PARTICIPATORY APPROACHES WITH OLDER ADULTS

PAAR-NET OPENING CONFERENCE PROCEEDINGS APRIL 17,2024

KRAKOW POLAND

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PAAR-Net is an EU-funded COST Action and stands for CA22167: Participatory Approaches with Older Adults. PAAR-Net focuses on reshaping ways to involve older adults in scientific research, policymaking, and practice. PAAR-Net aims to foster inclusive social innovation, by tapping into the knowledge and experiences of older adults, particularly those at risk of social exclusion, to address the complex challenges of ageing societies. As a networking framework, it brings together academics and old and young innovators both from wider Europe and elsewhere in the world.

PAAR-Net advocates participatory approaches, which emphasize collaboration between experts-by-training, typically academics, and experts-by-experience, older adults aged 65 and above. It actively endeavors to engage older adults who are at the margins of society, including those with migrant, refugee, and minority backgrounds as well as those with lower socio-economic status, health problems, and access problems. The participatory methods seek to move beyond traditional research models by actively involving older adults in all stages of the research process, from identifying research goals to the dissemination and valorization of research findings.

The Need for Change

There are significant gaps in how older adults are included in research efforts. Many research initiatives tend to limit older adults' involvement in data collection. These initiatives overlook their potential contributions to shaping research questions and interpreting the data and results. This oversight perpetuates age stereotypes and does not adequately challenge ageism. It also fails to harness the wealth of knowledge older adults possess.

Furthermore, even though policy and practice try to involve older adults in their processes, they are far from ensuring meaningful involvement, especially for those who are at risk of social exclusion. In this respect, they need new approaches and methodologies. Moreover, there are linkage gaps between research, policy, and practice.

Why It Matters

By advocating participatory approaches, PAAR-Net aims to create more inclusive, fair, and sustainable societies. Involving older adults in research, policy development, and practice ensures that solutions are better suited to their needs, experiences, and aspirations. This not only leads to more effective policies but also promotes social justice and equity for older adults across diverse contexts and jurisdictions.

PAAR-Net represents a forward-thinking initiative that seeks to empower older adults, challenge ageism, and drive positive change in ageing societies. Through collaboration and innovation, PAAR-Net aims to pave the way for a more inclusive future for older adults worldwide.

This document compiles selected research presented at the PAAR-net opening conference, held in Kraków 16.04 – 17.04.2024. We extend our gratitude to all participants and contributors for their valuable insights and dedication.

We hope these contributions provide valuable insights and spur further discussion and research in our field. Please stay connected with PAAR-net for upcoming events and opportunities for collaboration. Visit our website: paar-net.eu

Content:

Working Group 1

WG 1

Health, Care & Support

Working Group 1 focuses on knowledge co-production in research and in practice about participatory approaches with older adults living in community and other settings, with a particular focus on well-being, well-becoming, and the overall quality of life. The working group aims to promote an inclusive perspective that highlights living expertise and strength of people involved in participatory approaches rather than their possible health conditions and limitations as our primary focus. Tereza Tereza Menšíková & Dianne Seddon lead this group and organized WG1 session in Kraków.

Following speakers presented during this session: Charlotte Gruber, Heidi Kaspar, Bojana Matejic and Isabelle Tournier.

Charlotte Gruber, Austria

Socially Excluded Older Adults: Voices and Experiences. Personal Records and results as a co-creator

The research programme Socially Excluded Older Adults: Voices and Experiences -SEVEN applied a citizen science approach to gain insights on experiences of older adults affected by social exclusion. Measures introduced by governments and newly developed policies and services should remain relevant and accessible to the diverse needs of older adults.

SEVEN implemented an innovative approach of a participant-voice framework to include marginalised populations in multi-stakeholder research processes.

SEVEN had three objectives:

•Capture experiences, expectations and needs of socially excluded older adults

•Facilitate and advance ways for socially excluded older adults to express their voices thereby empowering them and their self-advocacy

•Harness learning from socially excluded older adults to develop policy and research recommendations

I was part of the project as an older co-creator and my intention was to bring in the following perspectives:

•my own perspective as a person living in a small rural village, but coming from an urban, academic background without many relations to the village population.

•using a friend as mediator who is chairing a village senior's group with more than 250 members to get an insight into the views and insights of older people who never left their rural and family environment.

My research questions were:

•What kind of communication with other people do older people in rural Austria wish?

•Where can they meet?

•What is needed to improve their social life?

•What is missing?

•What are the differences between urban and rural surroundings?

My approach to answer the questions was making interviews, holding a group discussion and writing an auto-ethnography

The interviews were organised together with my friend as a mediator, and we made the following interviews:

•with a couple (the woman has severe health restrictions)

•with an almost blind woman still living on her own

•with a woman who recently moved from Vienna to her birthplace into an assited living quarter

Together with my friend we also organised a group discussion with six women aged between 70 and 82 – men found many excuses why they could not take part.

Main findings of the group discussion:

•great satisfaction with living in a rural area (influenced by the Covid19 lockdowns)

•growing digitalisation excludes older people, they depend on young family members

•poor public transport also makes dependent on family members

•Shops, banks, inns are closing in villages

•importance of organised events

•to have a meeting place without compulsory consumption

•to have a motivated and fully engaged chairwoman like my friend

In various discussions with my friend I realised how important her role as a motivator and manager of group events is – her main complaint was that older people are very willing to take part in whatever she organises, but there are very few who want to take responsibility for activities themselves. Motivating older people to take up initiatives themselves is very difficult, but they highly appreciate offers of common events.

Being part of the programme SEVEN as older co-creator was a real personal gain for me:

•The interviews gave me an insight into the thinking and attitudes of village people – made me more grateful for the opportunities I had in my life

•I got a better understanding about the different attitudes of older men and women in my surroundings

•Writing an auto-ethnography about what it means to me to become 70 years old

•I learned to appreciate the work of my friend, I realised how imortant her voluntary engagement is for older people to organise events for them

•Being part of the group of co-creators I learned how important the professional instructions of the project team was and what being part of this group meant to all of us – especially for those already in institutionalises care felt a personal appreciation and felt honored that their contributions were highly acknowledged

I can only recommend taking part in programmes like that as an older co-creator; it enriches personal experiences and gives more meaning to life after retirement.

Heidi Kaspar, Bern University of Applied Sciences, Switzerland

Exploring the potential of caring communities with older adults. Five learnings.

This contribution presents five learnings from a community-based participatory research project to improve home health care for older adults.

Problem statement: In the area of care, outpatient services in Switzerland are often unable to provide sufficient long-term care at home. Households have to organize and pay for care services privately despite having health insurance. This is because, unlike nursing care, care work is hardly covered. This gap is often bridged by women through underpaid or unpaid work. The "CareComLabs" project is investigating the extent to which caring communities can contribute to improving long-term care at home. Caring communities place care work at the center of society and make it a joint task for professionals, authorities, and civil society [1].

Research design: Together with local Spitex organizations and other stakeholders from the political community, the civilian population and NGOs, we have set ourselves the goal of building caring communities at three locations in the regions of Berne and Zurich, Switzerland. These communities carry out the following three steps:

1. they explore and document local support needs and existing services;

2. They develop and implement initiatives and activities;

3. evaluate and improve them.

We combine innovative approaches from the fields of healthcare and technology development: Caring Communities [2] and Living Labs [3]. In our consistently participatory approach, we are guided by the Community-Based Participatory Research (CBPR) approach [4].

The project delivers two results:

a) an initial assessment of the potential of caring communities to sustainably improve long-term care at home and

b) insights into the process of initiating, developing and establishing caring communities, both theoretical and practical.

With a focus on the latter, we are preparing basic knowledge as well as findings and practical tips from this and other projects as a collection of materials. It is intended to support other interested parties (communities, individuals, associations) in building caring communities. During the course of the project, the initially planned three caring communities have already become five, so there is interest in this.

This project description has been published in German and French (Kaspar et al. 2021), please visit the journal Primary and Hospital Care for the mentioned references.

Five learnings on participatory research with communities that have yet to be formed are presented:

- Finding allies and building communities demands that researchers invest time, are present, are insisting and patience. You need to demonstrate that you are serious about this project and their meaningful contribution.

- If you are serious about participation, the planned procedure might turn out quite differently. The evolution of the four caring communities we initiated in four municipalities give testimony of the 'local power'. We applied the same procedure of three steps, but the initiatives developed differently with respect to pace, form, and outcome of each phase.

- If your project plan and funder allow you diverting from initially planned research designs and foci, this openness has a great potential of creating ownership in project partners. It also entails the risk of being dismissed and local partners 'owning the project' and continuing without academics involved.

- Being inclusive and engaging people who thus far are barely or not heard takes even much more time. In 3.5 years of duration just succeeded occasionally, but not systematically. It also became clear that including marginalized people was not a commonly shared goal.

Diversity and commonality are characteristics of caring communities; the latter of this paradoxical characteristics is easier to achieve.

- People join participatory research because there is something that catches their attention, raises their hopes and expectations or interest. The very topic in question might work as an attraction, or research itself. Science might work as a boundary object uniting persons from different perspectives.

For more information on the project and its members, please visit the website: Sorgendegemeinschaft.net

Reference: Kaspar, Heidi, Katharina Pelzelmayer, Anita Schürch, Fabian Bumer, Tanja Ertl, Shkumbin Gashi, Claudia Müller, Timur Serefliooglu, and Karin Von Holten. "Können sorgende Gemeinschaften die häusliche Langzeitversorgung verbessern?" Primary and Hospital Care: Allgemeine Innere Medizin 21(6): 188–90. https://doi.org/10.4414/phc-d.2021.10401.

Bojana Matejic, University of Belgrade, Serbia

Exploring Elder Abuse: Experiences from Participatory Research in Serbia

Main research question/objective: The global population ageing has contributed to a concerning rise in elder abuse. Older women, in particular, face a greater risk of elder abuse, but this public health issue is often ignored and mainly invisible in many societies. According to the latest available data, In Serbia, 16% of older women aged 65 to 74 experienced some form of violence after reaching the age of 65. This study aimed to assess the social norms and cultural attitudes toward older persons, to explore the range of attitudes and behaviours which are tolerated in society but represent violence and abuse, to explore the characteristics and impact of gender-based violence against older women, along with the degree to which various institutions respond to this issue and how the complex societal systems respond to their needs. This abstract aims to provide insight into the method used, particularly the participative research approach.

Methods: The project "Empowerment of Older Women: Prevention of Violence through Changing Social Norms in Serbia (EmPreV)", supported by the European Union and Austrian Development Agency, consisted of qualitative and quantitative research phases. The participatory research approach was applied during the qualitative phase of the study. Engaging older volunteers from the network of the Red Cross in research offered firsthand experience and insights into elder abuse issues within the community. They were engaged during pre-focus group planning, recruiting participants, connecting with the Roma communities, designing the structured guide for focus group discussion and case study for initiating the discussion, and during discussions and post-focus group analysis. Our research included 157 respondents participating in 17 focus groups across four regions in Serbia, from four cities and two villages. The focus groups included women from three age categories.

Findings: The participatory approach gave the well-designed research framework an additional quality. The assistance of non-academic partners in all practical steps of conducting our research is undeniable, from the planning phases to recruiting participants and organising focus group discussions. Initiating discussions on sensitive topics like elder abuse can be challenging; therefore, a real-life case study, prepared in the interaction with our volunteers and presented at the outset of the focus group, facilitated engagement and open dialogue with the participants. This approach encouraged open dialogue and empathy, offering a more comprehensive perspective of the complex issue of elder abuse. Sharing genuine experiences added authenticity to our research, ensuring that the discussion reflected the realities faced by older adults. A real-life story captivated the participants' attention, fostering more engaging and interactive focus group discussions beneficial to all parties involved, yielding insights on a topic of study for researchers, and providing actionable and empowering information for participants.

Furthermore, by participating in our research, our non-academic partners contributed ideas and initiatives to establish support mechanisms in local communities, including initiatives such as SOS telephone lines and the establishment of clubs and daycare centres for older people. They suggested utilising socially responsible media content and educational systems to promote positive family values, foster good neighbourly relations, raise awareness about intergenerational solidarity, and address the issue of elder abuse. Also, our volunteers encouraged older women's active participation in the local community through engagement in associations, organisations, volunteering, and other forms of involvement.

Conclusion: In future efforts to address elder abuse, it is essential to educate older women about the various forms of violence and risk factors, provide psychosocial support, ensure professionals receive ongoing training on the specific nature of abuse against older women, and enhance coordination among relevant local stakeholders to strengthen system responds. Evidence-based policies are crucial, and the participation of community volunteers as non-academic research partners is the practice that can support and upgrade these intentions.

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Isabelle Tournier Univ Paul Valéry Montpellier 3, France

Co-creation with people living with dementia: insights from the IDoService project on challenges and expectations

This presentation aimed to address potential barriers to participatory research to people living with dementia by sharing insights from the European funded IDoService project (2020-2022) . The aim of the IDoService project was to develop a user-friendly service for people living with mild to moderate dementia (PLWD) to realise themselves and contribute to society. The idea was for the service to allow people to plan, connect with and participate in tailored opportunities. Its aim was to reduce the observation that people living with mild to moderate dementia are reporting missing opportunities to be actively involved in activities meaningful for them (for example physical, social, or cultural activities) and it affects their wellbeing and social participation (Ziebuhr et al., 2023). The research team followed a service design approach that corresponds to a holistic, co-creative approach to improve the quality of service provision (Stickdorn & Schneider, 2011). The project relied on co-design to involve relevant stakeholders (people living with dementia, their care partners, as well as staff from age-related or activity-related organisations in Greater Manchester, UK). The project was organised in three successive steps involving a variety of relevant stakeholders, namely people living with mild dementia, care partners, staff from service providers, researchers, and designers. The first step (Step 1) was interviews and focus groups to learn more about preferences, barriers, and facilitators to participation in meaningful activities while living with dementia. The second step (Step 3) was co-design workshops to work together with stakeholders to design potential tools related to needs occurring in step 1. Based on inputs

from the workshops, the research team designed the I Can Do Pathway toolkit as the new service and outcome of the IDoService project. The co-design prototype was refined and tested in the last step (Step 3) and can be find online for free on the www.idoservice.org

Regarding barriers and facilitators to involve experts by experience during this research (i.e., people living with dementia and their caregivers) has been related to the Covid-19 pandemic situation which began only a few months before the project started and led to some adjustment of the initially planned project. The main adaptation is change from in-person interviews and focus groups largely to online delivery. We initially planned in person focus groups and interviews with people with dementia, their care partner, and staff stakeholders. Due to a national lockdown and the prohibition of in person meetings for approximately the 10 first months of the project, we held all focus groups online (Microsoft Teams) and most of the interviews online, too. Only four interviews were delivered in person, only with people living with dementia. As we estimated that the online format for the focus groups would not be suitable or comfortable for people living with dementia, we decided to finally not organise focus groups with them. The national lockdown and limited service provision also made recruiting experts by experience quite challenging, leading us to lower our expectations regarding their participation numbers. Fortunately, we managed to recruit a sufficient number of people living with dementia with the support of a local service provider, Age UK Salford, which was interested in the project's potential outcomes and experienced in participatory research.

Beyond the limitations due to the Covid-19 context, other adaptations had to be done regarding the research material to make it accessible to people living with dementia, who might have additional impairments besides cognitive ones. This included research activities itself, but also ethics forms, recruitment flyers, and deliverables. A significant challenge was making documents informative enough but still easy to understand, especially for people who never participated in research activities before. Besides using plain English and short sentences, an effort was made to use font big enough, sans-serif, with attractive colors and sufficient contrasts between the different parts of the document. As mobility can be an issue for older adults, especially for those living with dementia that often cannot drive anymore or take public transport, we offered transportation by a research partner or covered taxi costs to ensure they could comfortably attend the research venue. Participants were also encouraged to come along with a relative if it would make them feel more confident and at ease.

When possible, making research activities in a place familiar to experts by experience is recommended to enhance their comfort and confidence. For example, the IDoService co-design workshops with people with dementia were organized through Age UK Salford and held during their bi-monthly dementia cafés and participants in this study were regular participants in the dementia cafe. The familiar social environment provided a supportive context for participating in the co-design activities and expressing their views. The group had already previously participated in research projects and were aware of the consent process. All

participants were informed in advance of the event to decide if they wished to participate or not. Information and consent forms have been provided one week in advance to give them enough time to read through and consent was (re-) confirmed on the day. A pre-workshop lunch was held to allow participants and facilitators to become acquainted informally before starting the workshop. Finally, one very important point stressed by the groups we were working with was the need to ensure continuity of communication and to keep co-designer participants informed of the outcomes and further developments to ensure they feel that their input is being valued. To conclude, making the participation in research enjoyable and meaningful for participants has a beneficial impact on the immediate quality of data collected, on participants' wellbeing and on the willingness to participate in the future (Rodgers 2018; Zeilig et al. 2019).

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Working Group 2

Working Group 2 is dedicated to creating inclusive communities where older adults from diverse backgrounds feel valued and supported. Specifically, WG2 focuses on including older migrants, refugees, indigenous peoples, and those facing barriers in accessing services and infrastructure such as healthcare and transportation. By fostering inclusivity and diversity, WG2 contributes to creating a society where everyone, regardless of background, feels a sense of belonging and support.

Marion Scheider-Yilmaz & Charles Waldegrave lead this group and organized WG2 session in Kraków.

Following speakers presented during this session: Anne Ramos and Ute Karl, Fifi Kvalsvik and Marianne Storm, Mário Rui André, Marion Scheider-Yilmaz and Charles Waldegrave.

Fifi Kvalsvik & Marianne Storm, Department of Public Health, Faculty of Health Sciences, University of Stavanger, Norway

Exploring Paths from Solitude to Inclusion: A Glimpse into Depression, Loneliness, and Frailty in Home-Living Older Adults

Background: Understanding depression, loneliness, and frailty is critical to identifying supportive measures that promote greater social inclusion and improve the quality of life of older adults. These factors affect an individual's ability to fully participate in society. Depression and loneliness often lead to social withdrawal and isolation, while frailty can limit physical abilities and further reduce social engagement.

Objective: To assess changes in frailty levels among home-living older adults over 5 months and to examine the functional changes in depression and loneliness from a pre-study baseline (t1) to a post-study period (t2) and how these relate to frailty. At baseline, healthcare professionals assess participants to determine the most appropriate types of support. This may include participation in senior activity centers, group exercise classes, walking clubs, knitting clubs, and social dining.

Research questions:

- Are there identifiable changes in depression that can be observed from t1 to t2, and how do these changes relate to frailty?

- Are there identifiable changes in loneliness that can be observed from t1 to t2, and how do these changes relate to frailty?

Methods: This pre-post study, registered on ClinicalTrials.gov (NCT05837728), involves interprofessional teams of registered nurses, physiotherapists, and occupational therapists conducting health needs assessments. These assessments were conducted initially at baseline and again after five months. The sample consists of 40 home-living older adults aged 75 years or older who have applied for municipal health and care services in Norway. Data analysis consists of descriptive statistics, simple tests, and the presentation of plots and correlation coefficients.

Preliminary findings overview:

Depression and Frailty:

- Baseline (t1): identified 13 participants with depression, 5 very depressed, and 8 depressed.

- Five months later (t2): among these 13, improved (7), unchanged (5), worsened (1), and new cases (6).

- Frailty levels among those with improved depression: improved (2), worsened (3), and unchanged (2). The remaining participants maintained stable frailty levels throughout the study period.

Loneliness and Frailty:

- Baseline (t1): 2 participants were identified as very lonely, and 6 were borderline lonely. Note: "borderline lonely" refers to scores on the cutoff score between 'lonely' and 'not lonely.'

- Five months later (t2): loneliness level improved in all 8 participants, but there was 1 new case.

- Frailty levels among these participants: worsened (3), unchanged (5), and improved (1).

Key insights:

- Depression and loneliness: there have been notable improvements in both areas, highlighting the benefits of inclusive community-based social activities and support services.

- Frailty: The mixed result in frailty levels suggests a complex interaction between mental health and physical well-being.

- The emergence of new cases of depression and loneliness highlights the continuous need for comprehensive ongoing support.

Reflection: Our research has provided insight into the challenges older adults encounter when engaging with their communities. These challenges shed light on the factors hindering older adults' ability to connect with others, emphasizing the need for further research and targeted solutions. We support the implementation of personalized care plans that are adaptable and tailored specifically to meet individual needs, ensuring that all older adults can fully benefit from initiatives aimed at improving their inclusion in society. Although organizing social activities is inherently valuable, providing access to comprehensive health services is equally important. Together, these efforts help create a more inclusive and supportive environment for our older community members.

Marion Scheider-Yilmaz, PACTE Laboratory, University of Grenoble Alpes, France

Social inclusion of older adults at a glance. Design citoyen: a participatory research project with older adults

Background: A wide range of participatory approaches and research projects involving older adults are currently being developed in France and elsewhere. While the inclusion of older adults in research and projects directly concerning them has become a common goal, there is often insufficient attention to involving diverse groups and profiles. Consequently, participatory approaches tend to engage very homogeneous groups, thereby perpetuating the invisibility of others (e.g., older migrants, older women, older adults with disabilities).

Objective: This research project aims to develop a participatory method that involves a variety of older adult profiles in local decision-making processes. Initially, the prototype of the method is being tested in one experimental location (T1), and then it will be further tested in eight additional locations across France by a pool of researchers (T2). The method will eventually be assessed by the involved researchers using a common assessment framework and translated into a toolkit.

Research questions:

- Do the outcomes of the participatory process differ based on the groups of older people involved?

- Does shaping a method targeting the most excluded groups of older adults lead to greater inclusiveness in participatory research and, ultimately, in the decision-making process?

Methods: The research project involves the development and testing of a participatory method in which participants design and present concrete solutions to key local players and decision-makers. Two groups are constituted: one with older adults highly involved in social and civic activities, and the other with older adults who are usually less or not involved in such activities. The approach utilizes a set of inclusive tools to help the groups conduct a local diagnostic and develop solutions to the identified problems. The method has then been detailed in a toolkit and replicated by different research teams throughout France.

Preliminary findings overview:

- Diverse participation leads to varied outcomes: The preliminary testing of the participatory method indicates that the outcomes of the participatory process vary significantly based on the diversity of the older adult groups involved. Groups with different backgrounds and levels of involvement in social and civic activities provide distinct perspectives and solutions, highlighting the importance of inclusivity in participatory research.

- Enhanced inclusiveness through targeted methods: The method designed to include the most excluded groups of older adults – such as older migrants, older women, and older adults with disabilities – demonstrates a greater level of inclusiveness in both the research process and the decision-making outcomes. This targeted approach effectively brings marginalized voices into local decision-making processes.

- Effective use of inclusive tools and tips: The inclusive tools employed in the participatory method have proven effective in enabling older adults to conduct local diagnostics and develop concrete solutions. These tools facilitate engagement and ensure that all participants, regardless of their previous level of civic involvement, can contribute meaningfully to the project.

- Scalability and replicability of the method: The successful replication of the participatory method in multiple locations across France suggests that the method is scalable and can be adapted to different contexts. The common assessment framework and toolkit developed through this research provide a standardized approach that can be utilized by various research teams, ensuring consistent cross-analysis of the local results.

Reflection: The findings of this research project underscore the critical importance of diversity and inclusivity in participatory approaches involving older adults. By actively seeking to include a variety of older adult profiles, especially those who are often marginalized, the project not only enriches the decision-making process with diverse perspectives but also ensures that the voices of those who are typically unheard are amplified. The success of the inclusive tools and methods in engaging participants of varying backgrounds and civic involvement levels highlights the potential for these approaches to be adapted and scaled across different contexts.

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Participatory Approaches with Indigenous Communities to Improve Policy Responses

Objective

This research aims to provide co-created qualitative and quantitative information on kaumātua (Māori Elders indigenous to New Zealand) wellbeing and participation for culturally appropriate policy formation, environmental planning and culturally responsive services. The specific aim of the presentation was to outline the aspect of the research that was carried out to develop authentic kaumātua socio-economic measures (and scales) through co-creation gatherings that were designed to overcome Western assumption bias and were centrally focussed on Māori values and notions of wellbeing. It is part of a larger study titled: Tai Kaumātuatanga Older Māori Wellbeing and Participation: Present and Future Focus and is funded by the Ageing Well National Science Challenge in New Zealand.

The purpose of developing culturally based social measures was because the current indicator scales used to provide evidence for policy-making and developing services are Western and

don’t reflect key aspects of Māori values. While some aspects of loneliness, discrimination, and social connection, for example, are universal, other aspects are culturally specific. Older Māori value spirituality, collective ways of thinking and doing things and genealogical connections as primary ways of being that contrast with the Western focus on secularism, individualism and nuclear family structures. Western scales naturally reflect the cultures they have emerged out of, and so the evidence they produce for policy-making, for example, is appropriate to Western societies, but they do not capture the unique Māori specific aspects of say loneliness, wellbeing or even discrimination. If the evidence is not captured, policy-makers and those who develop services often simply focus on the evidence they have before them and the unique cultural aspects are disregarded. This may explain why outcomes for non-Western groups, and particularly indigenous people, are frequently less successful than for mainstream Western groups.

Methodology

A qualitative co-creation methodology with older Māori was used to construct an Older Māori Wellbeing indicator scale that reflected their world views and experience. This is one of six indicators being developed. The other scales focus on loneliness, social connection, discrimination, abuse, and neighbourhood wellbeing.

Co-creation hui (meetings) with Older Māori took place throughout Aotearoa (Māori word for New Zealand) with eight different groups of older Māori. These were led by Māori researchers who were members of the research team. The hui were participatory and occurred in a Māori way expressing their values and ways of doing things. Each group included: Karakia and mihi (Blessing and Welcome Speech); Waiata tautoko (support song); Mihimihi Whakawhanaungatanga (Introductions about who you are); Manaakitanga (hospitality); Hui Kōrero – (Promoting and encouraging open dialogue); Wānanga Kōrero – (Gathering of ideas and mātauranga (knowledge) – recorded with consent); Poroporoaki (Closing thoughts, reflection, and thanks); Koha (a gift for their time); Waiata and karakia ano (Song and blessing).

The Kaupapa, or focus, of the hui was about wellbeing and quality of life. Participants were invited to share about happiness and security that gives them a quality of life or wellbeing. They were invited to share the key things that gave them happiness as older Māori. What makes them and other Māori their age or older feel secure and comfortable? What reduces their happiness? What are the things that make them feel insecure and uncomfortable? What gives them and other older Māori friends and relatives a sense of fulfilment? The responses were recorded (with permission) and themed. The primary themes were developed into questions to create an initial Older Māori Wellbeing Scale.

The co-created Older Māori Wellbeing Scale, along with the other similarly constructed social scales referred to above, were then placed in a questionnaire which was administered to a national random sample of 2,000 plus Māori 50 years and over. In the analysis of results, we were able to test the scales for statistical reliability and validity. Thus, a participatory piece of

co-created research was able to be tested using quantitative methods regarding its fitness to be used as an indicator scale, in this case, a wellbeing scale.

Findings

The co-created responses were themed and 12 questions that reflected the most repeating themes were developed for the wellbeing scale. These were the qualitative findings in this study. Three examples of the twelve questions that emerged in the analysis, for example, were:

- I am well connected to Te Ao Māori (the Māori world)

Strongly agree/Agree/Disagree/Strongly disagree

- I enjoy a wairua (spiritual) connection in my life

Strongly agree/Agree/Disagree/Strongly disagree

- I feel respected and able to contribute to my whānau (extended family) and community

Often/Sometimes/Not often/Never

The 12 questions in the co-created Older Māori Wellbeing Scale were then tested for reliability and validity in a survey with a national random sample of 2,000+ older Māori. The results showed high scores, considerably above the threshold, using Cronbach's Alpha, when testing for internal consistency and reliability with a score of 0.843 for the 12 questions. The Confirmatory Factor Analysis scores were also strong. Using the R package lavaan. All but two questions had a factor loading score well above 0.4, seven questions were above 0.5 and three well above 0.7, demonstrating the validity of the scales.

Significance: The significance of this research is that it has developed an innovative methodology to draw on the knowledge of the people for whom the scales were created, to devise tools that can be used for evidence in policy-making and service provision for their own people. By developing co-created social indicator measures with these communities that include their knowledge and experience of quality of life in their communities, sharper evidence can be provided for inclusive policy-making and service provision. The standard international scale captures universal aspects of loneliness, but not the important culturally specific aspects.

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Working Group 3

WG 3

Technology and Innovation

Working Group 3 (WG3) targets older adults who may feel left behind in today's digital world. This includes individuals who may struggle with using computers, smartphones, or the internet, as well as those who may not have the necessary devices or software to engage with technology effectively. WG3 works to contribute ensuring that digital transformation is inclusive of older adults. Arlind Reuter & Peter Enste with Alexander Kucharski lead this group and organized WG 3 session in Kraków. Following speakers presented during this session: Leen Broeckx, Sonay Caner-Yıldırım, Cecilia Sik-Lanyi, María-Trinidad Herrero, Krzysztof Klincewicz, Arlind Reuter and Alexander Kucharski.

Leen Broeckx, LiCalab, Belgium

LiCalab (Living and Care Lab) – sustainable user involvement through living lab approach

Main research question / objective

At the PAARnet opening conference, LiCalab presented the living lab approach to participating in research on care technology and innovation.

LiCalab's main objective is to support organizations and companies to develop care innovations by involving the end user (citizens, care professionals and other stakeholders), from the very beginning of development until market introduction.

Methods

Living labs can be defined as open innovation systems in which stakeholders contribute to the exploration, co-creation, evaluation, and upscaling of solutions to create sustainable impact in real-life circumstances (European Network of Living Labs (ENoLL), 2023).

LiCalab is a research group of the Thomas More University of Applied Sciences in Flanders, Belgium. To a sustainable local innovation ecosystem builder, LiCalab has developed a large user community.

Building and maintaining a user community, also referred to as a 'user panel', holds many benefits for developers, researchers and citizens themselves.

Findings

Just over 60% of the user panel are in the age group of 60 years or older.

Involving older adults from the beginning of the innovation process is a win-win. For researchers, this participatory approach gives very valuable insights on the context of use. And the end user (the older person or patient) is offered the opportunity to contribute to a design process as an expert of his daily life. The ultimate goal is to design the innovative product tailored to the needs and expectations of the end user.

The user research in the living lab bridges between companies, care organizations and the older adults. Theres still is a gap and stakeholders are not always on the same page.

Taking older adults along this journey of care innovation, they learn new things about various kinds of aids and tools. Much attention is paid to digital inclusion. Everyone has to be on board and performing a real life test of a certain digital application, a step by step plan, personal coaching and helpdesk is being ensured by the panel manager.

Two important factors contribute to the sustainability of LiCalab. And that is the high quality of research and innovation activities and secondly the strategy for stakeholder involvement. These steps are outlined more extensively in the roadmap to establish a sustainable living lab that LiCalab developed for the ACSELL project (ACSELL, 2023).

LiCalab invests every day in actively recruiting individual users for specific projects and this is combined with community building activities on a long-term basis where the user panel can meet up and socialize.

When collecting individual data, it is important to create a secure space, both in face-to-face interactions and in online database management. The panel managers are the gatekeepers of the data of the user community. Handling the personal information of participants carefully, is the key to building a relationship of trust. Panel members are able to make choices in a truly informed and independent way by inform them transparently and using easily understandable words.

Community members enjoy coming to the research activities, stating things like “It is something positive in my life. I have good feelings about it.” and “When I come to LiCalab activities, I always feel at home.”. The LiCalab user community clearly shows a high intrinsic and altruistic motivation. Participants also receive an appreciative mail and a small incentive like a book voucher as an appreciation for their time and effort.

LiCalab champions human-centered design in the areas of medical care, rehabilitation, care technology, assisted living, active and healthy aging, and mental health. LiCalab explores and validates new products and services through participatory approaches like co-creation sessions and real life pilot testings. And this with high quality protocols. And always with a central role for the user.

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Sonay Caner-Yıldırım, Erzincan Binali Yıldırım Üniversitesi, Turkiye

Empowering an Older Adult Disaster Survivor and Support Provider: A Case Study of Technology Mentoring in Turkiye

Main research question / objective:

This single case study examines the influence of a year-long technology mentoring initiative on a 66-year-old mental health specialist who not only survived the devastating earthquakes in Turkey on February 6, 2023, but also volunteered to provide support in a post-disaster psychosocial program. The research employs a participatory and intergenerational approach to investigate the efficacy of individualized technology mentoring in fostering digital inclusion among older adults under these exceptional circumstances. The participant's unique dual role as both a survivor and a mental health professional contributes an additional layer of complexity to the study. By concentrating on this particular context, the research aims to add to the expanding body of knowledge on digital competence among older adults. Moreover, it sets itself apart from previous studies that have explored the impact of intergenerational learning and participatory research methods on digital literacy in this age group (e.g., Cheng et al., 2021; Lee & Kim, 2018).

Methods

The research employs a single case study methodology, utilizing both semi-structured interviews and standardized questionnaires to collect data on the participant's experiences and outcomes. Over the course of 12 months, the 66-year-old mental health specialist received individualized technology training from a 37-year-old instructional technology expert. The study gathered and analyzed qualitative data from the semi-structured interview and quantitative data from the Digital Competence Scale (Gümüş & Kukul, 2023) and an adapted Expectancy-Value-Cost (EVC) scale (Kosovich et al., 2015).

The participatory research approach ensured that the participant was actively engaged in the research process, placing his unique experiences and perspectives at the center of the investigation. This approach is consistent with recommendations for involving older adults in the design and implementation of digital literacy initiatives (Buffel, 2018; Xie et al., 2020). The participant's insights and recommendations, such as taking into account older adults'

cognitive capacities when developing training programs, underscore the importance of incorporating their experiential knowledge in the creation of effective interventions.

The intergenerational component of the study, in which a 37-year-old mentor provides personalized technology training to the 66-year-old participant, is especially relevant in the context of promoting digital inclusion among older adults. Research has shown that intergenerational learning can improve older adults' digital competence and enhance their attitudes towards technology (Cheng et al., 2021; Lee & Kim, 2018). By nurturing a collaborative relationship between the mentor and mentee, the study embraces the principles of intergenerational learning and fosters mutual understanding and knowledge sharing between generations.

The integration of participatory research and intergenerational learning is essential in this study, as it ensures that the technology mentoring intervention is customized to the specific needs, preferences, and beliefs of the older adult participant. This approach not only improves the effectiveness of the intervention but also fosters a sense of empowerment and ownership for the participant in their digital learning journey. The unique post-disaster context further highlights the significance of these approaches, as they allow the participant to develop digital competencies that are directly applicable to their role in providing psychosocial support to others impacted by the disaster.

Findings

The technology mentoring program had a positive impact on the participant's digital competence, with improvements noted in five of the six dimensions evaluated by the Digital Competence Scale. The most significant progress was observed in safety and data literacy, followed by communication and collaboration. The participant's enhanced digital competence positively affected his overall well-being, allowing him to provide better support to others in the post-disaster context. However, the mixed results on digital self-efficacy and the EVC scale emphasize the necessity of addressing individual attitudes and motivations when it comes to technology adoption.

The study emphasizes the importance of customizing technology mentoring initiatives to cater to the unique needs, preferences, and beliefs of older adults. The participatory and intergenerational approach utilized in this study presents a promising model for promoting digital inclusion among older adults, especially in extraordinary circumstances. The findings contribute to the expanding body of research on older adults' digital literacy and the effectiveness of participatory and intergenerational approaches in fostering digital inclusion.

The study's limitations include its focus on a single participant and the specific post-disaster context, which may restrict the generalizability of the findings. Nevertheless, the in-depth, longitudinal nature of the investigation provides valuable insights into the long-term effects of technology mentoring on older adults' digital competence and well-being.

Implications for practice involve the necessity of designing technology mentoring programs that take into account older adults' cognitive capacities, learning preferences, and situational factors. Engaging older adults as active participants in the design and implementation of these initiatives can ensure that their unique needs and perspectives are addressed. Moreover, the findings underscore the potential of digital technologies in promoting well-being and resilience among older adults in extraordinary circumstances, such as post-disaster contexts.

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Introduction the research of the 3D Virtual and Digital Realities Research Laboratory

Cecilia Sik-Lanyi, Hungarian Research Network, University of Pannonia, Veszprem, Hungary

3D Virtual and Digital Realities Research Laboratory

The laboratory examines the IT evolutions of 3D Virtual and Digital Environments and carries out engineering and scientific activities necessary for their development. The laboratory researches new human and artificial intelligence-supported cognitive abilities appearing in virtual space. The laboratory can develop 3D virtual worlds, e-learning, and special user

environments, in which the efficiency of the users is significantly higher than on traditional, usual window-based digital interfaces. Furthermore, the laboratory also recommends healthcare applications, e.g. to support rehabilitation processes.

The predecessor of the laboratory was the "Virtual Environments and Colour Science", then the "Virtual Environments and Applied Multimedia" Research Laboratories. The laboratory continues its work by keeping the traditions, scientific culture, and research areas of the previous laboratory. The research laboratory also deals with the proper processing and application of image information from a visual-physiological and visual-psychological point of view. For this purpose, research is being carried out on the optimal display of visual information in virtual environments.

Members of the research laboratory

Prof. Cecília Sik-Lanyi, D.Sc., professor

Prof. Peter Baranyi, D.Sc., professor

Dr. habil Mihálykóné Dr. Orbán Éva, Ph.D., associate professor

Dr. Tibor Guzsvinecz, Ph.D., associate professor

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International partners

Prof. David Brown, Nottingham Trent University, Computing and Informatics Research Centre, Interactive Systems Research Group, Nottingham, UK

Prof. Geraldine Leader, National University of Ireland, Galway Irish Centre for Autism and Neurodevelopmental Research, Galway, Ireland

Prof. Ilona Heldal, Western Norway University of Applied Sciences, Bergen, Norway

Dr. hab. Nils Haneklaus, Donau-Universität Krems, Krems, Austria

Dr. Renáta Cserjési, associate professor, ELTE, E-MIND Research Laboratory, Budapest, Hungary

Dr. Zeynep Şahin Timar, Karadeniz Teknik Universitesi Kanuni Kampusu, Trabzon, Türkey

Dr. Mostafa Abdallah Abbas Atwa Elgendy, Benha University, Kairo, Egypt

Methods

While we are developing new software, e.g. serious games for rehabilitation or skills development we always use participatory design. Participatory design in software development is an approach that actively involves all stakeholders in the design process to ensure that the outcome meets their needs and is usable. That is we always ask our future users and e.g. caregivers, therapists, special teachers, etc. their needs. Moreover, there are a lot of tests during the developing process until the product is released. We conduct user testing to identify usability issues and gather suggestions for improvement. By using collaboration and shared decision-making, drawing on the knowledge, skills, and perspectives of different participants we create more effective and user-friendly software solutions. So, the results in software that is easier to use and meets users' real needs and preferences, moreover we can improve the overall user experience.

About the laboratory:

The laboratory participated in 9 international consortiums supported by the EU, led 8 bilateral projects, and participated in 5 COST Action in the last 20 years. The laboratory also organized many international conferences.

Selected international projects

- Research in Design for All: “Design for All for eInclusion” within the project new materials dealing with supportive technologies and accessible design and publications were created

- Developing an internationally accepted 60 credits educational material on “Accessible Web design”.

- Designing supportive programs for the support of work and individual living for youth with learning difficulties and mental disabilities

  - “Game On Extra Time” project: UK/08/LLP-LdV/TOI/163_181

  - “Intelligent Serious Games for Social and Cognitive Competence” project: 2015-TR01-KA201-022247

  - TD COST Action TD1309 – ”Play for Children With Disabilities”

- Designing Virtual reality-based games for the rehabilitation of Stroke patients

  - “Telemedicine System Empowering Stroke Patients to Fight Back”, Information and Communication Technologies Collaborative Project: 288692 (EU FP7-ICT-2011-7)

- Developing and applying assistive technologies

  - COST Action CA19104, Advancing social inclusion through technology and empowerment

o COST Action CA19142, Leading Platform for European Citizens, Industries, Academia and Policymakers in Media Accessibility (LEAD_ME)

o COST Action CA22167, Participatory Approaches with Older Adults (PAAR-net)

- Development of a negotiation simulation game to aid education

o "Game On! Opportunities for Serious Games Development in Children's Health, Environmental Education & Language Learning" project (Hungarian- Austrian Bilateral Science and Research 2021-1.2.4-TÉT-2021-00007)

Findings

Based on our more decades of developing experience some highlighted findings, are things that a developer would not even think about until they encountered it. Game developers are good IT engineers not only because they can program well but also because they can take human skills into account when designing a software/game. Also, computer science engineers become really good game developers if they gain experience in designing for users with different needs. The complexity is further increased if special attention must also be paid to a possible disability of the future user. What we have learned during the above-mentioned projects' software development process, take care of

- Ecological validity,
- Cultural differences,
- Differences between patients' and therapists' ideas and needs and the developer idea's,
- Focus on user needs!

But the most important one is „Nihil de nobis, sine nobis" (Latin slogan), "Nothing about us without us"!

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Improving older adults' quality of life focusing in a participatory approach, early detection and tracking of troubles

Summary:

This article proposes a new approach to improving the lives of older adults implementing a robotic platform called Juno+. It argues that traditional methods often overlook the positive aspects of an older adult's life and proposes a more appreciative approach based on the concept of PAAR (Participatory and Appreciative Action and Reflection), analyzing various age-related issues that a robotic platform need to address, including loneliness, emotional problems, communication difficulties, hearing loss and cognitive impairment. Our robotic platform is testing in a nursing home, it will involve a larger scale study to evaluate the effectiveness of the platform and ensure it considers the diverse needs of its users for early detection and tracking of daily life troubles.

Improving older adults' quality of life

It is essential to contemplate democratizing reflective practice by taking into account participatory and appreciative action and reflection (PAAR) (1). This concept aims to explore

its potential to allow the advancement and improvement of work practices and people's lives, both in particular and communal contexts. Four strategic "turns" are required to employ PAAR: appreciative, empowering, ethical and participatory dimensions.

Then, it is compulsory to consider both the perception of individuals of their own health and different intervention and treatment process. For this purpose, in our interventions, we include PROM's and PREM's but previously concrete interviews in order to know the preferences and needs of each person. PROMs are assessment instruments that measure the patient's perceptions of their health status and quality of life, well-being, symptoms, abilities or level of autonomy. On the other hand, PREMs collect information about the care received, focusing on the humanity of the care, such as empathy, dignity, respect, understanding or personalized care, from the patient's point of view.

As the years pass by, the quality of life of older adults is being altered due to different factors and circumstances including loneliness, emotional problems, communication, hearing loss, cognitive decline or increased risk of falls. For this reason, our robotic platform could alleviate, early detect and track all these aspects.

Loneliness

People tend to live much longer than they did a few decades ago, being this life expectancy is higher in women than in men. The fear of being alone is one of the most widespread natural emotions in human beings. Loneliness is a complex problem that requires a multi-sectoral response, and it is essential to raise awareness and implement measures to combat it. The consequences can be serious, including depression, anxiety, cognitive decline, weakening of the immune system and increased risk of chronic diseases (2).

Emotional troubles

Older adults face a range of emotional problems that can significantly affect their well-being. These include depression, anxiety, feelings of isolation and lack of social connection, stress and bereavement following the loss of loved ones. These problems are treatable, and with proper diagnosis and treatment, most older adults can improve their mood and thus their quality of life. The occurrence of emotional problems in older adults is influenced by different factors such as age, gender, health status, level of social isolation or personal history.

Communication

Older adults have greater difficulties communicating with other people and, of course, also with doctors. The appearance of hearing, vision, mobility, and memory problems makes it difficult to communicate in the most appropriate way. Although talking to an older person can be a slower process, we must be patient and make them feel accompanied. New technologies that use telemedicine and electronic devices are increasingly technologically problematic for immigrants. However, t if adapted correctly, it could be a good tool to teach older people to communicate, and robotic platforms could be developed to detect problems early, to

intervene in time.

Hearing problems (Tinnitus)

Tinnitus is a chronic hearing disorder that shows an increasing rate of growth with age (3). Tinnitus can be defined as the perception of a sound that is not generated from any source external to the body. It can be perceived as a whistling, hissing, ringing and other types of sounds (4). Personalized sound therapy can serve as a distraction from tinnitus, providing a sense of relaxation by masking the sound produced by tinnitus (5-6).

Initial cognitive impairment

Initial cognitive impairment is characterized by impaired emotions and prosody (7). The technologies currently available allow us to carry out non-invasive analyses. These technologies allow the analysis of a person's emotional state through facial expression and voice (8–10). So, by extracting features we can train a model that allows us to recognize a person's emotional state, either through facial expressions or their voice.

Robotic platforms

The Juno robot is a prototype of an assistive robot that helps in the field of fall prevention for older adults, also allowing them to carry out cognitive stimulation exercises, in order to improve their physical and emotional health. Juno can be easily integrated into the furniture at the own home or at the nursing home. It can be teleoperated or sent to a location and once the target position is reached, it interacts with the user. In addition, a device is being designed to help medical professionals assess the risk of falls telematically. This device will be connected to a cloud application that will allow professionals to improve their diagnostic capacity remotely, so that the number of supervised user-patients can be increased without reducing the care provided.

Falls

One of the leading causes of injury and death in older adults is fall. As the years go by, there is an increase in the risk of falls; this risk is greater in women than in men. Various chronic diseases such as osteoporosis, arthritis or balance problems, depression, anxiety, dementia or the use of certain sedative or tranquillizing drugs are factors that increase the risk of falls. During the development of the proof of concept, a training dataset will be generated to train a model capable of predicting the risk of older adults falling. It will be evaluated by health professionals and therapists to improve its predictive capacity and will be integrated into the product to be marketed.

The proof of concept for 2024 aims to install the device in different institutions, so that a representative number of users can access the device, also considering intersectionality aspects. Neurometrics collected by devices such as Emotiv or Mindtooth are also integrating while performing cognitive stimulation tasks, allowing us to know the level of emotion, mental workload, fatigue or attention of a person while performing the exercises. In the future, it

would be ideal to have a fully personalized platform that can detect early signs of cognitive impairment by integrating information from facial recognition, prosody, hearing impairment and risk of falls, allowing family members, relatives, physicians and health workers to be alerted.

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Participation of older adults in product co-creation - discovery of needs and conative empowerment

Main research question:

The study aims to enhance our understanding of how the experience of participatory research triggers changes in everyday life of participants-older adults. This appears an inspiring research avenue for researchers, particularly in the context of innovations and technologies. While there is an extensive body of evidence as to why people join and continue participatory studies (see e.g. literature review in: Klincewicz et al., 2024b), we still need to better understand how various participatory approaches change the lives of participating individuals, including older adults.

The study benefits from a unique research setting: EIT Food RIS Consumer Engagement Labs, a project funded by the European Institute of Innovation and Technology based on Horizon 2020 and Horizon Europe programs and coordinated by University of Warsaw. The project implements participatory approaches through consumer co-creation: establishing a dialogue between consumers and producers, enabling them to jointly design new, previously unknown products that satisfy the needs of consumers. In 2019-2023, the project has been implemented in 19 countries with the participation of 106 consumer groups and 55 companies, resulting in 30 co-created products available on the market. In the project phases of 2019-2021, all participating consumers were older adults and hence, the project offered opportunities for accumulating rich insights about the food-related needs of older consumers, but also about the opportunities and limitations of participatory approaches involving this group of citizens (see also discussion of co-creation with older adults in: Klincewicz et al., 2024a).

Consumer Engagement Labs assigned an important role to older adults as co-designers of everyday products, including food and packaging. The participants were "average consumers", without expert knowledge or background education, unleashing their creative potential to co-design innovative products that met their needs, were better than currently available options and attractive for producer companies. The project is based on a unique methodology developed by University of Warsaw, replicated with each new creative process and each consumer group. The co-creation processes are orchestrated in the form of living labs, through recurring meetings, stepwise processes of uncovering the needs of participants and moving towards creative tasks that conclude with the formulation of new product proposals, which are subsequently analyzed by companies, screened for commercial attractiveness and developed for the consumer market.

The participation of older adults helped uncover their latent needs. An important aspect of the methodology is the use of projection: older adults were able to easily communicate their apprehensions, concerns about existing products that might be embarrassing at times (e.g. concerns related to digestive discomforts or chewing difficulties), while discussing the situation of a persona (an idealized consumer with representative features of a selected societal group) rather than real individuals. The methodology includes also multiple techniques that stimulate interactions in the external environment, including: analyses of products stored in the own household/kitchen with the frequency of their purchases and uses, visits to grocery stores to double-check the current offering in a given product category, as well as intensive discussions with fellow co-creators and friends.

For participatory studies, the post-participation experiences and broader consequences for personal lives have not been extensively researched, primarily due to the limitations of research design: the need to return to study participants after a given period of time to collect observations or self-reported changes. Co-creation in the form of living labs appears a highly relevant context for tracing the life-changing consequences, because the participation is intensive, spread over multiple days and yielding tangible, novel results.

Methods:

The study analyzed the experiences of participants of 14 Labs processes with 42 consumer teams in 14 countries, based on participatory processes implemented in 14 European countries in 2019-2020. In 2021, older adults, who participated in the Labs organized 2-12 months earlier, were invited to join focus group interviews. This was supplemented by individual interviews with 42 facilitators of the Labs and 12 individual interviews with older adults-Labs participants, aimed at further exploring these insights. The extensive qualitative material was recorded, transcribed, translated and coded through axial and in-vivo coding.

Findings:

The experience of participation results in the empowerment of participants, which could be interpreted through the lenses of tri-partite construct of cognitive, affective and conative empowerment (Harrison & Waite, 2015; Hilgard, 1980):

- cognitive empowerment: learning, acquisition of new knowledge, self-awareness and enhanced understanding as the consequences of participation,
- affective empowerment: emotional outcomes and attitudes towards products or companies, but also strengthened self-efficacy of participants (increased confidence in one's own abilities and creative potential),
- conative empowerment: resulting in proactive, purposeful and goal-oriented action (being empowered to act in new or better ways) (Warde, 2014), coupled with the individual agency and autonomy in the creative process.

The conative empowerment encompasses various consequences for everyday life, which could be summarized as three key directions for change:

1) „I have the voice as an expert in the matters of my own life" - with post-participation results that include: increased interest in product ingredients, best-before dates, labels or packaging, more attentive shopping, changes in planning for food, choice of shops or brands
2) „I am a healthier consumer" - changes in planning or composition of meals (frequency and timing of meals, elimination or increased consumption of specific products), improved diversity of consumed foods, use of new recipes and nutritious products (interestingly, the participants' views did not always match the widely accepted nutritional standards, as some participants had gained increased confidence in their own expertise accumulated in the Labs process and acted accordingly, but their knowledge was not necessarily verifiable)
3) „I live a better life" - the experience of teamwork and creative tasks made some participants re-evaluate their daily habits, motivating to celebrate meals and pay attention to the aesthetics of food, or consider meals as a practice of "self gift-giving".

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Sustainability of participatory approaches in ageing research: the Later Life Audio and Radio Cooperative

The flourishing of communities is a central objective in participatory action research (Kindon et al., 2007). Therefore, considering the sustainability of participatory action research beyond the research project is essential for establishing long-term impact and co-creating long-lasting change in communities. This presentation as part of the technology and innovation working

group symposium used the example of the Later Life Audio and Radio Cooperative to demonstrate how a participatory methodology supported a community's ownership of participatory research (Reuter & Scharf, 2023).

The main objective of this research project was to explore how older adults' civic participation can be supported by the creation of digital audio content. Despite a growing number of older people who are actively engaging online, older adults still tend to be overlooked as active content creators (Waycott et al., 2013). Even the development of new social media often prioritises accessibility functions to allow older users to view content produced by others as opposed to creating and sharing their own productions (Waycott et al., 2013). The lack of older people's voices in digital spaces is frequently reinforced by the ways in which older adults are often misrepresented in mainstream media discourse (Ayalon et al., 2021). Indeed, ageism, or the discrimination of people based on their chronological age, has become an established feature of digital platforms which can include design or algorithmic mechanisms that strategically deprioritise, disregard, or exclude older people (Rosales & Fernández-Ardèvol, 2020).

Methods

Using participatory action research over the course of four years, we collaborated with older adults in the UK who create their own radio shows. The presentation specifically highlighted the creation of a Radio Festival as a unique and immersive methodology that provided a platform for older radio creators in the UK to connect with each other. Participants present at the Radio Festival were older audio and radio creators, age-inclusive radio stations, third sector organisations working on ageing issues, and researchers from the community radio and ageing fields. The Radio Festival represents a type of methodological bricolage, in which data was collected in organic ways to create a dataset that supports a deeper understanding of older content creators' experiences. A fundamental goal of methodological bricolage is to seek understanding rather than demanding broadly generalisable data (Holstein & Minkler, 2007). Drawing on contextualised methods and taking methodological risks as part of this approach can support social change (Holstein & Minkler, 2007), which was an integral aim of the Radio Festival. Over the course of two days, we engaged with a variety of activities, such as live broadcasts that contributed to skill development, discussions to understand the importance of content creation for successful civic participation, and creative workshops that allowed us to develop new strategies. Throughout the workshops and discussions, participants voiced the ambition to connect more permanently and create a UK-wide network of older content creators and age-inclusive radio stations whose aim is to challenge ageist narratives within the mainstream media by providing talk-based content created by older adults.

The idea of forming a long-lasting network was further developed over the course of the following year. Collaboratively, the participants worked on establishing the Later Life Audio and Radio Cooperative (laterlifeaudioradio.org) based on a co-operative governance structure. The Cooperative's goals are to:

•Promote positive views and challenge negative views of age and ageing by providing talk-based audio and radio content created by diverse groups of older adults.

•Strengthen the visibility of content created by older adults in media and encourage the expansion of radio programming related to ageing and relationships between the generations.

•Engage older adults in broadcasting, facilitate skill development, and build communities by enabling discussion of a wide range of topics.

Overall, bringing older community radio content creators together at the Radio Festival led to the creation of a larger and more sustainable community in the form of a co-operative organisation. The journey towards a cooperative was characterised by a series of participatory action research cycles, beginning with a Radio Festival for older adults and leading to a form of organisation that is able to advocate successfully for strengthening older adults' digital citizenship in broadcasting. The project represents an innovative approach, in which the role of the participatory action researcher was to facilitate the creation of a community, which is now driven by older adults themselves. Placing importance on fostering community through participatory action research on technology can support sustainability in research projects beyond the end of the funding period.

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Participatory Design in Gerontechnology: Key findings and reflections of a systemic literature review

Background

The evidence of technologies or digital services to support older adults and ageing pro-cesses have been researched for a long time (e. g. Gutman/Sixsmith, 2013). At the same time, it has been acknowledged, that most technologies designed for such purposes have not been successful in the lifeworlds of older adults, as they only reached “limited uptake [and] high rates of abandonment” (Greenhalgh et al., 2016:2). Explanations for this finding are diverse. However, several studies conclude that there is a lack of awareness and/or interest of older persons towards these technologies, which in turn can lead to a lack of acceptance and use (Lee/Coughlin, 2015). Thus, to overcome non-ac-ceptance and nonuse, it was argued that devices need to focus more on older users’ characteristics, their needs and preferences (Künemund, 2015). Participatory approaches, which involve older users into the developmental process of technologies, have been regarded as a promising way to achieve this. Within this context, the approach of Participatory design (PD), which ideally involves potential users as “experts of their lifeworld” (Beimborn et al., 2016) in design-practices together with designers and researchers as full partners throughout the entire innovation process (Spinuzzi, 2005), had gained popularity. Still, critics claimed that that the realization of PD-approaches with older adults have not been done properly (Östlund et al., 2015; Beimborn et al., 2016). To see how PD is implemented and organized in practice, the presenter and his colleague, conducted a literature review, which has been published in 2018 (Merkel/Kucharski, 2018). The main objective of this conference contribution was to present critical key findings of this review and to connect it to newer work and future work of PAAR-net working groups.

Methods

The systematic literature review covered several databases (APA Search, GeroLit, PubMed, and Web of Science). The search strategy was based on three elements: (1) participatory methods and approaches with (2) older persons aiming at developing (3) technological devices, software and hard-ware for older adults.

Results

The search strategy revealed 557 publications in total. We reviewed 65 full-text papers, of which 26 were included in the final analysis. According to the technologies, the publications reviewed can be categorized in three groups: Studies that (1) use already existing technology with the aim to find new ways of use; (2) aim at creating new devices; (3) test and/or modify prototypes. We found that PD is used in diverse ways within the interdisciplinary field of

gerontechnology. Three findings can be summarized as the most critical of the review. Most studies integrated (future) users only in single phases of the innovation process (e. g. idea generation in early design work or user feedback in (pro-totype) testing) in qualitative studies with small sample sizes, oftentimes without clearly revealing sampling strategies, using single methods of more 'traditional research' (e. g. interviews, focus-groups, workshops). Additionally, none of the studies reported an evaluation of the process, i. e. providing evidence for higher acceptance of technologies due to participatory approaches as well as reflecting the experiences of older participants regarding their involvement as well as the outcomes. Finally, we found that whether older persons had the right to actively influence critical decisions or not, was mostly not described. Based on these findings we concluded that there is a lack of comprehensive strategies as well as a general mismatch between the normative presumptions of participatory ap-proaches and practical implementations in design practices for gerontechnologies, as the identified research approaches were mostly not transparent on their reasons for selected study designs. We rec-ommended that researchers and designers should ask themselves why participatory approaches should be included, who will be targeted as an audience, how (future) users will be involved and when they will be involved. Reflecting these questions could avoid the use of PD as tokenism, avoid biased samples and provide insights on the experiences of older adults as well as the outcomes of PD-pro-cesses and methods.

Reflections and outlook

The reported study was an early attempt at critically reflecting research with older co-creators and trying to formulate for criteria for participatory approaches in the design of tech-nologies. Since then, more efforts have been made focusing on different aspects as well as proposing more detailed criteria for participatory approaches (e. g. Fischer et al., 2020; Grigorovich et al., 2022). Still, as participatory approaches are a contested field by multiple disciplines and are applied for dif-ferent purposes in ageing and technology, there is a need to synthesize knowledge and formulate a framework for Technology and Innovation Research with older co-creators.

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Working Group 4

WG 4

Synthesis and Quality Criteria

Working Group 4 is dedicated to upholding ethical standards and ensuring meaningful participation of deprived, vulnerable, or marginalized older adults in research and policymaking processes. WG4 establishes ethical guidelines and quality criteria that promote the inclusive and meaningful participation of older adults in research and policymaking. Carlo Fabian & Annette Bielfield lead this group and organized WG4 session in Kraków. During this session following presenters delivered their presentations: Sandra Staudacher and John Andersen.

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Some reflections on the current level of involvement of older adults in participatory research

Main research objective: The first objective of this contribution is to reflect in how far older adults are involved in participatory research and what kind of fundamental underpinnings we need to be aware of for older people to actually have an influence. This leads to the second objective, which is to analyze what kind of methodological approach might support participatory research with older people.

Methods

The reflections are based on an unstructured literature review leading to a narrative review, which allows gathering relevant information related to participatory research “that pro-vides both context and substance to the authors’ overall argument” (Kastner et al., 2012, p. 4). The literature review and reflections are illustrated with examples of the Swiss National Science Foundation (SNSF) funded research project “Who has a say in nursing homes? An Ethnography on PartICipation of people living in long-term rEsideNTial caRE (EPICENTRE)”.

Findings

According to the UN Roadmap for the COVID-19 Recovers, there exists a knowledge gap regarding the design and effectiveness of mechanisms that promote meaningful participation of marginalised populations in the decision-making activities (United Nations, 2020). To anlayze in how far older adults are involved in participatory research, we need to bet-ter

understand what participation means. Participation has a large range of meanings. I argue that we need to make use of concepts of participation. We can differentiate between two major direc-tions of participation, as “taking part”, in the sense of being present and as “having a part”, which implicates that the participants are empowered to have actual influence (Simovska & Jensen, 2009). This goes beyond “participation by substitution”, whereby people are purely represented by others (Shivji, 2004). Already in 1969 Arnstein published her idea of a ladder of three ideal types of partici-pation, namely: citizen power, tokenism and non-participation. Citizen power at the top of the lad-der includes citizen control, delegated power and partnership. In the middle of the ladder is token-ism in which she includes consultation, information and placation. Consultation is widely used as a means of legitimizing already taken decisions, using a minimum of participation just to lend the process moral authority. At the bottom is non-participation in which therapy and manipulation are placed (Arnstein, 1969). This ladder is still at the core of more recently elaborated frameworks of participation (Cornwall, 2008; Morgan & Lifshay, 2012; Popay et al., 1998; Rowe & Frewer, 2005). However, in the literature there is relatively little attention paid to the structural context, such as socio-cultural, political, legal or economic aspects, when analysing participation of individuals or groups in society, which I argue would need to be taken into account to understand participation as embedded in a larger system. To understand the structural context of older people is crucial, as to translate voice into influence requires more than simply effective ways of capturing what people want to say; it involves efforts ‘from above’ and ‘from below’ (Gaventa and Robinson, 1998).

Having these diverse shades of participation in mind, I suggest asking the following key questions analyzing in how far older adults are involved in research: First, what is the social, economic, political, or cultural context shaping participation of older people? Second, how meaningful is their participation and why do they participate? Third, in which stage(s) of the research and through which means do they participate? And fourth, who is participating and is there a diverse and equitable inclusion of marginalized groups?

Analyzing what methodological approach might support participatory research with older people, I conclude that participatory research, that truly aims at taking up issues raised by old-er people, needs first, a long-term research perspective, which allows to address issues that came up by the targeted population in previous research. Second, participatory research needs an adaptive research approach and thus a research plan, which leave space to adjust flexibly for directions that come up through the research participants. This implicates starting thematically broad enough to allow targeted focus later in the research process. Third, the methodological approach needs a close look at diversity (e.g. different health issues, impairment, gender, socio-economic and migration background etc.) and intersectional aspects (e.g. blind, older woman, not speaking local language) coming up to ensure equity among different older adults. Equity is the “absence of unfair, avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by other dimensions of inequality” (World Health

Organization, 2022). Fourth, as researchers, we should be ensuring and furthering participation of older adults and/or their representation through participation of those closest to them but being aware of interests of all people/groups involved. Fifth, the methodological approach needs to consider the societal level and to ask what discourses are around and which legal, eco-nomic, political, cultural aspects need to be considered.

A promising methodological approach, which allows to focus on all those elements is ethnography (Silverman, 2017). Ethnography, which stems from Social Anthropology refers both to the methods of participant observation and to the product of the ethnographic study, the written report. Since the late 1980ies anthropologists conducting ethnographies elaborated a debate about (”crisis of”) representation, co-researching etc. An in-depth observational (ethnographic) study aims to produce a report on a social setting that does justice to the perspectives of the participants. An empathetic and detailed description, even if interesting in itself, is not enough; the "insider" description must also be a theoretical description (thick description). The "insider" view must be combined with the "outsider" view, which offers an analytical approach to social life. Through the constant empathetic interaction between older adults and “the field” with the researchers, people should be able to influence research.

In conclusion, the presented reflections illustrate the fundamental need for clarification of what kind and quality of participation of older adults we (usually implicitly) understand by participatory re-search approaches and what implication the latter has for how we should address it methodologically.

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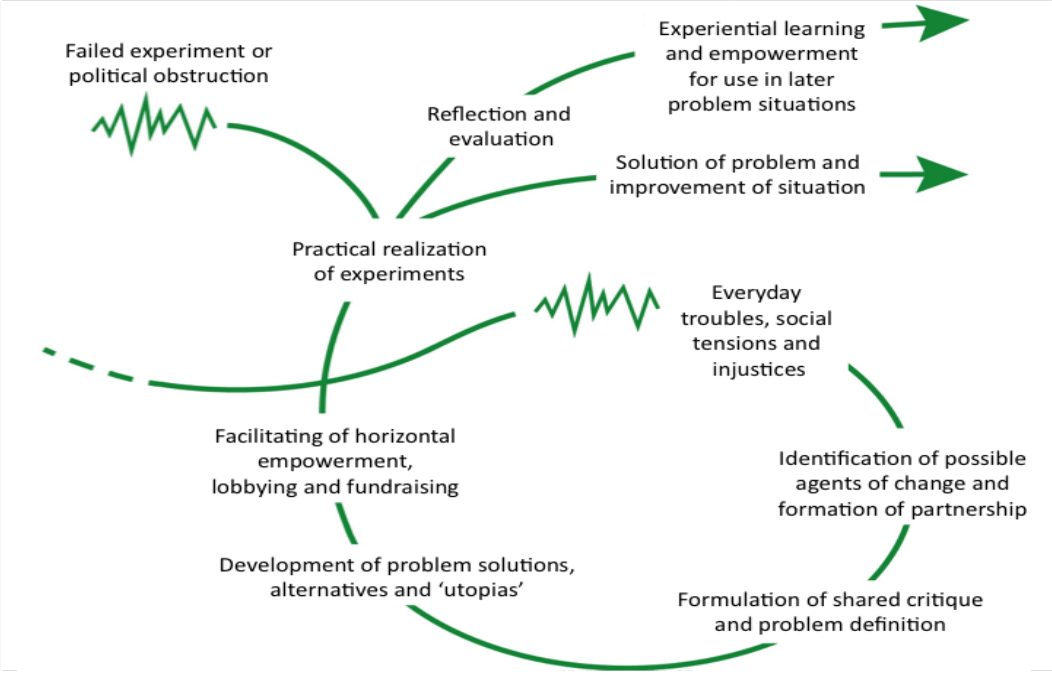
The promise of participatory action research (PAR)

Action researchers see themselves as 1. co-producers of knowledge with social actors working for social justice and citizens empowerment based on at a shared commitment to democratic change) 2. Action research underlines the connection between understanding and changing/transforming the world. 3. Hence particatory knowledge becomes products of a process in which actors come together to share experiences through a dynamic proces of action, reflection and collective investigation - while at the same time producing new knowledge (Brydon- Miller, 2014)

Action research can be seen as facilitation of experimental learning processes (in the foot steps of John Dewey) , her brilliantly summarized by Martin Frandsen, Roskilde University:



Source: Frandsen and Andersen, 2019

At Roskilde University we worked with action research af nursing homes with the the aim of changing a negative spiral of increasing inhumanity in elder care, and to develop practical and collective visionary alternatives in order to improve human social relations for both residents and employees. The context was a negative discourse in the public media about neglect in elder care. Scandals reported in the media. Employees accused of incompetence and inhumane care practices.

The generic experiences from the action research and participatory approaches, - in particular action research at nursing engaged in facilitation of older adults empowerment can be summarized

The first step is to 'collectivize' and document the frustration and critique of the existing situation and to – facilitatete a shift from individual and collective disempowerment to collective empowerment/collective action for change.

The second step is to articulate and develop concrete visions for alternatives - e,g, social quality in the care work for elderly, to strengthen the voice of elderly citizens in political and administrative decision making and management.

The third step is to negotiate and implement concrete changes in an ongoing collective learning and co-creation process in daily practices, the institutional set-up etc.

The challenges and dilemmas can be to keep the focus on the integration of both the employees and residents' needs and to empower the residents by involving them throughout

participatory projects. Another challenge in partipatory research: can be the role af advocacy vis a vis decision makers, the broader public etc.

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