Jun 23rd, 9:00 AM - Jun 28th, 5:00 PM

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Citation

Winton, E., and Rodgers, P. (2024) The co-design participatory power pyramid, in Gray, C., Ciliotta Chehade, E., Hekkert, P., Forlano, L., Ciuccarelli, P., Lloyd, P. (eds.), *DRS2024: Boston*, 23–28 June, Boston, USA. https://doi.org/10.21606/drs.2024.459

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doi.org/10.21606/drs.2024.459

Abstract: This paper presents an innovative co-design participatory power pyramid, which foregrounds how people living with dementia (PLWD) are (and can be) in volved in co-design projects. The pyramid provides a scale of participant involvement in co-design activities based on the premise that design is a process that encompasses a series of interlinked activities, actions, and thinking that, when combined, result in a designed outcome. The co-design participatory power pyramid has been created to define and better understand the spectrum of co-design projects when working with PLWD. However, it is anticipated that the framework will be applicable to other co-design research practices. The pyramid makes explicit the differences between co-design projects labelled as 'to', 'for', 'with' and 'by'. The paper provides examples to highlight how the framework is an appropriate tool as it encourages self-empowerment in collaboration and independence in action that are perceived to be aspirational in co-design activities.

Keywords: co-design; people living with dementia; framework

1. Co-design 'to', 'for', 'with'

Co-design is a type of design practice that engages users and interested parties in design journeys where active collaboration between stakeholders in designing solutions to a specified problem occurs (Sanders and Stappers, 2008). It promotes participation from specialists and non-specialists with various types and levels of knowledge to formulate or improve specific concerns (e.g., service, environment, conditions, or product improvements). The intention of a co-design approach is to empower participants to be active in making change, imbuing them with agency to implement solutions. The designers' role is chiefly to facilitate the co-design activities through activities, design tools and methods, and by planning engagement to elicit tacit knowledge, explore relevant themes, ideas, and solutions together (Mattelmäki and Sleeswijk Visser, 2011).

Co-design practice aims to break down barriers and unpack opportunities to ensure outcomes are designed, developed, and evaluated with non-designers, who are invested in the approach. The methods involved must be inventive, responsive, and accessible meaning the ways in which this occurs are often playfully experimental. Ideally, actions of the design researchers and the collaborators are inter-linked through collective responsibility, and empowerment to drive momentum for change. The informed and empowered position of participants builds upon the excellent review of to Ertner *et al* (2010) where they have developed 5 conceptions of co-design categorisation two of which identify approaches to the *"improvement of the life conditions of a specific demographic group(s)" achieved through* enhanced levels "of participation and possibility of achieving influence".

Over the past decade there has been sizeable uptake of co-design tools and methods that especially focus on services in public and third sector projects (Lam et al., 2012). However, it is rarely clear how collaborations align to an exploration within the whole of a deign proses

The 'co'ness of participant developed problem-solving approaches may differ greatly between one project and another. For example, front-end co-design models are used to highlight the special qualities that designers poses e.g. being attuned to seeing, understanding, and engaging in stakeholders needs and resolving them. This front-end practice of collaboration in formulating a brief or advising in problems might develop better designer-led solutions but do not necessarily afford consistent, holistic, and universal collaboration. The largest concern here is that the approach treats people as subjects of investigation for the designer as expert to fix by doing stuff ***'to'*** (designing to needs informed by initial investigation) and ***'for' them*** (designing on behalf of people to fulfil their more crafted insights) and, arguably only involving a modicum of ***'with'*** (designing in collaboration within a journey of multiple interactions and capability developments). Increasingly, the ***'with'*** component of co-design is being championed and encouraged, ideally, creating parity and greater inclusion en-route to compelling results. Fleischmann (2013) advises that more inclusive processes do not require deep knowledge of every aspect of a situation but achieve knowledge generation through a collective meshing of perspectives.

2. Background

2.1 Reviewing co-design with people living with dementia

Co-design can be used as a design tool and a method of shared-enquiry with groups and communities who have specific concerns, problems or needs. It is therefore common for co-design to be utilised when working with people living with dementia, this paper focusses upon this area of exploration but is informed by the authors wide experience of co-design with varieties of stakeholders across many areas of enquiry.

In undertaking a range of designing with people living with dementia projects we have attempted to ascertain how far participants have been able to proactively co-design outcomes and how deeply designed experiences have been achieved. The co-design methods in this project have formed repeated but tailored approaches by the authors for over a decade.

Central to which is an understanding that collaboration in creative practice is imbued with benefits of social inclusion, reaffirming personal identity and adapting to capabilities of people living with dementia. The application of the long-term collaborative methods focusses on capability and empower people to act within and to direct projects. In working through collaborative methods our most common concerns lay amongst the extent to which people living with dementia could actively design something. One of the significant findings was that the lack of a universal definition and description of what co-design is or means, especially in this area, leads to significant inconsistency in practice and critique of the term and subsequent methods. In many situations, the application of a co-design method appears not to outline a rationalized design process and therefore does not explain the ways evaluation of how any co-design activities are framed within a design process.

This paper proposes that for the most complete form of collaboration to exist, an entire design journey should be mapped, identifying where and when moments or opportunities for inclusive participation align to the design journey. The intention should be to facilitate consistent participation at each feasible stage through 'more democratized creative nurturing' (Rodgers, Hall, Winton, Land, Aurisicchio, 2013). For the fullest 'co'ness to be supported the largest number of stages should be engaged to the greatest extent possible or as David et al (2013) explain "Co-design refers to the conception or creation of artefacts drawing on a shared vision, social learning and mutual understanding".

To understand what this means in practice, it is helpful to look at what a design process or journey might look like. Milton and Rodgers (2013) explain the process of design as requiring the completion of a series of steps on route to the production of a designed outcome. Figure 1 illustrates the breakdown of the key stages involved in such a process. Although focused within the design of products, it can be mapped to most designed outcomes (e.g., services, environments, experiences, systems, etc.). The process supports reflection and review, which means that some stages may occur in a different sequence. Some might be omitted altogether, or others repeated to respond to requirements and revelations, influences and pressures.

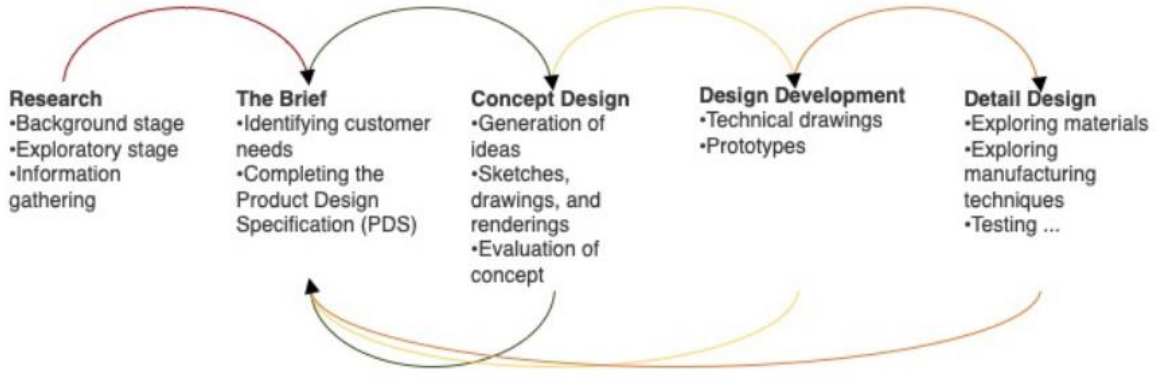

Figure 1 Main Stages of the Product Design Process (Milton and Rodgers, 2013)

This paper argues that for a design project to be seen as fully **co**llaborative, all participants and partners in the co-design activities should be expected to take part in a specific and significant number of the stages. It is proposed that such an approach leads to co-designed practice engendered with shared responsibility and ownership. It will also require a tempering of the position with the knowledge that certain skills might not be attainable for certain participants and that the design researcher holds a significant role as idea or concept translator and facilitator.

In academic texts the reader is often required to interpret the collaborative approach to a design journey. In many examples, it is difficult to find evidence that the process is open and shares agency or supports creative divergence. This is further exacerbated by universal adoption of the term 'design' which has become all-encompassing, broad ranging and specialism diverse meaning that reading around the subject can be chaotic and open to interpretation. Without the clear identification of what is meant by design and the diverse appropriation of the term co-design informs a lack of commonality which leads to fuzzy understanding of 'co'ness.

2.2 Co-design 'to', 'for', 'with', and 'by' people living with dementia

In the below examples an attempt to interpret and illustrate the processes of co-design that has been undertaken. These have been categorized based on the available texts and are presented as design done; 'to', 'for', 'with' and 'by'. The explanation of this results in the Co-design Participatory Power Pyramid FIGURE 2. Co-design 'to' people living with dementia projects are highly unlikely to be collaborative beyond user testing. For example, in the Design Driven Living Labs work of Braenkhart and den Ouden (2017) they frame their living labs work as environments of experimentations where people living with dementia have central involvement and influence. However, their work appears to favor a scientific model for interrogating the technology that already exists. In this form, the co-design activities focus on feedback and potentially influence upon experience of software from people living with dementia. The approach of design 'to' people living with dementia projects might include focused discussion, but their creative input will likely be minimal. In Neiderer et al (2020) the commentary is that "One important aspect in studies about people with dementia is that often they are not included", therefore suggesting that whatever is generated is done to people living with dementia based in input out with their own perspectives. The suggestion being that this might be informed by carers who are focussing on incapability rather than capability.

Co-design '*for*' people living with dementia projects are akin to consultative design tasks where questions are raised and addressed that may occur from creative tasks. Co-design '*for*' people living with dementia projects may fulfil requirements identified by users, but the co-design typically occurs towards the beginning of the project and is only revisited at certain key-points of the developmental process. For example, in Danckwerth's (2022) design of wearable technologies, the co-design process engaged participants in discussions and actions surrounding the project objectives that led to form-giving and materials exploration. Here, primary carers were informed experts, and their experience of supporting people living with dementia was seen as important to the creation of a set of wearable devices. This kind of co-design research is more akin to action-based, participative consultancy where non-designers support product design experts to design and develop product outcomes. This expert-to-subject approach can be valuable for affecting change. The process can help 'expert' designers achieve better informed positions through better knowledge. Blomkamp (2018) suggests that co-design '*for*' people living with dementia projects may be a misconception of the term and that practices such as these might be more closely described as a kind

of customer-facing approach where needs are identified through some form of face-to-face engagement. Co-design '*for*' people living with dementia projects do not give equal rights to act, shape and deliver the final designed outcomes which suggests that relinquishing control of design tasks for many experts appears to be difficult if not impossible.

Co-design projects '*with*' people living with dementia lead to outcomes that have common ownership and a real sense of shared values and achievements. Co-design '*with*' people living with dementia projects require individual contributions from all parties involved and a shared mindset that can only occur because of collaboration. The work of Neidderer et al. (2017), for example, advocate a participative co-design that "*invites mutual decisions and actions, and aspires to a meaningful and equitable co-creation within the design process*" where shared responsibility and involvement activates power to "*influence the values, process and content of the research*". They advocate an approach where their design techniques are blended throughout the duration of the project, encapsulating, and making use of 'traditional research participation' with bouts of ideation, where people living with dementia have shaped and informed the project.

This inclusive co-design '*with*' approach is rich in creative conversation and democratization of purpose, value, and participant esteem where people living with dementia are involved in creative activities throughout the project potentially even engaged in design embodiment stages of such processes. However, results are very much dependent on the specialist abilities of a designer to execute particular tasks.

Co-design '***by***' people living with dementia projects empower individuals through a design process which starts as collaborative to take ownership and to deliver an outcome through their own ambition, intervention, intention, and prowess. Co-design '***by***' projects embody personal achievements within and through true co-design processes. In Rodgers' Co-design '***by***' work (2017) the co-design project was designed in a manner that encourages absolute collaboration from all parties resulting in the (expert) design researcher adopting the role of obedient enabler to the creative desires of the collaborating participants. The project is tightly constrained, but the designed outcomes are generated entirely by people living with dementia. In many ways it is a simple project, but the collaboration is empowering as the individual participants have a sample product designed by themselves that could go be translated by manufacturers and put into production relatively quickly.

Many of the co-design '***to***', '***for***', '***with***', and '***by***' projects above and below (Table 1) are developed with the aim of creating tangible outcomes through hands-on designing and making, Craig and Fisher (2020) stress that co-design is not solely engaged with hands-on practices. They highlight changes to lived experiences and importantly what it means for collaborators to be included and valued in the process; evidenced in statements such as:

- "Rather than just talking, I've been able to learn new things. It's like gold"
- "You know you're telling me things that could alter my life"
- "What you've done for us has got me to the top... it's put me back where I used to be"

(Craig and Fisher, 2020; p.3)

These exclamations make explicit the importance of including people in the co-design process and open significantly important considerations of how people feel when co-design is undertaken appropriately to the situation no matter; '***to***', '***for***', '***with***' or '***by***'.

Project	Disciplinary Focus	Stage of Dementia	Aims	Outputs	Power
Treadaway (2017)	Textile Design	Late	Compassion	Hug Doll	***for***
Manchester (2015)	Education	Mid	Socialising	Narratives	***for***
Carey (2017)	Service Design	Early/ Mid/ Late	Supporting Carers	Service Mapping Tool	***with***
Jakob (2014)	Textile Design	Mid	Relaxation/ Stimulation	Sensory Room Guidelines	***to***
Hendricks (2014)	Design Interactions	Late	Empowerment and Compassion	Care	***for***
Craig (2020)	Design and Health	Early/ Mid/ Late	Supporting Wellbeing	Self-care Support	***with***
Robertson (2019)	E-Textiles	Late	Relaxation/ Stimulation/ Compassion	Sonic Birds	***for***
Danckwerth (2019)	Wearable Technologies	Mid	Improving Daily Tasks	Wearable Devices	***for***
Brankaert (2017)	HCI	Mid	Experiential Intervention	Artificial Reality	***to***
Rodgers (2017)	Product/ Service Design	Mid	Capability through Design	Tartan Products	***by***
Tan (2009)	Health	Mid	Capability through Design	Dementia Diaries	***with***
Bejan (2017)	Product Design	Mid	Improving Daily Tasks	Products	***for***
Chamberlain (2017)	Design for Health	Mid	Improving Daily Healthcare Situations	Service Design	***with***
Kenning (2018)	Design for Ageing	Late	Inclusive Design	Material Explorations	***for***

*Table 1. Sample Review of Co-design '**to**', '**for**', '**with**', and '**by**' People Living with Dementia*

The projects discussed help to define different types of co-design and the way that designers apply practices. This includes positions which vary regarding length/depth of engagement, relationship development, expectation, participation, and duration. The examples have been chosen from widely recognized projects and researchers working in the field and are a synopsis of the vast array of co-design projects flourishing in design with people dementia. This is by no means a comprehensive overview, but the work discussed helps to frame co-design (in its many guises) and how it is utilized in the field as a means for helping people to live as well as possible for as long as possible with dementia.

2.3 A model for co-design planning and evaluation

The Co-design Participatory Power Pyramid, presented in this paper, foregrounds how people living with dementia are (and can be) involved in co-design projects. The pyramid provides a scale of participant involvement in co-design activities based on the premise that design is a process that encompasses a series of interlinked activities, actions, and thinking (Design Journey or Process) that, when combined, result in a designed outcome (product, service, intervention etc.).

In many co-design conceptualizations, the principle is that collaboration should and must lead to complex solutions that cannot be derived without shared input. This is thanks to personal knowledge exchange and revelations of experience valued in devising a suitable out-

come. However, it is rare to see how the approaches are evaluated. In Burkett's an introduction to co-design two examples of co-design are posed one "Simple or Conservative Co-design" where input is sought through largely focus group or conversational practices and "Radical Co-design" which engages collaboration in much more experimental ways. However, the suggestion is that the processes will have somewhat pre-ordained "desired end". The 'Simple' approach appears to align with front end loaded models of user engagement common in many discussions of collaboration especially in design with dementia. In 2008 Sanders and Stappers introduced their model of co-design that required much fuzzy preparatory work by the design researcher which informs the collaboration that follows, here tools of structure and support are brought into well-planned process to facilitate co-design to happen, however, through the approach utilized in this paper a more open approach to generation of projects and appreciation of unexpected outcomes supports collaboration from beginning to end.

The pyramid applies a simple but effective product design process model where expected stages are engaged enroute to the production of a final designed outcome (Figure 1). The pyramid provides a framework for mapping the extent of the co-design activities including levels of collaboration, control, agenda setting, creative direction, task completion, and providing support to peers.

The Co-design Participatory Power Pyramid has been created to define and better understand a spectrum of co-design projects working with people living with dementia but is likely to be applicable to other co-design research practices. The pyramid makes explicit the differences between co-design projects labelled as '***to***', '***for***', '***with***' and '***by***'.

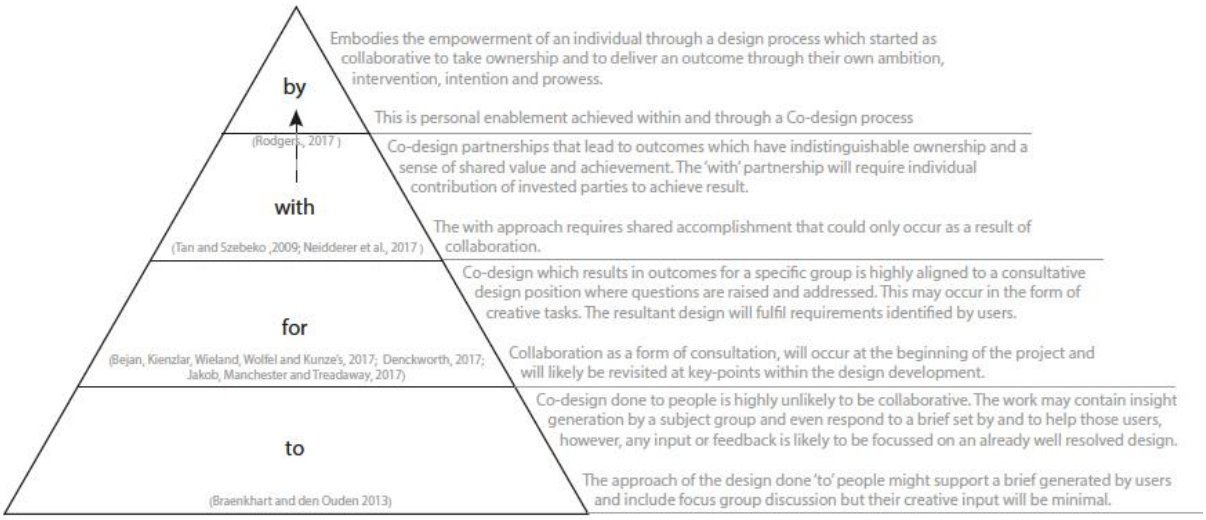

Figure 2 The Co-design Participatory Power Pyramid

3. The Pyramid in practice

The projects discussed here have been undertaken in collaboration with people living with dementia over the course of six years. Most of the co-designers were living with early-to-

moderate stages of dementia. The paper highlights a range of design practices and outcomes produced during 15 co-design projects (Figure 3). They provide evidence of free-thinking and self-belief achieved through designing, where collaborations informed stronger sense of capability, belonging and independence. The results of the 15 co-design projects include textiles, innovative products, proposals, systems, exhibitions, and a shop that demonstrate how those involved have been empowered by this research. The results have required analysis based upon observed, recorded, and displayed participation in the design process, the mixed methods have been articulated through content analysis (Crowley and Delfico, 1996) to generate key insights and commentaries.

The co-design projects presented here through practice caused high levels of collaboration. This has included the manipulation of graphic imagery, pattern making, product design, and service design. The results of these co-design projects have been disseminated to the public through a shop and participatory exhibitions. The 15 co-design projects also show clearly what is possible when collaborating with people living with dementia, carers, and dementia service providers. illuminating highly motivated and exceptionally active co-designers that are adept at contributing to the creation of research materials, providing rich insights around concepts, working within design process constraints *e.g.*, brief, data collection, design opportunities, negotiation surrounding prototyping, decision making, selecting, and refining detail designs and delivering solutions. The co-designers in these projects have also shown distinct abilities to challenge expectations and to change the remit of a project based upon their own creative endeavors. For example, not conforming to pre-defined aims but instead defining alternative opportunities, taking risks, and doing things differently.

The 'Co-design Participatory Power Pyramid' framework has been used in this paper to articulate how co-design commonly develops when working with people living with dementia. It was created to aid understanding of both co-design and, more precisely, the use of co-design projects with people living with dementia. Representing levels of co-design engagement across the 15 projects (Figure 3). A visual review of each project in relation to the stages and tasks undertaken in each project explored the co-design embedded in each process (Milton and Rodgers, 2011). This analysis interrogated to what extent each project was either design '***to***', '***for***', '***with***' or '***by***' people living with dementia in terms of the collaboration between the design researchers (authors) and the people living with dementia. Table 2 provides detail of where and how the co-designers engaged in each of the 15 co-design projects (horizontal rows). The statements dedicated to each stage of the design process (across the vertical columns) provides an overview of where and how they were involved in developing each co-design project. It is worth clarifying that the duration of the 15 co-design projects range from only one or two co-design sessions (days) to projects lasting months and in some cases years. To identify the balance of power, decision-making, and direction-setting red, amber and green coloured text was used to code the co-design activities of the researchers (authors) and the people living with dementia (co-designers). Red text Indicates little involvement in a specific design task or process, which may be a natural omission of the co-designer (*e.g.*, production by an external specialist), or identify positions where the co-designers were

not or could not be involved (*e.g.*, running the Designed with DeMEntia shop). Amber text indicates engagement in a process which is pre-ordained and largely prescriptive but is likely to have adapted to the actions of the co-designers and shapes the next step in the design process. Green text indicates high levels of direction-setting, ownership, and influence in the development of a stage and/or set of stages within a project. Blank cells indicate that there was no evidence of engagement in these stages or tasks of the project.

To understand the application of the 'Co-design Participatory Power Pyramid' model to the 15 projects the coded table of the co-design projects (Table 2) was used to elucidate the efficacy of each project in regard to the Co-design Participatory Power Pyramid (Figure 2). Through a process of color coding the reflective reviews of various stages undertaken within a process the 'power' of the PLWD engaged in the process becomes clearer. The consideration of the reflections came from the origination of thought and actions within each aspect which might include informing how practices should develop. A simple traffic light system was utilized to explain the engagement of the people living with dementia. The numbers of practices involved in a complete project were toted up to identify where the considered balance of 'power' existed.

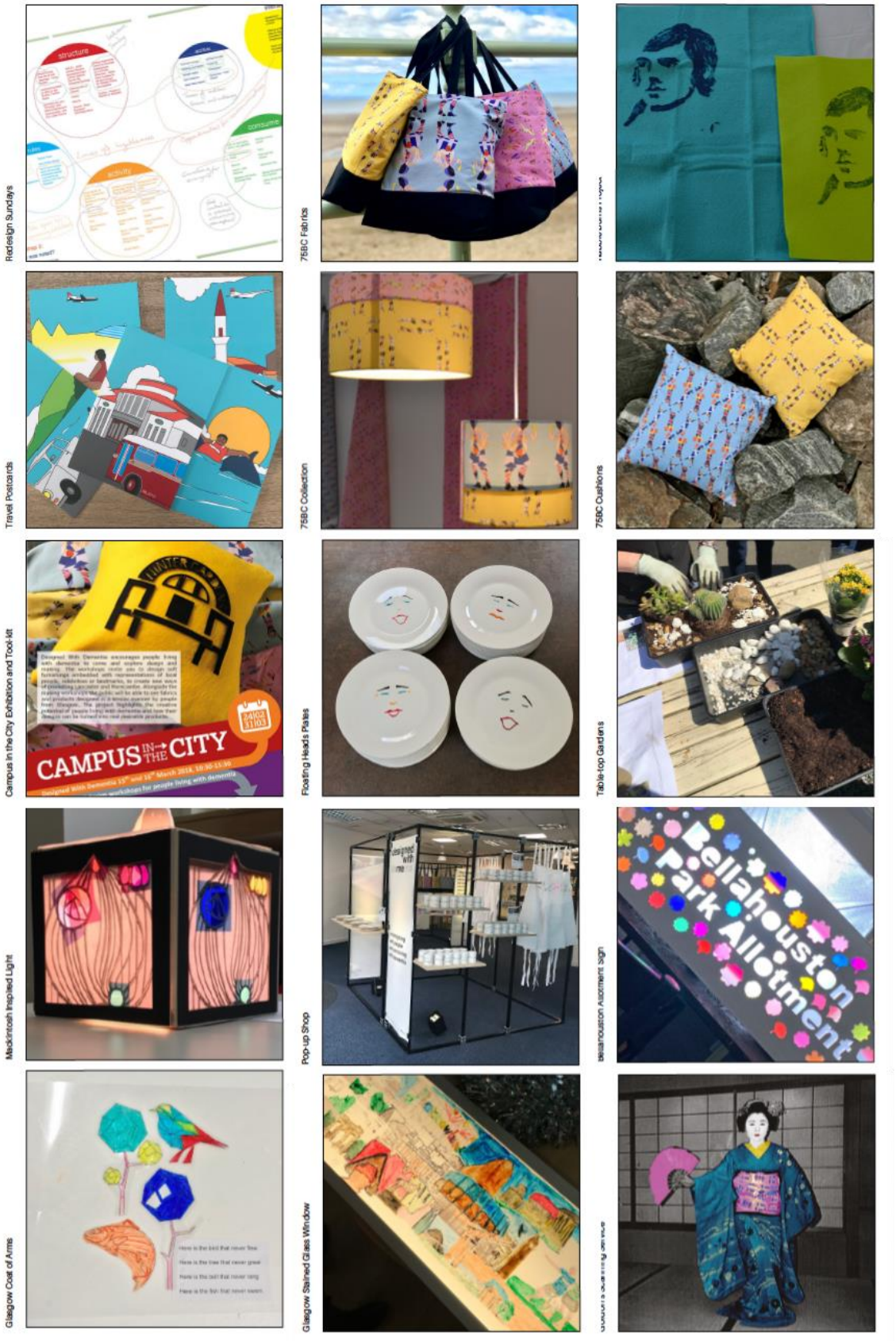

Figure 3 Fifteen Co-design projects with People Living with Dementia over 6 years

This analysis seeks to assess how many of the design stages were delivered '***to***' participants, delivered '***for***' them to engage with, developed '***with***' them from conception and as part of ongoing actions and reactions, or directed '***by***' them - controlled and delivered by their investigations, actions and delivery. In many cases, the mapping has developed an understanding of processes that moved between approaches *e.g.*, '***with***' and '***by***' or '***for***' and '***with***'. Where the process is less evenly balanced, for example more significantly '***with***' than '***by***', an arrow is used to express the direction of transfer of significance, *i.e.*, the arrow is directed towards the '***with***' state (Figure 3). As a result of this research and the creation of the co-design participatory power pyramid there is a hope that other researchers might evaluate their projects or plan their co-design processes with the pyramid in mind.

As has been stated, the co-design participatory power pyramid should be used in conjunction with a conventional design process model that has several key stages (*i.e.*, research, brief, concept design, design development, detail design, testing and production). One aim of this work is to encourage as much collaboration as possible when working with people living with dementia and provide real opportunities that shift the balance of power and responsibility of the collaborating parties. To recognize expectations and provide considerations of what might be achievable along with the messy qualities that come to the fore when undertaking co-design projects.

The 15 co-design projects also show clearly what is possible when collaborating with people living with dementia, carers, and dementia service providers. illuminating highly motivated and exceptionally active co-designers that are adept at contributing to the creation of research materials, providing rich insights around concepts, working within design process constraints *e.g.*, brief, data collection, design opportunities, negotiation surrounding prototyping, decision making, selecting, and refining detail designs and delivering solutions. The co-designers in these projects have also shown distinct abilities to challenge expectations and to change the remit of a project based upon their own creative endeavors. For example, not conforming to pre-defined aims but instead defining alternative opportunities, taking risks, and doing things differently.

In the table below three of the fifteen projects are displayed and the commentaries along with color coding aligned to the tasks explain the overall design process for each project

Projects in Chronological Order	1. Proposal	2. Research Phase			3. Concept Design			4. Evaluation		
		Background	Exploration	Information Gathering	Generation of Ideas	Visual communication	Verbal communication	Selection	Refinement	Defining
75 BC Fabrics	Subject of Billy Connolly proposed by group members based upon a previous walking tour	Initial walking tour taken as independent group and reflections on the Billy Connolly murals that they saw	Photographic Investigations (informed by one participants desire to use a camera) and in museum/ gallery craft making session	Three Site Visits; Street Tour, Gallery and Exhibition - Group Discussions	Discussion Informed Workshop of Participatory Making - Response to task	Visual form giving through collage workshop where unexpected results occurred including the basis of patterns and arrangements of multiple figures	Verbalisation of views intention and personal narrative, during activity, with fellow co-designers or with design researcher	Reviewing and selecting patterns formed from the collaging workshop results. Selecting 4 instead of the suggested 3 patterns	Identifying scales of patterns for reproduction.	
Floating Heads Plates	Project hijacked by participants to create own desired solutions	Specific exhibition visited at Kelvingrove Art Gallery and Museum where co-designers found more interest in another installation.	Photographic investigation	Visit to Kelvingrove Art Gallery and Museum	Diving into materials bag brought for workshop - this occurred as set-up was occurring for the proposed workshop. Their diving in created a wholly new project	Disrupted and reconfigured workshop due to actions of co-designers and their own explorations of available content.	Between co-designers in regards to how they enjoyed the alternative approach and how it linked to the installation they had seen at Kelvingrove.	Through material investigations, creative confidence and actions	By repetition of process by group members and group generated templates	The simplification of the final designs to eschew facial outlines
Table Top Gardens	From shared visits and discussions with co-designers regarding up-coming shop and gardening as an enjoyment or pastime of each co-designer		Photographic Investigations	Visits to Tramway hidden garden, Pollok Park and Bellahouston Allotments (Glasgow)	Group discussion of how a manageable system (table-top garden) might be approached and delivered	Collaged visions of personal table-top garden designs - magazines, supplied materials and textures cut and stuck within a specific sized design space	Discussion throughout creation of the designs which encouraged sharing of images and materials between the co-designers. Each person presented their intention and completed designs at the beginning and end of the session to the rest of the group.	The collaged content was reviewed with the design researcher so that he could formulate a shopping list	The supplied plants were used to complete the final designs but also to edit some selections or the execution of some of the ideas.	

	5. Design Development		6. Detail Design		7. Testing and Production				
	Technical Visualisation	Prototypes	Material Explorations	Manufacturing Techniques	Specialist Maker	Exhibition	Commercialisation	Service Delivery	Personal Display
75 BC Fabrics			Choosing base fabrics to be used in production	Digitally printed textiles produced to chosen specifications concerning materials	The final product making was shared with the group through filmed processes.	At Campus in the City. Through accessories in the Resource Centre. At the **designed with deMEntia** pop-up-shop.	Featured as the basis of many projects on sale in the **designed with deMEntia** pop-up-shop		
Floating Heads Plates		Quick direct actions on plates using ceramic pens and personally conceived templates	Creation of templates, the use of ceramic pens and applying visual forms straight onto ceramics.	Final designed solutions were produced in multiples using the available templates created by the group			Sold at **designed with deMEntia** pop-up-shop		
Table Top Gardens		The participants each made their own designs in physical forms using a bedding tray, soil, stones, plants and rocks to emulate their initial collaged design proposal. One participant could not attend this workshop but their prototypes were created to their collaged designs by the other group members. These were evidence that the designs could be translated by other people (including people living with dementia and demonstrated the camaraderie within the group to support each other. The designs were constructed on site at the Alzheimer Scotland Bellahouston Allotment					Designs intended to be sold as kits at **designed with deMEntia** pop-up-shop but time and material constraints did not allow this to occur. The design journey or photographed process of making the gardens was shared in a-project film displayed in the shop window.		In personal spaces including where two participants discussed the fact they had made particular spaces for their designs in preparation of them coming home. One participant even stated that she had intended to use it on her garden table-top as a centre piece for discussion.

Table 2 A selection of 3 Design With Dementia Projects Coded in their Co-design Journeys Green descriptions are independent action by PLWD, Orange are proactive engagement with tailored tasks and Red are actions that were undertaken by specialists or external groups and agencies but shared with the currently active co-design group to inform or progress action

4. Key Insights from the 'Co-design Participatory Power Pyramid' analysis

The analysis of the 15 co-design projects, conducted over a six-year period, shows that only one was predominantly completed '***for***' the group (Figure 4, Project 6). However, this project still supported a valued amount of design '***with***' people living with dementia. This was a project where the participants had significant involvement but could not provide contributions

in the final delivery and acted largely as asked within the workshop setting. In this sense, their contributions were effectively closer to consultancy rather than true participation within co-design. However, their actions and insights informed how the project would empower and engage visitor participation. Three of the 15 co-design projects were evaluated as being '***for***' and '***with***' people living with dementia (Figure 4, Project 1, 5, and 13) moving from an initial provision of an idea, service or project direction, that then gained creative traction and buy-in where the co-designers started to direct significant creative input. Three of the 15 co-design projects were adjudged to be significantly '***with***' people living with dementia (Figure 4, Project 3, 8, and 9) demonstrating cohesion within the groups and providing rich evidence of their ability to inform and shape the design process. Here, the design researchers (authors) played an equally significant role in connecting content and providing opportunities but the creative conversations provided a highly equal and inclusive design process for all parties involved.

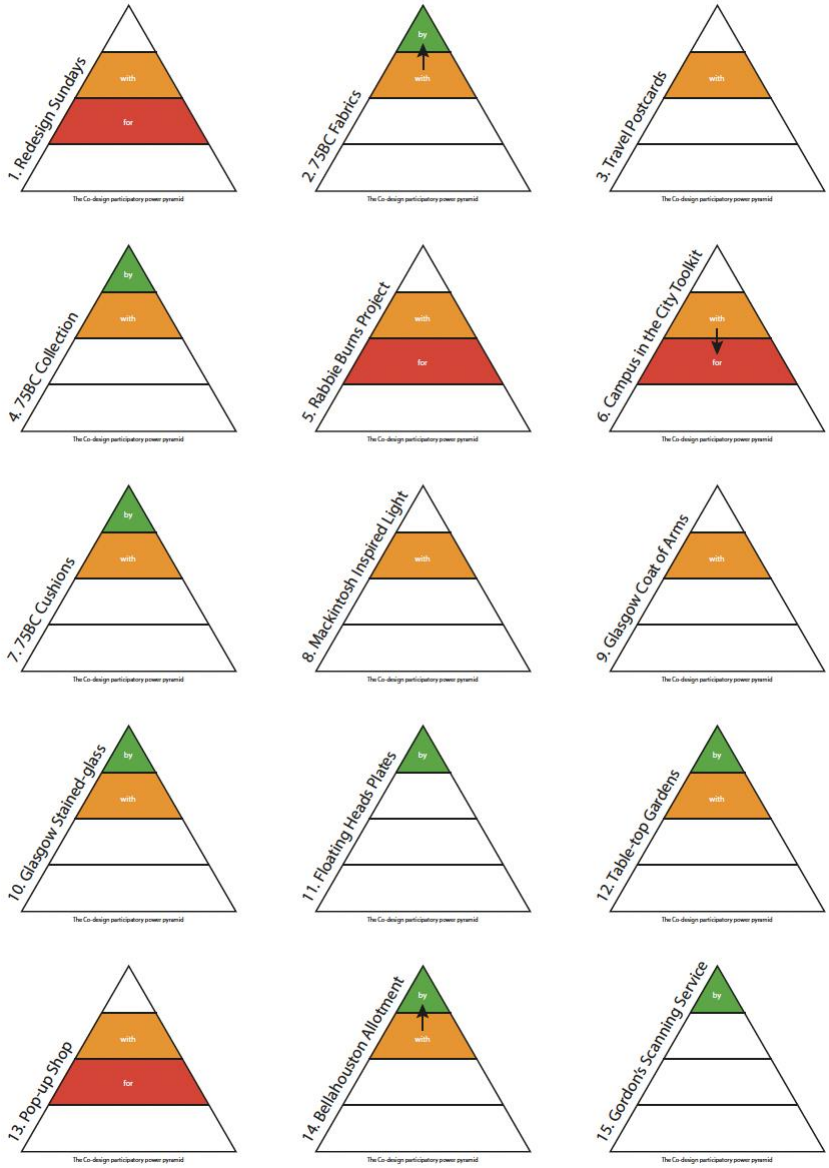

Figure 4 The fifteen co-design projects from this investigation analyzed against the 'Codesign Participatory Power Pyramid'

Four of the projects were significantly '***with***' and '***by***' (Figure 3, Project 4, 7, 10, and 12) meaning that ownership, origination, development and results were significantly moving towards a position of being based in rich positive and capable actions by the people living with dementia themselves. The results were projects that required tasks designed around their wants and desires but that showed real independence and collective cohesion en route to delivering designed outcomes. Projects that were shown to cross into the higher levels of '***by***' and '***with***' expressed particularly strong design actions and independence where the researchers (authors) witnessed unexpected designed outcomes develop and where the results could only have been achieved thanks to the way the co-designers engaged in the pro-

cess. Here, they changed initial expectations and directed longer-term goals or project objectives, purpose, and applications themselves. Although these projects were close to being termed '***by***', there was still important support provided by the researchers (authors) (Figure 3, Project 2 and 14).

Only two projects could be described as fully '***by***' the co-designers (Figure 3, Project 2 and 11). By changing the project focus, setting a workshop brief and disrupting project plans, the co-designers took control of the project from beginning to end. In the first project, the design researchers were able to sit back and observe. Here, the co-designers fed on one another's creativity, energy and excitement in the process that they had developed. They then refined the process and the prototypes before creating a system for producing multiples of their designs. By taking control, the group provided evidence of its belief in its ability to act, empowered to make and do things whilst testing their own, individual creative ideas. The second of these projects was far more akin to design direction by a highly impassioned and driven co-designer. The project differed somewhat from the other group-focused projects in that it was driven by one individual and aided by his primary carer. The scanning-lab service that became the ultimate result of this project was run by Gordon and his primary carer resulting in a design research project of his own, run by him for the benefit of other people living with dementia. The project ultimately resulted in a radio programme being made about the project and this remarkable man.

The original commission of the project was also based within his own interest in how images (in particular, images from a historic visit to Japan) could resonate and unlock deep memories and conversations about powerful and rich autobiographical accounts. His approach resulted in the design researchers (authors) working with him to achieve his goals and to put the power in his hands to advance his own agenda. Although different from the other co-design projects, the empowering of the individual, given the opportunity to fulfil his own creative desires, proved to be deeply meaningful. Although some technical delivery of this project was undertaken by the design researchers, the concept belonged to Gordon. The presentation of the project was undertaken by him to a large audience. He then developed the idea of a service based on his presentation and invited people to make use of his scanning-lab. Here, he collected stories and images from his peers and created a library of content to be explored further. Unfortunately, the Covid-19 restrictions in the UK in 2020 – 2021 halted the project.

In mapping the 15 co-design projects, it is possible to correlate where changes occurred in the structure of the group of people living with dementia. The new group formed at the time of the Mackintosh Light project (Project 8) when the projects were very much conducted '***with***' the researchers (authors). As this group of people living with dementia developed, greater engagement between one another and with the various visits and new projects led to greater cohesion as a group and their capabilities as co-designers. The group became so effective that by the end it set a comprehensive brief for the design researchers (authors) to undertake a project on its behalf similar to Arnstein's 'Citizen Power' (Arnstein, 1969) where the group asserted control and delegated. Unlike other examples achieved through creative

conversations in other projects, this process involved the co-designers dictating what was to be done and how it was to occur, including setting design objectives.

5. Conclusions

Throughout these 15 co-design projects and the subsequent analyses, it is clear that the participants took highly empowered positions that built upon their current capabilities. The approaches reinforced the rights to make decisions and to inform possibilities. More than this the participants became informed in design practices and learned that they could be valued agents in a variety of research focused approaches.

Throughout the open methods of investigation and imbued in the project pathways were considerate participant-led investigations where the ideas they generated had the power to transform expected practices or outcomes. The approaches to the design process collaboration reinforced a sense of ownership and collective value of their designed outputs.

The mapping and development of practices along a recognizable design process identified ways of strengthening the collaborations and the personal opportunities of participants to shape entire project intents and deliveries.

The development of the Participatory Power Pyramid allows designers and design researchers to expand their consideration of how co-design might be structured but also how an evolutionary system of project development can be evaluated. This tabulating of practices leads to an ability to meaningfully interrogate the relational dynamics in a project and champions participant's value within the process reinforcing the ownership and rights within practice. This is true of people living with dementia who regularly expressed elation of their abilities and outcomes which was tinged with a sense of disbelief at what they had achieved but could equally apply to any planned practice with non-designers.

For people living with dementia the projects strengthened personal support networks made links between personal experiences and developed stimulative connected scenarios across periods of time that would usually be avoided due to concerns around what may or may not be remembered.

What also became apparent was that that the process of co-design had periods where not much seemed to be happening, however, greater reflection identified that plenty was happening in terms of team building, sharing of ideas, collective and personal insights, camaraderie, and peer support. What was also clear was that particular considerations in collaborative practices with people living with dementia, to develop a whole design process that include:

- **Planning and delivery** - pertaining to a stage driven evaulatable process of doing co-design.
- **Knowledge, understanding and experience** – pertaining to capabilities and personhood of people living with dementia.

- **Time** – a consideration of the importance of time throughout of the individual and collective projects and actions involved in doing co-design for all parties involved.
- **Confidence and action** – Pertaining to individual and collective ability to contribute to, drive or even disrupt the projects.
- **Facilitator behaviours and actions** – pertaining to the behavioural and action based adjustments the design researcher had to be aware of.
- **Participation in design** – pertaining to design requiring structure, replicable methods, expectations and revelations that identify the process as being rigorous yet potentially unexpected for all parties.
- **Social, purposeful and meaningful** – identifies the social quality of designing which encourages collaboration and that might lead to deeply felt value which tangible outcomes might not explain or share.

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