and almost as much as Europe's population (Batsch and

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Mittelman 2012). In the UK, dementia and how we respond to it has reached a crisis point. It is a problem that improved public awareness or a better diagnosis alone will not solve. The management of long-term conditions associated with dementia is the key challenge facing the health and social care system in the UK. The UK Government's All Party Parliamentary Group (APPG) on Dementia believes we need to see profound changes to the way we view the person living with dementia as well as the overall system of health and social care (All Party Parliamentary Group on Dementia 2016).

The huge demographic shifts in our increasingly older society present massive challenges to society as a whole. Major changes are needed in our attitudes to ageing and how we will care for each other in the future. Design, in general, and design research, in particular, needs to embrace these challenges head on. However, rather than viewing these challenges negatively, design has an opportunity to be at the forefront of imagining visions of how we might live together and care for each other better in the future. It is now time, therefore, that design in all its guises (i.e. education, practice, research) grasps this opportunity to envision and realise the future that we will all be proud to share.

With this in mind, the co-design project presented in this paper shows that people living with dementia can continue to make a significant contribution to society after diagnosis. The approach taken here actively involved all stakeholders in the design process such as AlzScot staff, care workers, people living with dementia, and their family and friends to help ensure the design project presented here met their needs and would be valuable and useful. This co-design project was carefully developed to be more appropriate to people living with dementia's emotional and practical needs. Recent research suggests that designers create more innovative concepts and ideas when employing co-design tools and methods with others than they do when creating ideas on their own (Mitchell et al. 2015). In this respect, this co-design project goes a little way to help change the perception of dementia and shows that whilst the mood and behaviour of the person may be profoundly affected, their personhood is not; the individual remains the same equally valuable person throughout the course of the illness. Moreover, the co-design project presented in this paper aims to help reconnect people recently diagnosed with dementia to build their self-esteem, identity and dignity and keep the person with dementia connected to their community.

The nature of dementia

Dementia is the umbrella term for a range of brain diseases that are progressive and chronic in their nature. Symptoms include deterioration in cognitive function, behavioural changes and functional limitations. The illness has a profound impact on society and those directly affected by the illness. Globally there are an estimated 44.4 million people with dementia, which will increase to 135 million by 2050. The estimated worldwide cost of dementia is \$604 billion US dollars, which equates to 1% of GDP (Alzheimer's Disease International's 2013). In the UK there are an estimated 800,000 people with dementia with the current cost £23 billion (Alzheimer Society 2013). Amongst older people, dementia makes the largest contribution to the need for care, much more so than other types of impairment and chronic disease (Prince et al. 2013). This demand for health and social care services will continue to increase as a result of demographic changes. Responding to this challenge will require innovative ways of supporting people with dementia to live well from the early stages of the illness. Receiving a diagnosis of dementia creates a 'biographical disruption',

with the chronically ill ‘observing their former self-images crumbling away’ (Bury 1982). People need support from the point of diagnosis to come to terms with this life altering event, remain connected to their community and enable them to live well with this long-term illness. However, people typically do not receive support until the illness is advanced and often at the point of crisis (Alzheimer Scotland 2008). This pattern is becoming more acute as a result of pressure on health and social care budgets.

Philosophical debates on dementia have largely focused around the fundamental nature of being and what constitutes personhood. The failure to recognise personhood and the negative impact of inappropriate care giving can result in ‘malignant social psychology’, which includes labelling, disempowerment, infantilisation, invalidation and objectification (Kitwood 1990). One reason behind this malignance is failing to see a person and not showing the respect that properly accords a person (Kitwood 1990). Even when a person seems to have lost a significant part of what made them a unique individual, core elements of their identity will remain. These ‘characteristic gestures and ways of doing things are what keep alive the sense of the individual they once were, even if the more sophisticated levels of that individual have been removed’ (Matthews 2006). This has important implications for the approach to providing support and what people require in addition to the basics of daily living. A person’s sense of self and self-respect can be fostered through ‘reinforcing any remaining elements of conscious self-identity’; less conscious elements in a person’s identity can be preserved through physical surroundings to retain ‘physical links with their past, which help to support a sense of personhood’ (Matthews 2006). Whilst mood and behaviour may be profoundly affected, personhood is not; the individual remains the same equally valuable person throughout the course of the illness. Interventions to support the person with dementia should honour their personhood and right to be treated as a unique individual.

Disruptive co-designing with people living with dementia

The overarching aim of this research is to develop disruptive design interventions (e.g. products, systems, services) for breaking the cycle of well-formed opinions, strategies, mindsets, and ways-of-doing, that tend to remain unchallenged in the health and social care of people living with dementia in the UK. Low levels of understanding about dementia have led to various misconceptions resulting in the perpetuation of stigma. Consequently, people living with dementia are often isolated because of stigma or the possibility of negative reactions from neighbours and relatives to behavioural and psychological symptoms. The idea that nothing can be done to help people with dementia often leads to feelings of hopelessness and frustration (Batsch and Mittelman 2012). Moreover, people living with dementia and carers believe that there are negative associations for those diagnosed with dementia. Fear exists on both sides—amongst the general perception of society, but also in people living with dementia who are fearful of the reactions of others. Many people living with dementia have a sense of shame and inadequacy and low self-esteem. They perceive their status within society has been reduced as a result of their diagnosis (Katsuno 2005).

People living with dementia have never before been considered capable of designing a commercial product. Thus, this work sets out to disrupt existing forms of dementia health and social care through the setting and completion of a ‘live’ commercial product design (tartan) project with people living with dementia that routinely they would never

be considered capable of completing. The disruptive design intervention here is the ‘live’ commercial tartan project and the accompanying tartan design prototyping kit specifically developed for people living with dementia. The audiences, stakeholders, and participants whose perceptions were disrupted by this project include family members and friends of the people living with dementia, Alzheimer Scotland staff including directors, trustees, managers and care workers. Their appreciation of what is now possible by people living with dementia has been challenged and sheds new light on future possibilities for co-designed, creative and other interventions.

In a co-design context, this co-design project has attempted to engage fully with people living with dementia throughout the design process from the original setting of the design brief to the prototyping stages and through to the manufacture of the commercial ‘live’ product. The project has been devised and undertaken from a ‘designing with’ perspective where the user is not viewed as a ‘subject’ but rather as an active ‘partner’ in the project (Sanders and Stappers 2014). Thus, this work differs considerably from earlier collaborative design approaches adopted and outlined by the likes of Cohen and Weisman in their design of environments for people with dementia (Cohen and Weisman 1991), Day et al’s therapeutic design of environments for people with dementia (Day, Carreon, and Stump 2000), and Orpwood et al’s design of smart home solutions for people with dementia (Orpwood et al. 2005) where the focus has been on viewing the person living with dementia solely as a user of the designed intervention.

The disruptive design approach adopted here encourages the development of richer, more varied solutions to everyday issues by emphasising fun (Bisson and Luckner 1996), ‘safe failure’, and doing things in ways that those working with people with dementia would not normally do. The work presented here adopts a largely interventionist approach, which is based on a number of emerging theories emanating from research in economics, business and design (Christensen and Overdorf 2000; Scharmer 2011; Rodgers and Tennant 2014). This disruptive design interventionist approach, which celebrates jumping straight in, doing things in order to learn new things, and valuing failure, involves three main stages:

- (1) *Observe, Observe, Observe*—stops our over-reliance on Internet searches and downloading and requires one to totally immerse oneself in the places that matter most to the situation one is dealing with.
- (2) *Retreat and Reflect*—requires one to share and reflect on everything one has learned from the situations one has observed. The key question here is how can the researcher become a part of the story of the future rather than holding on to and embodying the past?
- (3) *Act in an Instant; Design and Develop Product, System and Service Prototypes*—to explore the future by doing; develop interventions that help us explore the future by doing, generating feedback from all the key stakeholders that allow novel ideas to evolve.

Co-design has been widely used in the commercial sector. However, recent research shows that co-design is quickly becoming widespread in the public sector, including voluntary sector organisations, the third sector, and small to medium sized enterprises, as a way of engaging citizens in design exploration (Lam et al. 2012). For example, co-design processes, tools and methods have, in recent years, been used in a number of health care contexts such as Wildevuur and van Dijk’s ‘Scottie’ tool for enhancing social connectedness in health care

contexts, particularly between people who share a close or an intimate relationship, such as a parent and child who are involuntarily physically and geographically separated for a long time (Wildevuur and van Dijk 2011). Also, Donetto et al's 'Experience-Based Co-Design (EBCD)' has been developed as a participatory research approach that draws upon design tools and ways of thinking in order to bring health care staff and patients together to improve the quality of care. In particular, Donetto et al. call for cross-disciplinary co-design practice to bring about reconfigurations of power relations, the appropriate role of design expertise within such processes and their eventual impact on the quality of patient care (Donetto et al. 2015). Also, Kanstrup's recent work that examines 'real-life' living labs that brings together designers and users in future co-designed innovations in care homes that focuses on the work carried out by care workers, service staff, residents and management living and working in the labs. Kanstrup's study recommends an attention to work balance, user gains and collaborative innovation in living labs. (Kanstrup 2016).

Many co-design techniques and tools, however, assume particular skills, expertise, and processes that rely on certain levels of communication, cognitive, and creative skills on the part of the participants. As such, many well-established co-design tools and techniques may not be appropriate and need adjustment (Wilson et al. 2015). Indeed, when working with people with cognitive and other impairments such as people living with dementia researchers may have to develop and adopt highly individual co-design approaches and methods (Hendriks, Slegers, and Duysburgh 2015).

The Disrupting Dementia tartan co-design project presented here was initially intended as an 'ice breaker' for the researcher to get to know better the staff at Alzheimer Scotland, people living with dementia throughout Scotland, their families and care support workers. It was also important that this initial project engaged with all of the stakeholders involved. Care was taken to consult with people living with dementia, their family members, and the care support workers about how they wanted to be involved throughout the project before the project started. In particular, it was vital that the planned design intervention supported the person with dementia and that it paid respect to their personhood and their right to be treated as a unique individual (Kinnaird 2012).

Kleinsmann and Valkenburg (2008) emphasise the importance of different people within a co-design process. Every individual brings specific knowledge in order to create a shared understanding and to help achieve the larger common objective—the new product, service or system to be designed. Each individual has their own strengths and weaknesses to bring to the co-design process. Consequently, the project presented here has been carried out *with* people living with dementia who, it is hoped, will benefit from it. Indeed, the key objective of this project is to care better for people living with dementia and remove widely held and largely negative preconceived ideas about what people living with dementia are capable of doing. It is, thus, strongly connected to Participatory Action Research (Bossen, Dindler, and Iversen 2012).

Adopting the three-stage disruptive design interventionist approach described earlier, which celebrates jumping straight in, doing things in order to learn new things, and valuing failure, the researcher launched the Disrupting Dementia tartan design project in November 2014. The brief for this project invited people living with dementia throughout Scotland to design the Disrupting Dementia tartan that will be used in a range of future products including ties, scarves and picnic blankets and sold worldwide to raise money for people living with dementia.

The project quickly gained significant interest from Alzheimer Scotland staff and care support workers across Scotland resulting in the researcher visiting 17 different Alzheimer Scotland Dementia Resource Centres, holding over 20 co-design workshops with over 130 people living with dementia participating in tartan co-design workshops across Scotland from Kilmarnock in the South to Shetland in the North and Stornoway in the West to Aberdeen in the East (Figure 1). The project has involved in excess of 1900 miles of travel, over 80 h spent travelling, and using over half a kilometre of coloured ribbon in the creation of the participants' tartan design prototypes. The main aim of the Disrupting Dementia tartan design project is to help change the perception of dementia by showing that people with dementia can offer much to UK society after diagnosis. Specifically, here, that people living with dementia are capable of designing a new product that will be sold across the world. Moreover, this project will help people recently diagnosed with dementia build their self-esteem, identity and dignity and help ensure that every person living with dementia and their families' quality of life and resilience is maximised.

In a co-design project such as this one, it is important that the designer does not take an overly dominant role. Typically, designers will embrace a supporting role in order to help the collaboration blossom. Ultimately, however, the goal is to achieve something like a *symbiotic collaboration*—a mutually beneficial relationship between different people or groups. Only when the participants get sufficient authority to determine and shape the project and the project's agenda, however, can a project be described as truly participatory. The instigator of the co-design project should be transparent about the project's objectives and clearly articulate the reasons behind embarking on a co-design project. In other words, the project rationale should always be known from both sides. Van Klaveren (2012) suggests such an ethical and transparent approach is the foundation for a truly symbiotic co-design relationship. However, the challenge of achieving such high quality co-design project participation is often not straightforward (Sanders and Stappers 2008).



Figure 1. Disrupting dementia tartan co-design workshop locations.

Each tartan co-design workshop commenced with a short presentation of the rules associated with the creation of the Disrupting Dementia tartan. Working closely with Alzheimer Scotland staff and family members, care was taken to ensure that the language used during the workshop was supportive and not offensive to people living with dementia. Also, the researcher supported by care support workers ensured that everyone taking part in the project was kept physically and emotionally safe at all times during the workshop. The rules of the Disrupting Dementia tartan project are that each participant must use no more than 6 colours in their design and one of those colours must be purple (Alzheimer Scotland's primary colour in their new brand identity). The creation of each participant's tartan design begins with an acetate-based version, followed by a physical prototype constructed using ribbon, and finally the creation of a digital version using a publically available Internet-based tartan design tool (Figure 2). Each participant was free to determine and shape the tartan design they created during the stages of the design process.

Working from the physical ribbon prototype, each person with dementia directed the researcher to co-create his or her digital design one colour at a time (Figure 3). In the example illustrated in Figure 3, one can see that the person living with dementia's main colour in their design is purple (Alzheimer Scotland's primary colour), followed by their choice of orange, green, blue and finally grey. At this important stage of the co-design process, the researcher adopted an empathic (not sympathetic) manner ensuring he was compassionate, un-patronising, tolerant, understanding and respectful. Many of the workshop participants held a significant position before their diagnosis of dementia including an eye surgeon, an architect, an economist and other roles so a respectful attitude was vital to the co-design sessions' success.

In recent years, the make up of co-design participants has evolved to ensure that those who will be affected by the design have a say in the process, rather than being just final users (Ehn 2008; Tunstall 2013). Today, participants are considered to be able to bring valuable



Figure 2. Tartan design creative process (left to right: acetate, ribbon and digital prototypes).

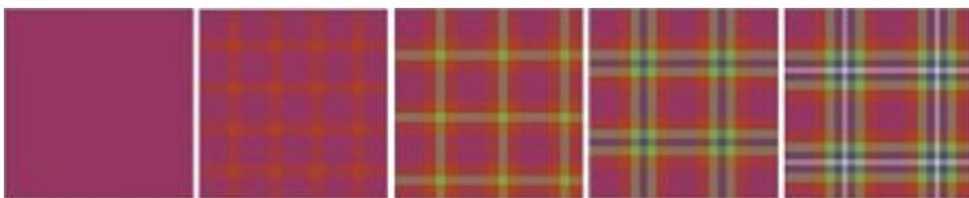


Figure 3. Co-creating the digital tartan prototype step-by-step.

local knowledge, ideas and competences to the process (Manzini and Rizzo 2011). Madden et al. (2014) view co-design as a partnership of experts. The co-creative aspect in co-design activities has also shifted perceptions of who the makers are in the process. Traditionally, the designer would be viewed as the one with making privileges. In recent co-design accounts, however, participants have been invited to get involved in making in order to explore and make sense of their own futures (Sanders and Stappers 2014). In this project, the participants' knowledge of local and regional tartans, the skills and craft of weaving, and experiences of working in the tartan industry was a major bonus. Often, during the creative stages of the project, the participants experienced a real sense of re-connecting to their 'past lives' during the project that evoked positive memories of association for many individuals.

Working from left to right, the person with dementia gradually builds up their tartan design based on the physical prototype they created earlier. This process involves a number of iterations between the designer (person with dementia) and the facilitator (researcher). Sometimes, the designer (person living with dementia) will go back and forth between different versions and sometimes they will alter the order of the colours to finally achieve the design that they are satisfied with. During this highly iterative stage of the co-design process, the researcher had to consider 'dementia time'. That is, being patient and allowing time and space for each individual and how they might keep track of their time. Many recent approaches to co-design emphasise the need to rethink and redefine the role of the participants (Rodil, Winschiers-Theophilus, and Jensen 2012; Van Klaveren 2012). For example, one has to be careful not to imply power relations through the terms we use (Holcombe 2010; Rodil, Winschiers-Theophilus, and Jensen 2012). In the project described here, the participants are seen as designers in the process and their input is valued as much as the co-design facilitator (author). Like Manzini and Rizzo (2011), this co-design project views the participants as active collaborative co-designers. The participants are creative; they have a range of experiences, skills, knowledge, and capabilities and they have enhanced the overall nature of the project by taking part. Several authors have proposed nomenclature such as 'vernacular designers' (Reitan 2006), 'silent designers' (Gorb and Dumas 1987) and 'design amateurs' (Leadbeater 2009; Manzini and Rizzo 2011) to describe the co-design participants.

It is worth mentioning that embarking on a co-design project not only changes the role of the participants in the design process, it also changes the role of the designer or researcher (Manzini and Rizzo 2011; Melles, de Vere, and Misic 2011). Melles, de Vere, and Misic (2011), for example, see this new role for the designer/researcher as that of 'facilitator' of co-designed or co-created outputs. Most, if not all, of the co-design literature relates (indeed implies) a collaborative and cooperative effort between two or more equally able agents. Many traditional approaches to involve a person in co-design activities, however, create issues as they assume that the participants are cognitively able, can deal with visual and hands-on techniques, and require certain levels of ability. This paper, however, describes co-designing with individuals that are not equal in the sense of their cognitive and communication abilities, which brings new challenges to co-design activities and projects. The remaining sections of the paper report on the significant outcomes of the project, reflect on the co-designing sessions, and present insights into successful practices when designing together with people living with dementia.

Outcomes

The results achieved, thus far, include over 130 unique designs for the new Disrupting Dementia tartan. Every one of the 130 + tartan designs created have been designed by a person living with dementia and these tartan designs have been uploaded to the Disrupting Dementia tartan project blog—<https://alzheimerscotlandtartan.wordpress.com/>. A judging panel of tartan design and manufacturing experts and representatives of Alzheimer Scotland short-listed 7 tartan designs from over the 130 created since the start of the project (Figure 4).

Next, digital versions of the 7 short-listed tartans were uploaded and exhibited on the Alzheimer Scotland website—<http://www.alzscot.org>—for people to vote for their favourite tartan design. After more than 8000 votes were cast from across Scotland, the chosen Disrupting Dementia tartan was designed by Nan from Inverness. Nan's winning design has now been manufactured and the plan is to develop a range of tartan design products that will be sold all over the world (Figure 5). This project shows clearly that a person living with dementia has, with a little support, designed a new product—the new Disrupting Dementia tartan. As such, this co-design project goes to show that people with dementia can indeed offer much to society after diagnosis.



Figure 4. Over 130 designs for the new disrupting dementia tartan (judging and short-listing session).

Recently, an exhibition of the Disrupting Dementia tartan co-design project was held at the award-winning Verdant Works in Dundee (Scotland's National Jute Museum). The exhibition, which tells the story of the project and ran from 23 January to 3 April 2016, attracted more than 3500 visitors and significant press interest (Figure 6). The exhibition has also been invited to the Stirling Smith Art Gallery and Museum, which will run from 25 November 2016 to 5 February 2017. This exhibition forms part of the Dementia Friendly Stirling initiative that strives towards making Stirling a dementia friendly place where people with dementia are able to live sustainable and independent lives. The public exhibitions of this research are playing a part in helping to change the perception of dementia by showing people with dementia can offer much to UK society after diagnosis.

Reflecting on the disrupting dementia tartan co-design project

Reflecting on the co-design workshop sessions with more than 130 people living with dementia, it is abundantly clear that people living with dementia can offer much to society after diagnosis. On completion of the co-design project, a questionnaire was sent to



Figure 5. Production of the disrupting dementia tartan.

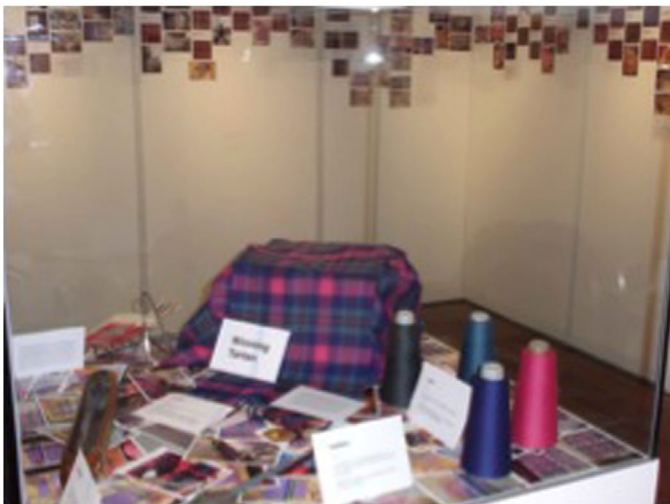


Figure 6. Disrupting dementia tartan design exhibition.

15 Alzheimer Scotland staff members who took part in the Disrupting Dementia Tartan co-design project. Alzheimer Scotland staff members were first asked how they felt participants responded to the tartan co-design workshops? All respondents felt the workshop experience had been positive for those who took part. People had been interested, engaged, and enjoyed the workshop and there had been concentration, focus and discussion during the co-designing activities. Next, Alzheimer Scotland staff members were asked if they felt the tartan co-design workshops were beneficial for those who took part? All respondents felt the workshops had been beneficial for those who took part. Benefits were highlighted as follows:

- The visual nature of the co-design sessions helped people to view their design.
- Playing with colours and getting creative.
- Satisfaction from being creative.
- Engagement with group.
- People felt part of something.
- Feel good factor and buzz in the group during the co-design workshops.
- Sense of achievement on completion of tartan design activity.
- Interesting subject, which evoked positive memories of association for many individuals.

Staff members were then asked about any lasting impact of taking part in the tartan co-design workshops for participants? Alzheimer Scotland staff members considered there to be lasting impact for participants in the way the co-design sessions gave people confidence to try new things—some people had been worried about taking part but were very relaxed during the sessions. Participants said afterwards that they would love to do something like this again. Impact has also been seen in a number of ‘spin-off’ projects, discussions, themed activities and outings. Also, participants have remembered their own tartan design and are able to identify it—each participant’s sense of pride is palpable. One lady continues to talk about the tartan she made and the memories of her childhood, army days and her father.

Alzheimer Scotland staff members were asked for their views on the tartan co-design project. The responses were positive and on balance staff felt the project had worked extremely well. Their reasons included the following:

- Not too demanding and a task that all abilities could engage in.
- It had a purpose and structure, but there was still a lot of scope for people to express their individuality.
- It was beneficial and people enjoyed taking part.
- Positive way of showing how people can design, show their ideas and be creative.
- People chatted and shared their results—lots of interaction.

Staff members were then asked if taking part in the tartan co-design project was beneficial for Alzheimer Scotland’s service? All but one respondent felt there had been a benefit for the services. The benefits outlined were:

- It had provided a different activity and engaged new people in design activities.
- It was well attended and brought in people who had not visited the resource centre before.
- Including a remote geographical area was appreciated.

- It was a positive activity that had been continued with the resource centre's own winner being selected and a collage of all tartans placed on the wall.
- The use of ribbons had brought calmness, satisfaction and a sense of achievement.
- Appreciation that an interesting specialist had brought their skills to engage participants to their fullest potential to take part.

Finally, Alzheimer Scotland Staff were asked if there has been any ongoing impact of the tartan co-design project for their care support service? Seven respondents considered there to be an ongoing impact. Comments provided were:

- Two participants had taken encouragement from the workshop and had since joined an art group running at the resource centre.
- Workshop had been well attended and generated more press interest in subsequent projects.
- Continued related and spin-off activities.
- Continuing to offer the ribbon and acetate elements of the co-design activity on Burns Night (25th January) and St Andrews Day (30th November) each year.

Conclusions

The Disrupting Dementia tartan project shows how co-design methods and tools can enable people living with dementia to make a significant contribution to society after diagnosis. Specifically, this work has shown how design thought and action can contribute to the co-design and development of a commercially available mass-produced product. In this respect, this co-design project has helped change the perception of dementia and shown that whilst the mood and behaviour of the person may be profoundly affected, their personhood is not. Moreover, the project has helped reconnect people recently diagnosed with dementia to build their self-esteem, identity and dignity and keep the person with dementia connected to their local community. Indeed, in the co-design workshop sessions undertaken it has been abundantly clear that people living with dementia can offer much to society.

Negative perceptions of individuals and society regarding dementia will continue to lead to the isolation of people living with dementia and also reinforce and extend isolation caused by the effects of the disease. The widespread assumption that people living with dementia cannot take part in ordinary activities, and that they have no quality of life or capacity for pleasure has been dismantled by this project. While the symptoms associated with dementia affect the way a person living with dementia interacts with others, and some activities may be inappropriate as a result, there are many activities such as designing in which they can participate. Both people living with dementia and their family members will benefit from continuing, whenever possible, to engage in as many activities such as this as they can. Moreover, people living with dementia should be encouraged to make decisions or partake in decisions that affect them for as long as possible, to maintain their dignity and self-esteem.

As the UK moves to an increasingly older society where more than half of the UK's population will be aged 65 and over, and there will be 101% more people aged 85 and over we have to face the reality of being underprepared. By the year 2030, over 80% more people aged 65 and over will have some form of dementia (a moderate or severe cognitive impairment) compared to 2010. Design, in general, and design research, in particular,

needs to embrace these challenges head on. However, rather than viewing these challenges negatively design has an opportunity to be at the forefront of imagining how we might care and live together better in the future. It is now time, therefore, that design in all its guises (i.e. education, practice, research) grasps this opportunity to envision and realise the future that we will all be proud to share.

To envision a future where people living with dementia can make significant contributions to society requires careful consideration and planning. First, researchers should always ask people with dementia how they want to be involved in research, including at what points and in what ways they want to be included. Second, people living with dementia should be involved in setting research priorities. That is, researchers should ask people living with dementia what positive outcomes of the research project might look like for them. Third, researchers must ensure that everyone taking part in the research project is physically and emotionally safe at all times. Fourth, researchers must use language that is supportive of people with dementia whilst avoiding language that may offend. Fifth, researchers need to be 'dementia aware'. That is, researchers must be empathic not sympathetic. They should also be compassionate, knowledgeable, un-patronising, tolerant, understanding, and respectful whilst working with people living with dementia. Lastly, researchers need to consider 'dementia time' in their expectations of research. For instance, finding out the best time to meet and how each individual keeps track of time. Following these guiding principles on how to best conduct co-design projects with people living with dementia will help deliver truly meaningful experiences and outcomes for all involved.

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