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External engagement and Co-Production: Research and practice review summary





External Engagement and Co-production: Research and Practice Review Summary

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Introduction

This document provides a summary of a programme of work carried out to inform the ongoing development of external engagement and co-production within the Healthy Lifespan Institute (HELSI). It is informed by a review of relevant evidence and interviews with a range of key informants. 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 and ensure new knowledge is created in collaboration with those who stand to benefit directly, or who are in positions that can affect change.

Broadly, external engagement refers to activities which connect researchers to non-academic audiences. This might be through consulting the general public and/or potential end users, or involving people as collaborators and co-producers. It may also entail working with non-academics as partners to help translate knowledge. Following consultation across the higher education sector, the NCCPE (N.d: N.p) describe public engagement as:

"the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit."

There are several definitions of co-production, though SCIE (2013) encapsulate its essence concisely: *"meaningful engagement of all stakeholders in the design of new services or knowledge"* (SCIE, 2015, N.p)

The term meaningful is key here, and refers to research that is not tokenistic, and where stakeholders (professionals, end users etc.) are instrumental in influencing the process.

Public participation and co-production can broadly be viewed as a spectrum of approaches based on informing, consulting, involving, collaborating and empowering (The International Association for [Public Participation](#)). While there will be inevitable overlap, co-production approaches generally start at the "collaborating" level.

Why carry out external engagement?

External engagement can: enable researchers to form greater insight into their research area (Brett et al., 2014); ensure decision-making and implementation is more tailored to the needs of individuals (Roper et al., 2018) and local settings (Beckett et al., 2018); contribute to system level change (Halvorsrud et al. 2019); generate new evidence (Heaton et al., 2015) and help to plug 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).

A growing 'know-do' gap has led funding bodies such as the Wellcome Trust, the UKRI research councils, Alzheimer's Research UK, Cancer Research UK and the National Institute for Health Research 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. UKRI Innovate UK (Campbell, 2018: N.p), refer to cross sector partnerships as crucial to ensuring a seamless progression from "lab bench to marketplace". The principles behind translating knowledge are also crucial to applying research based on the government's Industrial Strategy, which views coordinated working across sectors (and academic disciplines) as key to tackling grand challenges.

A systematic review of adopting co-production in health-related research found this was driven by: a strong moral argument, accumulating evidence of the benefits and recognition of the experiential knowledge and expertise in the community (Bee et al., 2018). 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 settings in which universities are located (Greenhalgh et al., 2016). Overall, these effects can lead to improved research relevance, a higher level of



accountability and transparency (Nass et al., 2012) and the opportunity for the voices of those of those traditionally less engaged to be heard (Beckett et al., 2018; Campbell and Vanderhoven, 2016; Walker, 2007).

Adopting elements of external engagement is not without challenges, such as 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). A frequently cited barrier is the perceived power imbalance between academics and end users, despite efforts by the former to mitigate this (Mitchell, 2019). 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 (Christian Aid and ESRC 2017; NDTi, 2015; Oxfordshire County Council, 2020).

It is widely acknowledged that some groups (professionals and end users) are less likely to engage with academic research. Regarding the latter, NHS guidelines (Healthwatch England 2016) refer to the importance of ensuring equitable access through giving regard to cultural, linguistic, religious or background barriers and to connect with organisations who work with diverse communities.

Carrying out external engagement

External engagement 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). It is asserted that external engagement, and in particular co-production is an achievable (and indeed, laudable) aim, as long as 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 really necessary if it is anticipated that it can improve quality, relevance or reach or overall research quality (Caress et al., 2010).

Most of the stakeholders spoken to during this project referred to the value of starting small and “giving it a go” (Baker and Sutherland, 2020; Pruszynski and Bower, 2020). This may be a case of thinking about how external engagement offers value, identifying who needs to be involved, then getting those people together (Baker and Sutherland, 2020). Pruszynski and Bower (2020) suggest working backwards, identifying what the intended legacy of the research activity is from the start to help support thinking about who needs to be involved.

During planning stages, it will be useful to take advantage of support available through the University and external funders, centres, and research councils (the full co-production report provides some useful resources as a starting point). It is also worth bearing in mind that some charities and local authority-based teams already support engagement type activities and may hold a database of potential participants. A compiled list of existing PPIE research groups included those operated through the university) can be accessed via [this link](#).

The box below offers guidelines on some of the areas that should be considered when carrying out external engagement (based on Beckett et al., 2018; Christian Aid and ESRC, 2017; Dayson et al., 2019; Farr et al., 2020; INVOLVE, 2020), though the best way to get to grips with it 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. The box covers the spectrum of external engagement, from basic consultation activities to full co-production, so not all of the tips will be relevant to all cases.



Box One, External engagement: 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, which can be 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 external engagement

This section considers existing examples of research and related activities carried out across the spectrum of external engagement, from communication (Setting up networks, partnerships and intermediaries; running activities) to consultation and collaborative approaches (co-design; co-research; user led research).

Engagement through partnerships, networks and intermediaries

When looking to establish ongoing collaborative approaches, the way in which these are badged will need consideration. Rather than looking to set up a steering group or similar at the outset, it could be a case of starting off more informally, to 'test the water' around what approach might work best. Baker (2020) suggests starting off by saying: "*we are looking to do something interesting, though we don't know what this looks like yet*".

Notable examples of cross-sector collaborative partnerships which support research include the University of Manchester's Institute for Collaborative Research on Ageing (MICRA and [Age UK](#) research partnership, Knowledge Transfer partnerships ([Gov.uk, 2015](#)), the Centre for Regional Economic Enterprise and Development ([CREED](#)) and the Fuse centre for Translational Research in [Public Health](#). The University College London host a [Co-Production Collective website](#) in which those with an interest in co-production are encouraged to join and get involved.

Setting up networks with end users is a particularly effective way of ensuring their voice is heard. Some examples include the [Older People's Reference Group, developed through the New Dynamics of Ageing Research Programme](#) and the [Older People's Reference Group](#), run by Brunel University London. Other successful collaborative approaches include the [Community University Partnership programme](#) run by the University of Brighton, which ensures the local community informs its strategy. The UCL have established 20 [communities of practice](#) across nine different service areas to enable staff to collaborate, share best practice and enhance service delivery.

Running events, workshops and symposiums

Another effective way to engage external stakeholders is through running an event, workshop or symposium. The literature around running successful engagement activities refer to the importance of planning and having a tangible goal (UKRI, 2020, Wellcome Trust, N.d) or 'key message' (European Research Council, 2020) in mind.

Some examples include the annual [Dementia Futures public meeting](#), supported through the Alzheimer's Society, where cross-departmental PhD students carrying out dementia-related research (based in: neuropathology, neuropsychology, nursing, sociological studies, human communication sciences), network with peers and present their research via a 'lay presentation' to the public. One off events can also be effective, such as [Futures of Ageing: AI](#) and the Digital Revolution in Care, supported through the ESRC Festival of Social Science. This event raised awareness of social science research and encouraged the public to question taken for granted assumptions about what care means to communities and find out about how new technologies can help support carers. The [Creative Lives symposium](#) brought together academics, galleries and older artists to share their research, experiences and observations on the issue of ageism. Through this, a strategy session where participants discuss how to successfully implement selected solutions is due to be run.



Other ideas might include running or attending online networking sessions, such as the '[Melting pot lunches: online series](#)' run by Kaleidoscope Health and Care, which brings together diverse groups from academia, the NHS, and beyond (e.g. Dr Sana Suri, a neuroscientist from the University of Oxford, in honour of Dementia Action Week, started a conversation on how researchers, clinicians and policymakers can work to improve quality of life in older age).

Communication strategies

To ensure take up and awareness of research by non-academic audiences are maximised, it is necessary to give some thought to how work will be communicated. The strategy adopted will depend on the nature of the research and the kind of knowledge that is being translated. Disseminating research via video, for example, has been shown to potentially build knowledge-based capacity, with conversion of written peer review journals into videos increasing the likelihood of busy health professionals both engaging with the research, and feeling they understood the findings (Mitchell et al. 2019). Infographics can also convey information, such as about the social determinants of health, in an effective and engaging way ([The Health Foundation, 2017](#)). There are also examples of research being reported in publications which reach a wide, non-academic audience, such as *The Conversation* or industry magazines.

Carrying out outreach work, especially in local communities 'where people go' can be a particularly effective way to reach an audience who may not necessarily enter a university environment. Some examples include raising awareness of STEM research to young people who are under-[represented in STEM](#) or research around specific [health concerns in communities with low levels of health literacy](#). A relatively easy way to run external engagement events is through UKRI run festivals, such as the [MRC](#). Community based events that gained particular traction include running a stall at a [park run](#) and a [crazy golf](#) course to raise awareness of health and wellbeing research. Other examples include: travelling around the community on a [vintage bus](#), running facilitated sessions in [caf  s](#) to raise awareness of health, wellbeing, [social science](#) and science research, and running a '[Heart and Lung](#)' shop, based in a shopping centre to stimulate discussion about cardiovascular and respiratory research topics. Engineers have raised awareness of marine and maritime engineering through engaging with passengers on [a ferry crossing](#). An example of a community based campaign which achieved wide reach is '[Look at Me!](#)' which ran different public engagement activities to challenge age-based stereotypes.

Digital communication strategies

Digital technologies offer a useful tool to connect like-minded people, enabling multi-way conversations, collaborations and multiple viewpoints (see Grand et al, 2016), with global reach (Doran, 2015). When used well, it can support democratization, where the public can access information that had once been closed to them (Winston, 2015). Health promotion interventions on social networking sites can communicate individually tailored content to a large audience (Syred et al., 2014). Academic journals are also starting to leverage social media as an engagement tool and are using online social media conversations, infographics and podcasts to promote publications (Chan et al., 2019). As with all aspects of external engagement, there are no set rules around the best digital platforms, with this being dependent on the nature of the research and the stakeholders engaged (Grand et al., 2016).

Looking specifically at health promotion initiatives, Veale et al. (2015) identified critical success factors as mainly interpersonal in nature, such as regular interaction, encouraging



conversation and uploading multimedia. These conclusions are supported by the Medical Research Council (N.d) who iterate that building a [social media presence](#) in particular requires regular upkeep, which has inevitable resource implications. [NCCPE](#) (2018) offer useful guidance and examples of where digital communication has been used effectively to reach hard to engage groups.

Examples of collaborative approaches

Consultation

Consultation activities vary considerably, it can include one-off 'light touch' exercises, such as Ageing Well Torbay, which [consulted with 400 older people](#) in the community on ageing positively. Consultation can also support "sense checking" at various (or across all) stages of research (including support around [health](#) and [technology based themes](#)). There are examples of applying tried and tested consultation approaches, such as priority setting to incorporate user perspectives around carrying out patient centred research on [older people and oral health](#). Consultation approaches have also been utilised to good effect to support public dialogue, such as the one run by [What Works Centre for Wellbeing](#), and identifying effective mechanisms to translate research, such as promoting healthy [eating to support eye health](#). Another benefit of carrying out consultation is it can provide an opportunity to listen to the voices of those who may not otherwise be heard, such as [people living with dementia](#).

Co-design

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). The NIHR funded CLAHRC Yorkshire and Humber Translating Knowledge Into Action Report outlines a number of examples of [co-designing health led research](#), such as promoting physical activity after a stroke, self-managing long-term conditions (also, see the Health Foundation's [Co-creating Health Initiative](#)) and more practical focused research, such as identifying how to reduce noise in hospital wards and reduce fuel poverty. [FLEX](#) followed a place-based approach to focus on how older people might dwell more socially as they age. Co-design methods are effective at identifying barriers experienced by hard to engage groups, such as those living with [hepatitis C](#). Other useful resources include learning reports, such as the [Big Lottery funded Ageing Better in Sheffield programme](#) which highlights examples of co-design interventions to help reduce the social isolation of older people. Some initiatives, such as [Hackaccessible](#), involve ongoing workshops and annual events to support co-design of assistive technology innovations. Another technology-based example includes research which co-designed [telecare and telehealth services](#) to promote higher levels of take up. Co-design frequently adopts [participatory research methodologies](#).

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).



Co-research models have been successfully applied to research with older people, such as to support [improved quality of life](#), [social care support](#), reduced [social isolation and loneliness](#) and promoting inclusion for groups who can be invisible in research, such as older [LGBT people who reside in care homes](#). User involvement has also successfully been employed in a [Cochrane supported systematic review](#), a [randomised control trial](#), development of a health [self-management information technology resource](#), to support [PPI](#) and [participation action methodologies](#), and to inform service tools (such as [therapeutic questionnaires](#), [quality indicators](#) for community services, both nursing). Co-research has also been used successfully to support dissemination of [health promotion initiatives](#) and community development approaches to improving the [wider determinants of health and wellbeing](#)

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). A good example is [Dementia Engagement and Empowerment Project \(DEEP\)](#), funded by the Big Lottery Fund to enable the 100 Dementia Engagement and Empowerment Project groups around the UK to undertake their own research.

Patient and Public Involvement and Engagement

PPIE in reality 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 a number of 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). For details of the PPIE resources for researchers based at the University of Sheffield, please click [this link](#).



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