Synthesis and Quality Criteria

PAAR NET

For Participatory Research with Older Adults

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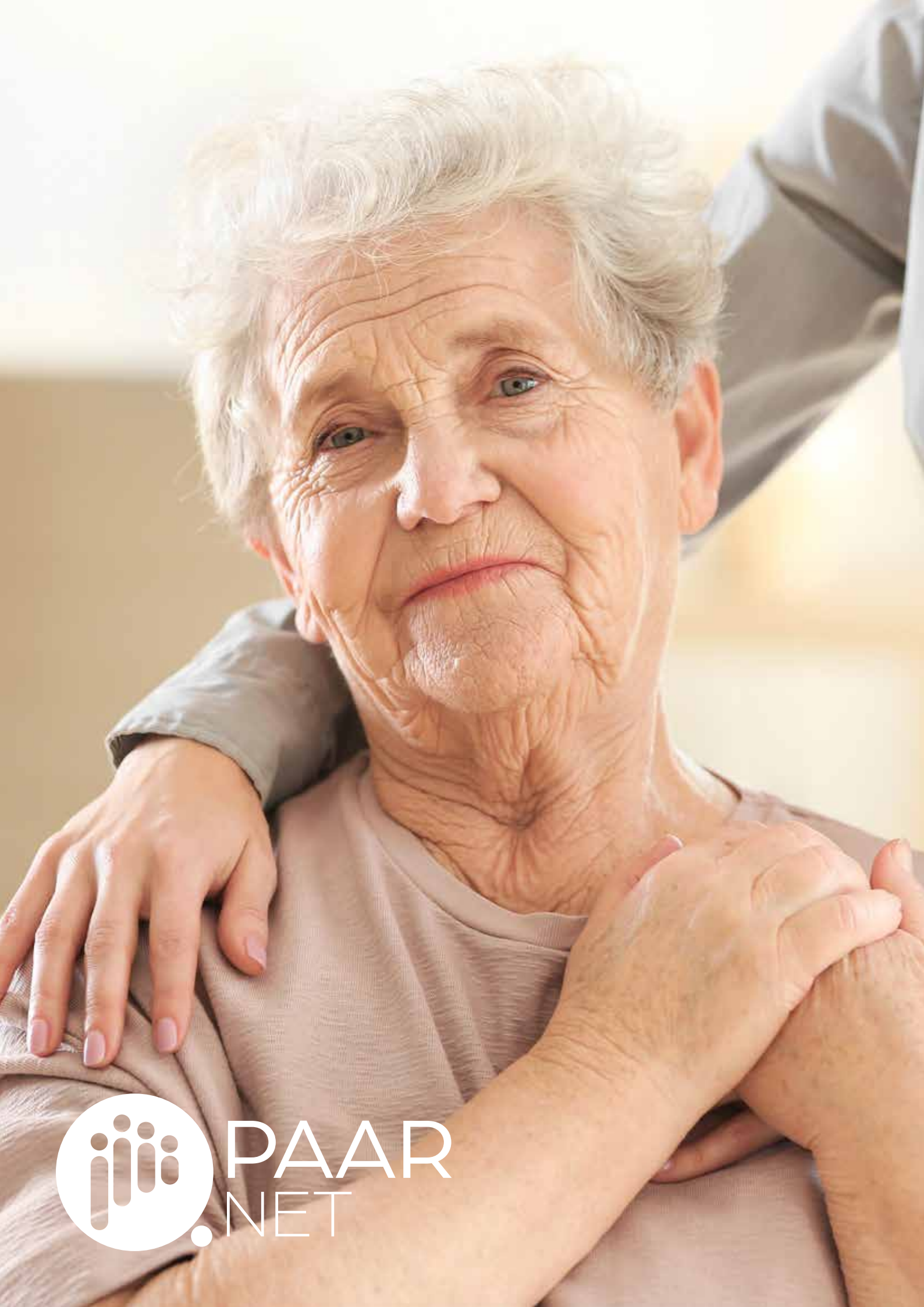
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Working Group 4: Synthesis and Quality Criteria for Participatory Research with Older Adults

International Explorations of Participatory Approaches with Older Adults in Research, Policy, and Practice: Challenges and Opportunities

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Executive Summary

Overview:

Purpose: To explore participatory approaches with older adults in research, policy, and practice.

Key Points:

- To highlight the importance of inclusive, participatory methods to drive social innovation and ensure equitable ageing societies.
- Recommendation on adopting participatory approaches to empower older adults, increasing their capacity and representation to articulate older adults' needs and aspirations in vis a vis decision-makers and to improve their life quality.

Background: The global ageing population continues to grow. The World Health Organization's Decade of Healthy Ageing campaign aims to address health disparities and promote healthy ageing.

Objective: The PAAR COST Action strives to develop inclusive, participatory approaches with older adults to drive social innovation in research and better advocacy in policy and practice.

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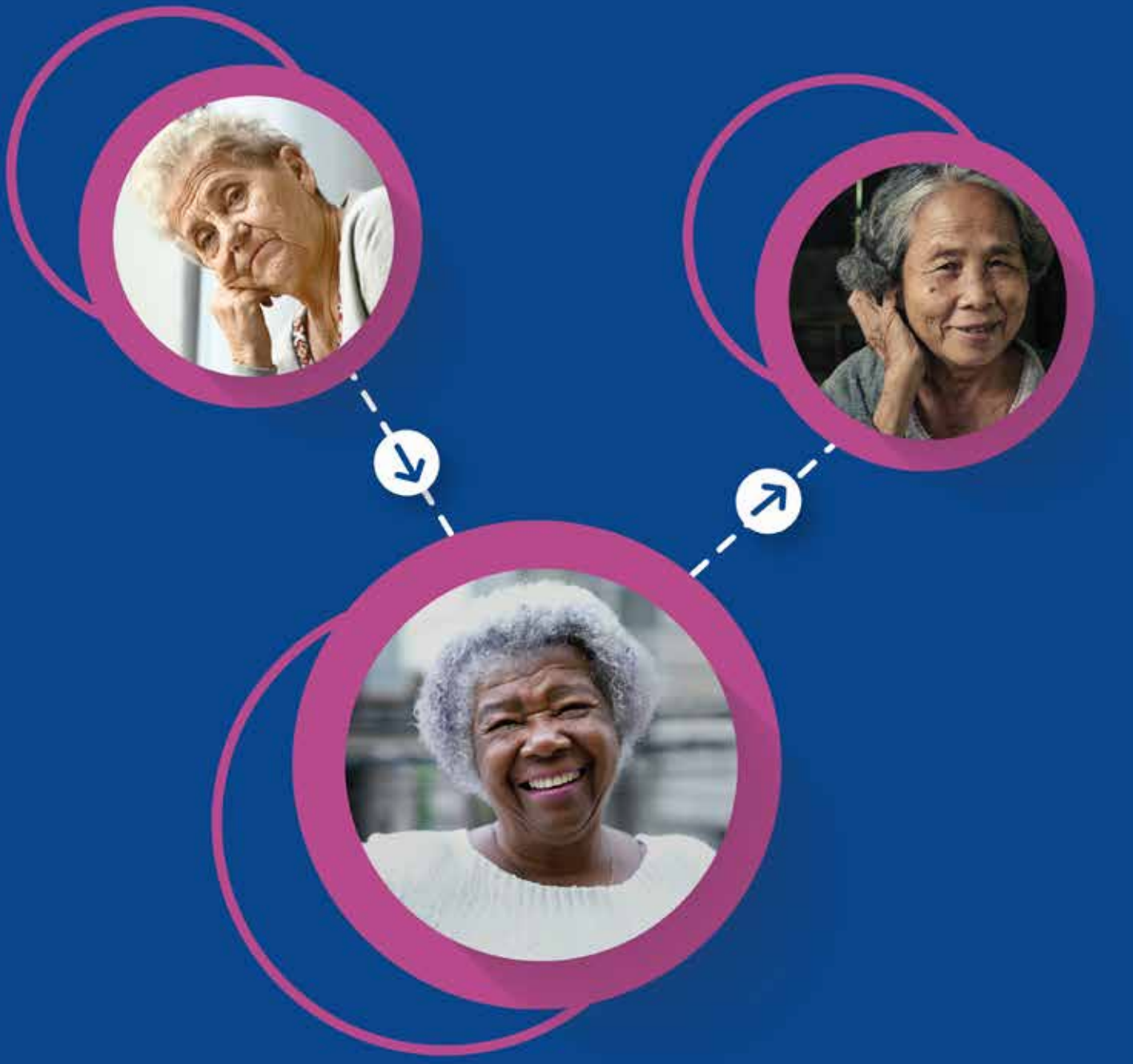
Case Studies identifying specific scenarios and challenges within different contexts in participatory approaches:

- **Bangladesh:** Empowerment through cultural traits and participatory dialogue.
- **Balkan Countries:** Incorporation of older patients' perspectives to improve treatment outcomes.
- **France:** Participatory research to improve mobility safety and reduce fall risks.
- **Poland:** Challenges and opportunities in co-production with older adults.
- **Denmark:** Participatory action research in nursing homes to improve quality of life.
- **Italy:** National coordination of active ageing policies through a multilevel and participatory approach.
- **United Kingdom:** Exploring inequalities of women over 50 in relation to work through co-produced art and research.

Conclusion:

- **Summary:** Involving older adults in research enhances the development of inclusive solutions and addresses their needs.
- **Final Thoughts:** Emphasises the importance of empowering older adults and ensuring their active participation in research, social innovation, and policymaking processes.



INTRODUCTION

Background

There is a significant international commitment to offering non-academics a more prominent role in science to support effective research. It is reflected in intensifying policy efforts across Europe to promote co-production and empower individuals and groups in need of better care and support through engagement in politics, practice, and research (EESC, 2023). A growing demand for research to generate impactful research influencing changes in policy and practice arises, and co-production in these processes becomes more commonly understood as part of a transformative process and improved, more effective policy and practice (Williamson et al., 2019). Hence, the research community has been increasingly committed to engaging older adults in research, aligning with the European vision of *"science for the people, by the people"* (Horizon, 2022).

The Swedish National Institute of Public Health (2006) defines the Healthy Ageing concept in the following manner: "*Healthy Ageing is the process of optimising opportunities for physical, social and mental health to enable older people take an active part in society without discrimination and to enjoy an independent and good quality of life*" (The Swedish National Institute of Public Health, 2006, p. 16). The core values include participation, justice, autonomy, and freedom from discrimination (Mahler et al., 2020).

The WHO campaign for Healthy Ageing advocates for the importance of "*connecting stakeholders around the world*" and "*listening to the voices of diverse groups of older people*" to ensure equality and more promising opportunities to age well (WHO, 2023). Therefore, it is crucial that older people across the world are involved in decision-making regarding their lives and participate in policy improvements, practice, and research on topics they value, and necessary to consider the views of the most marginalised and/or minoritised populations (EESC, 2023; Horizon, 2022).

Hence, the PAAR-net COST Action's (CA22167) fundamental objective is to develop inclusive, participatory approaches with older adults, integrating various disciplines and methodologies to drive social innovation in research, policy, and practice for diverse and equitable ageing societies. The PAAR-net COST action (CA22167) centres on four working groups, each focusing on key topics related to the ageing population. The WG4 synthesises insights from the other groups—WG1 (Health, Care and Support), WG2 (Community and Place), and WG3 (Technology and Innovation)—and collaborates with the Younger Researchers Forum and the Older Co-Creators Forum. WG4 intends to compile knowledge gained in these groups and forums to generate a clearer understanding of co-creation with older people. Through this, we aspire to expand conceptual thought on means to respectfully co-create with different older people's groups to gain insights into older people's experiences and listen to their voices.

Participatory research approaches include a range of terminologies and methodologies, such as inclusive research, user-led research, community research, participatory action research, collaborative research, co-research, and citizen science (Campbell et al., 2023). Participatory research with older adults has expanded in the past 20 years (Corrado et al., 2019). It employs numerous methods to involve older people in research question formulation, knowledge advancement, design, and change implementation (Buffel, 2018; James & Buffel, 2022). Collectively, it captures the voices, lived experiences, opportunities, and needs of different groups of older people as experts through experience. The WG4 investigates different participatory approaches in ageing research conducted in various national contexts across multiple disciplines and at different societal levels (micro-, meso-, and macro-level).

Based on an audit of various participatory initiatives in research and practice with older co-authors, **WG4 provides examples of good practice** for the benefit of all parties interested in meaningful involvement of older people (including those at risk of social exclusion) in participatory approaches to research, policymaking, or intervention designs.

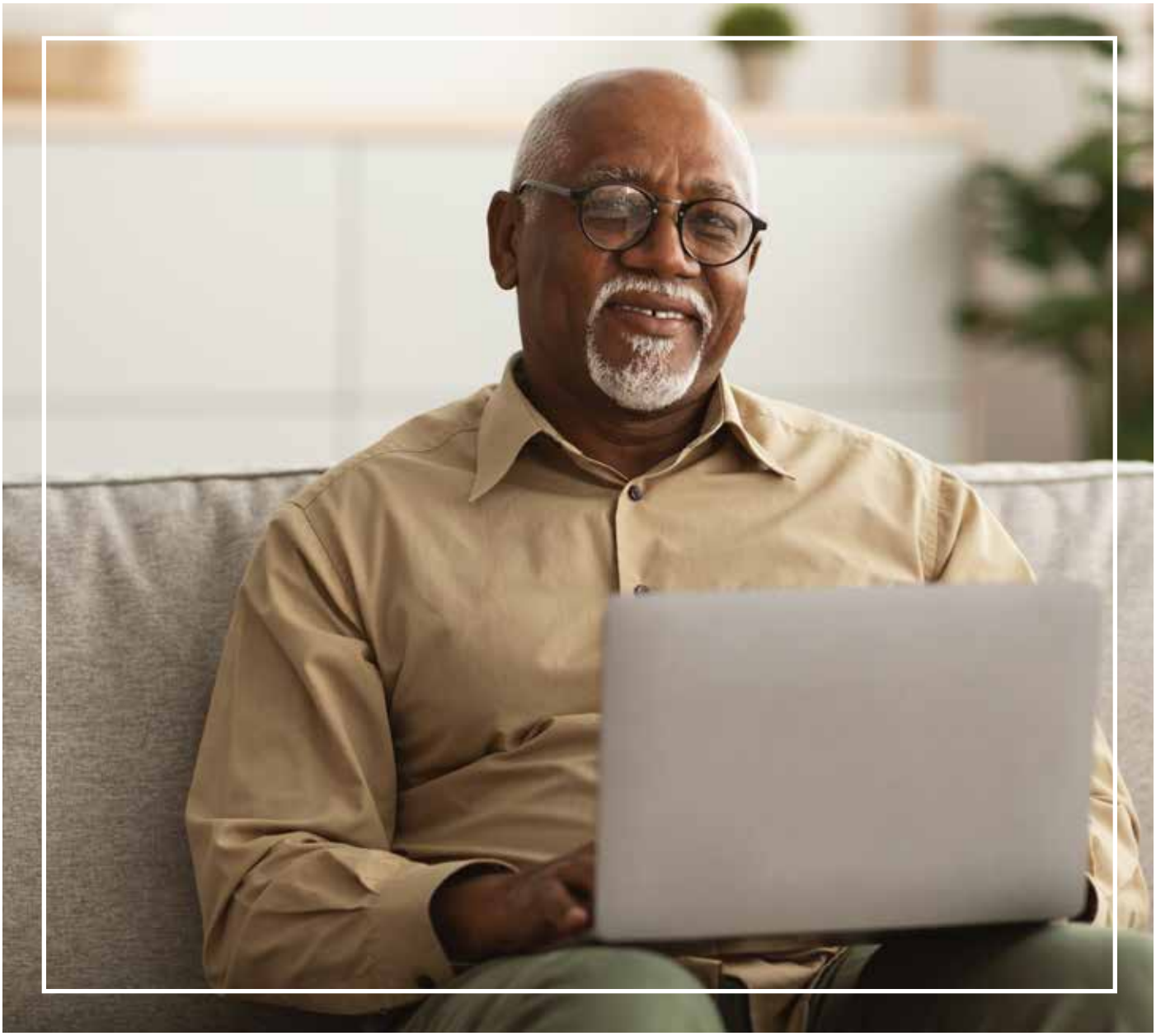
This White Paper outlines experiences from co-production with older adults in research, policymaking, and practice as a means of propelling social innovation across research, policy, and practice for inclusive ageing societies. Participatory approaches can be carried out in many methodological ways (Wanka & Urbaniak, 2023). We bring examples of research projects conducted and ongoing in diverse ways and different fields for a discussion about methods to be employed in participatory research with older adults to yield mutual inspiration and centralise substantial issues for quality criteria development. We also highlight the need to approach these issues critically to ensure clarity on what terminology such as participation means in every context. Moreover, we have selected several cases from various countries involving working group members. These span from bottom-up participatory approaches to multilevel participatory techniques.

The White Paper's Scope – What Can We Learn from Participatory Approaches to Research, Policymaking, and Practice?

Although there are various participatory research approaches, in general, the consensus is that it is paramount that research is carried out *with*, rather than *on*, participants – ideally, the participants should become equal partners and co-researchers (Dick & Greenwood, 2015). Participatory Research confronts the power dynamics and follows the traditions from which it emerged, such as feminist research and civil rights movements. It seeks to challenge the production and ownership of knowledge (Campbell et al., 2023).

The participatory approaches concept constitutes an umbrella term for research based on democratic and inclusive values, where "*democratically developed knowledge*" actively contributes to socially innovative and collective actions. Participatory approaches are characterised by researchers and practitioners uniting to promote democratic and social changes in "*a shared commitment to democratic social change*" (Brydon-Miller, Greenwood & Maguire, 2003; Urbaniak & Wanka, 2023). In democratic and change-oriented knowledge development, the researchers, participating citizens, practitioners, and other stakeholders collaboratively define the research questions and collective action agenda (Bilfeldt& Mahler, 2024, Brydon-Miller & Ortiz Aragón, 2018).

Co-authors in participatory approaches have the potential to acquire experience in active learning processes. Active learning goes beyond scientific tasks and can be understood as enabling the co-researchers involved to be empowered and offering all participants the opportunity to learn from each other (Banks & Brydon-Miller, 2019). Inspired by Dick and Greenwood (2015), we can argue that within participatory approaches with older people, the core values include a firm commitment to authentic participation and a determination to create a more just and equitable world for all older people (Bilfeldt & Mahler, 2024; Wanka & Urbaniak, 2023).



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How Can the PAAR-net COST Action (CA22167) Contribute to the Empowerment of Older Adults?

Participatory research, policy, and practice with participatory approaches aims to "democratically produced knowledge" actively contributes to socially innovative and collective action (Andersen & Bilfeldt, 2013).

The notion of empowerment, a crucial element of these participatory approaches, builds upon the works of Brazilian educator Paulo Freire, who defined empowerment as the ability "*to understand social, political and economic contradictions and ability to act against the oppressing elements of reality*" (Freire, 1974, p. 19). We may define empowerment as the process of improving social groups' ability to create, manage and control material, social, cultural, and symbolic resources (Andersen & Siim, 2004).

The participatory approach contributes to capacity-building and empowerment processes. Firstly, it fosters *horizontal empowerment*, boosting trust, commitment, and networks inwards and downwards, for example, between different groups in a neighbourhood or at an institution (e.g., residents, relatives, and staff at a nursing home). Secondly, it concerns *vertical empowerment* supporting power and the possibilities of multilevel influence outwards and upwards, e.g. about power centres outside the workplace, including governmental policies. Similarly to successful action research (Andersen, 2018), participatory approaches emphasise robust empowerment, emerging from a combination of horizontal and vertical empowerment processes that strengthen each other over time. However, it is crucial to be aware of the power imbalances occurring often in these research groups, resulting in the ongoing challenge of navigating and negotiating these differences (Bilfeldt & Mahler, 2024; Rose & Kalathil, 2019). That means respecting and understanding that "*the people with and for whom researchers work are crucial*" (Littlechild et al., 2015, p. 33) to achieve more significant social inclusion and equity (Raymon, Tremblay & Lebel, 2022; Hand et al., 2019).

Participatory approaches require continuous reflexivity due to participation inequalities, particularly with older adults (Bilfeldt &Mahler, 2024, Urbaniak & Wanka, 2023).

As we strive to empower older people and co-creators in participatory approaches, we share these orientations and take steps towards a more emancipatory approach.

What Are the Opportunities for the PAAR-net COST Action (CA22167) Working Group 4?

The White Paper focuses on the following issues:

- How to develop innovative, inclusive, participatory methods and concepts?
- How to co-create with older people through a respectful process where the co-creating participants' experience and knowledge combine?

The contribution of Working Group 4 relies on framing the quality criteria for participatory approaches to research, policy, and practice with older people and considering what that means in various contexts and countries. However, it should also set out guidelines on how to attain best practices and develop infrastructure to support participatory approaches.

The key to this task involves ensuring that the voice of older people is firmly established in the working group and that older contributors play a pivotal role in the achievement of these objectives.

To begin this work, we have gathered examples from research with participatory approaches with older adults about:

- Specific strategies to secure ownership for the participating older adults in the research process.
- Reflections on how older adults have contributed to the experience.
- Reflections on the power dynamics.
- Reflections on how the project or the initiative contributed to empowerment and better life conditions for older adults.

3

Case Studies

The White Paper draws on examples derived from reflections and experiences of research on participatory approaches with older people. The contributors display a broad expertise. The section's content emphasises the engagement of older people as co-researchers and co-authors in various national contexts and social levels (micro-, meso- and macro-level).

1. The Bangladesh Case: Experience of Co-Production in Knowledge Creation with Older Adults in Bangladesh

Owasim Akram

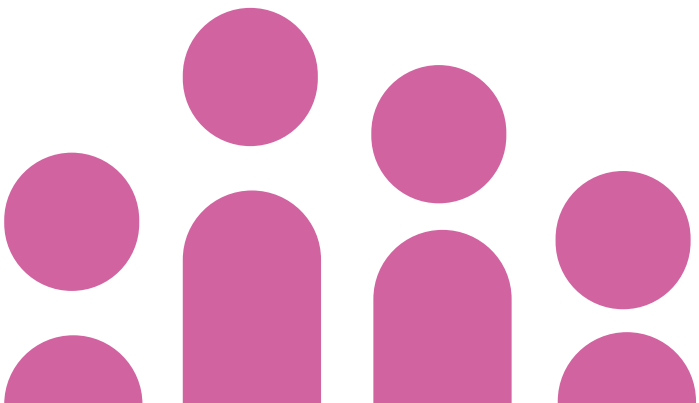
Postdoctoral researcher at the Department of Political Science at Örebro University (Sweden) and visiting researcher at the Department of Social and Political Science at the University of Bath (the United Kingdom)

The primary objective of this study, supported by the Swedish Research Council (VR), was to problematise the notion of "epistemic injustice", questioning the "way we know" the "severely poor" and the "way we lead" development with them (in this case older people, those with disabilities andminority ethnic groups). The term "severe poverty" is deliberately used to distinguish it from the "extreme poverty" defined by the World Bank, which refers to people living on less than $1.90 per day. The term "severely poor" can be understood as a subcategory of the extremely poor, living at the very lowest level, who usually lack capacity, authority, and political effectiveness. The latter features parallel what Gayatri Spivak (2003, 2005) describes as "subaltern" social groups. As an activist researcher motivated by post-colonial traditions, he believes that research should aim to empower the involved people. During the first phase of engagement with three groups of older adults in three communities and one-to-one interaction with several individual older adults, these research practices yielded two empowerment types, namely the following:

a) In situ empowerment and b) Epistemic empowerment.

The in situ empowerment takes place mainly through adhering to the cultural traits through which individuals' privileges (based on education, economic conditions, social status, career background and political associations) have been ceased, so the criterion to engage in dialogue defined through a participatory exercise was chronological age – note that Bangladeshi society features a structure based primarily on patrons and clients. Truly participatory and inclusive dialogue can only happen if the most marginalised members of the group are engaged on equal terms and conditions, thoughtfully designed through a collaborative process.

Without setting equal terms and conditions, the marginalised and the most vulnerable remained epistemically sidelined. The equal conditions resulted in encouraging the most unprivileged older adults to engage in the dialogue. Although caused a kind of discomfort for privileged society members who previously have always enjoyed unquestioned freedom to pursue an agenda, it is vital to consider that a decolonised (and/or post-colonial) activist approach should signify the research ought to aid in dealing with such disadvantages. Once everyone could speak up and engage in the process, the discomfort milieu ceased to be apparent. During the dialogue and exchange, it was necessary to recognise each participant as fully capable, and the role of a researcher became the curator. So, the discussion took place as an intra-group. Participants acted as active agents and knowledge holders, shaping the content and direction of the dialogue.



Epistemic empowerment is an ongoing process, starting at the research planning stage. In this project, epistemic empowerment took place when the most marginalised in the groups felt able to contribute and engage in the dialogue. The term "epistemic empowerment" refers to how people's own narratives continue to challenge the comfort zones surrounding the researcher's own and different epistemic takes on the same issue. It demonstrates that whenever narratives come from empowered participants, they are strong enough on their own to challenge academic standpoints and privilege. Older persons living in severe poverty endure profound levels of powerlessness in their day-to-day lives. Due to such conditions, their participation in the research process may be disrupted severely – unless it is resolved on-site to some extent. Simultaneously, empowering strategies adopted on-site can immediately impact breaking the cycle of oppression and change the power dynamics effectively at that moment.

In this work, enabling the participation and voice of the most negated and rejected from society involves establishing feasible conditions and facilitating ongoing negotiations to exchange discourse to serve as a starting point for changing research processes and, over time, research results.

2. The Balkan Countries Case: Involvement of Older People as Patients

Klejda Harasani

Department of Pharmacy at the University of Medicine of Tirana (Albania)

The concept of “participatory approaches”, also known as “patient and society engagement” or “citizen science”, is relatively new in the Balkan countries and remains mostly unexplored by researchers. Co-production in research, policymaking, or practice with older people appears even rarer because it is not required and incentivized by governments.

The inclusion of older people as patients or the public, with their unique perspectives and valuable input, offers abundant benefits for research and society. Currently, in the frame of a PhD program supervised by Prof. Klejda Harasani from the Department of Pharmacy at the University of Medicine of Tirana in Albania, two researchers are exploring the older patients' perspectives inclusion in improving adherence to pharmacological and non-pharmacological treatments. That is expected to enhance treatment outcomes, resulting from higher acceptance and motivation levels, and boost communication and trust with healthcare providers. Further plans are also in place to engage older patients to help define research priorities meaningful to them in the revision and dissemination of scientific publications.

Empowering older people to participate actively and impact multiple aspects of research, policies, and practices about them is overdue across the Balkans. However, it is crucial to:

- Raise awareness.
- Identify barriers and facilitating points.
- Motivate researchers.
- Support international networks on participatory approaches with older adults.

3. The French Case: Ownership and Co-Creation – Public Outdoor Environment and Fall Risks

Antoine Langeard

University of Caen Normandie, INSERM, COMETE U1075, CYCERON, CHU de Caen (France)

The ageing trajectory is profoundly influenced by the physical environmental contexts we live in. The outdoor environment often does not provide for safe mobility, leading to isolation or falls among seniors. Falls have severe economic and health consequences, affecting over one-third of individuals aged 65 and above annually. The management of the ageing population and the prevention of loss of autonomy and falls constitute core challenges. While top-down political activities can significantly impact such contexts, they often require time and resources. In addition, the specific needs of older adults tend to be rarely considered, making some urban spaces unsuitable and hazardous for older pedestrians. Bottom-up methods involving the populations directly may lead to positive environmental changes and engage groups that seldom have a say in decision-making. This research type has significant benefits. Particularly through mobile technology, which is used to systematically capture and collectively analyse data collected during pedestrian displacements in their environment. Enabling seniors to continue to have freedom of mobility is essential. Currently, we are conducting two studies related to this topic, namely the PARAGE project and a Delphi Study, focused on fall risks for older adults in public outdoor environments.

The PARAGE project, carried out in collaboration with the Stanford University “Our Voice” initiative, involved older adults as co-researchers to improve mobility safety and reduce fall risks in urban areas. Older adults documented environmental hazards through geocoded photos, GPS-tracked routes, and audio/textual narratives using a mobile application for data collection. The participatory approach ensured a sense of ownership of the research process by older adults, as they not only collected data but also co-constructed reports through collaborative data analysis. Cooperation with local urban policymakers is also a second part of the project planned in the following months. This method highlighted their unique perspectives, leading to actionable insights on urban planning to enhance mobility and prevent falls (King et al., 2020; Moran et al., 2017). This project was made possible thanks to the French national funding strategy for universities through the label “Science with and For Society’ label, enabling the award of a Science and Society research grant for participatory researc (https://www.unicaen.fr/prix-unicaen-science-societe) for the PARAGE project, and the creation of a support unit for these projects within the University of Caen Normandie.

The Delphi study engaged various participants with expertise about the research topic: the risk of falls in outdoor public environments. These stakeholders included older adults, healthcare professionals, urban planners, and local government representatives. They co-created the Delphi study and assisted in reaching participants from each group. The goal was to identify and prioritise fall risk factors in public outdoor spaces. Through an iterative, three-round survey procedure, participants provided their expert opinions and experiences, reaching a consensus on fundamental risks and potential interventions. This study highlights the critical role of older adults in decision-making processes and aims to gather expert knowledge and achieve consensus about fall risks.

4. The Polish Cases: Co-Production and Reflection Connected to Path-Dependence

Andrzej Klimczuk

SGH Warsaw School of Economics (Poland)

The "Guide – User co-production in standardisation" was developed within the Horizon 2020 PROGRESSIVE project (Huchet et al., 2018). It was not just a basic consultation process. This document was fully co-written and co-reviewed by various stakeholders, including organisations led by older people. While the process was time-consuming (it took nearly six months), it yielded a specific result. The Guide content was downsized to include only the most neutral and introductory descriptions due to the variety of comments received. Thus, it gives readers and users the freedom to select other sources of data with more specific descriptions of "co-production methodologies".

Nevertheless, the experience of co-creation in Poland often poses many challenges (and this is likely to be the case in other Central and Eastern European countries due to a similar historical "path dependency"). In Poland, there are currently 456 senior councils in 2,477 communes (MRiPS, 2023). Thus, 18.4% of all municipalities already have a council of older people. For comparison, in 2012, there were only nine such senior councils. The growth is, therefore, easy to notice. However, firstly, these are not entities that must exist in every commune. Secondly, despite significant progress, these are still only consultative and advisory entities that do not have much influence on local policymaking. Thirdly, their fundamental limitation is that they do not have separate budgets and funds for their activities, so their action tends to be restricted to meetings and discussions about local law. Fourthly, these entities are often created on the initiative of local government authorities (politicians), who need councils as "facades" to build the image of the commune's openness and age-friendliness (a clear example of tokenism). Finally, sometimes local government officials consider these councils to be "overdemanding" entities, meaning they are rather unnecessary because they can only hinder the exercise of power, which already has too many responsibilities related to – for example, the provision of public services (such as health, education, and infrastructure for young and middle-aged population).

The starting point should be to gain the understanding and consent of the leaders/authorities of entities associating with older people. Participation in projects of older people unrelated to any other entities of civil society is, in fact, extremely difficult, at least in countries that lack long-standing traditions of civic activity and public participation.

Nowadays, unfortunately, scientists in Central and Eastern Europe must use “top-down” approaches because few entities run by older people come up with “bottom-up” initiatives for cooperation with scientific units. If anything, such initiatives are supported by public funds, compelling the creation of partnerships between various entities. The Multiannual Program for Older People “Aktywni+” (financed by the Polish government) and the Erasmus+ Programme (European Commission), for instance. In other words, nothing facilitates cooperation between groups of older adults and other entities as much as access to financial resources.

In terms of specific solutions, the following can be considered as basic:

- Including representatives of organisations associating with older people in, for example, the advisory board of the project.
- Preparing easy-to-understand informed consent forms for project participants.
- Conducting training for older people regarding participation in research projects.
- Including older people in workshops and focus groups.
- Including older people as co-authors of research reports and/or publishing appropriate acknowledgements.
- Inviting representatives of older people to present the results of research they co-created (conferences and public events).

In practice, some of these solutions are still ‘fairly new’. However, the introduction of the General Data Protection Regulation (GDPR) in 2016 has certainly raised awareness of consent collection, and more careful use of personal data should be standard in the relationship between researchers and older people as participants and co-authors in research projects.

Hence, when considering participatory approaches and quality criteria within the PAAR network, it would be necessary to establish what good practice means, consider the possibilities in different contexts, and forge a set of stages for the development or transition to a more democratically equal co-production. Moreover, it is crucial to highlight the importance of infrastructures – such as support funding to further develop this co-produced process type.

5. The Denmark Case: Nursing Home Residents as Co-Creators of Participatory Action Research

John Andersen and Annette Bilfeldt
Roskilde University (Denmark).

The "Quality in Elder Care" (QEC) project was carried out as a participatory action research project with residents and staff as co-creators.

The project was organised as a participatory action research project with the aim to improve human social relations and the quality of life for residents at a public nursing home in Denmark through the utopia development within the Future Creating Workshops. The Future Creating Workshop (FCW) is a practical methodology developed by Jungk and Müllert for socially innovative experimentation (Jungk & Müllert, 1987). The workshop is an important tool for the development and concretisation of utopian ideas as a basis for breaking away from everyday ideas of what is possible (Nielsen & Nielsen, 2006). The FCW method provides an opportunity to "think outside the box" and to form utopias unlimited by "the power of reality" in everyday comprehensions of what can actually be accomplished (Andersen & Bilfeldt, 2016). Future Creating Workshops evolve around plenum and group sessions. The participants' statements are presented and commented on using posters, and researchers act as moderators.

Taking the residents´ relative lack of power into consideration, the project was structured in two parallel courses around two groups staff and residents/ relatives, respectively. The decision enabled residents and relatives to express critical opinions without fear of negative consequences for future cooperation with staff.

FCW has three phases: The critique phase, the utopian/vision phase and the realisation phase.

Step 1: Planning and identifying central issues

In the planning phase the researchers had meetings with the manager of the nursing home, with the residents´ and relatives´ user council at the nursing home, with the trade union representative, with elder organisations and with the municipal Elder Council. The researchers conducted a discussion with staff, relatives, and residents in group interviews – one with residents and relatives and one with staff.

The following issues were identified:

- Lack of resources.
- Employees were stressing the residents.
- Lack of dialogue between employees and residents.
- The residents feeling isolated.
- The impression among residents was that their perspective was ignored.

Outcome: "*Problem identification catalogue*". This cataloque was the kick-starter and the basis of the critique phase.

Step 2

Two parallel **Future Creating Workshops (FCW)** – one with the residents/relatives and one with care workers:

- **The Critique Phase** – *What is wrong? What do we want to change?* – The problems identified in the problem cataloque were further discussed and reflected on. This was opening up of a new communication space to enable a collective critique of the conditions for receiving and providing care.

- **The Utopian Phase** – *What results do we want to achieve?* – A series of specific ideas to improve the quality of care (e.g., a new living room, more social life for residents, involvement of residents in decision-making).

- **The Realisation Phase** – *We keep our visions but ask: how and with whom our alternatives can become reality*. – The task force groups were formed to develop the ideas. To initiate a plan of action and experimentation in which co-creators, supported by researchers, revised suggestions from the utopian phase and designed action and implementation.

Step 3

The co-creators developed the following action and experimentation plan: improving the suggestions from the Future Workshops, followed by designing a plan of action and implementation.

Examples of innovative outcomes developed by residents, their relatives, and staff included:

- The “town square” design – redevelopment of the physical space to provide a framework and enhance opportunities for informal social life and dialogue between residents, relatives and staff.
- The engagement of residents in staff recruitment meetings (impact on the care home).
- The development of a new cooperation practice between staff, residents, and their relatives.

When nursing home residents in future creating workshops – supported by relatives – can collectively reflect on problems, they can improve their understanding of their rights to influence everyday life at the nursing home. The confrontation with the residents’ and relatives’ critiques and innovative suggestions increased the staff´s awareness of the potential of continuous dialogue between residents, relatives, and staff (Bilfeldt & Mahler, 2024, Bilfeldt 2019).

Engaging residents and relatives throughout the project is crucial to overcoming and challenging of “dystopias” created by staff (such as “helping” residents to go to bed early to save time).

Reinforcing the possibilities for autonomy, participation, and self-determination for older persons living in nursing homes is also closely connected to the question of economic resources.

Regarding the context of scarce resources and (re)bureaucratisation of public service institutions, it is vitally important to counteract time pressure on staff and the lack of resources in welfare institutions. From a vertical social empowerment perspective an important outcome of the project was that researchers together with elder organisations and the municipal Elder Council and the trade union of care workers pressed for the development of a wider political agenda to bring resources to care work.

The PAAR's critical challenge concerns how we can pay special attention to older adults´ experiences and enable their voices to be heard - including older adults living in institutions. The participatory action research methodology can frame the inclusion of older adults not only in advisory capacity but as equal co-researchers.

6.The Italian Case: Participatory Approaches for Policymaking in Italy – the "National multilevel co-managed coordination of active ageing policies" project

Davide Lucantoni and Andrea Principi

IRCCS INRCA, Centre for Socio-Economic Research on Ageing, National Institute of Health & Science on Ageing, Ancona (Italy).

The project is based on two three-year grants (2019-2021 and 2022-2024) between the Presidency of the Council of Ministers – Department for Family Policies and the IRCCS INRCA (the National Institute of Health and Science on Ageing) of Ancona, aimed at the creation, implementation, and consolidation of a national coordination of active ageing policies in Italy, by adopting a multilevel and participatory approach. Given that, the project characteristic feature is the network of stakeholders, consisting of approximately one hundred organisations, including ten Ministries and four Departments at the Presidency of the Council of Ministers, all 19 Regions and two Autonomous Provinces, as well as fifty-five organisations of older people, pensioners' unions, NGOs, experts, and academics (an updated list of the stakeholders involved is available on the project website).

Besides the plenary meetings, the project involved the participation of organisations representing older people through a continuous feedback exchange (via questionnaires, online meetings, email, telephone, and any other communication channel available) on the drafted documents and proposed actions. Also, within the framework of the activities foreseen for the second three-year period (2022-2025), the regional networks of civil society organisations participated directly in the implementation of the regional active ageing policy conferences and in the process of identifying and implementing active ageing policy goals in every region of Italy through a series of online workshops. The contribution was acknowledged in the various reports, protocols, and materials published on the project website. Yet, more importantly, in this context, accountability was ensured by positioning participants and older people at the forefront of the decision-making process.

The experience gained by older people organisations in recognising and addressing the emerging needs of seniors through innovative ideas, projects, and initiatives represents the most meaningful added value of the stakeholder network created within the project. This, within the context of an ongoing dialogue with political players at different levels of government, allows for the identification and sharing of both good practices and critical issues, often hindering the success of the initiatives. Moreover, older people organisations involved in the project are committed to maintaining a high level of attention to the importance of active ageing in the political and public debates. In all, the project allowed for the avoidance of a top-down approach when creating policies.

The approach adopted within the project, in terms of power dynamics, cannot be considered top-down, as every action is co-designed and co-created with a network of stakeholders. However, it is also not entirely bottom-up, as the co-decision process needed careful and continuous mediation between the institutional level and the civil society perspective. Thus, the approach adopted includes elements of both the former and the latter to develop initiatives on the topic that are adherent to the needs of older people while respecting the interests, competencies, and responsibilities of the actors involved.

The project improved the older people's living conditions to the extent that, for the first time, they (through the meso-level organisations representing them) had the opportunity to directly and concretely express their needs for active ageing policies and influence decisions to meet those needs by taking their preferences and aspirations into account. Our experience allowed us to learn that providing a clear and solid organisational structure to the participatory process is paramount for its effective implementation. We should be aware that such a process costs time and human/economic resources employed. Also, due to the diversity of perspectives, these interests and experien-ces brought into play require a process of mutual adaptation and convergence towards a shared language and vision.

7. The United Kingdom Case: Uncertain Futures – Exploring the Inequalities of Women over 50 in Manchester in Relation to Work – Co-Producing Art and Research for Social Change

Sarah Campbell

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Uncertain Futures is a collaborative art and research project utilising socially engaged art practice, participatory research approaches, and community activism to explore and understand the experiences of women over 50 in Manchester (the UK) concerning work.

Manchester is an urban (de)industrialised city in the North West of England. The Greater Manchester (GM) region features an extremely diverse population, with 28.7% of minority ethnic communities. There are high levels of inequality, with some of the highest ranks of deprivation in the UK, with a third of those over 60 living in income-deprived households. The number of unemployed adults of working age between 50 and 64 is almost double the national average at 7.6%, and this has implications for older age poverty. There are also high numbers of people who are experiencing in-work poverty (Manchester City Council, 2021). Furthermore, women face increased likelihood of experiencing pensioner poverty due to women's employment records, meaning that because of the link between pensions and work within the formal economy, they are less likely to end up employed with a secure financial future (Grady, 2015). Likewise, a higher proportion of older women engage in unpaid work roles, and many have an elevated risk of poor health in relation to life expectancy.

Hence, the context for Uncertain Futures was to explore the inequalities experienced by women over 50 in relation to the following dimensions of work:

- **Seeking work.**
- **In-work experiences.**
- **Exiting work and retirement options.**
- **COVID-19 (due to the timeframe for the research, this was a pertinent issue).**

The project was led by Manchester Art Gallery – a civic-owned space belonging to the city council. The Gallery's ethos is to be "for the people" of Manchester (Akhter Azabany, Erinma Bell, Sally Casey, Atiha Chaudry, Rohina Ghafoor, Marie Greenhalgh, Jila Mozoun, Tendayi Madzunzu, Elayne Redford, Nadia Siddiqui, Circle Steele, Patricia Williams, Louise Wong). The feminist artist Suzanne Lacy (https://www.suzannelacy.com) was commissioned to develop a new piece of work for the gallery. Lacy is a socially engaged artist – her career spans four decades and aims to challenge inequalities and highlight the voices of often marginalised populations.

The rest of the project team consists of Ruth Edson, Communities Learning Manager, Manchester Art Gallery; academic researchers – Dr Sarah Campbell and Dr Elaine Dewhurst – as well as a group of 14 female activists and leaders from Manchester, working alongside every aspect of the project, and constituted the core of the work.

The work was underpinned by bringing together different expert knowledge:

- **Community Activism**
- **Gerontology**
- **Experiential knowledge**
- **Social Care**
- **Legal scholarship**

Intersectional approaches were an integral component of the project, assisting in developing research questions and recognising how older women's work relationships take shape through the interconnectedness of age along with other aspects of social difference and life experience – such as race, ethnicity, migration status, class, or disabilities.

Furthermore, the project draws on an ethics of care, as relationships and trust remain central to the work (Morse, 2019). The project featured interviews with 100 different women, and three exhibitions based on this work have been organised over the past five years: "Live Interviews", "The Research Process"; and "Women's Stories and Work".

The work's findings build on four interrelated themes:

- **Enduring Contributions of Older Women** – highlighting the significant unpaid contributions of older women in society, such as caregiving and volunteering, and calls for economic recognition of these roles.

- **Fragmentation of Women's Working Lives** – recognising how women's working lives are often fragmented due to caregiving responsibilities, and sometimes impacted by altered life course events such as health issues, and migration all of which leads to financial insecurity.

- **Inequalities as Obstacles to** – highlighting how gender, age, race, and disability discrimination pose major barriers to and within employment for older women, exacerbating their financial instability.

- **Creating More Certain Futures** – recommendations for recognising unpaid work, supporting volunteer-to-paid work transitions, and providing tailored job-seeking support to improve the financial security of older women.

It was particularly vital to highlight the diverse voices, specifically of older women from different racial and ethnic backgrounds in Manchester, as part of this project. Moreover, it was crucial in challenging dominant narratives and promote a more inclusive understanding of ageing and working across the lifespan for different women groups.

Inevitably, the challenges, such as navigating the institutional constraints of universities, have proven difficult along the way, particularly in terms of aligning ethics approval processes with project timelines**. It was also not always possible to enable consensus around decision-making despite the desire** to create an egalitarian and participatory research environment – at times, traditional power dynamics persisted. Leadership roles were held by the artist, the project coordinator, and the academic researchers, sometimes appearing to reinforce these typical hierarchies.

To counter that, it was necessary to ensure meaningful participation of all stakeholders, particularly those from marginalised communities, including making sure their input was meaningful, valued and had a measurable influence on the project's direction and outcomes. The project team adopted a collaborative approach to decision-making to mitigate power imbalances and ascertain the research as being as inclusive and representative as possible. The research processes flexibility and adapting schedules to accommodate the diverse needs of participants and responding to unforeseen challenges, such as the COVID-19 pandemic, was also important.

Furthermore, the team engaged in continuous reflection and dialogue about power dynamics and the impact of the work to help identify and address issues as they arise and to ensure that the project remains aligned with decolonisation and participatory goals.

Overall, the **Uncertain Futures Project** (https://uncertainfuturesproject.co.uk) highlights the importance of managing power dynamics and decolonisation in interdisciplinary, participatory research. It demonstrates that while challenges are significant, they can be navigated through a commitment to inclusivity, flexibility, and continuous reflection. Despite the project's success in terms of its processes, longevity and empowerment legacies, there is still a gap between utilising the research for lasting change in terms of addressing inequalities and enshrining recommendations into policy. The project has co-produced a manifesto, and the project actors continue to disseminate the work in both academic and non-academic media.

Conclusions

The inclusion of older people as active co-creators allows them to substantially contribute to the development of democratic and change-oriented knowledge, scientific progress, policymaking, and practical interventions, as some of our examples have demonstrated. More profound engagement allows older people to contribute to shaping research agendas, influencing policy proposals and facilitating the evolution of inclusive interventions catering to the diverse needs of diverse communities.

Their participation can range from co-formulation of research inquiries reflecting their perspectives to participatory research where researchers and older people collectively define research questions, produce insights, and develop collective action programmes (Lewin, 1948; Bilfeldt & Mahler, 2024). Older adults can also contribute to data collection, offer insights during data analysis, and help prioritise actions likely to enhance their environment and overall well-being and to improve society as such.

Despite efforts to include older adults physically, their voices may still be overshadowed or undervalued. Researchers, policymakers, and practitioner preferences might inadvertently sideline some perspectives. Nevertheless, every research, policymaking, and practical intervention phase related to ageing benefits from the input of older people. The "nothing about us without us" principle remains a key slogan in all processes to improve older people's lives (Charlton, 1998).

Severe poverty, marginalisation or exclusion, and the day-to-day experience of powerlessness can significantly affect their ability to participate in these processes. Addressing these issues on-site is essential for ensuring meaningful engagement. Empowerment strategies applied in these contexts can help break the cycle of oppression and deliver immediate benefits (Andersen, 2024). It requires a thorough understanding of the social dynamics, limiting older adults' influence and reinforcing their disempowerment.

Therefore, a careful approach is necessary to ensure that the voices of older adults in vulnerable situations are genuinely heard and considered throughout research, policymaking, and practice interventions.

Including older adults in participatory research, policymaking, and practical intervention designs constitutes important ethical considerations that ought to be addressed to ensure their participation is both meaningful and respectful.

The older adult's autonomy to make informed decisions about their participation is fundamental. That means providing clear, accessible information about the research, policy processes, or interventions and obtaining genuine consent.

It is crucial to prevent the exploitation of older adults, particularly those from vulnerable or marginalised groups – it involves safeguarding their rights and ensuring that their contributions are valued appropriately, with fair recognition and compensation for their time and input. Participatory approaches should be designed to recognise and mitigate power imbalances between researchers, policymakers, and older adults. Efforts must be made to ensure that all voices would be heard equitably and that the influence of older adults as co-creators would not be undermined by external biases or structural inequalities. Respecting the diverse cultural backgrounds and experiences of older adults is essential. Participatory methods should be culturally sensitive and tailored to accommodate different values, traditions, and needs, ensuring that all participants feel respected and understood. Researchers and policymakers should engage in continuous reflexivity to address and adapt to ethical concerns as they arise – regularly reviewing and adjusting practices in dialogue with older adults to ensure they remain aligned with moral principles and effectively support the well-being and dignity of seniors.

Finally, it is important to ensure that older adults' involvement leads to tangible benefits and improvements. Participatory approaches should result in actionable outcomes, positively impacting the lives of older adults and contributing to a more inclusive society at all levels. **Thoughtfully addressing these issues fosters more respectful, equitable, and impactful involvement, ultimately leading to better research, policy, and intervention outcomes.**

The paper highlighted the following key areas:

- **Empowerment and Inclusion –** the White Paper stresses the need for creating platforms where older adults can voice their opinions and contribute to research on equal terms. Designing inclusive processes that consider the unique challenges faced by marginalised groups and acknowledging the existence of a plurality of perspectives.

- **Financial and Institutional Support** – leveraging the necessary financial backing and institutional support and infrastructure to facilitate the active participation of older adults in research and community activities.

- **Interdisciplinary Approaches –** the document advocates for interdisciplinary collaboration, bringing together experts from various fields to address the complex issues related to ageing. Such a holistic approach ensures that the solutions developed are comprehensive and effective.

- **Sustainable Practices** – the White Paper calls for long-term strategies that not only address immediate needs but also ensure the continued involvement and empowerment of older adults in the future, emphasising the importance of sustainability.

- **Case Studies and Best Practices –** the document illustrates successful examples of participatory action research, highlighting the positive outcomes and lessons learned through various case studies. These examples serve as valuable references for future initiatives and highlight the challenge of defining the best practices and meaningful participation.

- **Challenges and Opportunities –** the White Paper acknowledges the challenges in implementing participatory approaches, such as resource constraints and sometimes resistance to change. However, it also identifies numerous opportunities for innovation and improvement, encouraging stakeholders to adopt flexible and adaptive approaches.

In conclusion, the White Paper calls for a concerted effort to integrate older adults into research and policymaking. Fostering a culture of inclusivity and collaboration enables us to harness invaluable insights and experiences of older adults, leading to more effective and equitable solutions for societal challenges. The document serves as a comprehensive guide for researchers, policymakers, and practitioners committed to advancing the well-being of older adults through participatory action research. Including older adults as active co-creators allows them to significantly contribute to scientific advancements, policymaking, and practice interventions.

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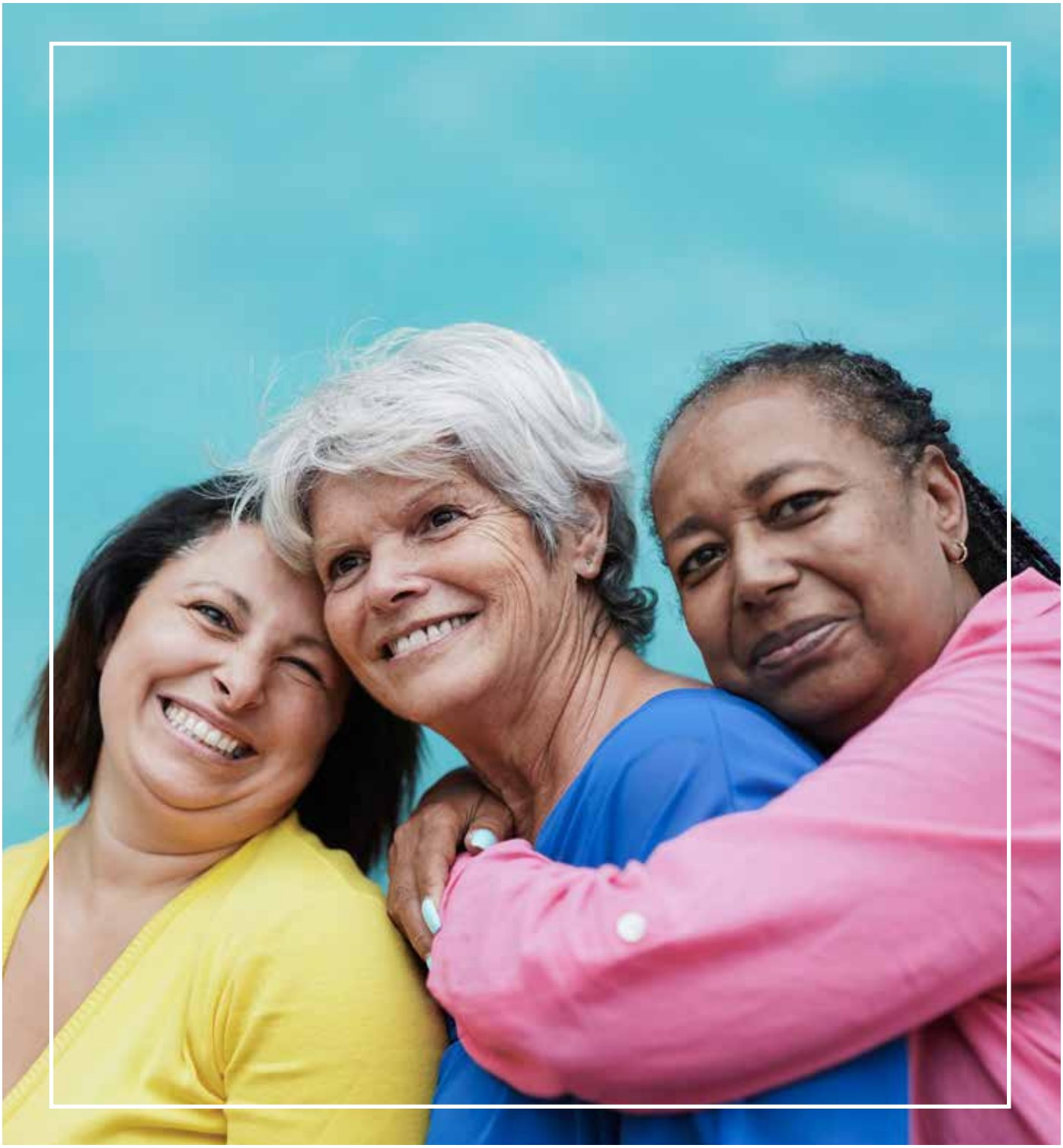

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