EMPOWER
Dementia Network+

Co-production Toolkit

—

A guide to working in co-production
with people living with dementia

Contents

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We are the EMPOWER Dementia Network+

- A national network committed to addressing inequalities in dementia care and research.

- Funded by the Alzheimer's Society, Economic and Social Research Council (ESRC) and the National Institute of Health and Care Research (NIHR).

- Bringing together lived experts, community partners, researchers, and health and care practitioners from across primary, social dementia, and palliative care to co-develop inclusive, impactful solutions.

About this toolkit

Co-production is at the heart of the EMPOWER Dementia Network+. We believe research is stronger, more relevant, and more ethical when it is shaped and delivered in partnership with those most affected by its outcomes.

This toolkit brings together practical tools, resources, and guidance to support meaningful co-production. Whether you are a researcher, a lived expert, or a community partner, this is a space to help you plan, reflect on, and strengthen your co-production practice.

Our definition of co-production

A collaborative approach that prioritises equity, shared power, and shared responsibility among all participants in a safe space. Our approach recognises that everyone has a right to be involved in research and changing practice. It ensures the ongoing involvement of diverse and inclusive groups, especially those directly affected, from the outset.

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Co-production should be considered at every stage of a project

Planning

Delivery

Outcomes and dissemination

Impact
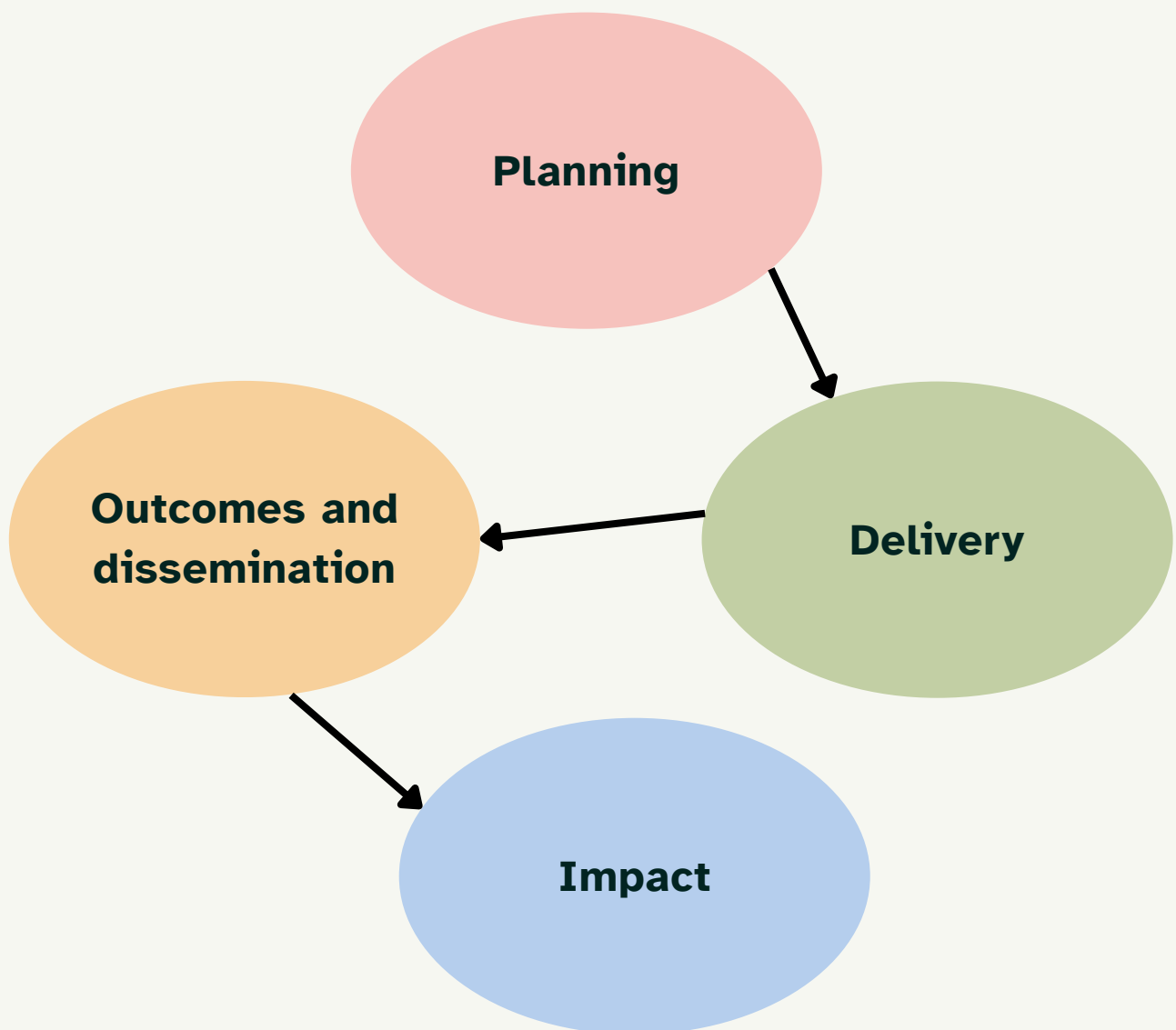
To ensure success, it is important that we consider the potential challenges to co-production and what solutions we can use to help.

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Planning stage

- Engage lived experts from the very start

- Respect their choice in participation

- Build trust by understanding their experiences and sharing your own

- Plan for personalisation and accessibility of materials, meetings, travel and payment

- Co-produce aims and agree expectations

- Keep communication open with regular check-ins

- Prioritise opportunities for meaningful contributions

- Prioritise relationships, shared understanding and mutual respect

- Continue to engage with individuals throughout planning process to strength research and improve outcomes

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Case study:
The PLEDGE group
by Stefanny Arroyo

Researcher, Stefanny, shares her reflections of working with People with Lived Experience of Dementia Group – EMPOWER (PLEDGE)

"As our project moved from vision to delivery, planning became its own form of co-production. What started as a small group of three lived experts soon became eight, each bringing rich experience and ideas. Our original terms of reference no longer fitted, so we had to adapt quickly. We also updated our introductory materials to explain the purpose and structure of the project in a more accessible way.

We began by checking in with each member individually, recording communication and access preferences in a shared log – this included practical details like working hours and memory support needs, to what kinds of tasks people found most meaningful or enjoyable based on their personal and professional experience.

Some of these preferences changed over time and that was okay. We reviewed them together, ensuring they remained accurate and useful. One key learning: coordinate internally before reaching out, so Lived Experts aren't asked the same questions more than once. And make sure new staff are familiar with this log to avoid making Lived Experts repeat themselves.

EMPOWER's Co-creation Event – October 2024

![EMPOWER Dementia Network+ logo]

People wanted more updates between meetings, so we started a biweekly bulletin. At first, I wrote it myself and shared updates. It was well-received, but after a few months, one of the Lived Experts suggested co-writing it – and that small shift transformed the dynamic. It became more engaging, personal, and genuinely co-produced. Saying yes to that suggestion created a more equal working relationship.

Planning also meant learning how to handle mistakes and **keeping a log of this feedback**. When things went wrong (and something always does) what mattered most wasn't offering a long explanation. It was offering a sincere apology and a plan for repair. Saying, 'I'm sorry this happened, here's what I'm doing to fix it', went further than formal justifications ever could.

We often think of planning as a behind-the-scenes task, but in co-production, it is the work. And it often happens while managing other responsibilities. This work takes time – time that must be recognised and protected in your workload.

Key lessons: be honest and treat people as equals (as you would a colleague, not a client), ask for help and acknowledge mistakes, keep a record of decisions and conversations, and make space for Lived Experts' suggestions, even if it changes how you normally work."

Delivery stage

- Start every session by revisiting the Terms of Reference and ensuring they guide the group

- Use tools like "I want to speak" cards to support contributions and expression

- Balance structure with flexibility: allow organic conversation but respect preferences for agendas

- Check-in after sessions to reflect and adjust for future meetings

In-Person

- Arrange travel and accommodation thoughtfully; offer alternatives like home visits or escorted transport

- Send accessible info packs with itinerary, photos and venue details

- Provide a welcoming space, light refreshments and seating that encourages interaction

- Offer quiet, low-stimulation areas

- Offer creative tools for self-expression

- Reimburse promptly or communicate delays clearly

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Online

- Offer opportunity to meet before meeting starts

- Allow extra time for tech setup

- Begin with introductions and co-produced Terms of Reference

- Use soft starts and informal icebreakers to build connections

- Keep presentations short and slides accessible

- Practice using breakout rooms and only use when necessary

- Prioritise people with dementia to speak promptly

- Co-chair to monitor chat and support with technology

Hybrid

- Dedicate a facilitator to support with online participation, and to monitor and support with technology

- Ensure technology is avaliable to enable in-person and online participants to connect

- Ensure everyone can see and hear each other; check sound

- Set ground rules to reduce disruption for participants

- If using breakout rooms, keep online participants together with a few in-person attendees

- Continuously evaluate whether hybrid sessions are equitable; consider fully online if more inclusive

Case study: Sensory Trust

Sensory Trust is a national charity based in Cornwall. It's flagship dementia project Creative Spaces supports people with dementia and their carers to enjoy accessible nature experiences.

The project involves the running of 9 dementia-friendly activity groups which involve walking and other nature-based activities. The project encourages co-production by:

- Asking members to chose a group name, their walking routes and activities

- Inviting members to help with refreshments, fostering a culture of taking care of one another

- Always asking the group their thoughts should external opportunities be presented

- Creating an Ambassador role, for those who are keen to speak about and promote their group

- Supporting individuals to bring their unique skillset and shaping activity around this

- Training volunteers to support the group rather than lead (apart from when First Aid or Safeguarding is required)

Outcomes, dissemination and impact

- Involve lived experts in writing, reviewing, and launching outputs, not just in project delivery

- Support them to engage directly with academic texts, beyond easy-read formats

- Offer flexible dissemination options: recorded talks, interviews, films, exhibitions, creative outputs

- Recognise the lived experts' intellectual contribution and authorship visibly

- Integrate qualitative insights into research outputs to strengthen impact

- Use co-produced outputs to influence policy, practice and public understanding

- Lived experts can be looking for different impact and it's important this is captured and shared

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Case study:
The Photobook Project

The Photobook Project CIC invites people living with dementia around the world to document, share and celebrate their lives and perspectives through the arts, primarily photography. Participants have the opportunity to co-create their very own professional 'photobook', capturing their life story and present experiences.

Between 2020 and 2022 the project team collaborated with David Truswell and Ronald Amanze to deliver "My Dementia Life Matters". The project highlighted the unique challenges experienced in African, African Caribbean and Chinese communities when living with dementia in the UK.

Flexible funding from the Race and Equality Foundation and UnLtD enabled the team to be open to the right outcome for the project as it evolved. Inspired by the desire to reach younger audiences, Ronald suggested producing a film. This led to the creation of Amanze, capturing Ronald's former life as a Pirate Radio DJ and his experience of The Photobook Project.

Launched in 2022, the film AMANZE has won multiple awards and be shown at six film festivals nationally and internationally, breaking the mould of how projects can share power equitably and continue to create meaningful impact.

Ellie from The Photobook Project reflects on the importance of regular online chats to build rapport and being open to the project evolving in new and unexpected ways. Ronald shares the impact for him on the following page:

The Photobook Project

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"This project sewed the seeds from which I now have the confidence to run my own groups in my community. It's my example of meaningful inclusion"

"The Photobook Project is my example of what is possible"

AMANZE
'A PORTRAIT OF A PIRATE'

DIRECTED & PRODUCED BY LUCY HAWES

The Photobook Project
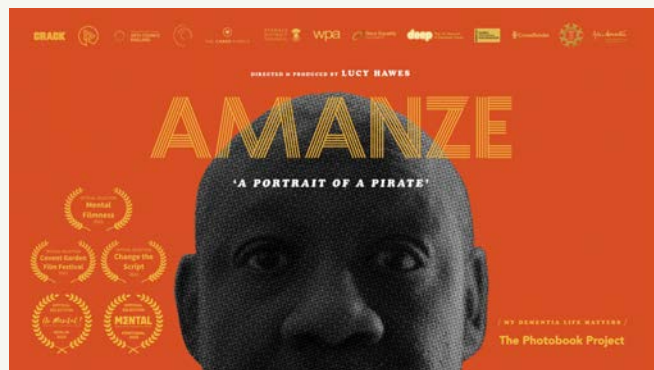
The diagnosis might be an ignition for people to embrace another phase of life.

Challenges and solutions

- **Fluctuating participation:** Accept that lived experts' capacity can vary due to "foggy days", appointments or health changes

  Solution: Build flexibility into session plans and consult participants on how to proceed in a way that best suits them

- **Emotional intensity:** Sensitive topics (e.g. palliative care) may cause distress

  Solution: Provide one-to-one support, check-in during and after sessions, and remind lived experts they can opt out at any time

- **Health conditions:** Physical and mental health conditions may affect consistency

  Solution: Be attentive, continue to speak with lived expert and signpost appropriate support (e.g. Mind, dementia helplines)

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- **Balancing participation and wellbeing:** Co-production can be demanding for both lived experts and researchers, especially early career researchers

  Solution: Check-in regularly, set clear expectations, revisit Terms of Reference and formalise communication protocols (response times, boundaries, out-of-office guidance)

- **Scope expansion:** Co-production may broaden research questions, creating additional workload

  Solution: Maintain flexibility, share decision-making with the team and prioritise tasks collaboratively

- **Isolation:** Challenges can feel difficult to manage alone

  Solution: Use peer support networks and maintain open dialogue with colleagues and lived experts to share responsibility and problem-solve collectively

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Top tips

- **Support participation** through practical measures: accessible materials (e.g., Helvetica, size 18), printed copies, Zoom instead of Teams, regular check-ins and flexible involvement

- **Be open to adapting** the project journey and outputs based on participants' needs

- **Keep an impact log** to track lived experts' input and demonstrate the impact of their contributions to them

- **Plan a realistic budget** that allows for diverse engagement and fair payment (e.g. NIHR standard £25/hour)

- **Don't make assumptions:** keep asking questions, staying connected, and responding to feedback.

- Learn from other project teams and **share best practice**

- Create your own top tips as you learn about the participants. Everyone is different, so **tailor your approach**

Other tools and resources

This section brings together practical tools, templates, and guides developed by others working in co-production.

We have included materials that can help with different stages of co-production. Wherever possible, we have included credit and links back to the original authors.

This toolkit is a living resource. As new tools and insights emerge, we will continue to update and grow it.

If you have a resource or approach you have found helpful, we would love to include it. Please get in touch by emailing us at:

EMPOWER_Dementia_Network@kcl.ac.uk

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[Alzheimer's Society – Co-production Guides](#)	Guidance on running co-production with people with dementia, including pros, cons, and practical resources
[Co-Production Collective (UCL)](#)	A continuously updated library of case studies, toolkits, articles, videos
[DeNPRU Exeter – What Works When Working Together](#)	Practical guidance for running online meetings, offering flexibility for participants with different requirements
[Dementia Enquirers](#) • [The Dementia Enquirers Gold Standards for Co-Research](#) • [The Dementia Enquirers Gold Standards for Ethical Research](#)	Provides Gold Standards for co-research and ethical research with people living with dementia
[IMPACT](#) – • [Co-production Approach](#) • [Academic Seminar, Theories and Practice of Co-Research](#)	a programme that co-produces care and support research and services with people who draw on care and carers
[KCL Digital Health Hub – Co-design Workshops](#)	Flexible training in digital health, co-creation, and data skills
[MinD – Designing for People with Dementia](#)	Supports co-design and wellbeing-focused design for people with dementia, mental illness, and neurodiverse conditions

[NIHR – Community Engagement Toolkit](#)	Guidance on co-producing a research project
[NIHR ARC East Midlands – Training Video](#)	A session introducing co-production e.g., what it is (and isn't), why it matters, and practical tools and tips
[NIHR ARC West](#) [Map of Resources](#)	A guide and resource map in co-producing health and social care research
[Sensory Trust - Access Chain: an inclusive design tool](#)	An inclusive design tool to review access and plan events from the visitor's perspective
[SCIE & Citizens UK – Community Engagement Sessions](#)	Co-production training and resources to help health and social care staff, service users, and carers work together to improve services
[SMARTIES Edinburgh Group](#)	Guide on key points about co-producing research with people living with dementia
[Stronger Together – Ageing Better Toolkit](#)	A toolkit co-created with older people to share learning, stories, and resources
[VOX Scotland - Making Co-production Work](#)	Guidance to help genuinely co-produce mental health policy and practice with people who have lived experience

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Visit our website:

www.empowerdementia.co.uk