Co-production: research and Practice review Full Report

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Introduction

This report on co-production forms part of a programme of work carried out to support and inform the development of the public engagement and co-production workstreams within the University of Sheffield's Healthy Lifespan Institute (HELSI). One of the core objectives of HELSI is close engagement with stakeholders and end users in the fields of ageing, frailty and multimorbidity. The commitment to user engagement stems from the conviction that it will improve both the quality and the efficacy of research and related activities (referred to as 'research' hereafter). The co-production workstream is in place to ensure new knowledge is created in collaboration with those who stand to benefit.

Section One covers current debates around what co-production is, why it is important, and how it can be successfully incorporated into research (alongside potential challenges). Section Two provides some relevant real-life examples of co-produced research and related activities and resources to help support potential PPIE work (where researchers wish to carry this out). An additional document has also been produced which supports public engagement activities, and can be accessed [here](). The evidence which informed both reports is based on a review of relevant literature and interviews with a selection of informants (Please see Appendix 1 for a more detailed methodological approach and details of key informants).

SECTION 1: Background and Overview

What is co-production?

Co-production, a term originally coined by the political economist Eleanor Ostrom in the 1970s (Ostrom & Ostrom, 1978) has diverse academic and service-based roots. Co-production emerged independently in several fields and subsequently the theories, models and conceptual framing is diverse. That said, the main principles share common features (Greenhalgh et al. 2016) that tend to emphasise; non-linearity, unpredictability and a collaborative element (Raftery et al. 2016). The term itself can be rather daunting, with some commentators suggesting that true co-production can only take place when it is embedded across a service or research process.

We follow that elements of co-production can be effectively applied at all stages of a research or activity, or indeed with a specific purpose in mind (e.g. a consultation exercise at the outset, support with dissemination). What is perhaps more important is that the underlying principles are followed, where communities and service users become more active research or design users, where an inductive paradigm of partnership working and shared leadership is actively encouraged (Brocklehurst et al., 2018) and where sufficient regard is given to the process, as well as the intended outcomes of research (Greenhalgh et al. 2016). Others emphasis the need to ensure diversity of expertise and that sustainability is embedded (Dayson et al., 2019; Norstrom et al. 2020) through a methodology that gives regard to building capacity (Roper et al. 2018). There are several definitions of co-production, though SCIE (2013) encapsulate its essence concisely, referring to it as:

> "*meaningful engagement of all stakeholders in the design of new services or knowledge*" (SCI 2015, N.p)

The term meaningful is key here, and refers to a research activity that is not tokenistic, and where stakeholders (be that professionals, end users etc.) are instrumental in influencing the process. Most identify the active involvement of end users (or 'knowledge users' Jull et al., 2017) as a crucial element to co-research (Voorberg et al., 2014). When considering what is meant by an end user,

Graham et al. refers to 'those who use research'. Taking on this broad definition, co-production activities may involve patients or community groups, but also professionals. Coutts et al. (2019) emphasise this different way of approaching research:

> *"Co-production implies that no one sector or person has all the skills and knowledge necessary to solve real world problems, or even to improve or develop services. Co-produced evidence moves away from the idea of academics as 'experts' or the 'big fish' within their fields. It requires the 'big fish' to swim over to join the shoal of small fish."* (Coutts, 2019:10)

With specific regard to older people, a co-produced definition, developed through the National Development Team for inclusion views it as:

> *"organisations working together to design and deliver opportunities, support and services that improve wellbeing and quality of life."* (NDTi, 2009:3)

It is important to note that whilst co-production values different forms of knowledge, this doesn't mean that research evidence is disregarded in favour of personal views or preferences, rather, all findings from evidence need to be balanced (Woodall et al., 2019) avoiding falling between 'epistemic drift' (Mode 2) or 'academic fundamentalism' (Mode 1)[1] (Zimpel-Leal, 2020).

Though similar principles apply, definitions of co-production across different research activities have a slightly different emphasis, and are provided alongside real-life examples in Section Two.

Why co-produce?

When looking at engaging patients and the public specifically in health-related research a recent systematic review (Bee et al., 2018) identified that an increasing focus on co-produced research has been driven by: a strong moral argument, accumulating evidence of the benefits and recognition of the experiential knowledge and expertise in the community. Greenhalgh et al. (2018) point out that knowledge translation activities alone are not always sufficient to generate impact, especially if the knowledge is perceived as generated primarily by the university. For example, older people's own understandings about ageing with regard to products and services tend to be far removed from those of scientists and service professionals (Walker, 2007). Regarding health care professionals, research shows that decisions are largely formed, modified and applied through tacit and experiential sources (referred to as 'clinical mindlines) (Beckett el al., 2018)). There is also a growth of social movements who expect and desire to influence research (and policy) that will affect them (Walker, 2007). Greenhalgh et al. (2016) attribute qualities of co-produced research, such as the emphasis on civic engagement, collaborating across sectors and power sharing as the main mechanisms which lead to stronger and more lasting impact on health and wider outcomes in the local or regional setting in which universities are located.

Research co-production can help support the so called 'knowledge to action' gap (Gagliardi and Dobrow, 2016), where traditional approaches are often less successful at getting research into practice (Wolstenholme, 2020). This growing 'know-do' gap has led funding bodies such as the Wellcome Trust, the UKRI research councils, Alzheimer's Research UK,

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[1] Mode 1 represents the conventional form of knowledge production. Problems are defined in an academic context by the members of the scientific community. Mode 2 refers to the interactive production of knowledge within the context of application (Gibbons et al. 1994)

Cancer Research UK and the National Institute for Health Research (NIHR) to significantly increase their emphasis on the need for public involvement in research, and funding bids must evidence effective methods and approaches to achieving this. Other key organisations, such as the NHS (2017: 34, in Healthwatch, 2018) view that without genuine involvement of patients and communities, progress around addressing the main health challenges faced will not be possible, as end users have an in-depth knowledge of how issues affect them.

Evidence shows that co-production can support end users to feel more confident and empowered (Brett et al., 2014) and help researchers gain a greater understanding and insight into their research area (Brett et al.,2014). Other findings refer to co-production ensuring that decision-making and implementation is more tailored to the needs of individuals (Roper et al., 2018) and local settings (Beckett et al., 2018), which in turn contributes to system level change (Halvorsrud et al. 2019), and a greater likelihood of generating new evidence (Heaton et al., 2015). Co-production can help strengthen existing and foster new relationships (Greenhalgh et al. 2016; Heaton et al., 2015: 1488), as well as lead to stronger and more lasting impact on health and wider outcomes in the local or regional setting in which universities are located (Greenhalgh et al., 2016).

Overall, these effects can lead to improved research relevance and a higher level of accountability and transparency (Nass et al., 2012) which can support a smoother ethics review process (INVOLVE, N.d). Co-production can also help support wider reach through more diverse dissemination processes which potentially reach a wider audience (Bee et al., 2018) and more accessible outputs (Beckett et al., 2018). This way of working can build social capital and remedy some of the issues caused by having people who are removed from an issue attempting to fix it (Centre for Co-production in mental health and social care, N.d)

Linked to the moral imperative, as with discussions around involvement and engagement more generally is the move toward democratization of the research process, especially when it provides the opportunity for voices of those of those traditionally less engaged to be heard (Beckett et al., 2018; Campbell and Vanderhoven, 2016) this is especially the case for older people who may have experienced discrimination or social exclusion (Walker, 2007). Gordon, an Independent Dementia Advocate with lived experience, explains the impact of research involvement:

> *"Research was an important part of my rehabilitation, getting me out of the house and engaging with others... Now it is an important part of what I am trying to achieve in my own small way...I do not do research for myself, any successes may come too late for me. I see research as a legacy I will leave for my children, grandchildren and those that come after."*
> (Gordon and McKeown, 2020:100)

Co-production can be applied to research across disciplines, at different stages and to support diverse activities (e.g. it has been used to good effect to support systematic reviews). This is explored in more detail later when we explore some real-life examples.

Theoretical and conceptual underpinnings
The epistemological and ontological positioning of co-production is markedly different to more traditional approaches to research, it is non-linear, following a relationship-based and (usually) system level approach. Collaborative research itself has diverse and interdisciplinary roots, which tend to be aligned more to critical and participatory models,

capacity development or network building, in addition to traditional impacts framed around value for money or behavioural change (Rafferty et al., 2016).

Implementation science (sometimes referred to as translational research), draws on a range of theories and models to attempt to explain or predict why an intervention may or may not be implemented (NIHR, CLAHRC), defined as:

> *"the scientific study of methods to promote the systematic uptake of research findings and other EBPs into routine practice to improve the quality and effectiveness of health services and care"* (Nilsen, 2015:2)

Conceptual frameworks are recommended as a way of applying theory to enhance implementation efforts. There are several conceptual models and frameworks designed to support co-research design and implementation, such as the Knowledge to Action framework for Implementation (see Field et al., 2014 for a more detailed overview). Generally, approaches have in common built in mechanisms to ensure external partners, the public and end users are better enabled to contribute to research. Suffice to say here that though useful, the unpredictability of collaborative research means that at best, a framework or model should only be viewed as a guide.

Key components

When discussing the key components of co-production more generally, the core themes identified across the literature include: an element of 'equality' or sharing of power (including joint ownership of decisions), reciprocity, a relationship-based focus, the need for flexibility and a reflective outlook (Jo Woodall et al, 2019; Farr et al., 2020), which seeks to identify ways to ensure external partners and end users can influence the process (Greenhalgh, 2016a). SCIE's (2013) key principles of co-production are frequently cited and include:

- define people who use services as **assets with skills**
- **break down the barriers** between people who use services and professionals
- build on people's **existing *capabilities***
- include ***reciprocity*** (where people get something back for having done something for others) and ***mutuality*** (people working together to achieve their shared interests)
- work with **peer and personal support networks** alongside professional networks
- facilitate services by helping organisations to become **agents for change** rather than just being service providers.

N8/ESRC (2019) refer to relational factors such as re-defining relationships between research participants from being essentially extractive or transactional to being interactive, where the boundaries between the academic and non-academic become increasingly blurred. Where research becomes a collaborative, shared endeavour and where the impact focuses on the process, as well as the outcomes. Co-production requires a shift from 'us and them' (National Collaborating Centre for Mental Health, 2019) toward a culture of openness (and honesty) and a system where all who contribute are recognised and rewarded, and most importantly, are able to engage, fostering an environment where people feel comfortable challenging or asking 'difficult' questions (Jo Woodall et al., 2019) and where traditional hierarchies are flattened (National Collaborating Centre for Mental Health, 2019).

Reflections on the process

Adopting elements of co-production is not without challenges, and these need some thought at early stages (as this research model has a level of complexity built in, some of these are unlikely to emerge until later in the process, which is why a flexible approach is so important). Some common challenges refer to the complexity of the model itself, which can make positive outcomes difficult to replicate (Gagliardi and Dobrow, 2016), or indeed identify in the first place (Beckett et al., 2016). Where change is identified, it can sometimes be difficult to maintain beyond funding cycles (Dayson et al. 2019). Following a review of the literature, Greenhalgh et al. (2016:393) identified that collaborative research "failures" could often be tracked to not following three broad principles:

1) a systems perspective (assuming emergence, local adaptation, and nonlinearity)
2) the framing of research as a creative enterprise with human experience at its core
3) an emphasis on process (the framing of the program, the nature of relationships, and governance and facilitation arrangements, especially the style of leadership and how conflict is managed).

If we take the first point, a "logic model" mind-set, where the goals are linear and less adaptable, will be less responsive to ongoing learning as processes remould intended outcomes beyond the researcher's direct control (Greenhalgh et al., 2016; Zimpel-Leal, 2020). So acknowledging that a collaborative approach is necessarily 'messy' and should be viewed as a journey and opportunity to learn through the process (Dayson et al., 2019; National Collaborating Centre for Mental Health, 2019) can help ensure that the impact of so-called 'mindlines' are acknowledged and factored in (Beckett et al. 2018, Andrews et al., 2015).

On a more practical note, resource issues are a commonly reported problem, with some referring to a lack of infrastructure to support collaborations which move away from siloed approaches (Gagliardi and Dobrow, 2016). An additional factor around cost is that funding to support involvement typically only arrives after the successful securement of funding and is not available to applications which have been unsuccessful. Similarly, it may be difficult to support end users in the dissemination of results when funding has stopped at the end of a grant (Jackson et al., 2020).

Other issues reported include confusion around responsibilities (Gagliardi and Dobrow, 2016) administrative burden (Kothari and Mays, 2019) and pressures on people for whom research is not their primary activity (Batalden et al., 2015). Some refer to a heightened risk of disagreement or conflict (e.g. around research terms, priorities and framing findings) (Kothari and Mays, 2019). Regarding end users, there is sometimes a lack of diversity in those who choose to participate (Batalden et al., 2015) with a tendency (especially for PPI) to work with the 'usual suspects' and fail to engage underserved groups (National Collaborating Centre for Mental Health, 2019). A systematic evidence review of patients who contribute to PPI showed an identified lack of training and support, and sometimes a sense of feeling overburdened (Brett et al., 2014).

With specific regard to dissemination, while end users may prefer to see research translated in different formats, others may wish to contribute to more 'traditional' methods, such as co-authoring a peer reviewed article. Yet one patient involved in Tinnitus research explained that he had felt intimidated setting up an ORCID profile, which asked questions about his 'specialist research areas' (Harrison, 2020), others referred to access, including negotiating paywalls and blurring of intellectual property (Christian Aid and ESRC 2017; Farr et al., 2020).

A challenge frequently cited by commentators was the perceived power imbalance between academics and end users, despite efforts by the former to mitigate this. Mitchell (2019) who consults on various projects as a person with lived experience of dementia, refers to the importance of 'demystifying' the process for people who may struggle to follow elements of

the research or the process. Some suggested ways of achieving this are identifying 'neutral' spaces, ensuring people get involved as early as possible in the process (Indeed, users involved in the New Dynamics of Ageing programme (NDTi, 2015) reflected that they would have preferred to have got involved earlier in the process) and supporting all to contribute to dissemination (Christian Aid and ESRC 2017; Oxfordshire County Council, 2020).

Co-produced research is often disseminated through methods as diverse as co-authored books, podcasts, zines, artworks, films, exhibitions, posters, apps, guided walks, pamphlets and soundwalks. Bespoke forms appropriate for the project in question are also frequently employed. Though within this, there is a need to acknowledge the requirement for researchers to publish peer-reviewed articles in high-ranking journals. Bell and Pahl (2018) suggest that to help foster solidarity and trust, that these (sometimes competing) requirements are discussed openly. The Sheffield School of Public Health Research Involvement Group (ScHARR, 2020) in a review of three PPIE groups emphasised the importance of creating an informal atmosphere (which links to the need to provide neutral spaces).

Finally, there are also cultural elements to consider; for example, though specific communities in high income countries may be unfamiliar with user involvement in research, terms such as PPI are less familiar in low- and middle-income countries, so translating terms relating to power relations and terminology, will need some thought (Jackson et al., 2020).

Though these challenges are not unsurmountable, they do draw attention to the need for planning around engagement, accessibility and the need to factor in additional resources. We turn to these considerations in more detail below.

SECTION Two: How to *do* co-production

Incorporating co-production in research

Approaches vary and there is no 'one size fits all' even within different types of co-production (Oxfordshire County Council, 2020). The purpose of this section is to offer some general guidance, and real-life examples of how elements of collaboration have been applied to research. The discussion in this first section is informed by interviews (including HELSI members) and key organisations and funders.

It is asserted that co-production is an achievable (and indeed, laudable) aim, if the intended approach has been thought through, is fit for purpose, and provides some level of meaningful engagement (be that consulting on a potential funding bid, getting support to design a new product or brokering access to a political community) (Kothari and Mays, 2019). Essentially, a more in-depth collaborative approach is only necessary if it is anticipated that it can improve quality, relevance or reach or overall research quality (Caress et al., 2010).

When planning an activity, it will be useful to take advantage of the support available at the University, and through external funders, centres and research councils (Appendix 2 provides some useful resources as a starting point). It is also worth bearing in mind that there are charities and local authority organisations who are already supporting involvement type activities, or who have a database of people. For PPIE research, a compiled list of some of these groups can be found (alongside those operated through the university) can be accessed via this link.

Norström et al. (2020) argue that successful knowledge co-production is more likely if it is context based, pluralistic, goal-orientated, and interactive. Looking from a policy change angel, Sciencewise

(2020) identify critical success factors based on: utilising existing networks; harnessing multiple digital channels, using trusted experts, ensuring transparency, enabling the public to have a key role in setting the agenda the need to be informative, transparent and honest. The NIHR Director for Public Voice, Jeremy Taylor (NIHR 2020), writing during the ongoing COVID-19 pandemic, reflected that to move involvement forward, there is a need to 'keep it simple, make it normal and make it universal' (i.e. so all sections of a community can participate).

Mitchell (2019), who lives with dementia succinctly captures the importance of using the right language. Mitchell talks about a group in she attends called Minds and Voices, which is made up of people living with dementia. During this meeting the group were initially asked: "who would like to be involved in research"? No one put their hand up. But when asked "who would like to be involved in changing how dementia looks in the future", everyone put their hand up. Essentially, if the approach is not right at the start, this can impede engagement from the very people who need to be involved.

Box 1 provides suggestions on what needs to be considered when carrying out collaborative research, which is based on the wider literature (Beckett et al., 2018; Christian Aid and ESRC 2017; Dayson et al., 2019; Farr et al., 2020; INVOLVE, 2020). As highlighted earlier, this is essentially a guide – and the best way to get to grips with doing co-production is to give it a go and "muddle through" (Grand et al., 2016), learning from your own experience and that of others along the way.

Box 1: Co-producing research: Some basic tips

Partners
1. Involve the right people: people who have lived experience relevant to the health condition/social care situation etc. being researched, and where relevant senior management and/or decision makers.
2. Ensure people who may normally be excluded are enabled to take part.
3. Involve enough people to provide a reasonable breadth and depth of views on the issues that are likely to be important to the people the study will aim to recruit, and who it is intended to benefit.
4. Involve people in as many aspects of the study as is feasible, productive, and appropriate to the research.
5. Clarify the purpose and motivations of research partners and check assumptions (e.g. professionals may regard academics as more 'detached' from end users).

Design
6. Research questions and purpose: be clear about goals and purpose at the outset.
7. Consider different approaches to research design: will this take place 'centrally', or be more responsive and evolve based on views of external stakeholders/service users.
8. Give regard to the kinds of knowledge that will inform evidence and how the different voices in the research will be heard and contribute to knowledge production.
9. Make it informal, avoid it looking too "professional". Key to this for Christian Aid (2017) was having a toolbox of creative methods and approaches that could be adapted, refined and added to accordingly.
10. Avoid jargon, the language of co-production can appear technocratic and be off-putting and has in the past been associated with tokenism and top-down decision making, using language that people understood and describing activities in ways that make sense to people is vitally important.

Practicalities

11. Who is implementing the research, what roles are needed to make it a success, who is designing, collecting and analysing data, is there space to co-develop, share learning? Need a shared understanding of 'data'.
12. Ensure there are enough resources to cover what will be needed (e.g. does it require a training budget, reimbursement, refreshments, venue hire etc.). INVOLVE (N.d), run by NIHR, provide detailed guidance.
13. Establishing roles, responsibilities and ways of working, identifying if any additional support is required. Important to think about spaces of communication.
14. Factor in time to build relationships and trust and understand the priorities and norms of different communities. This time must be costed appropriately.
15. Ensure meetings give regard to accessibility, flexibility and resources. Take it slow, have regular breaks, use plain English, ensure different sectors/individual contributors are mixed up, more group work – fewer presentations, acknowledge power differentials, be creative.

Reflective practice
16. Take stock of the resources that each party can bring, including individual attributes, formal training/qualifications, institutional capacity.
17. Take time to map out and understand nature of the partnership, who is responsible for internal communication, how to facilitate communication across different languages, agendas and interests and regularly review 'during' the partnership.
18. Ensure any findings or changes as a result of involvement are communicated back.

Examples of co-production research and related activities

While these examples have been placed in categories, there will be some inevitable overlap, it is just for ease of navigation. The examples are not necessarily the 'right' way to do co-production, and as highlighted earlier, this will depend on the specific purpose. Rather, the aim is to provide a flavour of the kinds of research that have been carried out, with information on how to find out more about those of interest. The below tables provide a brief overview, and it is recommended that readers refer to the original to gain a more detailed understanding of the research approach and reflections for each. A reference list of all the examples provided in this section can be found in Appendix 3 and a direct link is also included in text.

Consultation
Consultation activities vary considerably, it may refer to a one-off 'light touch' consultation exercise at one point in time, or a more established network set up to inform and guide throughout the research process. Some elements of consultation overlap with knowledge translation activities, and what tends to distinguish the two is the while the latter may only inform or promote research activities (though the process will inevitably influence process or outcomes in some way), consultation should always lead to some level of influence/change in the research itself.

Table 1: Examples of consultation

Author and title	Brief description
Devonport et al., 2018 *"It's not just 'What' you do, it's also the 'Way' that you do it: Patient and Public Involvement in the Development of Health Research"*	A reflective account and evaluation of Patient and Public Involvement (PPI) in the development of obesity and binge eating research. **Further information here**
Gordon and McKeown, 2020 *"Co-producing research: A personal experience"*	Example of where a peer-reviewed article includes a person with lived experience as an author, who reflect on their experience as a member of South Yorkshire Dementia Research Advisory Group (see http://sydemrag.group.shef.ac.uk/) **Further information** here
NCCPE, 2016 University College London (UCL), NIHR Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust, Community kitchen. "*Eating for Eye Health*"	This project was based on translating research about sustaining healthy eyes via healthy eating and cooking whilst strengthening the relationship between the local community and UCL. **Further information here**
Ageing Well Torbay (funded by the Big Lottery Fulfilling Lives Programme, aimed at reducing social isolation across the older population), 2020, "*Good food and friendly faces*"	Ageing Well Torbay asked 400 older people who lived in the local community, "what helps you to age positively?" to help identify what the programmes priorities should be. **Further information here**
Brocklehurst et al., 2015 "*Older people and oral health: setting a patient-centred research agenda*"	This research used a 'Priority Setting Partnership' approach, to incorporate users' perspectives to prioritise research agendas and are based on a series of sequential steps to build consensus. **Further information here**
Newhouse et al., 2017 "*Engaging patients with heart failure into the design of health system interventions: Impact on research methods*"	The purpose of this study was to engage patients with heart failure (HF) to assess if changes needed to be made to the design, methods and outcomes of a research study when transferring interventions used in urban/community hospitals to rural hospital settings. **Further information here**
The SPHERE (Sensor Platform for Healthcare in a Residential Environment) Project (2015)	SPHERE is an engineering-based research project which developed sensor systems that provides accurate information about health-related behaviours. An 'engagement team' was set up to work with those who might benefit from the SPHERE

Universities of Bristol, Reading and Southampton	technologies in the future, to ensure the technologies are practically and ethically acceptable. **Further information here** Also see this Vimeo
What Works Centre for Wellbeing, 2013 (cross sector partners, including academic) *"What Works for Wellbeing Project: Public Dialogue"*	A public dialogue was commissioned by the What Works Centre for Wellbeing with support from Sciencewise, Public Health England and the Cabinet Office, as well as several academic institutions. It focused on three themes: work and learning, sport and culture, and communities. **Further information here**
Mitchell, 2019, *"Working with vulnerable groups. Your expertise along with our expertise is a winning formula"* (blog for AMRC)	Mitchell, who is living with dementia, discusses her experience of reading and providing views on a number of documents written by researchers. **Further information here**

Co-design

Conceptualisations of co-design and the key principles that guide it are generally similar to co-production, co-research and co-creation, though tend to refer more specifically to a range of stakeholders/end users creating something together:

"Co-design engages end-users in the design of products or services so they will better serve their intended purpose" (Roper et al., 2018:2)

Table 2: Examples of co-design

Author and Title	Brief description
Newbronner et al., 2013 *"Sustaining and spreading self-management support. Lessons from co- creating health phase 2"*	The Health Foundation's Co-Creating Health Initiative promoted self- management in the NHS. Patients and professionals in England and Scotland were trained to facilitate patient self-management of chronic pain, diabetes, depression, and chronic obstructive pulmonary disease. **Further information here**
Ali, A., 2019 *"Promoting physical activity after a stroke"*	This project used a mix of co-design methods to involve end users in shaping provision for stroke survivors in Sheffield. **Further information here**
Dayson et al., 2019, CRESR, Sheffield Hallam "Evaluation of Age Better in Sheffield: Co-production Learning Report 1 -	Based on research, reports on the range of approaches necessary to co-design interventions to help reduce the social isolation of older people. **Further information here**

Understanding the Approach to Co-production"	
Hackcessible, 2019 Collaboration between the University of Sheffield's iForge, the Centre for Assistive Technology and Connected Healthcare (CATCH), and Assistronix.	Hackcessible is an Assistive Technology innovation incubator consisting of series of workshops and an annual make-a-thon that brings together engineers, designers, computer scientists, students and others to collaborate with individuals with disabilities and create workable products that support their needs. **Further information here**
Wolstenholme, Poll and Tod, 2020, *"Innovating access to the nurse-led hepatitis C clinic using co-production"*	Using research evidence from a study conducted by the lead author as a starting point, a series of co-production workshops were run using creative co-design methods to identify the barriers to engagement with clinics. **More information here**
Townley et al., 2019 *"Pain, Pain, Go Away: Co-creation of a toolbox to standardize pain-assessment"* The Integrated Knowledge Translation Research Network (IKTRN) is funded by a Canadian Institutes of Health Research seven-year foundation grant	This research set out to develop the Chronic Pain-Assessment Toolbox for Children with Disabilities (the Toolbox). Multidisciplinary stakeholders were engaged throughout the development and implementation of the Toolbox, including physicians, nurse practitioners, nurses, occupational and physical therapists, medical fellows, management staff, youth and family leaders. These stakeholders provided insights in development on the toolbox. **Further information here** (this resource also offers additional examples from the IKTRN network).
Mayrhofer et al., 2020 *"Young onset dementia: Public involvement in co-designing community-based support"*	This study aimed to establish what was known about the range of post-diagnostic interventions designed for people diagnosed with young onset dementia and their family caregivers, which elements of support were perceived as most effective by people affected by young onset dementia through a co-design approach. **Further information here**
Wherton et al., 2015 *"Co-production in practice: how people with assisted living needs can help design and evolve technologies and services"*	The low uptake of telecare and telehealth services by older people may be explained by the limited involvement of users in the design. The researchers conducted co-design workshops with participants – including users of telehealth and telecare, their carers, service providers and technology suppliers to explore perspectives on the design features of technologies and services to enable and facilitate the co-production of new care solutions. **Further information here**
Locock et al., 2014, *"Testing Accelerated Experience-Based Co-Design: A Qualitative Study of Using a*	This research used a national video and audio archive of patient experience narratives to develop, test and evaluate a rapid patient-centred service improvement approach. The intervention was an adapted form of a participatory action research approach in which patients and staff work together to identify and implement quality improvements.

National Archive of Patient Experience Narrative Interviews to Promote Rapid Patient-Centred Service Improvement"	**Further information [here]**
NIHR Devices for Dignity MedTech Co-operative (hosted by Sheffield Teaching Hospital NHS Trust) in partnership with Lab4Living (SHU), N.d	Children and their families worked with key opinion leaders from healthcare, academia and industry to incentivize the development of new breakthrough innovative prosthetic products for the NHS, aimed at supporting a healthy lifestyle. **Further information [here]**
Nobles et al., 2020 *"Let's Talk about Physical Activity": Understanding the Preferences of Under-Served Communities when Messaging Physical Activity Guidelines to the Public*"	The aim of this study was to understand the preferences of under-served community groups about how the benefits of physical activity, and associated guidelines, can be better communicated to the public, through co-developed participatory workshops. **Further information [here]**
Ali, P., 2019 *"How Health Practitioners can support DV survivors from Black and Minority Ethnic (BME) communities*"	Co-design workshops which explored domestic violence and abuse (DVA) experienced by migrant women and those from black and ethnic minority (BME). **Further information [here]**
Easton, K., 2019 *"Co-designing a virtual agent to support self-management of long-term conditions*"	This project co-designed a virtual agent to support self-management of long-term conditions through co-design workshops. **Further information [here]**
Astin,F., 2019 *"Reducing noise at night in a hospital ward"*	This project set out to co-design how hospital-based staff could take small steps to make a difference to support patients impacted by noise through workshops held in a hospital setting and patients/carers with experience of overnight hospital stay, clinical staff, support workers and a porter were recruited to take part. **Further information [here]**
Evison, M., 2019 *"Developing a treatment decision support tool for people with malignant pleural effusion"*	Used co-design to develop a prototype for a decision support tool, a set of workshops were run, which involved patients, carers and clinicians from UK NHS hospitals. **Further information [here]**
Light et al., 2013 *"The FLEX programme" (Flexible Dwellings for Extended Living) project*"	Both experts and the public participated in co-design workshops that focused on how future generations of older people might dwell more socially as they age, better serving companionship, resource sharing and social resilience in the community. **Further information [here]**

Harris, J., 2019 "The creative co-design approach to implementing weight management guidance in Doncaster'	A co-design approach was applied to support development of The Chartered Society of Physiotherapy (CSP) carried out co-design workshops with patients to support development of an online practice guidance resource for members. **Further information here**
Tod, A., 2019 *"Being warm Being Happy – the extent of fuel poverty in the UK"*	A co-design element was incorporated into a larger mixed method study and involved working in partnership with a range of stakeholders to help translate knowledge from research on fuel poverty into practical ideas **Further information here**
Webber, R., 2019 *"Improving educational resources for people with lower back pain"*	This project co-designed educational resources through running workshops designed to increase understanding of how back pain impacts on people's day to day lives, with an exploration of differences and similarities between healthcare professionals and patient priorities. **Further information here**
Poll, R,. 2019 *"Improving access to the Hepatitis C clinic"*	This project identified that some people who live with Hepatitis C are particularly hard to engage, and the aim was to devise tool/s to improve access to a specific clinic, through running co-design workshops. **Further information here**
Boaz et al., 2018 *"Stakeholder Engagement in EQUIPT (SEE-Impact)"*	The EQUIPT study set out to work with stakeholders to develop a tool to help government officials, policy-makers and healthcare providers across Europe examine the cost effectiveness and impact of anti-smoking initiatives. An earlier version had already been successfully piloted with local authorities around the United Kingdom, which encouraged the research team to fully integrate stakeholder engagement into the European study. **Further information here**

Co-research

Co-research is referred to by many terms, which include: knowledge mobilisation, co- production of knowledge, Integrated knowledge translation, participatory research, collaborative research, engaged scholarship, Mode 2 of knowledge production and co-creation. The following definition, from Kothari et al., based at the Integrated Knowledge Translation Research Network, offers a succinct definition which can be applied to all the examples here:

"a model of collaborative research, where researchers work with knowledge users who identify a problem and have the authority to implement the research recommendations" (Kothari et al. 2017: 1)

Specifically referring to health services Vindrola-Padros et al. (2019:67) offer the following:

"partnerships (which can involve researchers, practitioners, managers, commissioners or service users) with the purpose of creating, sharing and negotiating different knowledge types used to make improvements in health services."

Table 3: Co-research

Buffel, T (MICRA). 2015 *"Researching age-friendly neighbourhoods* *Co-producing policy* *within the age-friendly city of Manchester"*	This project aimed to improve the quality of life of people in low income communities and involved older people in Greater Manchester as co-researchers. **Further information <u>here</u>**
Ryan, T and Taylor, B. 2020 The Consensus Development project (CPD), unpublished Part of the Strategic Research Alliance with the Royal College of Nursing	CDP aims to co-produce a consensus statement addressing recommendations for action and change health education England, Kings Fund, local MP and further afield. The result will be a final, amended consensus statement which will agree key points for future research in relation to questions being asked. The findings of the project will be used by the RCN to influence health policy and the NHS and nursing profession organisations and aim to promote a safe and effective nursing workforce in the future. **More information on the consensus model is <u>here</u>**
Thomas-Hughes, H., (University of Bristol), N.d Productive Margins: Regulating for Engagement Programme (Funded by ESRC)	This programme supports a bottom-up mechanism arising out of the everyday lives of those who are caught up in regulatory regimes. Most community researchers were directly recruited for involvement in projects as either participants, researchers or volunteers by representatives from the community organisation or academic researchers working within an organisation. Community researchers undertook research training, conducted fieldwork and analysis, in many cases co-designing and co-writing outputs, activities and leading follow-on initiatives. **More information <u>here</u>**
Willis et al., 2018 *"Turning the Co-Production Corner: Methodological Reflections from an Action Research Project to Promote LGBT Inclusion in Care Homes for Older People"*	Older lesbian, gay, bisexual and trans (LGBT) residents are often invisible in long-term care settings. This article presents findings from a community-based action research project, which attempted to address this invisibility through co-produced research with LGBT community members. It considered what conditions enable co-produced research to emerge in long-term residential care settings for older people as well as critically reflecting on the ethics and effectiveness of this approach in advancing inclusion in context. **More information <u>here</u>**
Williamson et al., 2010 *"Impact of public involvement in research on quality of life and society: a case study of re- search career trajectories"*	This research reviewed the impact of recruiting older volunteer researchers to research assistant roles in a study exploring loneliness and isolation among older people. They received training in research methods to enable them to engage in decisions regarding the research design and were involved in peer interviews of other older people. **Further information <u>here</u>**

Pollock et al., 2015 *"User involvement in a Cochrane systematic review: using structured methods to enhance the clinical relevance, usefulness and usability of a systematic review update"*	Stroke survivors, carers, physiotherapists and educators were involved in an update of a Cochrane systematic review relating to physiotherapy after stroke. The systematic review brought together international literature to answer a specific healthcare question. This group guided the project to update the review, and had responsibility for making a number of key decisions throughout the review process, including decisions about any amendments to the methods from the previous versions of the review. **More information here**
Andrews et al., 2015 *"Developing Evidence-Enriched Practice in Health and Social Care with Older People, Funder: JRF UK"*	The aim of this project was to tackle two central issues inhibiting improvements in social care for older people namely: limitations to the use of evidence in social care and prevailing negative discourse associated with older age. Diverse partners were involved in a range of co-production activities to help participants engage with the evidence (including research findings transformed into engaging summaries and stories told from older people, carer and staff perspectives. **More information here**
Goldsmith et al., 2019 Co-producing Randomized Controlled Trials: How Do We Work Together? Frontiers in Sociology	This article describes challenges and solutions when designing and delivering a coproduced randomized controlled trial of mental health peer support. **More information here**
Jennings et al., 2018 Best practice framework for Patient and Public Involvement (PPI) in collaborative data analysis of qualitative mental health research: methodology development and refinement	The aims of this study were to develop a methodology for involving PPI co-researchers in collaboratively analysing qualitative mental health research data with academic researchers, to pilot and refine this methodology, and to create a best practice framework for collaborative data analysis (CDA) of qualitative mental health research. **More information here**
Caress et al., 2010 Exploring the needs, concerns and behaviours of people with existing respiratory conditions in relation to the H1N1 'swine influenza' pandemic: a multicentre survey and qualitative study.	This project explored the risks of swine flu for people with chest problems and worked with a service user reference group of people with lung problems, who were contacted via the British Lung Foundation. The user reference group helped to conceptualise the project, and contributed to the study design, methods, and consideration of the burden on participants. **More information here**
Gainforth et al., 2019 *"Using IKT to Translate the Spinal Cord Injury Physical Activity Guidelines in A*	Health promotion initiatives aiming to promote physical activity in the spinal cord injury (SCI) population are needed but often overlooked, this project worked with partners to widely disseminate the physical activity guidelines using an integrated KT approach to plan and execute end-of-grant KT by partnering with a community-based

Community-Based Organization"	organization to disseminate the physical activity guidelines and evidence-based intervention strategies to various target audiences. **Available here**
Coates and Hasselback, 2019 *"From Coalition to Action Plan: Addressing Malnutrition in Older Adults through IKT"*	Developed local Integrated Knowledge Translation (IKT) activities to address malnutrition in older adults on Vancouver Island. Initially organized a workshop for a cross-sector coalition, where national and international best practices were shared, and partners presented local findings, successes, resources and ideas. The presentation of the initial findings led to the formation of the Coalition and IKT activities. **Available here**
Chambers et al., 2016 *"Service user involvement in the coproduction of a mental health nursing metric: The Therapeutic Engagement Questionnaire"*	This document describes the involvement and views of service users in the development of a nursing metric—the Therapeutic Engagement Questionnaire. **Available here**
Jackson et al., 2020 *"Patient and public involvement in research: from tokenistic box ticking to valued team members"*	Delivered PPI within the context of the Asthma UK Centre for Applied Research (AUKCAR), a UK-wide virtual centre bringing together academics and clinicians to collaborate on key areas of research to improve the management of asthma. **More information, here**
CATCH. N.d *"Intelligent shoe research project steps into the spotlight"*	The research to develop this explored the models of post stroke rehabilitation and how they might be translated into an ICT based system underpinned by theories of motor relearning, neuroplasticity, self-management and behaviour change. The methodologies used in this study ensured that the interactive technology developed has been driven by the needs of the stroke survivors and their carers in the context of their journey to both recovery and adaptation. **More information here**
Fulfilling Lives. 2019 *"Changing systems for people facing multiple disadvantage, Community Fund"*	This project brought people with lived experience together with the University of Sheffield and the Making Every Adult Matter (MEAM) coalition to do research into preventing homelessness. **More information here**
REF, 2014, Case study University of East London Interventions improving the wider determinants of health and wellbeing	This research into community development and co-production has informed the design of health improvement interventions, delivered through the cross-institutional, community-based Well London project. Research findings have driven Big Lottery funding priorities, contributed to parliamentary debates on health, informed NICE and Local Government guidance, shaped Marmot Review Team and NESTA policy, and led health authorities to commission new services and adopt new approaches to service delivery.

	More information **here**
Davies et al., 2009 Developing quality indicators for community services: The case of district nursing	The university team ran a series of focus groups with community nurses, conducted service user, specialist nurse and commissioner interviews and reviewed research-based standards and relevant research to comprehensively explore and capture dimensions of quality within community nursing practice. In Phase 2 the quality indicators were tested through implementation within 12 community nursing teams. **More information here**
REF 2014 case study: Robert Gordon University, University of the Highlands & Islands The Older People for Older People (O4O) Project: Creating Services, Improving Health and Challenging Perceptions	The O4O project operated Participatory Action Research with local community members who were supported to design, develop and run their own organisations to deliver services with, and for, rural older people. **More information here**
University of Bristol, School for policy studies. N.d *"Dementia Communication: Training videos"*	University researchers worked with co-researchers living with dementia, the Forget Me Not research group, to create a series of five videos that address common issues in communication. **More information here**
Dayson et al., 2019 *"Evaluation of Age Better in Sheffield: Co-production Learning Report 1 - Understanding the Approach to Co-production"*	Discusses learning based on a co-evaluation approach, working with older people affected by social isolation in Sheffield. **More information here**

Co-research/user-led

User research is where people with lived experience are supported to take the lead in directing the nature and direction of a research study. Typically, people with lived experience are involved in generating ideas, proposals, funding bids, publishing and presenting the findings and are likely to be involved in conducting the research by interviewing participants or facilitating focus groups. This model is characterised by the shift in balance of control to the people with lived experience (Hughes and Duffy., 2018).

Table 4: co-research/user-led

Dementia Engagement and Empowerment Project (UK)	This project recently received funding from the Big Lottery Fund to enable the 100 Dementia Engagement and Empowerment Project groups around the UK to undertake their own research, through this, a Research Interest Group called 'Dementia Enquirers' – a group of people with dementia supported by

	Innovations in Dementia who have received funding from the National Lottery for people with dementia to lead on research. **More information here**
Littlechild et al., 2015 "Co-research with older people: perspectives on impact"	The participatory research project focused on older people's experiences of transitions between care services. Co-researchers received training and were involved throughout the study including designing the research method and tools, recruiting and interviewing participants, identifying key themes during analysis and the dissemination of findings. **More information here**

Patient and Public Involvement and Engagement

PPIE can straddle all research activities; some may utilise this at the beginning of the research process, to 'test' research problems or questions with intended end users, whereas other models involve patients throughout. ScHARR (based at the University of Sheffield, and who facilitate PPI groups) define it as:

"research which is done with or by patients and the public, rather than to, for or about them. Involvement in research refers to an active partnership between researchers and patients and the public in the research process. This often means that patients and the public have a decision-making impact on one or more stages of the research process (ScHARR, N,d)"

A review of grey literature identified many examples of universities, research centres and hospital trusts who have public or patient advisory groups attached to specific research studies and trials. These were often in specific geographical locations or in relation to specific health conditions, usually with support and funding from the NIHR. Whilst there were some published evaluations of the impact of these models, few have been subjected to peer review (Hughes and Duffy, 2020).

HELSI members talked about the importance of PPIE resources to their research. For example, Highley (2020) based in SITraN, explained how his department frequently work with patient groups when writing lay abstracts and proposals, such as the local Motor Neurone Disease Research Advisory Group that meets in SITraN. Field (2020) talked about how the Sheffield Addiction Recovery Research Panel (https://www.sheffield.ac.uk/scharr/ppi/sharrp), has supported him to set up preliminary research and develop grant applications, referring to running a focused PPI session, with an intention to update the group on progress later in the year.

For details of the PPIE resources for researchers based at the University of Sheffield, please click on the following link.

Concluding thoughts

As referred to in the introduction, this programme of work aims to provide a starting point. In the spirit of co-production, HELSI members will ideally not only be able to benefit through gaining initial ideas, but also feel able to provide ideas and shape how this essential element can evolve and be shaped by the ambitions of individual members and HELSI.

Appendix One Methodological approach

This appendix provides a brief overview of the research approach. The interviews and information gathering apply to both the co-production and the public engagement report, as in most cases, informants provided views on both. The research was carried out between January and June 2020.

Literature Review

A review of the current evidence and more recent advances in knowledge of, and approaches to co-production (across the last decade or so) was carried out. For the conceptual discussion, classic/seminal papers were also considered.

A range of sources were searched, and both academic and grey literature, where relevant, was considered for inclusion. The main sources of information were gathered from: The University of Sheffield StarPlus search engine (Medline (Ovid), EMBASE (Ovid), CINAHL(EBSCO), Global Health (Ovid), SocINDEX (EBSCO), Scopus (Humanities and social science) Abstracts (ProQuest), ProQuest Dissertations, and Theses Global. Dissertations); Google and Google Scholar; relevant research centres and cross sector organisations (paying particular attention to clinical, nursing, social care and those which focus on older people); social media sites (including Twitter and LinkedIn); other online sources (Vimeo, YouTube) and through recommendations provided by informants.

The inclusion criteria was limited to evidence and research viewed as relevant to the research and related activities carried out by HELSI. As the institute adopts a life course approach, examples are not limited to older people, but include people of all ages. It should be noted that not all relevant examples could be included. Rather, the discussion and real-life examples are provided for illustration, and the reader is encouraged to explore these further via the references provided. The real-life examples were chosen to reflect the different elements of co-production (i.e. consultation, co-design, co-research etc.) as well as a range of research and related activities (e.g. theory/science based, applied research, policy based etc.). Most examples refer to university led co-production initiatives; though there are some which relate to co-production initiatives that are third or public sector led.

Informant interviews and information

To gain a better understanding of the University of Sheffield context, and to gather ideas and suggestions to help inform the report and real-life examples, face to face and telephone interviews were carried out with 15 professional and academic staff (see Table below) due to lockdown restrictions – telephone interviews were carried out from the end of March 2020 onwards). Researchers and professional staff also responded to an email request for information (n = 10).

Information on existing groups that can help support Public and Patient Involvement and Engagement (PPIE) was also gathered and a document created which provides details on: main contacts, specific health condition/circumstances of participants and details on the type of supported offered (ranging from consultation through to supporting a more established co-production approach).

Table of informants

*For information on key contacts for PPIE, please refer to separate document

Chris Baker. Head of Innovation and Knowledge Exchange, University of Sheffield
Amy Sutherland Jarvest, Project Manager, University of Sheffield

Hayley James, Research Associate, School of Social Sciences, Faculty of Humanities, University of Manchester
Katie M Pruszynski, Faculty Engagement Manager, Faculty of Social Science, University of Sheffield
Lucinda Bower, Industrial Strategy Partnerships Manager, Faculty of Social Science, University of Sheffield
Jesamine Hughes, Research Partnerships Officer, Faculty of Science, University of Sheffield
Venelina Koleva, Research Hub Manager, Faculty of Science, University of Sheffield
Erika Williams, Knowledge Exchange and Operations Manager, Faculty of Engineering, University of Sheffield
Ceri Batchelder, Consultant, Royal Society Connect & Create
Sue Smith, Lead Knowledge Exchange & Commercialisation Manager, Sheffield Healthcare Gateway, Faculty of Medicine, Dentistry and Health, University of Sheffield
Tony Ryan, Head of Division: Health Sciences School Division of Nursing and Midwifery, Faculty of Medicine, Dentistry and Health, University of Sheffield
Dan Wolstenholme, Centre for Quality Improvement and Clinical Audit, Royal College of Obstetricians and Gynaecologists
Louise Whitehead, PhD researcher, Sociological Studies, University of Sheffield
Bethany Taylor, Research Associate, Health Sciences School, Division of Nursing and Midwifery Faculty of Medicine, Dentistry and Health, University of Sheffield
Samaira Khan, Public Involvement Lead, NIHR Research Design Service, ScHARR, Faculty of Medicine, Dentistry and Health, University of Sheffield
Sue Yeandle, Director, CIRCLE, Faculty of Social Sciences, University of Sheffield
Matthew Lariviere, UKRI Innovation Fellow on Care, Ageing and Technology, CIRCLE Faculty of Social Sciences, University of Sheffield
Lorna Warren, Senior Lecturer in Social Policy, Sociological Studies, Faculty of Social Sciences, University of Sheffield
Daniel Holman, Research Fellow, Sociological Studies, Faculty of Social Sciences, University of Sheffield
Julie Simpson, Senior Lecturer in Translational Neuropathology, Course Lead for MSc Translational Neuropathology, Medical School, Faculty of Medicine, Dentistry and Health, University of Sheffield.
J Robin Highley, Senior Clinical Lecturer in Neuropathology, Medical School, Faculty of Medicine, Dentistry and Health, University of Sheffield.
Matt Field, Professor of Psychology, Department of Psychology, Faculty of Medicine, Dentistry and Health, University of Sheffield.
Elizabeth Goyder, Professor of Public Health, ScHARR, Faculty of Medicine, Dentistry and Health, University of Sheffield.
Jason Heyes, Professor of Employment Relations, Director of the Centre for Decent Work (CDW), Management School, Faculty of Social Science, University of Sheffield
Stephen Harrison, Volunteer with Lived Experience, Tinnitus Works

Appendix Two: Useful resources

(I have added things I have come across during my review – there will no doubt be other useful resource out there – so this can be added to)

Useful resources and signposting

Toolkits and guides	
Christian Aid, ESRC, The Open University, 2017 Rethinking research Partnerships	Discussion guide and toolkit. provides ideas and approaches to enable researchers to think through research partnerships. Drawn from a seminar series that brought together academics and NGO staff to reflect on their experiences of research partnerships.
The Big Lottery Ageing Better programme	This offers a co-production toolkit, "Stronger Together" and a YouTube channel.
National Development Team for Inclusion, health toolkit	NHS England and NHS Improvement and Coalition for Personalised Care has designed a Co-production in mental health toolkit and a Co-Production Model.
Centre for Social Justice and Community Action, Durham University	The Centre has developed toolkits and guides aimed at researchers embarking on (or considering) a community-based research project. The Community Toolkit is written by members of a community organisation and therefore offers guidance for organisation's considering working in partnership with a university.
What Works for Wellbeing Centre	Developed a public dialogue toolkit https://whatworkswellbeing.org/blog/public-dialogue-toolkit/
The James Lind Alliance	Aim to enable clinicians, patients and carers to work together to identify and prioritise the questions they would like answered by research and have various resources and publications.
Books and guides	
NIHR, CLAHRC for YH, 2019 The translating Knowledge into Action Report: Using Creative Methods to co-design better healthcare experiences – referred to in co-p report	The TK2A (Translating knowledge to action) theme has developed a booklet with a focus on techniques drawn from design and the creative arts.
NIHR PPI Patient and public involvement in health and social care research: A handbook for researchers	Information about ways in which patients and the public could contribute to the in the research cycle. Available here
Farr et al., 2020. National Institute for Health Research (NIHR) ARC West and People in Health West of England; University of Bristol and University of West of England.	*A map of resources for co-producing research in health and social care.* Available here: https://arc-w.nihr.ac.uk/Wordpress/wp-content/uploads/2020/05/Map-of-resources-Web-version-v1.2.pdf

Cochrane Training Involving People: A learning resource for systematic review authors	The resource provides best practice and practical suggestions for finding and involving people throughout the review process; including guidance documents, interviews about first hand experiences, and links to case studies and examples of good practice. More information here
IKTRN, 2019 How We Work Together: The Integrated Knowledge Translation Research Network Casebook	This casebook shares some examples of research projects which have used integrated knowledge translation (iKT) approaches, as well as the challenges, benefits and impact of working collaboratively. More information here
What co-production means, our projects and how to get involved. Oxfordshire County Council	Produced a handboo from the perspective of a statutory local authority in England. Click here for the handbook
McClure, R. J, 2020 Research 'with' not 'on', yes, but with whom and how?	This editorial covers the importance of co-production, an opinion piece on what co-production is, and more on the impact of co-production in health services. It also features a range of relevant articles. More information here
Edited by Bee et al., 2018, A research Handbook for Patient and public involvement: A research handbook: For patient and public involvement researchers, Manchester University Press	A text book aimed at those involved in health research as experts from experience, developed during a five-year research programme funded by the UK's NIHR Aimed to improve service user and carer involvement in care planning in a mental health services. The handbook is available here
Cochrane Training. Involving People: A learning resource for systematic review authors	The resource is a 'one-stop-shop' to find out best practice and practical suggestions for finding and involving people throughout the review process; including useful resources, guidance documents, interviews about first hand experiences, and links to case studies and examples of good practice. More information here
IKTRN How We Work Together - The Integrated Knowledge Translation Research Network Casebook	This casebook shares some examples of research projects which have used integrated knowledge translation (iKT) approaches, as well as the challenges, benefits and impact of working collaboratively. More information here
Farr et al. 2020 Making Media with Communities: Guidance for Researchers (AHRC funded)	Guidance for Researchers provides a framework for the development of community media projects. More information here
National Co-ordinating Centre for Public Engagement (NCCPE)	This document provides resources to support ethics in participatory research. More information here

Ethics in Participatory Research	
NIHR: That Co-production Podcast!	A range of accessible podcasts, mainly academics discussing topics such as using creative approaches, valuing relationships, difference between co-p and public involvement.
Websites	
NIHR, INVOLVE website	Guidance and advice on organising and carrying out PPI as well as an evidence library of papers on PPI in health research and a resource on developing training and support for PPI. Available here
University College London Co-Production Collective website	University College London Co-Production Collective website co-producing change together and Co-Production Collective's Allies Group.
Beresford, P et al. 'COVID-19 and Co-production in Health and Social Care Research, Policy and Practice'.	Open access book which covers methods and approach.
The Centre for Society and Mental Health and the Institute of Psychiatry, Psychology and Neuroscience at King's College London	Including a publication, Research Methods: A practical guide to Peer and Community Research" and free online training courses.
Academic led Centres and partnerships	
Centre for Coproduction in Mental Health and Social Care, Middlesex University, London	Useful discussion around co-production and examples of using a co-production approach in research. Available here
Centre for Collaborative Innovation in Dementia Liverpool John Moores University	The Centre works in partnership with people living with dementia and interested partners to provide an open environment in which to innovate and validate potential solutions to the real-life challenges of living with dementia. The Centre is widening its reach by working with co-creation groups across health and social care. More information here
The N8 Research Partnership (ESRC supported)	A collaboration between eight research-intensive universities in the North of England with non-academic partners to maximise the impact of collective research. Produced a useful resource: Knowledge that matters: realising the potential of co-production
The Patient-Centered Outcomes Research Institute (PCORI)	Based in Washington DC, work to ensure patient-centred research with meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders through the entire research process. It has a range of resources for public engagement. More information here

Appendix Three: References

References: co-production real-life examples

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