Transdisciplinary Development of a Framework for Co-Creation With People Living With Dementia

Jonas Rehn-Groenendijk, Darmstadt University of Applied Science, Germany
Evangelia Chrysikou, University College London, United Kingdom
Loukia Minetou, London College of Fashion, United Kingdom
Eva Hernandez Garcia, University College London, United Kingdom
Eleftheria Savvopoulou, Synthesis Architects, Greece
Hina Lad, University College London, United Kingdom

Abstract
When aiming for built environments and systems that foster resiliency and resources, one of the most crucial aspects of design is to properly address the users' needs. While comprehensive research and an empathetic mindset are important prerequisites of this process, the inclusion of all relevant stakeholders cannot be compensated by any methodology. With regards to co-creation with people with dementia, this can pose additional challenges as participants might have difficulties to articulate their feelings and thoughts or design teams might struggle to come up with interactive formats that fit the current mental and physical abilities of the participants. Therefore, understanding key requirements and principles that are particular for the field of neurodiversity can be of great help in order to successfully engage users in the design process. In this paper we outline a transdisciplinary research process conducted by scholars from UCL in cooperation with other stakeholders from academia and practise. This multi-stage process aimed at creating a framework for developing co-creation workshops and approaches for people living with dementia and other forms of neurodiversity.

Keywords: Co-Creation, Transdisciplinarity, Design and Dementia, Built Environment

iafor

The International Academic Forum
www.iafor.org

Introduction - Addressing the specific context of dementia und neurodiversity in co-creation sessions

One of the most crucial challenges of design is to address the needs and requirements of all user groups related to the design output. This applies in particular to designing objects, spaces and systems that aim at serving vulnerable user groups such as people living with dementia and their caregivers. In recent years, actively involving various stakeholders – including patients, caregivers and service providers among others – proofed to be of significant usability, as it allows design teams to gain first hand knowledge of the context without being biased by their own ideas (e.g. Sanders & Stappers, 2014).

Co-design or co-creation intensely involving participatory approaches can be playful and low-threshold methodologies in complex design processes. However, when being applied together with people living with dementia or other forms of neurodiversity, new challenges arise that need to be addressed by design teams when developing co-design workshops (see e.g.Hendriks et al., 2015).

In order to facilitate this process of planning and conducting user-centred co-design workshops that include people living with dementia, a group of researchers, practitioners and both professional and informal caregivers from various institutions and countries participated in a mult-session research- and transferproject that aimed at creating a framework for developing co-design workshop with people living with dementia[1]. The major focus of this project was the design of the built environment. While some aspects might apply to other topics of co-creation with people living with dementia, this was not explicitly object of attention.

In line with current transdisciplinary research approaches (e.g. Defila & Di Giulio, 2019; Belcher et al, 2019) this project was conducted in close collaboration of experts from academia, practise and personal experience. In this way both scientific evidence and anecdotal and implicit knowledge could be taken into account. Furthermore, specific results and concepts where continuously evaluated and adapted from both a scientific and practical point of view.

A multi-session process for creating the framework

The overall process comprised four separate phases in which different experts provided knowledge and shared experienced before insights where consolidated and merged into a framework. All steps where performed online.

Phase 1: Panel presentations by early career academics

In this first phase, early career academics from various fields such as architecture or psychology presented methodologies and approaches for co-creation. These presentations purposely did not focus in particular on people living with dementia. While this was neither excluded nor required, the main focus in this phase was to collect and discuss the approaches

---

and their unique potentials and limitations with regards to the element of including user groups.

Phase 2: Round table discussion with experts & SWOT analysis

Subsequent to this, a round table discussion with experts in the field of dementia and neurodiversity was conducted. This discussion was moderated focusing on understanding the needs and requirements of people living with dementia and their caregivers.

In contrast to the panel presentations, here co-creation was not the major focus point. However, ideas and aspects that related to co-creation where occasionally addressed.

Parallel to this round table discussion a virtual whiteboard displaying a SWOT-template was used to collect insights and statements regarding "Strengthes", "Weaknesses", "Opportunities" and "Threats" of co-creation with people living with dementia related to the needs and requirements of this vulnerable user group. More precisely, the field of "Strengthes" elaborated on the questions "What are the benefits when co-creating with people living with dementia?". "Weaknesses" related to "needs to be considered". "Opportunities" describe aspects that "create an added value when co-creting with people living with dementia?". In this context, "Threats" referred to "What might be risks and difficulties regarding the co-creation process?".

This SWOT-chart was complemented with a field for "advice for co-creation & built environments" and "other notes…".

The whiteboard was filled-out by a scholar simultaneously during the round table discussion.

Phase 3: 3h-Workshop with early career academics and experts

Based on both the panel presentations (phase 1) and the round table discussion (phase 2), a workshop was conducted that aimed at revisiting the insights gained so far and consolidating them into a applicable framework. Therefore, the explicit goal of this workshop was to "Create a framework for developing co-creation workshops for and with people living with dementia & neurodiversity – focusing on the built environment".

During this workshop, participants discussed and brainstormed further key insights and important issues derived from the round table discussion using the extended SWOT-diagram.

In a second step co-creation approaches and tools were collected and discussed based on the panel discussion and own experiences.

In a research-based brainstorming all participants then collected and grouped general aspects that should be considered when developing co-creation workshops for people living with dementia in a mindmap.

Finally, during a focus group discussion participants ideated relevant phases in a co-creation session and useful tools and methods while considering the specific needs and requirements of people living with dementia.

Phase 4: Follow-up workshop iteration

Since both the mindmap of general aspects and the table of phases proofed to be highly complex, a second workshop with partly difference early careers and experts was conducted to deepen the knowledge and practicability of both tools.

Output

A. Building Blocks and Considerations

One of the two major outputs of this process is a mindmap illustrating the building blocks and considerations for co-design workshops for and with people living with dementia. The herewith presented version (see Fig. 1) is still work in progress and currently updated by the project team.
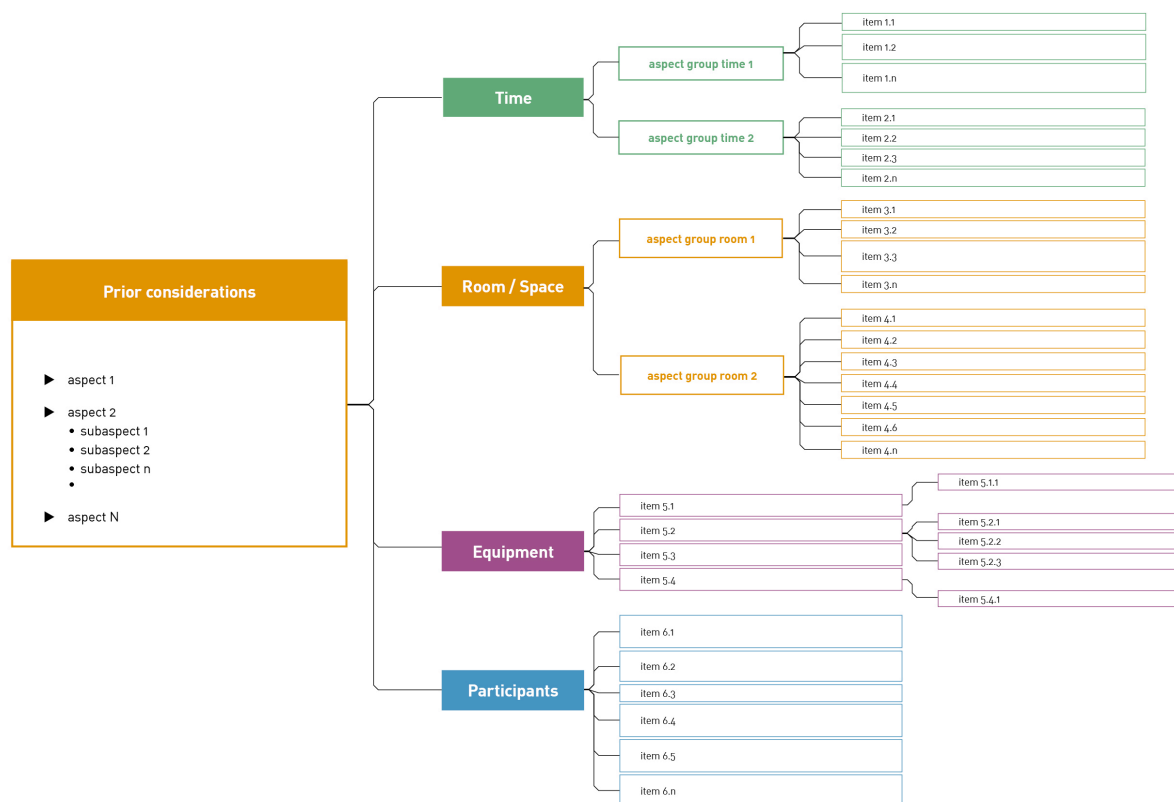
Figure 1: A Building Blocks and Considerations for Co-Design Workshops for and with People Living with Dementia. (interim version)

B. Phases and Tools

Secondly, a table comprising phases and tools for co-design workshops for and with people living with dementia was developed (see Fig. 2 for an interim version of this framework). This is a open-ended framework that is currently being updated and extended by the project team. Furthermore, this table is meant to be a basic structure which needs to be adapted and extended with regards to the individual and unique project and group of users at hand.
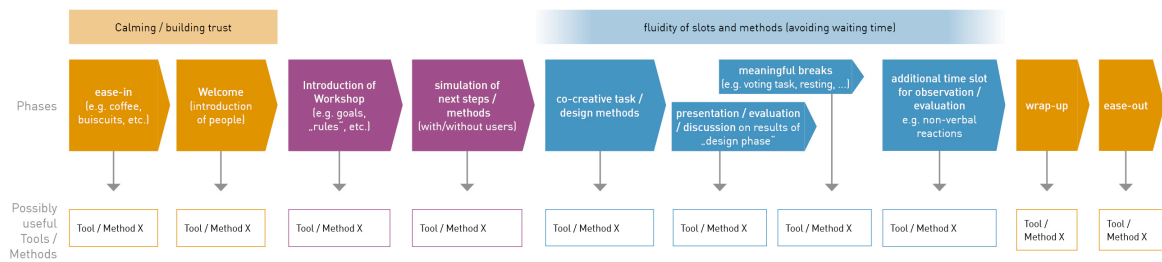
Figure 2: B. Phases and Tools for Co-Design Workshops for and with People living with Dementia. (interim version)

Conclusion

This transdisciplinary process proved to be highly interactive and led to new insights that most likely would not have been derived from several workshops with disciplinarily separated groups of participants. The heterogenic mix of scholars, practitioners and informal caregivers created synergies and emergent knowledge partly built on implicit knowledge of the experts.

However, it is worth mentioning that the herewith presented mindmap and table is a first and interim version of the framework that is currently updated and extended. Therefore, these tools are at the moment the mere basis for scientific discussion before they are rolled-out to the public to be applied in real life workshop scenarios by design teams.

Therefore, more research is needed to evaluate the use and effectiveness of this framework once it is finalized and published.

References

Belcher, B. M.; Claus, R.; Davel, R.; Ramirez, L. F. (2019): Linking transdisciplinary research characteristics and quality to effectiveness: A comparative analysis of five research-for-development projects. *Environmental Science & Policy* 101, 192-203. DOI: 10.1016/j.envsci.2019.08.013

Defila, R.; Di Giulio, A. (Eds.) (2019). Transdisziplinär und transformativ forschen, Band 2. Eine Methodensammlung. Wiesbaden: Springer Nature. Online available at https://directory.doabooks.org/handle/20.500.12854/25939

Hendriks, N.; Slegers, K.; Duysburgh, P. (2015). Codesign with people living with cognitive or sensory impairments: a case for method stories and uniqueness. *CoDesign* 11 (1), 70-82. DOI: 10.1080/15710882.2015.1020316

Sanders, E. B.-N.; Stappers, P. J. (2014). Probes, toolkits and prototypes: three approaches to making in codesigning. *CoDesign,* 10 (1), 5-14. DOI: 10.1080/15710882.2014.888183