# ASSESSING PROCESSES & OUTCOMES OF CO-PRODUCED RESEARCH: A RESOURCE

A selection of systematic reviews and
peer reviewed articles

*ARC KSS Co-production theme*
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**NIHR** | Applied Research Collaboration
Kent, Surrey and Sussex

**About this resource**

We wanted to look at what evidence there is for co-production processes and how co-production enhances research and other outcomes. We wanted to see whether the literature identifies what enhances the process for those involved and how that might add value to the outcomes. This guide updates our previous one, 'Systematic reviews for Researchers, Services and Commissioners' which focused on measuring co-production and capturing outcomes with examples of systematic reviews across three areas (older adults, end-of-life care, children, and young people) and included several reviews on the outcomes of co-production.

We have carried out a literature search on Web Science for reviews of co-produced health and social care research from the last five years. Some reviews focused on patient and public involvement or co-design of research, and we have included these where there is a useful overlap and lessons that are transferable.

The reviews and papers included here have consistent messages about the facilitators and barriers to involvement, co-design, and co-production, these can be seen in Figure 1 below.
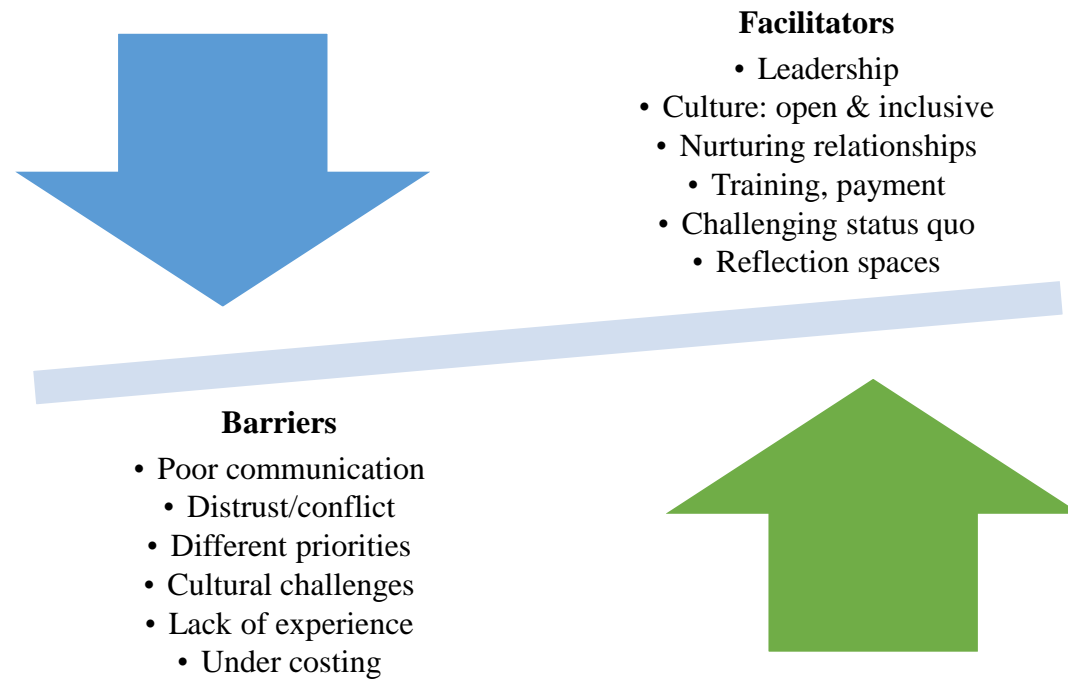
**Facilitators**

- Leadership
- Culture: open & inclusive
- Nurturing relationships
- Training, payment
- Challenging status quo
- Reflection spaces

**Barriers**

- Poor communication
- Distrust/conflict
- Different priorities
- Cultural challenges
- Lack of experience
- Under costing

**Figure 1: Summary of facilitators and barriers to co-production**

When it comes to the outcomes or impact of research drawing on public involvement, co-design, and co-production there is a consensus that there is a lack of robust evidence. However, most studies report similar *types* of impact, these can be seen in *figure 2*.
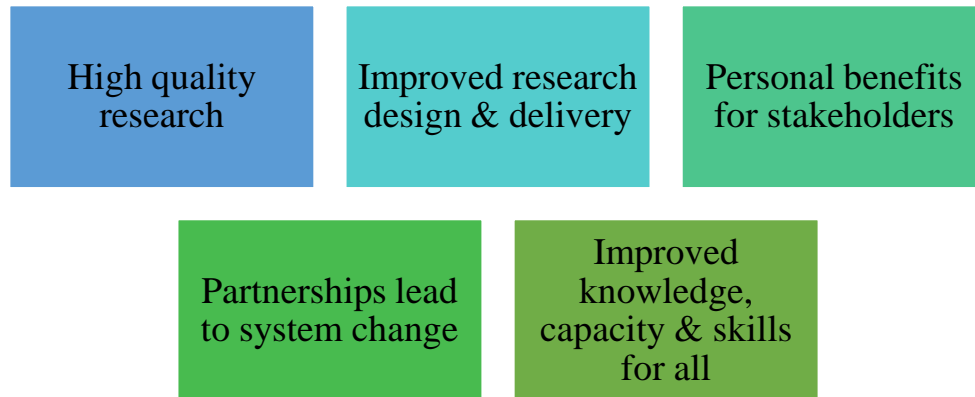
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| High quality research | Improved research design & delivery | Personal benefits for stakeholders |

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| Partnerships lead to system change | Improved knowledge, capacity & skills for all |

**Figure 2: Summary of potential outcomes of co-production**

Whilst the emerging literature on co-production process and outcomes is useful, there is scope to understand more about which principles and strategies are successful, how, in which contexts and under what circumstances. This is an area of research being explored by the Co-production theme.

We hope that sharing these reviews and papers will help you embrace co-production in your research!

Dr Nadia Brookes, Dr Vanessa Abrahamson, and Lisa Richardson

n.k.brookes@kent.ac.uk | v.j.abrahamson@kent.ac.uk  l.j.richardson-29@kent.ac.uk

# Reviews – includes those focused on co-production, co-design or PPI

| | Aim | Type of systematic review, method & studies included | Study overview and the main strengths/limitations |
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| *Chambers et al 2019* | To review the evidence for **PPI in Palliative Care Research** and identify, facilitators, impacts, barriers, gaps. | **Methods:** Integrative review approach, thematic analysis.<br><br>**Eligibility:** Eligibility criteria were based on the SPICE (Setting, Perspective, Intervention, Comparison, Evaluation) framework. A total of 93 records were included.<br><br>**Analysis:** Thematic Synthesis was used due to volume of papers. Descriptive and then analytical themes were developed to understand facilitators and barriers. | **Findings:** Eight main themes were identified, mainly concerning facilitators and barriers to effective patient and carer involvement in palliative care research: Definitions/roles, values/principles, organisations/culture, training/ support, networking/groups, perspectives/diversity, relationships/communication, and emotions/impact (see table 3 for more information).<br>**Evidence on the impact of involvement was limited, but could bring about positive benefits for all, including improving the relevance and quality of research.** Evidence gaps were found in non-cancer palliative populations and for collaborative/user-led involvement.<br>**Conclusion:** Involvement in palliative care research is challenging. Professionals can be reluctant to undertake involvement, and beliefs that patients/carers do not want to be involved persist. Better infrastructure, involvement-friendly organisational cultures needed.<br>**Strengths:** Synthesises a large literature, offers solutions and strengths as well as shining a light on barriers. PPI involvement in the review process.<br>**Limits:** Focuses only on adult and western populations. |
| *Dawson et al 2017* | Characterize and critique the empirical literature on **BME-PPI involvement** in health and social care research. | **Methods:** Systematic review.<br><br>**Search strategy:** six electronic bibliographic databases, literature published between 1990 and 2016. Inclusion: All study designs reporting primary data that involved BME groups in health or social care research (includes some Community Based Participatory Research studies). | **Findings:** Involvement mostly occurred during **the research design phase** and **least in data analysis and interpretation**. **Seldom any involvement** in development of the **proposal and funding application**<br>- Studies **do not widely report how they identified people** to be involved<br>- **Advisory group** is the main means to involvement (using face-to-face meetings)<br>- No justification provided on **rationale for the methods/activities** of involvement |

| | | **Screening**: Conducted by two reviewers. Data extraction focused on the level(s) of PPI involvement and where PPI activity occurred in the research cycle. Studies were quality-assessed using the guidelines for measuring the quality and impact of user involvement in research.<br><br>Forty-five studies (majority undertaken in the USA focusing on African Americans and indigenous populations).<br><br>**Analysis:** narrative approach. | - **Barriers:** cultural challenges, lack of previous experience and reluctance of contributors to take responsibility, concerns about the level of expertise, distrust, conflicts because of distrust and difference in priorities, time commitment, inadequate communication, disregarding cultural beliefs and language and friction because of budget cuts leading to gaps in communication.<br>- **Facilitators:** compensation, building trust and resolving conflicts, spending more time with contributors to understand their problems and concerns, bilingual researchers, open agendas, time for listening and discussing health problems.<br><br>**Conclusion:** Widespread support for BME involvement, this is limited to particular phases of the research and particular ethnic subgroups. There is a need to understand factors that influence BME involvement in all parts of the research cycle.<br><br>**Strengths:**<br>- First review to focus solely on BME groups participation in PPI.<br>- Acknowledges the different sub-groups involved in the studies<br><br>**Limits:**<br>-Findings whilst useful are based on substandard reporting of PPI in original articles<br>-Findings and implications are presented as a whole, without consideration of differences between different BME groups. |
| *Hoekstra et al. 2020* | Describe a review of reviews focusing on four key domains of **research partnerships**: | **Review of reviews** using PRISMA guidelines. Twelve databases, inception to January 2018, updated in April 2018.<br><br>**Main inclusion criteria**: reviews that focused on partnership research, participatory research, knowledge translation and knowledge transfer and | **Background**: the project consists of a **series of literature reviews** conducted across six Canadian universities.<br>**Findings**: *Outcomes and impacts* were synthesised into five subcategories that related to researchers and stakeholders, the relationship between them (and the broader community), and the research process. Two-thirds were classified beneficial outcomes/impacts and included the research partnership **creating high quality research; stakeholders experiencing personal benefits and/or increased capacity, knowledge and skills; and the research partnership** |

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| | principles, strategies, outcomes and impacts. | specifically how partnerships work and the outcomes or impacts.<br><br>**Analysis**: methodological appraisal tool and three rounds of direct content analysis to extract principles, strategies, outcomes and impacts. Included a **Consensus Panel of stakeholders**.<br><br>**86 reviews:** majority (83%) were published between 2012-18, Western. | **leading to system changes or action.** However, each of these was only identified in 10-15% of studies.<br><br>**Discussion:** most useful were comments on gaps in the literature which included:<br>- limited understanding of **which principles and strategies were successful** in which contexts and under what circumstances<br>- mainly focused on **perceived/self-reported outcomes and impacts**, and failing to differentiate between the two concepts<br>- the **reasons for negative outcomes/impacts.**<br>**Strengths**: lots of further information available on the study [website](website) |
| *McCarron et al 2020* | Aim to understand the engagement practices of **patients** who assume roles **as partners** in health research. | **Methods:**<br>Searched two academic databases (MEDLINE and EMBASE) and grey literature sources.<br>**Screening:**<br>119 sources were included in the review.<br>**Analysis:**<br>Thematic analysis. Findings organized into three higher levels of engagement, described by the Patient and Researcher Engagement framework (Manafo et al, 2018). | **Findings:**<br>Five themes were developed around patient role: documenting and advancing PPI, relevance of research, co-building, capacity building and impact on research. **Improved research design** was the most common reported outcome and the most common role for **patient partners was as members of the research team**, and the most commonly used strategy to support involvement was **by meetings**.<br>**Conclusion:**<br>The evidence collected will aid researchers and policy-makers in the development of approaches and tools to support engagement.<br>**Strengths:**<br>-Suggestions for involvement best practice<br>**Limits:**<br>-Lacks a rich description of methods of involvement to support replication |
| *Slattery 2020* | Research **co-design** in health: a rapid overview of reviews | **Research Questions:** (1) what approaches to research co-design exist in health settings? (2) What activities do these research co-design approaches involve? (3) | **Findings/ conclusions:**<br>- 23 reviews included<br>- Research **co-design widely used but rarely described or evaluated in detail**. |

| | | What do we know about the effectiveness of existing research co-design approaches? | - Broad range of approaches, from low effort and low risk to higher effort research co-production approaches. |
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| | | **Methods:** Review of three academic databases, three grey literature databases, and a hand-search of the journal Research Involvement and Engagement. | - Rarely tested empirically or experimentally<br>- Existing research suggests it can **benefit researchers, practitioners, research processes and research outcomes**.<br>- Clearer and more consistent terminology, **better reporting of the activities involved, and better evaluation needed to realise the benefits further**.<br>- Table 1 has list of different terminology & what was included e.g. participatory methods. Table 2 provides guidance for planning co-design. |
| | | **Screening:**<br>-Systematic or narrative reviews (quantitative or qualitative studies) of research co-design<br>-Providing:  Examples of research co-design (e.g. review of primary studies where engagement took place); Description of research co-design methodologies (e.g. synthesis and presentation of framework for research engagement); Evaluation of research co-design (e.g. a meta-analysis of engagement effectiveness in influencing patient outcomes or experiences)<br>**Analysis:** Narrative synthesis of reviews | **Strengths:**<br>- Useful principles provided for planning co-design<br>- Inclusive in what is covered, e.g. PPI, participatory methods and co-production<br>- Recognises the challenge in use of different metrics to evaluate co-design practices<br>**Limits:**<br>-Absence of experience-based co-design as a method |
| *Smith et al 2022* | Scoping review to systematically map recent literature on **co-production** in applied health research in the UK to **inform co-** | **Methods:**<br>- created an evidence map to show the extent and nature of the literature on co-production and applied health research<br>- described the characteristics of the articles and scope of the literature and summarized conceptualizations of co-production and how it was implemented.<br>**Screening:** | **Findings:**<br>- Nineteen articles reporting co-produced complex interventions<br>- 64 reporting co-production in applied health research<br>- Lessons for the practice of co-production and requirements for co-production to become more embedded in organizational structures included (1) the **capacity** to implement co-produced interventions, (2) the **skill set needed** for co-production, (3) **multiple levels of engagement and negotiation** and (4) **funding and institutional arrangements** for meaningful co-production. |

| | **production practice** and guide future methodological research | Included any type of published literature relevant to co-production in applied health research or complex intervention development. Literature provided definitions or conceptualizations of co-production or implications for future research. UK only, since 2018.<br><br>**Analysis:**<br>Extracted implications for co-production practice or future research. Used content analysis to identify lessons for co-producing research. | - Themes for <u>future research</u> on co-production included (1) **who to involve** in co-production and **how**, (2) **evaluating outcomes** of co-production, (3) the language and practice of co-production, (4) documenting **costs and challenges**, and (5) vital components or **best practice** for co-production.<br>**Conclusion:**<br>- Researchers are operationalising co-production in various ways<br>- Lack financial and organizational support required and the right conditions for success.<br>- Argue for accepting the diversity in approaches to co-production<br>- Call on researchers to be clearer in their reporting of these approaches<br>- To support co-production of research, changes to entrenched academic and scientific practices are needed<br>**Strengths:**<br>-Offers different ways of realising co-production<br>-Pragmatic in conclusions around accepting the diversity in approaches to co-production whilst calling for researchers to be clearer in their reporting of learning, including failures.<br>-Argue for the value of creating exploratory spaces through co-production, as opposed to focusing on it to deliver impact/ outputs and learn by doing.<br>**Limits:**<br>- Findings specific to context of UK research, typically funded by NIHR, may not generalise to other contexts |
| *O'Mara-Eves et al. 2022 (not peer reviewed)* | A rapid critical review aims to: (ii) **Map the evidence** and identify typologies of co-production based on the | **Methods:** Rapid critical review in three stages (to address each aim). **Co-produced process and reporting.**<br>- Focussed only on the two largest bibliographic databases where the exemplar studies and those relevant studies from the reviews were also indexed (SCOPUS and Web of Science) and Google and Google scholar. | **Findings:**<br>*Identification of the values of co-production*<br>- There is **no single definition of co-production**; it tends to be **characterised by a set of values (principles) or conditions**.<br>- The review **identified more principles underpinning co-production than existing standards indicate.** The principles often overlap and are interlinked, but they are likely to be important to distinguish when developing guidance or planning a co-produced research project. |

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| values and activities.<br>(i) Explore and identify the **characteristics of theoretical studies** that examine co-production (the values/principles described, attempts to implement the values, and the barriers/ facilitators)<br>(iii) Identify and summarise the **value/impacts/ influences of co-produced research** | **Screening:**<br>- Undertaken between academic researchers and co-researchers (members of the co-production collective).<br>- To be included in the initial results the study had to use at minimum the term "co-production" but may have used other terms alongside this AND we searched for terms for Value OR Values OR Benefit as well as identified any subject headings relevant to each database<br><br>**Analysis:**<br>- Differed for each stage of the review (as did the number of papers reviewed), for further information refer to report. | *Identify different ways of doing co-production through exploring how values are enacted (or not)*<br>- Identified **four main types of co-produced research report**: (1) Rich co-production and co-authored (7 studies); (2) Rich co-production but not co-authored (3 studies); (3) Co-production vision but not execution (5 studies); and (4) Other PI approaches (13 studies).<br>- More than half of the sample of studies **did not report that they had adequately implemented key principles of co-production**, despite using the term co-production. It is unclear how much of this is due to a lack of reporting of key details.<br>- **Co-authorship of all co-producers on research publications was often indicative of richer co-production** and ensured that the different voices were retained throughout the project.<br>*Explore benefits/drawbacks of different typologies of co-production*<br>- Reported **benefits of co-production were rarely formally evaluated**; they were typically anecdotal.<br>- Consensus that co-production is a positive approach for **improving research projects and meeting their goals, plus outcomes for co-producers such as satisfaction, development of skills and knowledge and self-esteem**.<br>- When participant outcomes were mentioned, they **often focussed on the lived experience public members only, not the broader team**.<br>**Conclusion:**<br>- Co-production should be values based and will look different depending on the team and project aims.<br>- Amongst the range of potential **barriers** to co-produced research mentioned, **current academic culture and practice was one of the most mentioned**.<br>- Potential facilitators typically involved **ensuring that the underpinning values were considered and planned for.**<br>- Co-production requires systems change |

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| | | | - Better evaluation and reporting of co-production is needed and there are implications for reporting standards.<br><br>**Strengths:**<br>- Co-produced approach to the review<br>- Reasonably accessible report<br>- Novel in considering how the values of co-production are enacted in research<br><br>**Limits:**<br>- Not peer reviewed (as yet)<br>- Strength of reporting on processes and impacts limited by what is reported/ evaluated in the primary research<br>- Anecdotal evidence available<br>- Short timeframe of the review |

# Research – selected papers with co-production insights

|  | Aim | Research/Project partners & methods | Study overview and the main strengths/limits |
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| *Bennett et al. 2022* | Case study description sharing **practical insights** and evidence for the role that **young co-researchers** (YCoR) had in a co-produced project on online help seeking. | **Partners:**<br><br>Ten members of NeurOX Young People's (aged 14–18 years) Advisory Group were involved in the core project. The YCoR collectively contributed over 130hrs to the research project over 3 months, and additional hours for dissemination activities.<br><br>**Methods:**<br>- On- and off-line approaches and adapted research methodology (incorporation of YPs perspectives throughout the research process).<br>- **Involvement was evaluated against the five principles of co-production** and to capture what YCoR thought were the benefits to them, an anonymous Padlet was provided. YCoR were prompted to add reflections to open questions in/after each session. | **Findings:**<br>- The **blended process** was welcomed by most YCoR in facilitating scaffolding exercises, peer-peer learning, relationship building and shortening of on-line sessions.<br>- **Use of pre-and post- meeting work** supported the ability to learn, understand and build the capacity to engage with the research<br>- **Scaffolding and learning opportunities** appeared to provide sufficient support and understanding of tasks in the short time frame<br>- YCoR were able to add to, and **challenge assumptions** of, the adult researchers' interpretations<br>- **Developed personal skills and their confidence increased**. The YCoR indicated that they had also **extended their knowledge and awareness of mental health issues** and felt more able to develop their **analytical and interpretative skills** to incorporate different perspectives.<br><br>**Conclusion:**<br>Demonstrates how flexible approaches co-production with YCoR can balance ethical and epistemological impact in complex mental health research.<br><br>**Strengths:**<br>- Detailed overview of processes used<br>- Full details of study and impact on theme development described in separate paper, but role described within this case study |

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| | | | **Limits:** |
| | | | - No formal evaluation of the adult researchers. |
| | | | - Not an independent evaluation, so whilst feedback was anonymous, YCoR may have been reluctant to make critical comments |
| *Armstrong et al. 2019* | -Describes the research to develop a **self-evaluation toolkit** for **self-advocacy** projects <br> -Discusses how co-producing this research **added value**. | **Partners:** <br> Two activists (Alan and Simon, Barod) paired with two academics (Jan and Bryan, independent researchers) and a supporter/graphic designer (Mal, Barod). There were a Partnership Group and a Reference Group <br> **Methods:** <br> - Training <br> - In person meetings <br> - Trying things out (focus groups) <br> - Analysing data together (intensive hotel stay) <br> - **Develop a toolkit** <br> - Checking and launching the toolkit <br> - Reviewing whether the project was co-produced at the end (self-review) | **Findings:** <br> - Having self-advocates made it easier to set up and run the focus groups. Having academics made it easier to match the research methods with the research question. <br> - **Everyone was an equal part of the team on their own merit.** This meant everyone could use their knowledge, skills and experience. <br> - **Self-advocates opened doors to the people that needed to be reached and helped build rapport** with participants. <br> - If people only get **paid for the length of the project**, they may lose support to stay involved in things like writing papers and sharing what is produced. They lose status and role as well as payment. <br> **Conclusion:** <br> - Co-produced research draws on everyone's skills, and everyone is equal <br> - Opportunities for everyone to learn and develop <br><br> **Strengths:** <br> - Everyone involved in the production of the paper, and this makes it accessible <br> - Details of the process and reflection explained <br> - Describes not only what went well, but also what went wrong |

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| | | | - Would have been good to see definitions offered for different terms, e.g. Inclusive research, participatory research and emancipatory research, with description of how these converge/diverge<br>- Questions to reflect on whether the research was co-produced only decided upon at the end. More opportunities for capturing the reflection throughout could have better captured some of the shared learning.<br>- Self-critique suggested that the authors thought that the development of the toolkit was not co-produced. Further analysis on co-production at different scales would have been beneficial here. |
| *Buffel, 2018* | Insights into the process of co-producing a research project with **older residents** living in **low-income** neighbourhoods in Manchester. | **Partners:**<br>Eighteen older people as co-researchers who worked on all phases of a study aimed at developing "age-friendly" communities. Three strategies to recruit potential co-researchers were used: criterion sampling, snowball sampling and maximum variation (reflecting the ethnic and social diversity of the research areas).<br><br>**Methods:**<br>- The project ran a series of workshops, to work collaboratively in developing the different phases of the research.<br>- The co-researchers completed 68 interviews with residents aged 60 and over who were experiencing social isolation.<br>- All participated in two training sessions and three dissemination workshops. | **Findings:**<br>**Co-researchers motivations were**:<br>- desirability of maintaining an active post-retirement lifestyle; commitment to neighbourhood change; and opportunities for personal development.<br>- Co-researchers identified a range of benefits and challenges associated with the peer-to-peer approach adopted in the project.<br>**Benefits:**<br>- Capacity to create a **supportive and relaxed interview situation**.<br>**Challenges:**<br>- The **co-researchers' 'busy ethic' emphasised norms of activity and engagement as the basis for a 'successful' life in retirement.** This may be insensitive to the pressures facing people experiencing social exclusion (evident in the way some of the co-researchers talked |

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| | | - Four reflection meetings with the co-researchers, focused on their motivations for working on the project and relationships with the interviewees (reported in the paper).<br>- The study started with a broad aim, to 'research and develop the age-friendliness of communities', which was discussed with the co-researchers, this was refined in the workshops.<br>- The group selected qualitative interviews for the study and went on to discuss possible interview themes via brainstorming and prioritisation exercise.<br>- A joint coding framework for analysing the transcripts was agreed by the group.<br>- A strategy for evaluating the impact of co-producing the research and strengthening the links between the University and the co-researchers was developed. | about their interviewees and **offering 'solutions' to the issues experienced by some of their interviewees**).<br>- The co-researchers **formed a permanent group** and are applying for funding for age-friendly activities.<br>**Conclusion:**<br>- Co-production is a viable method for accessing the expertise and knowledge of older people; an effective means for accessing and incorporating the views of seldom heard or hidden populations; and provides a forum for **meaningful social engagement and mutual learning between several stakeholders**.<br>- Shown the potential of co-production to i**nspire innovative approaches to engaging older residents as leaders** in developing the age-friendly agenda.<br>**Strengths:**<br>- Shared decision making around the focus of the research (based on pre-existing broad aims) and throughout.<br>- Impact beyond the research itself, creation on a permanent group to support the aims related to the research<br>**Limits:**<br>- Acknowledges the challenges of co-researchers' positionality but does not critically reflect on the 'recruitment' of the group based on this.<br>- Would have been interesting to hear more about the academic researchers' personal reflection of co-production as well as exploring the research participants experience of the interviews. |
| *Farr et al 2021* | **Commentary** reflecting on a project that aimed to: | **Partners:**<br>The project was developed by a team of three applied health researchers, a public involvement lead and three public contributors (with in-depth experiences of co- | **Key points discussed:**<br>**Who is involved and when**<br>- **Research priorities and designs** often made by researchers before others are involved, often due to lack of |

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| | share **learning about co-produced research**, understand how to enable more **equal relationships** within co-production and develop training and resources to support co-produced research. | produced research) undertaken within the National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) West.<br><br>**Participants/ Methods:**<br>Five project workshops, spoke to eleven researchers from five disciplines; six practitioners; and eleven public contributors with involvement and co-produced research experiences. | funding to pay public contributors to develop funding applications.<br>- **Tension** between the number of people that can be involved, and diversity of the group.<br>- Problematic claims to **'representation'**, people within a co-production group cannot speak for everyone—need to look for opportunities to draw other perspectives in.<br>- Need to support people to take on **different roles**, to have choices and work from their strengths- not everyone has to do everything!<br>- **Training, support and mentoring** needs to be factored in.<br>- **Payment, contracts, research governance** processes need to be addressed from the start if public are co-researchers and collecting data.<br><br>**Power Dynamics**<br>- Difficult to maintain a focus on power relations in the face of a strong tendency to **emphasise practicalities**<br>- **Accountability and formal responsibility** for delivering a funded research project, creating **constraints** where **projects must deliver what is described not what emerges** from the process.<br>- Many researchers may still end up putting **discretionary time** into projects to make co-production a success<br>- **Doing everything by committee and consensus** can impede progress- no decisions made until everyone present at meetings. Power dynamics between people does not always ensure decisions are agreed by everyone.<br>- **Potential for public contributors to be excluded from informal discussions and decisions** in day-to-day tasks.<br><br>**Communication and relationships** |

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| | | | - Researchers may also need to **drop the 'professional' mask** and share more personally and expose their own vulnerabilities<br>- Communication and relationships **delegated to 'junior' researchers, and often women**<br>**Conclusions:**<br>- To work towards co-production principles means **consistently challenging 'business as usual'**—need to maintain support systems to do this.<br>- Establishing **reflective processes** that encourage consideration of power issues are essential.<br>- **Honest reporting of projects** needed- their outcomes and the balance between the benefits and challenges of trying to implement the principles. |

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