MANCHESTER 1824
The University of Manchester
Institute for Collaborative
Research on Ageing

LOTTERY FUNDED

AN INTRODUCTION TO CO-PRODUCTION FOR THE AMBITION FOR AGEING PROGRAMME

The Manchester Institute for Collaborative Research on Ageing

Written by Dr. Anna Goulding

THE AMBITION FOR AGEING PROGRAMME

Ambition for Ageing is a £10 million programme of work which will develop an approach to building age friendly communities. The programme presents an approach to social isolation that places older people at its centre, ensuring their contribution to civic, cultural and economic life is maximised and fully recognised across Greater Manchester.

The programme aims to:

- **Connect communities and people through the creation of relationships.**
- **Help to create places that are age-friendly and that will empower people to live fulfilling lives as they age.**
- **Embrace the celebration of age, creating the opportunity for people to contribute to the ageing agenda, offering choice and helping them to make more and better connections so that they can live fulfilling lives in their communities.**

This guide looks at the principles that inform co-production, and why using this approach makes both ethical and practical sense.

Co-production can help develop older people's independence and their influence on policy decisions affecting them. Critically, policy makers can benefit as older people are the most knowledgeable experts about the opportunities and challenges provided by living in an area. To make co-production work, traditional notions of the 'expert' versus the 'layperson' (Porter, 2010) need to be challenged. However, this does not mean diluting the integrity of the research process (Martin, 2013).

There are considerable challenges of co-producing all stages of a project, and this guide aims to help you look at how to plan, implement, monitor, and evaluate the process. The case studies in section three have been selected to give examples of the kinds of challenges faced in different settings and the lessons we can learn.

Co-production offers older people greater control over the research and design process, with the aim of developing sustainable projects that are relevant to the needs that they identify.

Co-production is an effective way of using 'experiential expertise' (Collins and Evans, 2007) which can highlight areas neglected by 'experts' (Fischer, 2000).

Using such principles helps us to consider the unequal power relationships involved in developing and delivering policies and services. Importantly, using a collaborative approach can lead to different outcomes for older people, their communities and the public services they use (McGarry cited in Buffel, 2015).

Opportunities for co-production are needed as Buffel (2015) notes that older people are rarely themselves central to the creation and development of policies. Blair and Minkler (2009) note the following advantages of adopting a co-produced approach:

- **Ensures that the topic under investigation matters locally**
- **Improves the relevance and cultural sensitivity of survey questions and other data collection tools**
- **Adds nuance to the interpretation of findings**

Blair and Minkler argue that using co-production can be more effective than relying on the traditional research model of researcher and research participant with some 'seldom heard' groups.

They suggest that projects using these methods with minority ethnic older people report improved recruitment and retention – they speculate that this is because the more reciprocal relationship removes the level of distrust connected with being a research 'subject' and having research done 'on' as opposed to 'with' you.

For example, Dickson and Green (2001) who worked with Aboriginal women in Canada (see case study 3.2), argued that an initial lack of trust seemed to come from a skepticism of academic research and an unwillingness to be positioned as a community in need.

> The underlying aim of the project which was to promote health had to be incorporated into other bonding activities which required the researcher to give over more trust than is normally given.

Blair and Minkler note that it is critical that older people determine the extent of their own involvement and observe that participants may not be interested in every aspect of projects, for example data collection or analysis. Another challenge in terms of keeping participants motivated are the delayed time frames in which outcomes can be delivered.

There are many different layers to the co-production processes involved throughout the Ambition for Ageing programme. In the various projects older people will not only participate in the research, but will themselves be the researchers.

They will also be directly involved in co-production with statutory and non-statutory policy makers and service providers.

1. INTRODUCTION

1.1 DEFINITION

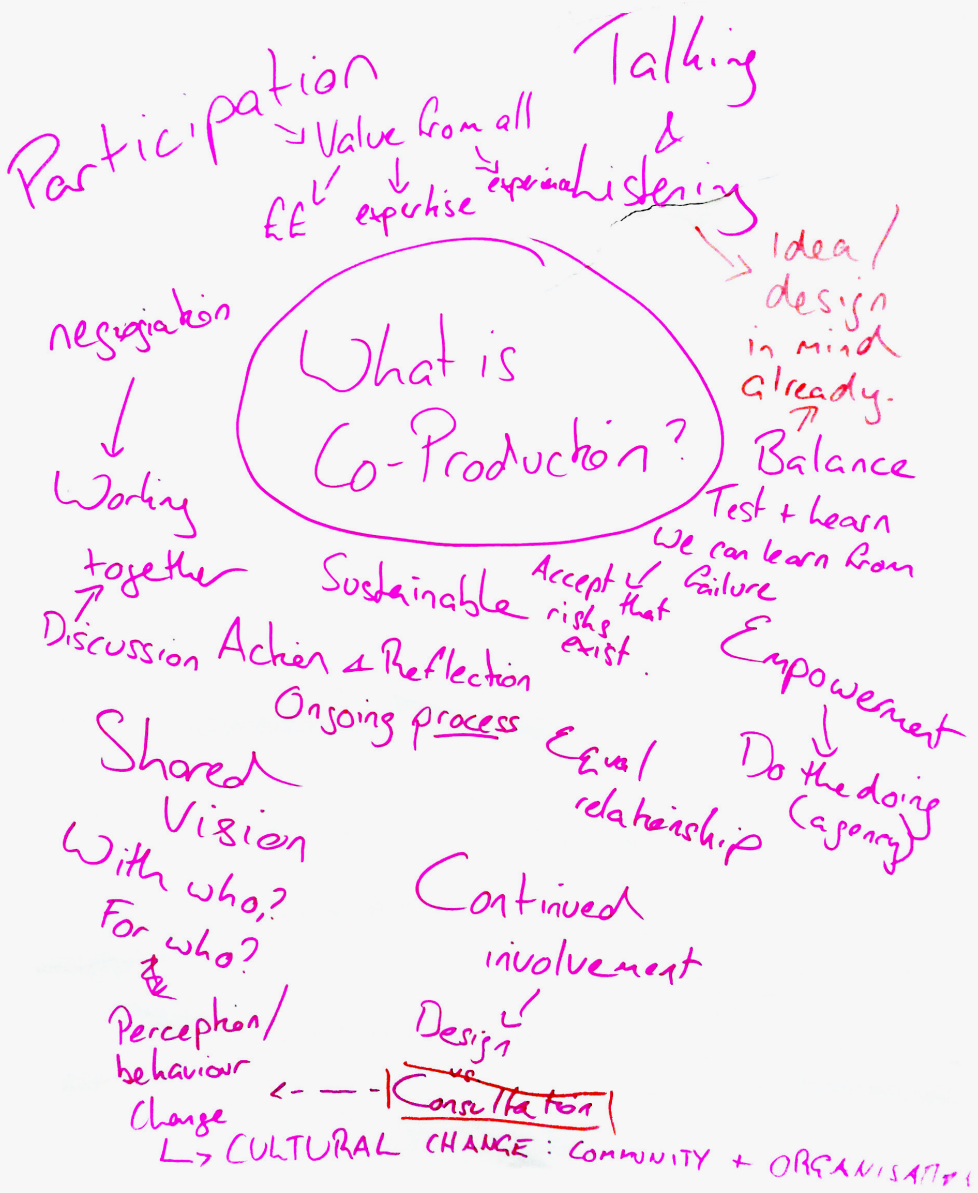
In the context of the Ambition for Ageing programme, co-production involves a partnership between older people, their families and communities, and statutory and non-statutory organisations. All partners will work together to research, design, develop and deliver projects with the aim of reducing social isolation and creating more age-friendly communities.

- **It is not synonymous with mere consultation**
- **It depends upon on an equal and reciprocal relationship**

1.2 WHAT ARE THE PRINCIPLES OF CO-PRODUCTION?

- **Older people are involved in all stages - the development, delivery and evaluation of projects**
- **Older people feel safe to speak and that their perspectives are valued**
- **Issues which are relevant to older people are addressed**
- **The decision-making process is transparent**
- **The skills and experience of older people, including the most vulnerable, are involved**
- **The meetings, materials and infrastructure are accessible to older people**

Adapted from AFE-INNOVNET (2015) Your definition of co-production (below) These diagrams were generated by our Local Delivery Lead partners during a workshop on co-production



- Participation > value from all (financial resources, expertise, experience)
- Talking and listening – the balance between having an idea/design in mind already and drawing from older people.
- Test and learn – we can learn from failure and the programme accepts that risks exist
- Empowerment/agency
- Equal relationship
- Continued involvement throughout design process
- Shared vision – with whom? For who?
- Negotiation > working together > discussion

1.3 WHY CO-PRODUCTION?

ADVANTAGES FOR OLDER PEOPLE:

- Older people feel heard and valued as peers
- The self-esteem, independence and agency of older people is strengthened
- The needs of older people are better understood
- The image associated with older people is improved
- New partnerships and networks are created
- The co-production process helps prevent older people's social exclusion

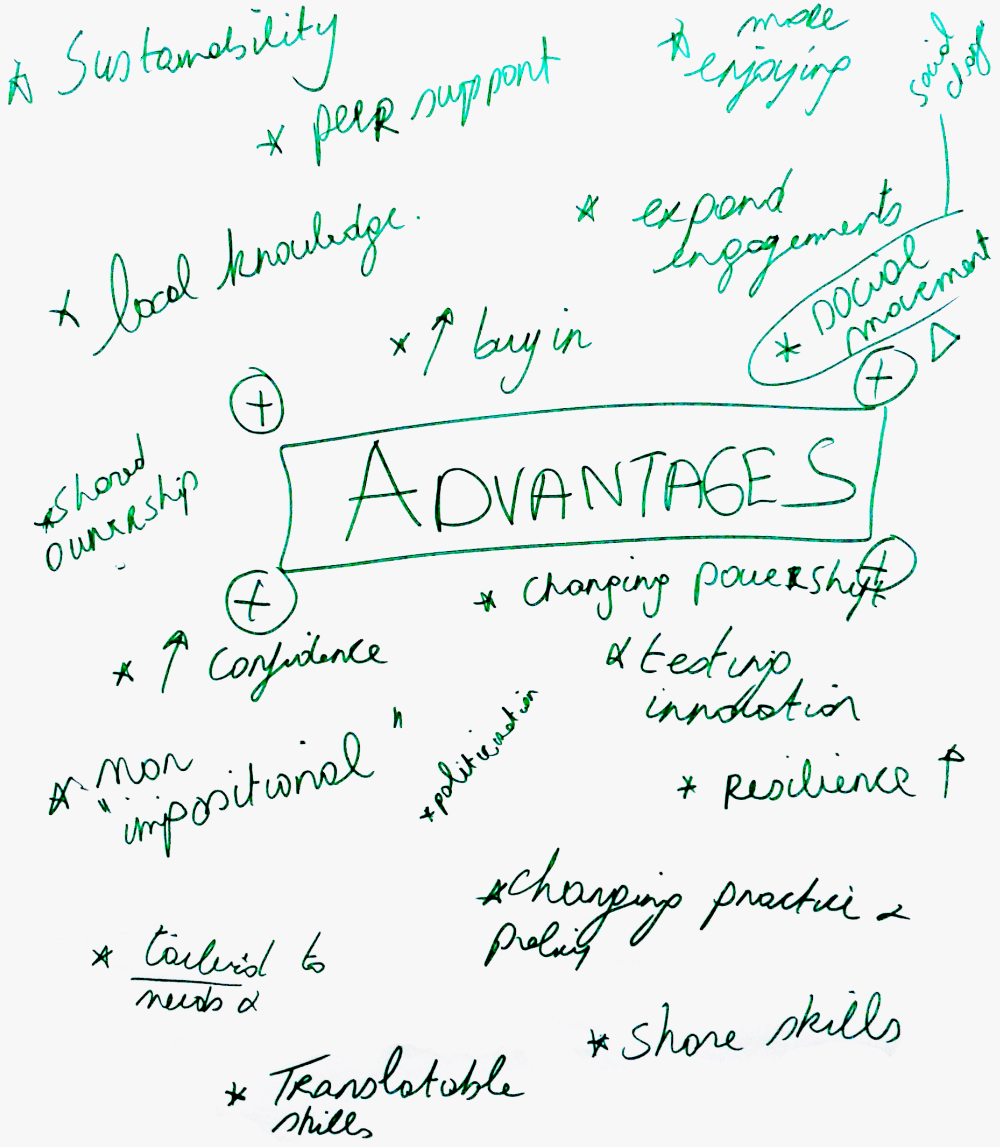
ADVANTAGES FOR POLICY MAKERS:

- They can benefit from the knowledge and experience of older people
- In better understanding the needs of older people, policy and services can be tailored accordingly
- Older people's experiences and knowledge makes them invaluable experts
- Older people tend to have lived in their neighbourhoods for a long time so they have access to networks and resources that may be unknown to arms-length professionals

- In terms of recruiting further volunteers and promoting programmes, older people are the most appropriate advocates – they are likely to be trusted and respected sources by other older people because they are experiencing the same issues

Source: adapted from AFE-INNOVNET, 2015.

The advantages from your perspective (below)



- **Projects more likely to be sustainable**
- **Provides peer support**
- **Leads to more people enjoying the process**
- **Expands engagement**
- **Leads to or has the potential for social movement/social changes**
- **Participant buy-in**
- **Strength of local knowledge**
- **Changing the power dynamic/shifting power relations leads to increased politicization**
- **Provides an opportunity to test innovation**
- **Provides an opportunity to share skills**
- **More likely to change policy and practice**
- **A Non-impositional process**
- **Everyone has shared ownership**
- **Projects can be tailored to particpiants' needs**
- **Develops participants' confidence**

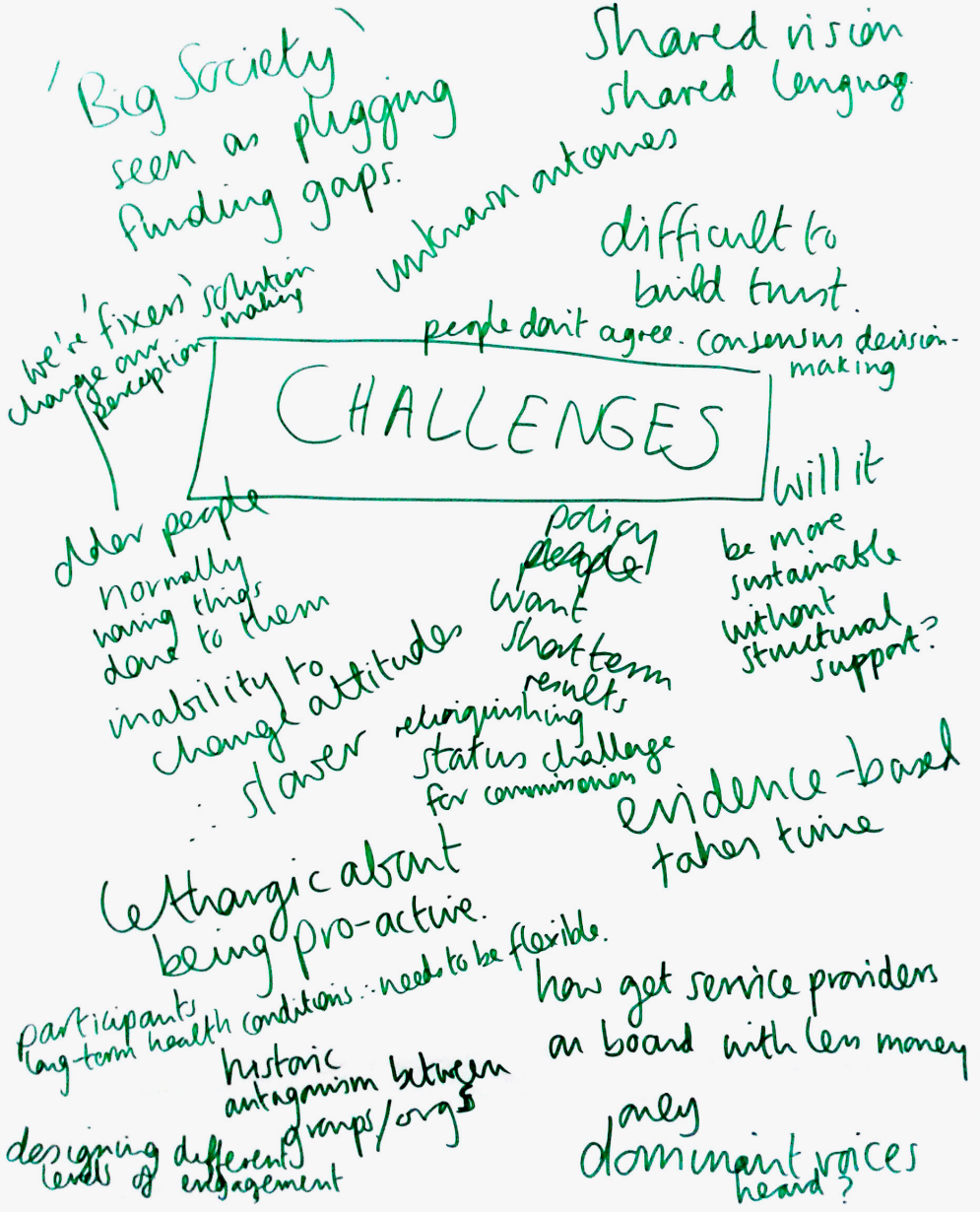
1.4 CHALLENGES OF CO-PRODUCTION

Partly because genuine co-production between all stakeholders is rare, starting out can be daunting. By its nature, the process is likely to be time-consuming, particularly in terms of staff time, for example, recruiting participants, establishing the ways of working and facilitating meetings to make sure everyone is able to express their view points. Before co-production can work we need to ask: Is everyone represented? Is everyone involved able to voice their ideas? How do we reach consensus?

There are challenges for older people and policy makers: Challenges of co-production (Source: AFE-INNOVNET, 2015)

Older people	*Policy makers*
People may not feel confident expressing themselves. They may not feel as though their perspectives are valued. They may not have been asked to contribute to policy or service delivery to this extent before. People may be unaware of the knowledge that they can provide to policy makers and feel discouraged from participating.	It needs to be made clear that older people's participation is invaluable. It is important to devote energy to ensuring a range of older people are represented.
It can be difficult to identify needs. It takes time to refine ideas.	A safe environment needs to be created which allows time for ideas to develop. Moderating discussions is a way of making sure everyone gets to voice their opinions. There needs to be the opportunity to trial ideas, fail and learn from mistakes.
People may feel unable to participate due to physical, psychological and psychosocial constraints (e.g. loss of hearing or eyesight, memory loss, mobility problems, lack of confidence).	Allowing sufficient build up time before the start of projects to encourage participation with conversations aimed at building confidence can help reduce psychosocial barriers to access. Ensuring provision is made for people with physical and/or cognitive impairments is essential.
Not everyone in the community receives information about these opportunities.	Energies need to be devoted to contacting those who are socially isolated. The support of older people can help identify and approach 'seldom heard' people.
People may feel that they are too old to learn about ICT and lack interest in learning.	Scaffolding progression (whereby the facilitator provides successive levels of temporary support that help the learner reach higher levels of skill acquisition – like physical scaffolding, the supportive strategies are gradually removed when they are no longer needed. The facilitator gradually hands over increasing responsibility to the student, taking a step back, offering support as needed) takes skill and patience – constructive feedback related to the specific ways people have approached or completed tasks as opposed to non-specific positive praise can be more useful in terms of encouraging progression.

The challenges you identified (below)



- **'Big Society' – seen as plugging funding gaps**
- **Developing a shared vision and shared language?**
- **Unknown outcomes (therefore greater risk?)**
- **Difficult to build trust**
- **People don't agree – consensus over decision-making difficult**
- **Will projects be more sustainable without structural support?**
- **Building up evidence takes time**
- **How do we get service providers on board with less money?**
- **How to counter historic antagonism between different partners/organisations?**

- **Participants may/will have long-term health conditions, therefore issue with retention – needs to be flexibility in terms of attending/arranging meetings etc.**
- **Older people are used to having interventions 'done to' them, with the accepted idea that services are 'fixers', so engendering choice and agency can be a lengthy process. Is there an inability to change attitudes?**
- **Participants can be lethargic about being pro-active**
- **Building confidence**
- **Defining roles**
- **Uncertain levels of commitment**
- **Perception that despite input, nothing will change**
- **Is the balance of membership representational?**
- **Getting people interested**
- **Financial expectations?**
- **Reverse money issues (payment of participants when perhaps they don't want payment)**
- **Formal issues relating to volunteering e.g insurance, training, CRB checks.**

Challenges you identified to the recruitment process (bottom)

2. PUTTING PRINCIPLES OF CO-PRODUCTION INTO PRACTICE

2.1 PLANNING

Before you start ask why are you using a co-production approach?

- **Who will be involved? Participants, policy makers, older people who will use the services, community organisations, service providers.**

- **Define and negotiate team roles.**

- **Gaining Informed Consent from participants – participants should be fully informed about what you are aiming to achieve and what their participation will involve.**

- **Participants may be suspicious about the purpose of the research or exploited or sensitive about being perceived as a group in need.Therefore, the reason for the research and their role as co-producers needs to be articulated.**

  Expectations also need to be managed – it needs to be stressed that the project might not result in a specific service they want and that there needs to be consensus over decisions. Explain why you want them to be involved; that they have the experience of living and ageing in their neighbourhood in a way that distant professional 'experts' do not.

- **It is important to continue to emphasise that participants are free to withdraw at any time without any consequence or without giving any reason.**

  An information sheet should be provided with all this information and with the contact details (including postal and

telephone) of a relevant member of staff if people have any further questions.

Confidentiality of data and what will happen with any information they give should be explained, including the kinds of publications findings will be published in and forums the information will be shared at.

Then, participants should be given a cooling off period to go away and think about whether they want to take part. Then formal informed consent should be taken – participants should be given a copy of the consent form and the information sheet to take away with them.

- **Identify the risks and how you might mitigate them. For example, what do you do if participants drop out?**

  (See case study 3.1 'Photographing the lived experience of chronic pain' for reasons why participants may drop out.) Have you recruited enough people? Do groups need to be split up so that everyone gets a chance to voice their views?

- **What resources do you need?**

  Human, time and financial. Who will arrange transport to and from meetings? When and where will meetings be held? Who is going to facilitate the discussion? Who will take notes? Who will be responsible for making sure that people complete action points? How are budgets to be devolved? How are you going to evaluate success?

- **Think about your communication strategy – ask participants about how they want to be kept informed.**

2.2 THE RECRUITMENT PROCESS

Challenges	*Possible solutions*
Participants are not representative of the target group	Choose different recruitment channels to ensure that your sample is representative of your area. Use the knowledge of older people already involved with the project to think about recruiting more 'hard to reach' participants. Spend time talking to local community organization leaders – their advice is useful, but remember that you do not want to just involve those who are already engaged (the 'usual suspects').
People do not all participate actively	Create an environment of trust and respect where people feel they can give their opinion. Moderate discussions. Make sure enough time is allowed so that after each discussion point you can go round individually and ask everyone what they think – offer the opportunity for people to give their opinion one-to-one if they find group discussions dominated by more confident speakers.
People do not attend meetings	Organise meetings in a way that people feel motivated to attend and participate, consider previously problems with the transport, mobility, care responsibilities, insufficient information about the time and venue.
It is difficult to achieve commitment from people involved	Older people must feel that their contribution is an essential part of the process.

- **Define your recruitment strategy:**

  Who will spend time recruiting a range of older people? How will people be contacted? Who will make initial visits to explain the project? Who will spend time building up the confidence of those who have never participated in such a project before? How much time will be factored into the pre-recruitment stage?

ONCE YOU HAVE RECRUITED OLDER PARTICIPANTS, DEVELOP AN ACTION PLAN:

- **Containing major objectives and activities of the process as well as (realistic and achievable) indicators to assess results**

- **Include details of specific tasks and responsibilities of all of those involved in the process**

2.3 MONITORING, EVALUATION, DISSEMINATION

MONITORING

- **Monitoring the level of participation and the achieved objectives**
- **Ensure regular feedback is given to the participants and stakeholders**
- **Provide minutes/feedback of meetings/activities with the summary of the decisions taken**
- **Volunteers and co-researchers need to feel that their contribution has an impact**

EVALUATION

It is important not only to evaluate in order to assess whether aims and objectives have been met, but to ensure that the process informs future development.

- **What do we need to improve?**
- **Compare the results with your original aims and objectives**
- **Evaluate the effectiveness of the methods used**
- **Consider whether changes were achieved**
- **Evaluate the number of people involved and whether the sample was representative**
- **Evaluate the equipment, costs and materials used to achieve the objectives**

DISSEMINATION

The outcomes and the lessons learned through the process should be clearly communicated to participants and the wider community.

You can highlight:

- **The lessons you have learnt (What was good? What needs to be changed or improved? Where there delays? Why? Were there detected risks?)**
- **The good practices you want to share with other organisations**
- **The impact of the co-produced work (impact on the wellbeing and participation of older people, impact on the local area/region, etc.)**
- **Co-production in dissemination: workshops, websites, blogs, twitter, facebook, youtube, seniors associations, local papers, ...**

3. CO-PRODUCTION IN DIFFERENT SETTINGS

There are not many examples of projects that have involved principles of co-production from start to end and have resulted in long-term change in policy and practice.

However, there are examples on a small scale, particularly those using action research methods with older people.

Here are a number of case studies which we can learn from – sometimes the changes the older people suggested may not have been implemented, but the fact that participants were engaged in the process is important itself in terms of initiating cultural change within and across institutions. Some of the projects described below involve older people becoming co-researchers whereas some have more of an emphasis on working groups aiming to make practical changes to services delivery.

CASE STUDIES

3.1 CULTURE CHANGE IN CARE HOMES

Shura, R., Siders, R., A., and Dannefer, D. (2011) Culture Change in long-term Care: Participatory Action Research and the Role of the Resident, *The Gerontologist*, 51(2): 212-225.

INTRODUCTION

The study aimed to advance the process of culture change within care homes by using participatory action research involving residents, family members and care home staff.

WHAT DID THEY DO?

Groups met for one hour every week for four months. Each group consisted of 4-7 residents, 1-2 family members, and 1-3 staff. Residents had varied levels of cognitive impairment and physical difficulties. The groups met to generate ideas for improving their care home community.

WHAT WERE THE MAIN CHALLENGES?

» *Staff involvement*

Despite many staff initially volunteering to take part, few staff came to meetings regularly. Staff said that their work tasks meant that they did not have time to take part but residents suspected that staff were suspicious of the project.

» *Sustainability*

The project required heavy input from staff; both external researchers and administrative staff, alongside care home staff. As researchers withdrew from the project after the planned four months, group members wanted to continue. In one home a home an administrator agreed to continue facilitating meetings.

» *Possible solutions to sustainability?*

Residential homes taking on the responsibility for organizing participatory action research groups would be a way of embedding this way of working into the life of a care home. However, beyond organizational priorities and budgeting, the independence of such groups could become compromised if they were supported in this way.

WHAT DID THE GROUP CHANGE?

Changing organisational practices

- In two homes residents felt the dining experience was 'loud and clangy'. They improved the ambiance by using tablecloths, placements and flowers, diming the lighting and using candlelight; couples who ate together were given their own table. Residents also helped set the tables.

- In one home it was suggested the dining room was moved to the hall to allow more space for wheelchairs to fit around tables. One resident suggested having a bell to signal to everyone that dinner was ready – interestingly, this suggestion called for more of an institutionalized regime. Neither of these suggestions were taken further by the groups, but going through the process of identifying problems and suggesting solutions was seen to be a valuable end in itself.

Celebrating residents' achievements

- Notice Boards were hung lower down which enabled people in wheelchairs to read the information; also the print on notices was made bigger. Positive news and achievements such as residents' artwork were posted up on the boards.

Relationships between staff, residents and family members were strengthened

- Residents conducted informal interviews with staff to get to know them; they then made a staff 'face book' with the biographical information and photographs.

- To improve interpersonal contact between staff and people with severe dementia, staff were encouraged to sustain eye contact, smile and use touch.

- Daily diaries were shared between residents, staff and family members to enable everyone to learn more about each other and to stimulate discussion about the different day-to-day experiences of different members of the community within the home.

- Another home discussed the idea of producing a drama performance to help improve empathy and understanding between staff and residents.

- The group outlined principles and practices that should be followed by everyone in the home. Suggestions included giving compliments and praise and taking time to share good conversations with each other. The policy was then distributed to residents and staff and family members and an anonymous box was set up to collect feedback. The group did not receive much feedback from staff, so the group decided to learn more about their working experiences.

- They created a questionnaire for staff asking about their perceptions of respect from residents, and support from management. Although only 7-10 staff out of a total of 50 completed questionnaires, the group was interested in the diversity of opinions represented by the results and felt that staff morale was low – they continued to talk about how to improve this.

Provided opportunities for meaningful social engagement

- The residents wrote their own newspaper after discussing work and hobbies such as journalism and photography that they had not had the opportunity to pursue since moving into the home. The newspaper prompted a further two projects – the use of a star pinned up to commemorate loved ones who had died in the armed services and a Veteran's Day celebration.

- Provided opportunities for civic activity.

- They developed volunteering opportunities such as helping local cultural organisations' mailouts.

WHAT CAN WE LEARN?

The participatory research process improved residents' quality of life by providing a forum for meaningful social engagement and integration between staff, residents, and family members.

The project developed leadership skills in the residents – this shifted the emphasis away from the idea of residents being helplessness, passive recipients of care and instead provided the opportunity for people to demonstrate competence.

Participants valued the co-production process being formalized – they liked the regular meetings and the fact that members of the group committed to attending meetings.

The co-production process stimulated ideas for change and it was not a sign of failure when suggestions were not implemented.

The success of the approach relied heavily on the support and strong rapport between the administrators and facilitators to try and negotiate any resistance or unfamiliarity on the part of staff to the project. For example, meetings were scheduled not to clash with other meetings in the home.

3.2 HEALTH PROMOTION WITH OLDER ABORIGINAL WOMEN

Dickson, G., and Green, K., L. (2001). Participatory action research: Lessons learned with Aboriginal grandmothers. *Health Care for Women International*, 22, 471-482.

INTRODUCTION

The project was a three-year project operated by the local community health clinic aiming to promote better wellbeing as the city authority had identified Aboriginal women as having unmet health needs. Older Aboriginal women from remote areas of Saskatchewan, Canada, had relocated to the city and since their move the women were described as, 'living a culture of silence, invisibility, and isolation' - the group had experienced social inequality related to their race, social class, gender, and age. Participants had a range of educational experiences ranging from no formal schooling to having nursing diplomas; some had never been active outside the home whilst some had had long-term employment.

It took two-and-a-half years for the grandmothers and researchers to work together to establish a working relationship and develop their health promotion programme. After a year of weekly meet ups, 25 participants became involved, with the turnout to the weekly sessions varying from four to fifteen.

WHO WAS INVOLVED?

Older Aboriginal women in Canada and professional researchers.

GROUP ROLES/THE RESEARCH TEAM

» *The Grandmothers/participants*

In total 40 aboriginal grandmothers attended the weekly meet ups, half of whom were interviewed for the health assessment. They endorsed the design of the interview frameworks, consent forms, work plan and contracts for Research Associates. They verified the data by checking through it and participated in secondary analysis by reading the various drafts of the final assessment report. They acted on some of the suggestions that arose from meeting as a group.

» *The advisory committee/co-researchers*

Seven Aboriginal women guided the set-up of the project for the first year. They helped contribute towards the development of the Health Assessment criteria. Co-researchers trained in data analysis and provided knowledge and understanding of Aboriginal community traditions for the academic partners.

» *Research Associates*

Two middle-aged Aboriginal women were trained by the paid academic researcher. They were employed for four and a half months and they conducted interviews with 40 participants. They worked with researcher to design interview guides, consent forms and conducted a secondary analysis of preliminary written reports.

» *Paid project staff*

The community health clinic's promotion director, a project coordinator and an outreach worker.

» *Paid academic researcher*

The researcher guided and facilitated the programme.

WHAT DID THEY DO?

Research design; data analysis; editing final report; consultation with policy professionals.

The group met up for half-days every week consisting of:

Healing circles combining various traditional Aboriginal rituals; education sessions on various health related topics of the grandmothers' choice; planning and organising the overall project; working on the health assessment report – reviewing data or drafts of the report; field trips to picnics or health fairs; cultural events such as planting trees on sacred sites; socialising over tea and food.

WHAT WERE THE MAIN CHALLENGES?

» *The negative perception of research by marginalized groups*

Initially the grandmothers felt a level of exploitation as target group for a health intervention. When the project started the focus of the health assessment was on needs but the grandmothers did not want to be seen as a 'problem'.

Therefore the specific health assessment was integrated with other activities but this meant that some of the research became less visible.

» *Achieving a balance between helping the grandmothers and fostering their self-reliance*

Paid staff gave lifts to participants, and intervened in helping them communicate with health and social services. Whilst this could be seen as appreciating participants and developing relationships, it could also be argued that this did not help develop participants' self-reliance.

» *Employing Aboriginal research associates*

Employing and training two Aboriginal participants to become researchers showed the feasibility of developing research skills aligned with, and in conjunction with, local communities. However, in this particular instance the two research associates had social problems which meant they could not consistently contribute to the standard required.

» *Recognizing the limits of the grandmothers' capacity to be co-researchers*

Whilst the grandmothers enjoyed and participated in the socializing and the traditional events, they did not necessarily attend regularly, were hard to access for some of the research elements, and resisted engaging in business or political aspects of the project. For some, poor health inhibited participation. Others felt uncomfortable with translations from English in to their language Cree and culturally were not used to expressing their beliefs and feelings verbally.

Engaging the grandmothers in critical analysis

The grandmothers did not feel comfortable being directly questioned about their problems. They felt as though this level of analysis seemed political, which was the type of engagement they wanted to avoid. The paid researcher felt as though they had absorbed a culture of silence, and that this was something the project was not able to change.

WHAT DID THE GROUP CHANGE?

The grandmothers developed wellbeing in their new urban setting through developing coping strategies. The project established a new social support system and it was argued that participants reclaimed their traditional role as sources of wisdom, guidance and love.

The group continued to meet beyond the research funding.

WHAT CAN WE LEARN?

Because the specific health assessment was integrated with other activities it meant that some of the research became less visible. This integration meant that the full contribution of all team members was not clear and therefore the project cautioned against underestimating the level of resource needed in terms of staff time.

3.3 PHOTOGRAPHING THE LIVED EXPERIENCE OF PAIN

Baker, T., A., and Wang, C., C. (2006). Photovoice: Use of a Participatory Action Research method to Explore the Chronic Pain Experience in Older Adults. *Qualitative Health Research*, 16 (10): 1405-1413.

INTRODUCTION

Photovoice is a participatory action research method in which people photograph their lived experiences. They then engage in a critical dialogue (participants ask questions to gain a deeper understanding of the photos and stories shared by other participants. They reflect upon, analyse and evaluate different ideas and positions) about their work, and produce exhibitions for educational workshops or to effect change. In this case study participants were asked to record their responses to experiencing chronic pain. They were given inexpensive cameras and taught how to take photos capturing their everyday realities and then asked to write accompanying narratives.

The research wanted to explore the usefulness of photovoice as a tool to communicate and analyse chronic pain – it was felt that this method might be used as an alternative way to throw light on the experience of pain to help researchers, health care professionals and policy makers understand different aspects of the pain experience not visible through quantitative scales.

WHO?

The project recruited 27 Black and White adults aged 50+ who were experiencing chronic pain and professional researchers. In total 13 participants completed the project.

WHAT DID THEY DO?

The project was structured in the following ways:

- **An initial orientation session was held where the purpose of the project and the rationale for using cameras was explained. The session also looked at the ethics and risks involved with taking photograph of people without permission, and taking photos in a non-secured environment. However, clinic based participants were more physically impaired so were unable to attend the orientation sessions – they were contacted by, and communicated directly on a one-to-one basis with project officers.**

- **Participants were then asked to go away and take photographs, select four photographs, and write a brief passage describing how their image reflected their experience.**

- **In the next phase, participants were asked to take photographs of what they would like their life to be without pain. Finally participants were interviewed about their participation in the study, their experience as a photographer and their experience of pain.**

WHAT WERE THE MAIN CHALLENGES?

Because of the participants' physical difficulties, and problems with transportation, the majority of participants were not able to attend group sessions or present their work at public forums. Participants found writing the narratives, revealing feelings and choosing which photographs to showcase as difficult.

OUTCOMES

Participants felt that they were helping themselves and other people to cope with pain by creating these visual narratives. Going through the process helped participants learn more about the physical and emotional associations of pain. It provided an alternative way of allowing participants to assess their own needs and communicate how they experience pain and cope with it in their day-to-day lives.

Using photovoice provided a method for allowing policy makers, health professionals and researchers to consider what health concerns of the patient have been overlooked, unconceptualised, unrecognized, or ignored.

WHAT CAN WE LEARN?

Participants suggested that less time between the phases, more direction from the research team to stay on task, having an open discussion about the work, and taking fewer photographs would help improve the effectiveness of such a programme.

Only 13 participants out of the original 27 completed the project. A possible reason for this is the number of steps participants had to take to complete each phases. Perhaps the requirements were too challenging? There needs to be a greater focus on how to work effectively with participants in clinical settings. Participants experiencing chronic pain are understandably likely to be preoccupied with seeing medical professionals, as opposed to participating in a research project.

3.4 GRANDPARENT CARERS

Roe, K., Minkler, M., and Saunders, F., F. (1995). Combining research, advocacy, and education: The methods of the grandparent caregiver study. *Health Education Quarterly*, 22: 458-475.

INTRODUCTION

The research set out to explore the physical and emotional health of African-American grandmothers raising their children as a result of the grandchildren's parents' crack cocaine addiction. Participants were identified through health and social service providers, a network of community contacts, invitational flyers and referrals from other participants.

WHO?

Academic partners identified the topic but they then partnered with an older person's organization, a health centre and set up an older person's advisory group. Because the principle researchers were both white, a number of steps were taken to overcome the difficulties of cross-cultural research to make sure the study was able to accurately and sensitively capture the perceptions of African-American grandparents. A larger research team was established which included someone to liaise with participants and four African-American graduate students; and a community advisory committee largely made up of African-American women.

WHAT DID THEY DO?

In terms of the research, the older person's advisory group expanded the sampling criteria, refined interview questions to make them more culturally sensitive and helped with data analysis.

OUTCOMES:

- **Established a regional coalition on grandparent caregiving**
- **They expanded a telephone support line**
- **They established a Church-based respite for grandparent caregivers**
- **They produced a newsletter for and by grandparent caregivers**
- **Participants developed research skills, particularly research design**
- **Participants planned celebration events to honour each other, sharing initial research findings, and getting other participants' suggestions on how to use the research findings**
- **They participated in advocacy events on local media**
- **The group continued for six years beyond funding of programme. The people involved went on to get funds to support their initiative such as the respite centre, the newsletter, the resource centre**

WHAT CAN WE LEARN?

The recruitment of African-American women to the reference group and as interviewers was a way of trying to make sure the research picked up issues and perspectives of the African-American participants. They were also key gatekeepers as helped recruit other participants.

3.5 DEVELOPING STROKE SERVICES

Jones, S., P., Auton, M., F., Burton, C., R., and Watkins, C., L. (2007). Engaging service users in the development of stroke services: an action research study. *Journal of Clinical Nursing*, 17: 1270-1279.

INTRO

The study wanted to develop local stroke services by involving people who had been affected by stroke, both patients and their carers. They wanted to work with people affected by stroke to prioritise service development. The project was undertaken across one Primary Care Trust and three Hospital Trusts in the North West of England.

WHO?

Stroke patients, carers, an action researcher and health professionals. The action researcher had no formal relationship with the stroke services. In total, 50 Patients were recruited from hospitals, and five from the community. Attempts were made to ensure representation of participants with cognitive and communication difficulties. Two carers were interviewed independently because one participant had severe communication problems.

WHAT DID THEY DO?

Stroke service users and their carers were identified through General Practitioner stroke registers and then interviewed in focus groups. The focus groups were externally facilitated. Then for the next phase, participants, carers and professionals used the data to identify service development priorities to develop action plans. Several practical recommendations were made, but these have not been implemented.

WHAT WERE THE MAIN CHALLENGES?

The intention was that each working group would nominate a facilitator who took over the responsibility of the workgroup from the paid researcher. But this was not possible as the volunteer facilitators did not feel as though they co-ordinate and organise the groups across the three sites.

The plan around providing long-term support aimed to involve all the patients and their carers in their transfer into the community by increasing carer involvement, providing home visits and overnight stays and developing individual discharge plans. However, this work has not been taken forward because of the complex issues around the transference of care.

WHAT DID THE GROUP CHANGE?

The stroke patients and carers were able to identify and prioritise issues around service development. The study authors felt that with external facilitation it is possible for patients to play a meaningful role in service development that goes beyond consultation.

WHAT CAN WE LEARN?

The way sessions were structured: The focus groups explored the concept of an 'ideal' stroke service. To ensure relevance, questions were underpinned by a policy framework broken down in to the four main components: prevention, immediate care, rehabilitation, long-term support.

Once the data was collected, summaries of the interviews were sent to participants to check that they accurately represented their views. Verifying the research findings with participants has been advocated by many authors (Guba and Lincoln, 1981).

3.6 CREATIVE ENGAGEMENT AND RESILIENCE

(https://blogs.ncl.ac.uk/annagoulding/author/nag47/ also Goulding 2013)

INTRO

The project wanted to explore how different forms of cultural engagement, such as visiting art galleries, museums and heritage sites, taking part in participatory theatre, taking part in musical activities or going to concerts, or reading or painting might develop older people's resilience.

Cultural participation has been argued to have wellbeing benefits for older adults (Bernard et al, 2014; Goulding 2013), but others have argued that it is social participation per se that is important (Miles and Sullivan, 2012). Is there something about the art form, or discussing the art form, that might stimulate people to think about the world and their place in it?

Can these discussions help develop different types of relationships that might help people adjust to life transitions such as moving into sheltered accommodation or widowhood? The project had a clear policy angle in terms of exploring the relationship between engagement and wellbeing. When thinking about wellbeing in older age, not everyone is able to age successfully – is resilience a more useful term because it describes how people and communities cope with, and bounce back from, challenges?

Can people flourish (or become stronger) not despite of, but because of setbacks? Because terms like 'resilience' or 'wellbeing' come in and out of usage in public policy, we partly wanted to test whether these terms were at all useful for ordinary people – and what did resilience mean to older people?

To probe these questions further, we paired up a group of people living in a sheltered accommodation unit who were not currently culturally active with a group who had been taking part in various projects run by an arts charity. We accompanied them on a tour around three local art galleries and museums.

A workshop was then facilitated by an outreach officer from a theatre who specialises in participatory drama. In the workshop the older people were asked to create mimes, make tableaus, write group poems to explore their responses to the visits and how cultural engagement might relate to resilience. They were then invited to come and present at a series of workshops involving academics, policy makers and arts and care professionals.

WHO?

A group of researchers, eight older people from a sheltered accommodation unit who were not currently 'culturally engaged', a group of eight older people who had been working with an arts charity over a few years and a participatory theatre facilitator.

WHAT WERE THE MAIN CHALLENGES?

Gatekeepers such as wardens of sheltered accommodation units are vital in encouraging initial engagement. For the first visit to one contemporary art gallery it was important to discuss how extensive regeneration of the area made participants feels as though they did not belong – the warden played a key role in challenging feelings of inferiority.

Under financial cuts to the sheltered accommodation housing sector, wardens' job remits have narrowed and it will be difficult to replace the pastoral support role they play. By starting to use processes of co-production now and developing different kinds of networks in communities, there is the possibility of mitigating against such further organisational structural changes.

WHAT DID THE GROUP CHANGE?

The academic literature around resilience tends to focus on individual traits such as hardiness or humour which can negate the role of the state in providing support. Participants brought up a range of life course events that had tested, but ultimately helped, develop their resilience.

They felt that experiencing the war, their attachment to their locality and their immediate community made them stronger. They felt that resilience was both a useful and relevant term. However, the exercise revealed the extent to which policy language can exclude people; participants would apologise for mispronouncing the word, and excuse themselves for not being intelligent enough to provide a definition despite providing perfectly articulate explanations.

Discussing the art and objects in the museum stimulated participants to reflect on their own lives, for example, the educational opportunities they had experienced, particularly as women. The art also prompted discussions around macro-level events such as 9/11 or the Miners' Strike (1984-85).

These conversations allowed participants to get to know each other and the sheltered accommodation warden observed that it changed the way one resident was seen by others in a positive way.

It was important that participants were not using the art to reminisce – they valued contributing to contemporary societal debates. A group of the older people continued to come to events or seminars held at the University and became an advisory group for future research projects.

Although not attributable to involvement in the project, when the warden in the sheltered accommodation unit went off on long term sick, the same participants instigated a coffee afternoon for other residents – it could be argued that taking an important and valued role in one form of civic participation can help develop agency or a sense of control in other areas of life.

WHAT CAN WE LEARN?

It takes time to develop confidence and reduce psychosocial barriers to access – it had taken the group who were involved in cultural projects at least three months to feel comfortable. For some this could be longer. A lot of staff time was needed – initial one-on-one visits were made to see participants, weekly phone calls were made to confirm taxis and to get feedback on sessions.

Cultural engagement is a form of social participation older people value – reflecting on their own lives and discussing societal issues contributes to people's subjective wellbeing. Also, using some form of art, drama or music to explore issues or themes is an effective way of getting people to work together and express themselves non-verbally. It makes sense to involve older people in discussions and definitions around policy terms that are used to refer to them.

3.7 WALKING INTERVIEWS

Hammond, M. (2013). Old Moat: Age-friendly Research and Evaluation Toolkit, Southway Housing Trust, Manchester City council, Manchester Metropolitan University and University of Manchester.

INTRO

Walking interviews were used as a way of exploring how age-friendly the area of Old Moat in Manchester was felt to be by older residents. Participants were identified by a neighbourhood officer who worked for a Housing Trust. The researcher arranged to meet the interviewee at a location of their choice, as some felt uncomfortable with being met at their home.

The participant was asked to take the interviewer on a walk, choosing any route. Sometimes the route followed the way participants used to get to the shops, whereas sometimes a tour was given of locations they wanted to share. Questions asked were more conversational in tone and much less structured than an interview framework.

Usually, the walks started off with a broad question such as 'What is it like to live in Old Moat?' The discussion on the walk used features on the walk to prompt reactions and perceptions.

To record the interview, digital recorders were used, alongside photographs of any important features. Once back in the office, the researcher noted the route taken and transcribed the conversation. Transcripts were then shared within the research team.

DEVELOPING A WALKING INTERVIEW METHOD

Clark and Emmel (2010) give useful advice around conducting walking interviews. Before starting they discussed the interview in advance with participants, explaining the rationale, the research questions and what was expected of them.

Consent and confidentiality was explained and participants were asked whether they objected to having their interview recorded. A good quality small microphone (preferably a lapel microphone) with a wind guard is essential, but even with this equipment not all discussion will be recorded because of traffic noise, wind and other passers-by.

The researchers purposefully did not offer prescriptive instructions to participants about how the walking interviews should be completed. They simply told participants that they were interested in finding out about their neighbourhood, without imposing a definition of neighbourhood or limiting the geographical boundaries considered.

The researchers did not want to provide guidance which would limit or constrain participants; instead wanting them to present their neighbourhoods as they saw them. Participants were encouraged to take the researcher to any places they felt were appropriate (note that they were not instructed to take the researcher to 'significant' or 'important' places) and that the walk could be as long or as short as they wanted and follow any route. Participants were given disposable cameras to take photographs along the way.

The walking interviews produced a commentary on the neighbourhood, and answers to questions provoked by the narrative and the spaces and landmarks considered important. The data comprised an audio recording of the walking interview and a photographic record produced by the participant.

It was important not to lead participants towards either positive or negative judgements about their neighbourhood, for example, it was for the participant to bring up cracked pavements or nice seating areas and not the researcher. Here are some suggested questions to prompt discussions:

We can do this walk in whatever way you think best; we are interested in how you think about your neighbourhood, as well as where we go. I can prompt you and offer advice, but I am keen that you use your own ideas.

I will ask you some questions about where we are going and about the sorts of people, landmarks and activities you raise. And I will seek clarification about how you feel connected to these spaces and why these are important to you.

- **What do these places mean to you?**
- **What memories do you have of these places?**
- **Where do you go?**
- **Where would you not go?**
- **Where might you meet (bump into) people you know?**
- **Do you use any of the services in the area?**
- **Do any of your friends, acquaintances, or other contacts live or work in the area?**
- **What do you like and not like about the area? Favourite/ least favourite places?**
- **Do you know people in this area?**
- **Are there people who you greet or acknowledge?**
- **It is important to stress the embedded nature of this questioning, for example, asking questions like, do you always walk on this side of the road?**

CLARK AND EMMEL SET OUT THE REASONS WHY WALKING INTERVIEWS ARE AN EFFECTIVE METHOD:

- To understand how people conceptualise and understand their neighbourhoods.
- To understand how people articulate their neighbourhoods.
- To understand how people locate their social networks and express their sense of community in relation to local places.
- The method gives greater control over the research process to the participant as they decide the route to follow.
- The participant gets to show rather than describe significant places – it can suit different learning styles. Placing events, stories and experiences in their spatial context can help participants to articulate and arrange their thoughts.

- Walking through an environment can prompt discussion in a way that might not occur in a room-based setting.

- The methods can provide opportunities for the serendipitous and the unanticipated. Walking interviews can throw up issues of contradiction. For example, in one walking interview Clark and Emmel came across racist graffiti that prompted a discussion about cohesion and tolerance that may not necessarily have been considered in a room-based interview.

- The method can be adapted to fit in with a participants' everyday life, whilst simultaneously demonstrating their everyday practices. For example, during one interview, one participant picked up her children from nursery, revealing ways in which local spaces are integral to networking practices.

4. CONCLUSIONS

The booklet argues that using a co-produced approach makes ethical and practical sense. All stakeholders have the potential to benefit from working in this way – older people's agency can be developed through engagement and policy makers can draw from expertise and knowledge embedded in localities.

Traditional notions of the expert and the layperson need to be broken down, but this does not mean the research process is any less rigorous. However, there are considerable challenges, for example, recruiting all the necessary participants so that as many representative viewpoints are expressed. Care needs to be taken when facilitating meetings to ensure all voices are heard and valued, yet some form of collective consensus is reached.

It is difficult to build in time for reflection to projects when working the external deadlines. But if we are guided by the principles informing co-production set out here, we can ensure that we are not merely consulting with older people.

The case studies presented offer ideas of different contexts where the principles of co-production have been implemented – from the care home to research in a Primary Care Trust setting.

The examples foreground some of the issues when working with people who are not necessarily used to vocalising difficulties they face in a formal setting.

In the case of the Aboriginal women, they did not want to be labelled as a needy group and therefore the researcher incorporated the health promotion aspect of the project within other group bonding activities. In the Grandparent carer project, there was the need to recruit African-American women to the reference group and as interviewers to make sure the research picked up culturally-sensitive issues specific to their community.

The case studies show how to use different participatory methods to capture different aspects of lived everyday experience – walking interviews, photographing the experience of chronic pain, or using art as a stimulus for debate.

The methods described can be seen as alternative ways of gaining insights from older people about their neighbourhoods and what can be changed.

For further reading about researching age-friendly communities, including working with older people as co-investigators please refer to:

Buffel, T. (2015) Researching age-friendly communities. Stories from older people as co-investigators. Manchester: the University of Manchester. [ISBN: 978-0-9576682-2-5]

This booklet provides useful advice on conducting interviews and holding reflection meetings, together with older people's perception of their involvement in the co-production process.

For further reading about co-production in public policy design, please refer to:

Richardson, L., & Durose, C. (2016). Designing Public Policy for Co-production: theory, practice and change. Bristol: Policy Press/ University of Chicago Press.

This book contributes to a growing debate, arguing that traditional technocratic ways of designing policy are inadequate to cope with increasingly complex challenges.

Drawing on twelve international contributions from practitioners, policy makers, activists, and academics the book explores how democratic involvement in the policy process from outside the political elite can shape society. This book offers insight into why and how to generate change in policy processes, arguing for increased experimentation in policy design.

References

AFE-INNOVNET. (2015). Guidelines for coproducing age-friendly environments with older people. Accessible online at http://afeinnovnet.eu/sites/default/files/AFE-INNOVNET_D4.3_PRINTED-VERSION.pdf

Baker, T., A., and Wang, C., C. (2006). Photovoice: Use of a Participatory Action Research method to Explore the Chronic Pain Experience in Older Adults, Qualitative Health Research, 16 (10): 1405-1413.

Bernard, M., Rickett, M., Amigoni, D., Munro, L., Murray, M., Rezzano, J., 2014. Ages and Stages: The Place of Theatre in the Lives of Older People, Ageing and Society, [online] <doi:10.1017/S0144686X14000038> [accessed 11 June 2014].

Blair, T. & Minkler, M. (2009) Participatory action research with older adults: Key principles in practice. Gerontologist, 49, 651-662.

Buffel, T. (2015) Researching age-friendly communities. Stories from older people as co-investigators. Manchester: the University of Manchester. [ISBN: 978-0-9576682-2-5]

Clark, A., and Emmel, N. (2010). Realities Toolkit #13: Using walking interviews, ESRC National Centre for Research Methods.

Collins, H., M. and Evans, R., J. (2007). The Third Wave of Science Studies: Studies of Expertise and Experience. Social Studies of Science, 32 (2): 235-96.

Dickson, G., and Green, K., L. (2001). Participatory action research: Lessons learned with Aboriginal grandmothers. Health Care for Women International, 22: 471-482.

Fischer, F. (2000). Citizens, Experts, and the Environment: The Politics of Local Knowledge. Duke University.

Goulding, A. (2013) 'How Can Contemporary Art Contribute Toward the Development of Social and Cultural Capital for People Aged 64 and Older', The Gerontologist, 53 (6), pp. 18-31.

Heslop, M. (2002). Participatory research with older people: A sourcebook. London: HelpAge International.

Jones, S., P., Auton, M., F., Burton, C., R., and Watkins, C., L. (2007). Engaging service users in the development of stroke services: an action research study. Journal of Clinical Nursing, 17: 1270-1279.

Martin, S. (2010). Co-production of social research: strategies for engaged scholarship. Public money and Management, 30(4): 211-218.

Miles, A. and Sullivan, A., 2012. Understanding Participation in Culture and Sport: Mixing Methods, Reordering Knowledges, Cultural Trends, 21(4); 311-324.

Porter, L. (2010). Unlearning the colonial cultures of planning. Surrey: Ashgate.

Roe, K., Minkler, M., and Saunders, F., F. (1995). Combining research, advocacy, and education: The methods of the grandparent caregiver study. Health Education Quarterly, 22: 458-475.

Ross, F., Donovan, S., Brearley, S., Victor, C., Cottee, M., Crowther, P., Clark, E. (2005). Involving older people in research: Methodological issues. Health and Social Care in the Community, 13: 268-275.

Shura, R., Siders, R., A., and Dannefer, D. (2011). Culture Change in long-term Care: Participatory Action Research and the Role of the Resident, The Gerontologist, 51(2): 212-225.

WHO. (2007). Global age-friendly cities: a guide. Geneva: World Health Organization. Available at:

https://extranet.who.int/agefriendlyworld/wp-content/uploads/2014/07/AFC_Vancouver-protocol.pdf