



Co-production case studies

**A retrospective review of case studies
carried out within the ARC KSS**

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Co-production theme

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Introduction

The Co-production Theme of the Applied Research Collaboration Kent, Surrey and Sussex (ARC KSS) is a cross-cutting theme and aims to promote collaborative working, shared learning and innovation amongst KSS researchers, health and social care organisations and the local population. To help achieve this the Co-production Theme intends to undertake a comprehensive programme of work to explore co-production approaches across several ARC KSS projects. This programme will move beyond description of individual projects to develop our understanding of how best to support co-production mechanisms/processes and measure the outcomes of co-production. By developing our understanding, this will support the future implementation of research findings to ensure impact. This guide was produced as part of a 'stock-take' of what has already been happening across ARC KSS.

This guide presents studies utilising aspects of co-design or co-production to share learning and support the reader's own co-production journey. These are not 'off the shelf' approaches, rather we hope the case studies inspire and provide some pointers for you to adapt as appropriate for your own setting.

The case studies have been selected from ARC KSS core themes including:

- **Starting well:** care leavers support during and post lockdown ('Beyond Lockdown'),
- **Primary and Community Care:** young people's mental health (related to suicide and self-harm) in primary care settings ('Practice Hope'),
- **Social Care:** Co-producing Covid-19 Resources with Ethnic Minorities ('Co-REM').
- **Dementia:** the effect of the Covid-19 pandemic on the lives of people with dementia (Quality of Life for Carers and people living with dementia (PLwD) and Remote Memory Assessment Service).

We co-developed this guide with the ARC KSS Implementation Managers and asked them to share examples of co-production or co-design. We started by discussing with them the idea of using case studies to share learning, then drafted and agreed a brief protocol and interview topic guide. The co-production team interviewed the Implementation Managers and reviewed study materials and online resources. Once a basic draft of the guide was written, the Implementation Managers added, amended and made changes. This went through several versions before we all felt the content reflected our intentions.

You may wish to read this in conjunction with our earlier guide to 'Co-production for researchers, services and commissioners' ([Co-production ARC KSS](#)), in particular where we provided two definitions of co-production (p3-4). Central to both definitions, co-production means everyone working together, sharing power and responsibility throughout a project.

We hope you find this guide helpful, if you have any questions or want to discuss how we can help, please get in touch! The Implementation Managers can help you identify relevant contacts and networks and the Co-production team work with specific projects to embed co-production into the project from the start.

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Introducing the case studies

Beyond Lockdown

Implementation Manager: Becca Randell

Aim: To understand the effect of the Covid-19 pandemic on care leavers daily lives and mental health and consider the support they needed during and as lockdown ended (work undertaken between June and December 2020).

Rationale: Leaving the care system can be daunting for young people and they can often feel unprepared for this change. They may experience financial insecurity, poor mental health and feel unsure about what support is available to them. The pandemic and associated restrictions are likely to compound what is an already difficult time in the lives of these young people. Understanding their support needs and responding to these will be important for their wellbeing.

Focus: Care leavers

Partners: Care Leaver Expert Working Groups made up of care leavers in Kent and East Sussex, and stakeholders through two communities of practice. These stakeholders included not only care leavers but also Leaving Care Teams, Voice and Participation Teams, Voluntary and Community Care sector, Department of Education and NHS England.

Method: Rapid research, starting with an online national survey of care leavers about the impact of lockdown and their support needs. Online workshops (Care Leaver Expert Groups) with care leavers from the Kent, Surrey and Sussex region to discuss the survey findings and to co-create key messages for other care leavers and organisations which support them.

Outputs: The *Beyond Lockdown* research project produced key messages, videos and presentations, all available on the website below. Care leavers were involved in presenting the research and messages at ARC events and at both Young People's Benchmarking Forum for Care Leavers (where they presented the research and further co-produced messages from care leavers from 103 local authorities) and the National Leaving Care Benchmarking Forum for those working with care leavers. Thirty-three Pledges were also made by stakeholders in response to hearing the research and key messages from care leavers.

Why this is co-production:

- Researchers worked with care experienced young people and professionals providing services to plan the work together.
- Care leavers were involved in making decisions about the project and setting the agenda for all meetings.
- Care leavers were actively involved in the co-creation of the key messages and dissemination thereof.
- The process of co-production encouraged national, regional and local stakeholders to make pledges (33 in total) in response to the research findings and key messages. The progress of action linked to each pledge was then reported back at a community of practice.

More information: [Beyond Lockdown - A rapid response study asking care-leavers what support they want as lockdown ends](#)

Key learning

- Don't overthink or over theorise the process of co-production but do **think and talk about what it means to you and others** to use a co-production or co-design approach.
- **Ensure a co-production thread is present all the way through** the work, from the very start of planning your project right up to implementation.
- Planning is important at the beginning but otherwise **allow space for things to develop** organically.
- Think through who your **key stakeholders** are early on and ask yourself 'are all the right people going to be around the table?'. It is important that key **decision-makers** are on board from the start alongside those **who will be implementing the research findings**. For example, a Director of Children's services was part of this project team and was an important contributor, able to influence changes in care pathways and budgets.
- **Fund the co-production element** sufficiently.
- There is no **'one size fits all' approach**, you must consider what will work for and with the team/project you are working on.
- **Build relationships**, but do not expect this to happen overnight, it takes time so ensure you allow for this.
- **Short pieces of work**, with quick outputs can be really **engaging for young people**, keeping them interested.
- **Creative methods** are a great way to engage young people.



Practise Hope

Implementation Manager: Sam Fraser

Aim: As a development programme this project aimed to change the culture and improve services around provision of mental health support for young people in primary care.

Rationale: Young people who are thinking of suicide or self-harming need safe spaces to talk about their thoughts and feelings, it is especially important to be able to raise their concerns with their GPs as primary care provides a front door for those seeking support. For young people to feel able to do this they need their GPs, and those who provide primary care to be able to engage with them around these issues in a way that instils trust and is supportive.

Focus: 10 – 25 year olds who are thinking of suicide or self-harming.

Partners: Children and young people with lived experience of mental health problems and their families, and a collaboration between Health Education England (Darzi Fellowship scheme), Sussex Partnership NHS Foundation Trust, 25 primary care practices in Kent, Sussex and Surrey), Mind and Olly's Future.

Method: Primary care staff completed a survey around competence and confidence in supporting children and young people with thoughts of suicide or who self-harm. The results showed that some GPs (and practice staff) did not feel equipped or confident to support children and young people exhibiting these distressing thoughts and behaviours. From a survey with young people, it was also found that young people did not know they could go to their local primary care surgery for help with mental health issues. Through all the partners working together, the project utilised co-production in the development of the surveys, considering the findings and using these to develop new ways of working in collaboration.

Outputs: From the research, all partners agreed on the development of a Suicide Prevention Training, which is now being delivered on-line and is coordinated by Olly's Future (some of the trainers are clinicians). Children and young people contributed to the training by providing first-person video accounts. Individual primary care practices have also been supported to put together their own development plans through their involvement in the project.

Why this is co-production:

- Working in partnership with children and young people and organisations with a vested interest in making GP surgeries spaces where young people feel able to talk about their mental health and concerns about self-harm or suicidal thoughts.
- Issues of power relations considered, young people had an active role in decisions to enable them to take ownership of the work, going beyond being asked their opinion.
- There was not a pre-defined output but reflecting all stakeholders' ideas and needs, the team created something meaningful that GP surgeries could implement and young people would benefit from.

More information: <https://ollysfuture.org.uk/trust/>

Key learning

- **Acknowledge you're not the expert**, being **open, honest and transparent is an asset but** can be difficult for those in senior positions and/or big organisations.
- Keep reminding people **you're there to listen and understand**, not provide the answers – this frees you up, makes the uncertainty more tolerable and is less stressful. It is okay to say you don't know the answer because it's a complex situation but if we work together, we will be able to reach a solution.
- Be able to tolerate silences!
- **Trusting people** – that they hold answers. They will need to feel comfortable and heard to develop trust in return. Offer some **humility** and be willing to **trade power** with partners who bring different types of expertise and knowledge.
- Acknowledge **it takes time, there won't be a quick fix**, it is a process and don't be disheartened by the time it takes.
- Brokering with **big organisations** that want fast results might pose a challenge, so it can be good to **make shorter goals/quick wins**.
- **Going to where people are** rather than expecting them to come to you.
- Acknowledge people's **time commitment** – it is not for free.
- Find **people who are trusted by communities** and can **create bridges** with the project team. Nesta calls it a **catalyst person** who can help you get permission to sit around the table and ask the necessary questions.
- Co-production is not 'them and us' but a **collective process**. **Agree the mission statement**, what it is everyone is trying to achieve. For example, the group mantra for this project was 'practice hope'. Come back to this when things get difficult, when it feels like things might go off course or you are unsure how to move forward.
- Acknowledge that some people will drop out. Acknowledging people's contributions can help **keep them on board** and foster **confidence in the process**. We established ground rules but they were open to change and re-visited each session, an iterative process. For example, if one person dominates consider how to ensure quieter members are heard. It is better to have these conversations in advance.



Co-producing Covid-19 Resources with Ethnic Minorities (Co-REM)

Implementation Manager: Becky Sharp

Aim: To produce culturally sensitive information at the start of Covid-19 for the Indian and Nepalese community in Kent, Surrey and Sussex.

Rationale: Early in the pandemic there was evidence suggesting people from some ethnic minority groups, particularly those of South Asian descent were disproportionately affected by Covid-19 in terms of mortality, morbidity, and health outcomes. Evidence suggests that culturally tailored and sensitive information has more impact than generic leaflets which have been translated literally without considering cultural aspects.

Focus: Indian and Nepalese older people (≥65yrs) and their families and community members.

Partners: Brighton and Sussex Medical School, Implementation team, elderly minorities and their families, healthcare professionals and community leads.

Method: This was a Rapid Response Covid-19 project. Interviews with older people from Indian and Nepalese backgrounds were undertaken to gain insight into their understanding of Covid-19 guidelines. Three co-production workshops were held to develop relationships, reflect on the findings of the interviews and a literature review to decide how best to produce and disseminate information about Covid-19 to these groups. The materials produced were tested for usefulness and acceptability with members of the Indian and Nepalese communities.

Output: Leaflets (in various formats for Hindi and Nepali communities) disseminated via community groups engaged during the project, through social media and also through the ARC and AHSN Networks, which spread the information across the country.

Why this is co-production:

- Active participation and collaboration with each member from the beginning of the process to the end through the co-production workshops allowed for co-decision making.
- The voices of elderly minorities and families were listened to. Rather than passive recipients of resources, they became active members of the co-production process.
- Resources were developed through an iterative process and refined until agreement was reached.

More information: <https://www.bsms.ac.uk/research/primary-care-and-population-health/public-health/co-rem/co-rem.aspx>

Key Learning

- **Tap into existing connections and use what you've got:** we needed to capitalise on existing networks and connections and cultivate them over time for subsequent work. It was doing the groundwork that paid dividends. Our Principal Investigator is Nepalese and embedded within her community which meant that she was already known and trusted.
- **Developing trust over time:** the project was led by researchers who already had established links with the communities of interest. Given the short timeframe, small budget and urgency of Covid-19, this enabled rapid buy-in from all stakeholders which is unlikely to have happened without pre-existing links.
- **Equal participation and inclusivity:** three co-production workshops worked well because everyone worked together, with equal status, and grounded in the trust that had already developed between participants (older people, clinicians, researchers).
- **An iterative research process:** this links with equal participation – during the workshops we reflected on the findings collectively. Ideas were developed, tested and then implemented.
- **Impact:** think about this right from the start – how will you share findings as the project develops? What's your mechanism for sharing outputs at each stage? How will you evaluate impact of the project overall, and that of co-production?
- **Challenges:**
 - Expect the unexpected: it was surprisingly difficult to recruit enough clinicians.
 - Budgeting for co-production and dissemination activities: We discovered that one of the key channels for dissemination would be community radio channels but did not have the resources to pursue this.
 - It would have been informative to do follow up interviews a few months later – we have evidence that the leaflets were widespread (locally across KSS, across England, into Scotland and even picked up by a major media outlet in Nepal). We are now reviewing how we can better measure the impact in terms of improved understanding and behavioural change.



Covid-19 Pandemic on people with dementia and their carers

Implementation Manager: Kath Sykes

Aim: To explore the impact of Covid-19 on the life quality of people with dementia and their carers.

Rationale: At the start of Covid-19, dementia services were closed, staff re-deployed and charities were unable to carry out their normal functions. Voluntary services stopped almost overnight and staff in commissioned services were furloughed. Two projects, with similar aims, combined forces to share findings on the impact of Covid-19 on the quality of life of people with dementia and their carers. The findings highlighted key messages for services, commissioners, and service users.

Focus: People with dementia living at home with their carers.

Partners: Brighton and Sussex Medical School, Implementation Managers, University of Plymouth, UKRI, Improving Dementia Care and Sussex Partnership. We worked with an established group, the Lived Experienced Advisory Panel (LEAP, under the umbrella of the Sussex Partnership Foundation Trust).

Method: The Time for Dementia (TfD) Covid sub study followed a group of 245 family carers already participating in the TfD study during Covid lockdown. Carers completed quality of life (QOL) questionnaires about factors affecting wellbeing before and during the pandemic and 16 carers were interviewed, their QOL was compared to their QOL before Covid.

The DETERMIND-C19 (sub-) study compared QOL information collected before the pandemic to QOL gathered during it. Changes in mental, physical and social well-being were explored with 93 people newly diagnosed with dementia and 113 carers; service use was evaluated; and 21 people with dementia and 42 carers were interviewed.

Output: The TfD Covid sub study was developed in conjunction with the LEAP, members of the LEAP reviewed the qualitative findings, and key messages were developed with the lived experience advisory panel. Leaflets for commissioners/services and lay audience (various formats) were disseminated to target audiences throughout KSS, and national networks, informing Dementia and carer strategies, and support service delivery.

Why this is co-production:

- The LEAP were involved in the development of the TfD Covid sub study protocol development, they helped decide the approach and when researchers carried out QoL measures and interviews; they discussed interim findings; and helped co-design key messages over two virtual workshops where the researchers presented key findings prior to co-designing the leaflets.

More information: [Time for Dementia – BSMS](https://determind.org.uk/), Determind: <https://determind.org.uk/>

Key learning

Benefits and Challenges:

- The key benefit was the **added insight**, making us consider issues that we may not otherwise have thought about. The findings resonated with people on the panel experiencing this first hand.
- **Breadth of experience:** LEAP was excellent. It is more challenging to involve people with dementia and when they are involved, they are often reliant on their carer to help communicate their perspective. One couple had to drop out as the condition of the partner with Dementia deteriorated, and some members were not recent/current carers.
- Some people found it easier to **attend meetings virtually** as it reduced travel time and the need to find someone to cover their caring responsibilities. Some members of the LEAP had stopped being involved when it had to become virtual. A **hybrid** (virtual and face to face) **approach to engagement** and co-production needs to be developed to ensure everyone can be involved.
- **Diversity of participants:** we did not manage a wide diversity of lay advisors, reflecting local demographics and who was available. Try to increase diversity through existing networks but access and funding is key to facilitating engagement.
- Our workshops developed a leaflet that was co-designed with the LEAP but the chief investigator had final sign off, and at that stage the document was amended. The lesson being to **include everyone from the start**, including chief investigators.
- There had to be a rapid turnaround in response to Covid-19 so it was not possible to co-design the funding bid. Ideally, we would have involved **all stakeholders** in **co-designing** the bid.
- **Measuring impact:** the leaflet has been shared widely across academic networks, regional dementia strategy groups, and national dementia clinical networks. This has informed dementia and carers strategies in the region, and we have had some feedback on other likely impact, e.g., informing how dementia support staff may approach their work. However, it was difficult to measure impact of process having been co-produced.

What helped or would have helped in hindsight?

- LEAP was already **established** and the study team already had **links** which enabled relatively rapid co-production but lacked diversity (as above). It might have been preferable to develop a study specific Patient and Public Involvement and Engagement (PPIE) group, drawing from the LEAP and other networks across KSS but this needs to be balanced against having too many people involved.
- LEAP enjoyed an **equal working relationship** with the project team, reflected in co-decision making and co-designing the leaflets. However, we should have involved the chief investigator earlier to be more inclusive.
- **Funding upfront** for co-production/co-designing application: this is always a challenge but if people are giving their time for free, then they are not equal partners.



Remote Memory Assessment practice guidance: an evidence-based toolkit for clinicians and managers (Remote-MAS)

Implementation Manager: Kath Sykes

Aims: To understand patient and clinician satisfaction with a remote pathway for memory assessment and dementia diagnosis; to support people living with dementia and their carers to engage with remote memory assessment; to support clinicians and managers in memory assessment/dementia diagnosis services with evidence-based guidance toolkit and a set of standards to implement the remote pathway with confidence.

Rationale: At the stage the project was initiated, memory assessment services had been closed due to Covid and pragmatically some services started to offer a Remote Memory Assessment Service (RMAS), implemented in a variety of ways, but with no evidence to support pathways. This study allowed a rapid evaluation of these services, including satisfaction about how they were delivered.

Focus: People with subjective cognitive impairment, people with dementia living at home alone or with their carers; clinicians and service managers carrying out memory assessments with this client group.

Partners: A lived experience advisory panel (LEAP) consisting of people living with dementia and carers; the North West Sussex memory assessment service; a Memory Assessment Service (MAS) in Surrey; and the MAS at South London and Maudsley Trust (clinicians, managers and commissioners).

Method: The study recruited 81 participants to complete an experience and satisfaction questionnaire and 20 participants/dyads to complete interviews about their experience of remote memory assessment across three sites. Statistical analysis explored factors associated with high levels of satisfaction and dissatisfaction with the remote pathway.

Output: An animated film explaining the remote video pathway to patients and carers and a downloadable toolkit for clinicians/managers outlining recommendations for successful conduct for RMAS.

Why this is co-production: LEAP were involved in the design, satisfaction questionnaire and family facing documents. The toolkit was co-designed with all partners using on-line workshops. We made sure everyone had time to speak - clinical academics, carers and one person with dementia.

More information: <https://arc-kss.nihr.ac.uk/research-and-implementation/living-well-with-dementia>

Key learning

Challenges and Benefits:

- The toolkit was clinically orientated so it would have been easy to focus solely on clinicians' views. However, it was equally important to include the perspective of those with dementia accessing these services.
- Carrying out workshops and working on documents remotely was challenging; it would have been more natural/fluid if we had been in the same room.
- Again, lack of diversity was an issue (as it was the same group, LEAP, see p10) although there was reasonable diversity amongst clinicians.
- Dementia academics were clinicians and cognisant of the importance of the patient/carer perspective but there is always the danger that professionals can dominate.
- The toolkit will be a clinical document so it needs to meet specific standards, this creates constraints which may not be familiar to all partners in the co-production process.
- Funding determined implementation: we were lucky to secure additional monies to support implementation.
- Evaluation: impact of the research is already clear – we have already informed regional services with various models for memory assessment services post Covid: One county was considering a remote first model, one had returned fully to face to face, and one was offering a mixed hybrid model to its patients.
- Various outcomes inform services: With support people with subjective cognitive impairment can utilise remote consultation technology, and some prefer it; contrary to expectations (including the LEAP and some clinicians), we found that everyone preferred video consultation to telephone because they could see the other person; the benefits of remote memory assessment services go beyond Covid, and should be part of a pathway offer.
- It will be harder to evidence the *impact of co-designing* the toolkit and video.

Tips:

- **Getting started:** With rapid studies responding to emerging need, researchers need to think about output and implementation to have most impact in a responsive way.
- **All stages, all views:** researchers should involve service users/carers in all parts developing the care pathways to understand different views at different stages e.g., receiving a diagnosis via a video link may be different to having an assessment remotely; and include people with a range of opinions to ensure **breadth of both opinion and experience**.
- **Power issues/hierarchy:** think through right at the start the role of co-production in recommending clinical pathways. Agreeing and regularly reviewing ground rules, expectations and roles can help to ensure clinical standards are met, while benefitting fully from lived experience.