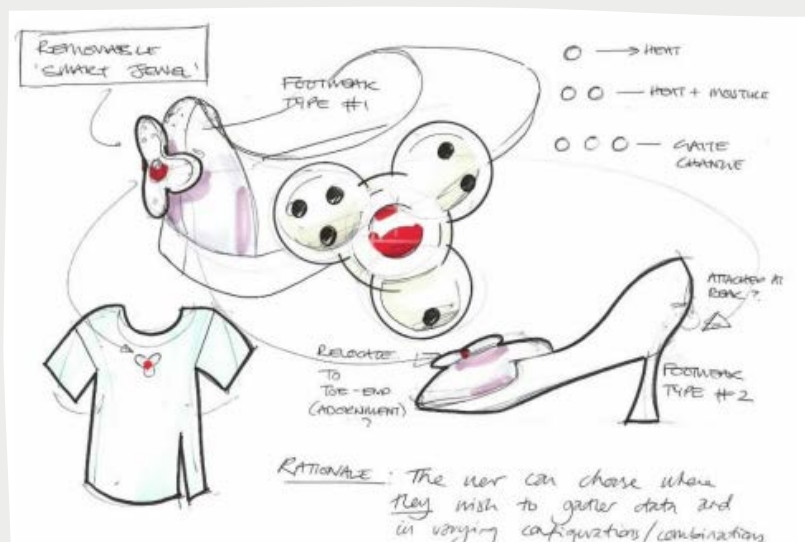# Practical tips on co-creation with older adults and informal carers

SETTING UP CO-CREATION IN AN EU-FUNDED RESEARCH PROJECT SETTING

maturolife

What is co-creation and why involve older persons and informal carers?

Co-creation is a process of involving end users in the creation of a product or service from the beginning and throughout its development. It is based on the idea of equal value of expertise, whether that be design, health, academic or personal experience: good design ideas come from different life experiences. [1]

Although the active involvement of older adults and informal carers has been slower to develop than that of some other end user groups, a growing number of studies have shown the added value for both the user and the research/design team:

Co-creation activities build empathy in the design professionals (designers, engineers, material scientists, researchers, etc.) involved as they see the perspective of the user more clearly and understand their requirements. Participants are provided insight into design processes, perspectives and methods and they may feel the satisfaction of contributing to important research, and that their contributions are valued.

Maturolife co-creation workshop, 2018

1 An informal carer is defined as a person who provides, usually, unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework.

How to involve older persons and informal carers: Practical tips from MATUROLIFE

Before the co-creation activity

Build trust: Establish clear communication and build trust to ensure the quality of interactions with older persons and informal carers.

- TIP: Favour face to face contact for introducing the study.
- TIP: Seek advice, inform, and involve well in advance national or regional organisations that represent and provide services to older persons and/or informal carers about the project and co-creation activity. Their additional presence may help participants feel at ease and they will open up and discuss more freely when they feel in a more informal setting.
- TIP: Ensure that the same researcher is present for the participant throughout the study
- TIP: Limit perceived burdens such as discomfort, fatigue and travel to successfully recruit older persons and informal carers.
- TIP: Consider organising a first session for participants to get to know each other and share their (caring) experiences.

Photo by Renata Venaga on Unsplash

Prepare clear and simple materials : [2]
Advertisements, participant information sheet, informed consent form, participant inclusion criteria checklist.

- Use a basic typeface or font, such as Arial at 12 points or larger
- Avoid ornate and complex typefaces
- Avoid italics, justified text and all caps
- Use bold for emphasis and minimise underlining
- Use plenty of space between lines to increase readability
- High contrast (dark text on a light background) works best
- Rely on more saturated, intense colours
- Use plain background and a clean, simple image
- Choose a single image rather than a collage of images
- People and objects in the image should be clear and visible

🔑 TIP: Consider splitting materials into 2 parts: one simple overview part + additional detailed information if required.

Timing: Make sure to leave sufficient time to prepare and ensure a successful recruitment process.

🔑 TIP: To ensure participation, plan co-creation activities outside of typical vacation times.

🔑 TIP: Enlist support of local organisations on the ground with knowledge on how best to reach out and recruit older people and/or their carers.

Photo by Billy Williams on Unsplash

Data protection: Ensure processes are in place to manage the privacy of data shared by the participants.

💡 TIP: Rethink whether the collection of personal and sensitive data is actually needed.

💡 TIP: Ensure that your co-creation is GDPR-compliant (General Data Protection Regulation) e.g. by using https://gdpr.eu/checklist/

💡 TIP: Check whether all participating countries fall under GDPR or if data is gathered/shared with non-EU/EEA countries.

Target group: Define the target group and the list of inclusion/exclusion criteria.

💡 TIP: One person can have overlapping roles e.g. they may be an older person but also providing informal care. Their feedback could be attributed to their experience as an older person, an informal carer, or both.

💡 TIP: Consider whether it might be useful to organise workshops with older persons and their carers separately. This can encourage them to open up and speak more freely.

Ethical approval: Find out if ethical approval is needed; from which organisation(s) e.g. in each country separately, and factor that in as obtaining ethical approval may take some time.

💡 TIP: Avoid overlapping timelines of phases that can block each other e.g. without ethical approval recruitment cannot start.

Scheduling appointments: Confirm appointments by phone and follow-up with a reminder of the appointment 1-2 days in advance.

💡 TIP: Prepare a "back-up" list of participants in case of no-shows or cancellation.

Translation: Ensure documents and co-creation workshops are in the local language.

- 💡 TIP: Prepare materials in the main language spoken, and ensure the language used is adapted and easily understood by participants (also for the translated versions)!
- 💡 TIP: Clarify who will translate documents and interpret during workshops – budget and time need to be allocated accordingly.

During the co-creation activity

Physical environment: the location of the co-creation needs to be accessible for people with mobility or balance impairments (including accessible toilets).

- 💡 TIP: Avoid noisy spaces or spaces with too much echo to make conversations easier to follow.
- 💡 TIP: Choose venues with restrooms with disability access and avoid venues that are difficult to access (e.g. avoid venues on the top floor).
- 💡 TIP: Privilege organising several workshops with fewer participants to get the discussion flowing and more detailed feedback. This may require more facilitators and break-out sessions. Ensure that data from different workshops are recorded and brought together afterwards for analysis.

Maturolife co-creation workshop, 2018

Transportation: Ensure the co-creation location can be easily reached by (public) transport.

💡 TIP: If possible, organise and finance transportation e.g. through local cab services. At a minimum, reimburse travel costs.

Compensation: Compensate informal carers for their time, should they need to take time off work, or if their participation means they need to organise respite care (=short-term relief for primary caregivers) for the person they are caring for.

💡 TIP: If sessions involve informal carers (not working) there may be a need to pay for any respite care while they attend the workshop. If participation involves (working) informal carers, compensation for equivalent time of their salary – including the time it takes them to travel to and from the workshop and to participate in the workshop – is needed.

Length of the session: The co-creation activity should be long enough to gather the necessary data but not too long to avoid alienating and fatiguing people.

💡 TIP: Plan regular breaks and provide nice refreshments throughout, which may include a proper meal (and a hot meal if organised during the winter time).

After the co-creation activity

Show appreciation: Identify opportunities to show appreciation for the participant's voluntarism and effort.

💡 TIP: Write personalised welcome and thank you letters at the beginning and end of the co-creation activity.

💡 TIP: Provide a brief summary of the findings and value they added at the end of the study + a thank you for participants' contributions.

Further inspiration for co-creation

CIDER – A guide to co-creating digital public services

https://co-creation.mobile-age.eu/en/

COSIE – Towards a roadmap for co-creation

https://storage.googleapis.com/turku-amk/2019/04/

Mind the gap!
Multi-stakeholder dialogue for priority setting in health research

https://www.kbs-frb.be/

NESTORE – Report on Needs, Values and Suggestions to Co-Design

https://nestore-coach.eu/

Blended Learning Networks – Swedish Family Care Competence Centre

http://www.anhoriga.se/information-in-english/blended-learning-networks/

What is MATUROLIFE?

MATUROLIFE is an Innovation Action funded for 36 months under the European Union's Horizon 2020 Research and Innovation Programme. MATUROLIFE brings together 20 partners (SMEs, academics, designers, research organisations and NGOs) from 9 countries to develop fashionable technologies to make older persons' lives easier and more independent.

To develop these assistive technologies – a smart sofa, garment and shoes – interviews and co-creation workshops were conducted with older persons and their carers in Belgium, France, Germany, Italy, Poland, Slovenia, Spain, Turkey, and the United Kingdom. This co-creation manual is based on the lessons learnt and good practices from these workshops.

MATUROLIFE Project Title: *Metallisation of Textiles to make Urban living for Older people more Independent and Fashionable.*

For more information and to join the MATUROLIFE community, visit: **www.maturolife.eu**