

Co-Production: "The Real PPI"

The Researcher's Toolkit



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Co-Production: An Overview



What is Co-Production?

Co-Production is a collaborative approach to research, where people with:



experience work together to conceptualise, conduct and disseminate research¹⁻³



Co-Production involves incorporating some key principles:

Ownership and understanding of research and co-production by all team members

Facilitating a culture of openness and honesty

Commitment to sharing power and decision-making with team members

Communicating in lay language and avoiding scientific jargon



Co-Production takes place throughout the research process, while **co-design** typically takes place when conceptualising a research project

Benefits of Co-Production

Co-Production benefits a multitude of groups:

Researchers



- Enables more meaningful and insightful research
- Challenges preconceptions and stigma associated with a condition

Clinicians



- Improves evidence-based, person-centred interventions
- Facilitates more collaborative clinician-patient relationships

The Lived Experience Community



- Enables the community most affected by the research to shape it
- Dissolves barriers, builds trust, and allows EbEs to acquire a unique skillset



Members of the Public



- Highlights the societal importance or nuanced aspects of a condition
- Improves understanding of a condition for parents, carers or loved ones



Co-Production strengthens many aspects of the research process:

Acquiring Funding



Co-production aligns with many funders' priorities.⁴ It reassures funders that your approach is comprehensive and addresses real-world problems

Publications



Following co-production principles reassures journals that your research will be impactful and can be understood by many different audiences

Co-Production Gone Wrong: Faux-Production

Faux-Production⁵ occurs when co-production becomes a 'box ticking' exercise & performed thoughtlessly, and can look like some of the following things:

Tokenism



Including EbEs within your research without giving them a meaningful way **to contribute**

Rubber Stamping



Only including EbEs who are likely to agree with study decisions made by traditional research teams

Power Imbalances



Traditional research teams not addressing emerging or existing imbalances during co-production

Unused Feedback



Collecting feedback from EbEs only to disregard or not use it when making important research decisions

Implementing Co-Production



Getting Started

Before Your Research

Including co-production means you will need to account for extra time to **accommodate individuals**, and extra costs or resources to **adequately compensate** members of the lived experience community

Use focus groups or lived experience panels to **identify research priorities** for the community in question. These can be groups developed by yourself, or existing organisations!

Connect with peer researchers or researchers with lived experience of the community in question to **ensure the lived experience is embedded** across the project

Ensure there are **no surprises** between members of lived experience and academics. What does co-production look like for your particular study?

Allocate time & resources
for co-production

Develop or connect with an
existing lived experience
network

Engage with or add peer
researchers to the team

Establish roles, shared
goals and expectations
from the outset

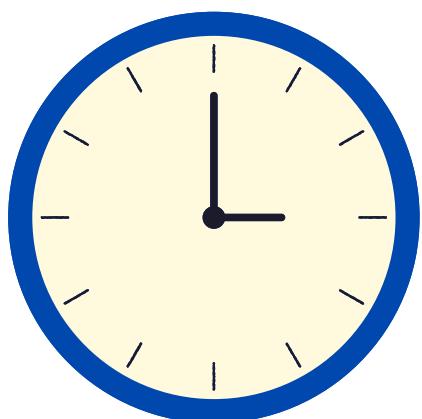
Getting Started

Time & Resources



Allocate Time & Resources for Co-Production

Co-produced research **generally takes longer** to conduct compared to research not implementing co-production.



More time is needed to:

- Collaboratively and iteratively design research
- Train members of the lived experience community on a given research approach



Ethical co-production involves **compensating** all participants and experts-by-experience who helped shape the research.⁶

Additional funding is required to:

- Compensate PPI or lived-experience collaborators and research participants, as well as support PPI events

If monetary compensation isn't possible, communicate this transparently and consider alternative options such as co-authorship or learning and development opportunities.



*See Appendix A.
for compensation
recommendations*

Getting Started

Lived Experience Networks



Develop or connect with an existing lived experience network

Either identify an **existing** lived experience network, **or form one** as part of your study design

(If forming a network, make sure you sustain it in the long-term!)



*See Appendix B.
for examples of
research groups*

- Connect with established community organisations or charities focused on your research
- Seek other research groups in your discipline who have conducted co-production
- Do your own research to identify relevant communities online and via social media



If developing an existing lived experience network...

Compensate your lived experience members, and include these costs in your study budget!

Getting Started

Peer Researchers



Engage With or add Peer Researchers to the Team

Peer researchers are individuals who have **personal experience** with the topic being studied and actively participate in the research process

Peer researchers are involved in bringing their **unique perspective to the research**. They are involved in research activities such as:



- *study design*
- *data collection*
- *analysis*
- *interpretation of findings*

While neither act as research participant, **peer researchers and researchers with lived experience** come from slightly different places:

- Unlike researchers with lived experience, peer researchers are not researchers by professional background

Inclusion of a researcher with lived experience does not exclude the benefits a peer researcher can bring to the team!

Sorting out a specific contract for your peer researcher can be tricky: general practice for employment of peer researchers is still being established.

It's recommended you **consult recommended salaried or per-meeting rates^{6,7}**, and discuss with your local research & development team.

Getting Started

Establish Roles

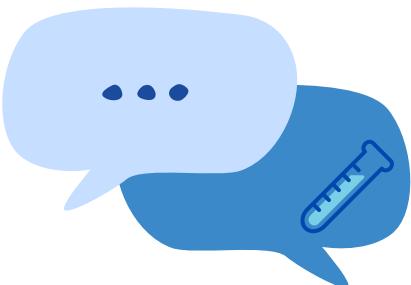


Establish roles, shared goals and expectations from the outset

Whether working with experts by experience on a panel, or co-designing a study with a peer researcher, there is **a lot of information that needs to be conveyed**, such as:

Information About Research

- *What is the study about in lay language?*
- *How is the research relevant to the lived experience perspective?*
- *How can co-production help? What are the levels of co-production needed for the study?*
- *What is the size of the research team?*
- *What does the study timeline look like?*
- *What are the expected outputs of the study?*



Information about Co-Production



- *What is the role of the lived experience member? In what ways is this role similar or different to the academic's role?*
- *What does the timeline for lived experience participation look like (i.e., length of role)?*
- *How accessible is the research, and will the research team need to make any amendments to accommodate or support experts by experience?*
- *Will the expert by experience receive or need to undergo any training for their role?*
- *What can the expert by experience expect after co-designing or co-producing the research?*

In the Thick of it

During Your Research

Conduct workshops, or even additional studies, to identify **important priorities for the lived experience community** you are working with



Identify important research questions

It is important to ensure that members of the lived experience community, where possible, are able to **equally engage** with recruitment approaches and research activities



Ensure that your research incorporates accessible recruitment & approach

Are there **evaluation tools that have been adapted** to better fit the context of the lived experience community you are working with?



See if you can use adapted measures in your research

Make sure you provides continuous cycles and opportunities to **modify boundaries, expectations and roles** for lived experience members and academics co-producing research



Implement iterative adjustments during research co-production

In the Thick of it

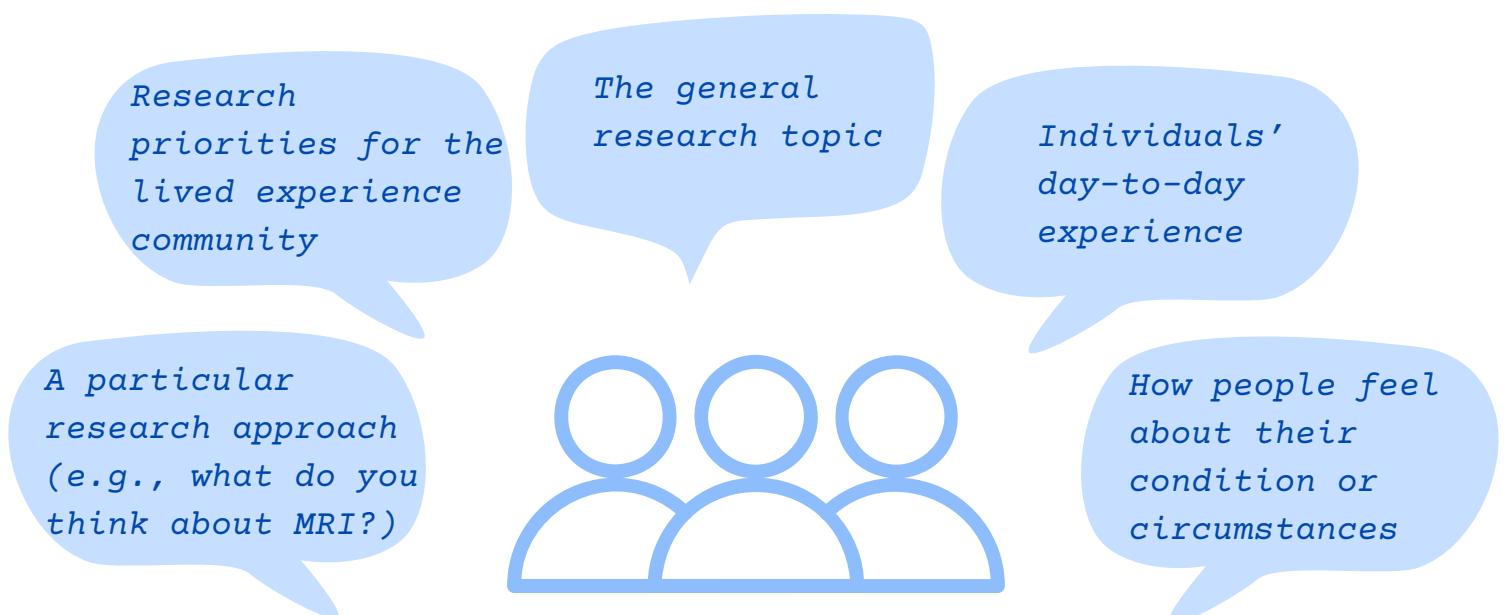
Research Questions



Identify important research questions

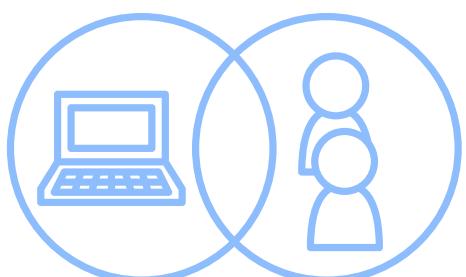
Consider running **workshops** or **focus groups** to hear from the lived experience community:

Think about including the following topics:



Online or In-Person?

An **online** format can facilitate discussions on a more inclusive level (e.g., geographical location)



An **in-person** format can promote more engagement with other group members and conversational topics

Conduct Preliminary Research!

Demographic survey?



Quantitative?

Qualitative?

Semi-structured interviews?

Running **preliminary research** also provides you with evidence to strengthen a research study rationale, ethics application or funding bid

In the Thick of it

Accessible Recruitment



Ensure that your research incorporates accessible recruitment & approach

Think about **modalities** to disseminate information about research.



(e.g., online or in- person flyers, audio/video recordings, etc.)



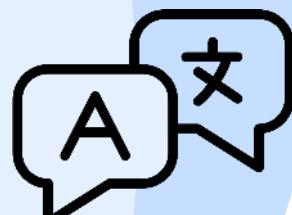
Consider potential **under-served** groups associated with the research

what **accommodations** need to be implemented to ensure equal engagement with the study?



Think about **typical** barriers to study access, as well as barriers **specific to your research** topic or study:

(e.g., age, ethnicity, geographical location, level of education, household income, language, etc.)⁸



In the Thick of it

Adapted Measures



See if you can use adapted measures in your research

Adapted measures are instruments, questionnaires or techniques that have been **modified to suit a new research context or population**



For instance, take a look at the [Generalised Anxiety Disorder-7](#) and [Patient Health Questionnaire-9](#) adapted and [validated](#) for those with intellectual disability⁹

Ask individuals with lived experience...



what they might think about the **standard approach**,

present them with **adapted tools** where possible,



and ask them whether **they would prefer** an adapted tool be used!

However...

It is important to make sure adapted tools have been **scientifically validated**!

In the Thick of it

Iterative Adjustments



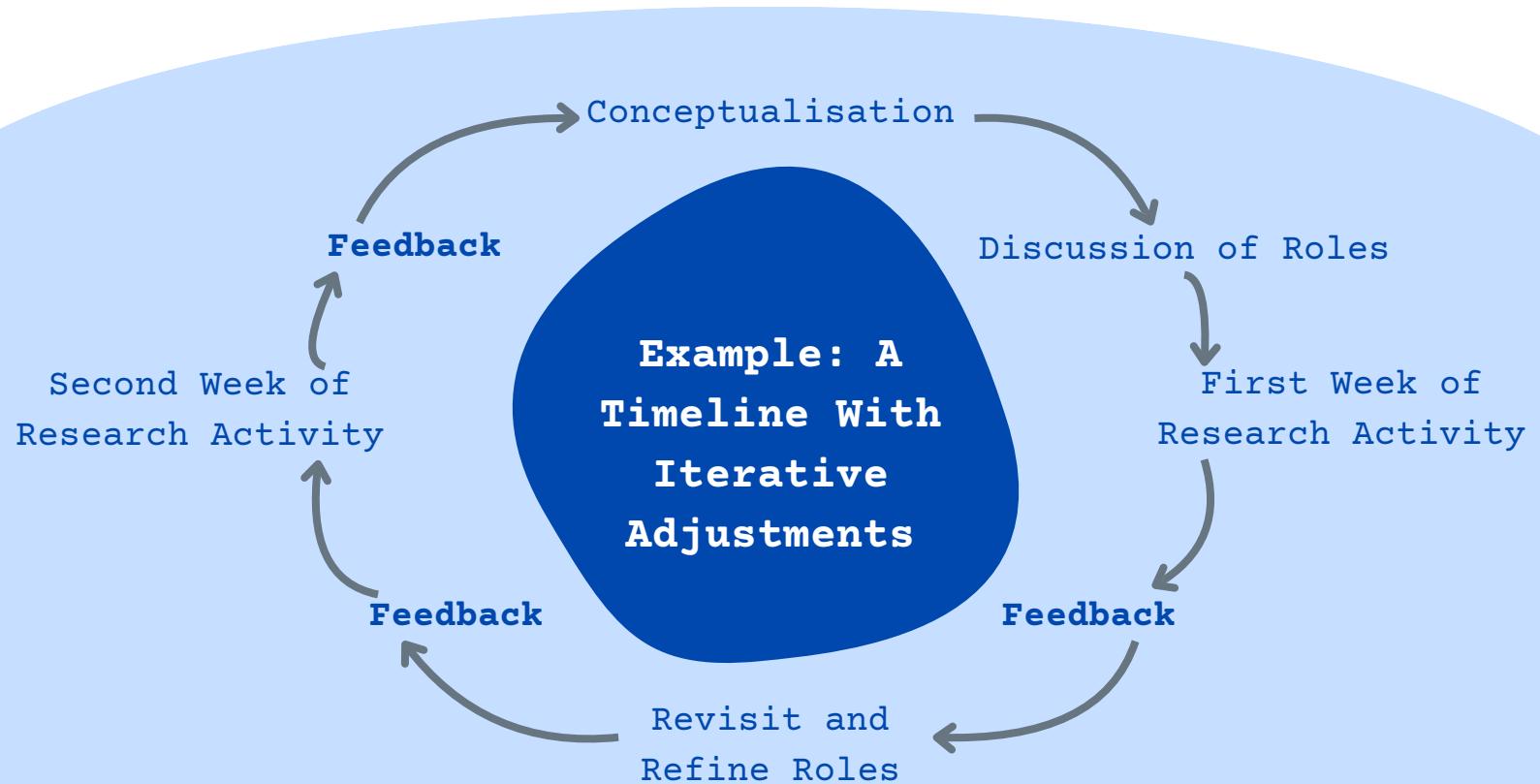
Implement iterative adjustments during research co-production & approach

Revisit agreements and boundaries for co-production established at the beginning of the research process

Is there a new research approach that could be incorporated into your study?

Have team members' circumstances changed, and will this impact allocation of responsibilities?

Have power imbalances started to emerge since initial co-design of research?



Pencil in **regular meetings** with your entire research team to regularly revisit team member responsibilities!

Winding Down

Finishing Your Research

If you have a peer researcher on the team: is the peer researcher willing to partake in analysis of data?



Have Peer Researchers

Analyse Data

Enquire with involved community members on whether they may be able to **feed back their thoughts on your findings**. They may be **interested in reviewing** your conference abstract, manuscript or lay summary



Have community members or peer researchers review your research output

Think about how to **report the level of PPI involvement** for the research. Consider the tools or guidelines available to help out



Think about how to report PPI involvement

Winding Down

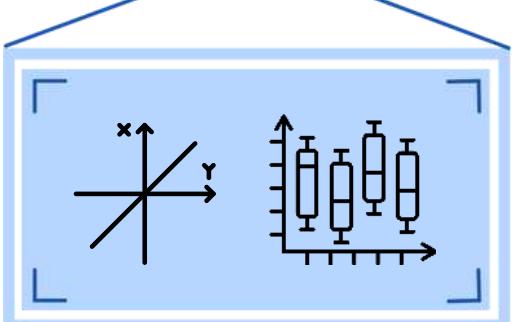
Have Peer Researchers Analyse Data



Have peer researchers analyse data

Consider the **types of data** that your research study will be collecting...

What kind of analysis could peer researchers help out with?



Also acknowledge the amount of time you and the peer researcher have **agreed to**, and consider any research activities with this **context in mind!**



If the peer researcher on the team does not have research experience:

Is it possible to provide them with training or experience to meaningfully contribute?

This not only enhances your research quality, but benefits the skillset of the peer researcher!



See **Appendix C.** for a list of free online training courses provided by higher education institutions or reputable research funding bodies

Winding Down

Review Research Outputs



Have trusted community members interpret findings

Including peer researchers, consider **members of the community** that could provide lived-experience-led interpretation of your research findings and output

"This finding could be really important to provide recommendations for interventions"



"The use of language in the manuscript may need more thought"



"Does this work consider the intersectionality of lived experience community members who also experience [X]?"

Remember: It's best practice to compensate community members for their time taking part!

If there is limited funding, consider alternative forms of payment, such as **co-authorship**

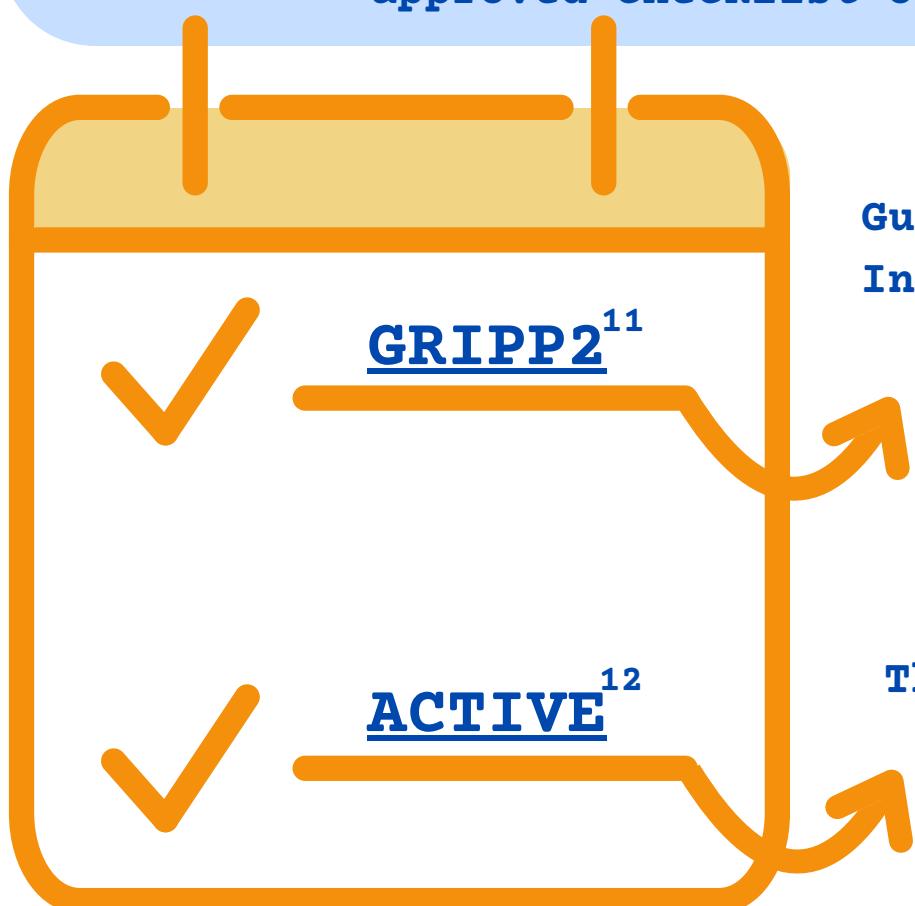


Think about how to report PPI findings

Accurately reporting the level of lived experience involvement in your research is not only useful for audit purposes and transparency, but is also recommended to improve research standards¹⁰



Aside from noting the level of co-production in any research outputs, consider using an **approved checklist or tool**



Guidance for Reporting Involvement of Patients

Used in primary research
(Complex version;
simplified version)

The ACTIVE Framework

Used in Systematic Reviews
(Full version)

Spreading the Word

Disseminating Research

Research participants have spent time contributing to your research, and it's best practice to **share your findings** with them when possible



**Share research findings
with participants**

Similar to recruitment and research participation, make sure research dissemination is accessible - **use different modalities and formats** to make sure everyone can access your findings!



**Provide accessible lay
summaries in multiple
formats**

If there are opportunities to showcase your research, **include** peer researchers, lived experience community members, or research participants in presentations



**Present research outputs
with lived-experience
community members**

All your hard work co-designing and co-producing research with a lived-experience community should not disappear once the research has ended - **keep up the momentum!**



**Take steps to create a
lived-experience network
for future research**

Blank checklists of all research steps may be found in **Appendix D. and used for your own research!*

Spreading the Word

Share Research Findings



Share research findings with participants

It is best practice for researchers to share their study findings with participants

Depending on the study's sample size, consider:

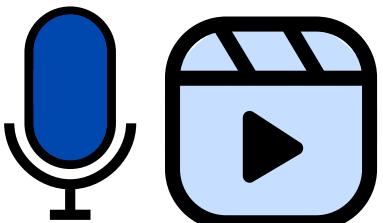
Lay summaries and infographics



One-to-one discussions



Recordings or videos of findings



Also inform participants about the **future of the research**: will it contribute to a future funding bid? A validated intervention?

*If a future manuscript is not open access, provide all participants with a **copy** to read!*

Spreading the Word

Lay Summaries



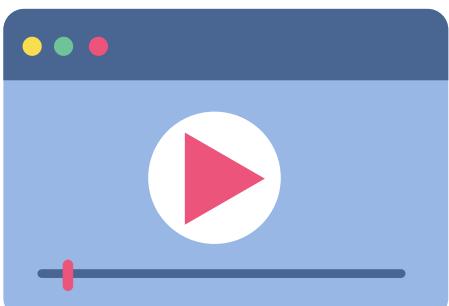
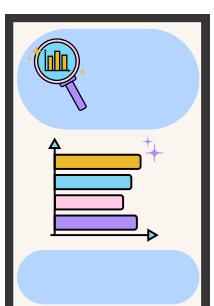
Provide accessible lay summaries in multiple formats

Lay summaries, or summaries of research with non-scientific jargon, are crucial approaches to research dissemination

Lay summaries have the following characteristics:

- Use of **plain language** or explanation of technical terms if they are important to include
- Language is easy to understand and is **concise**
- Accessible to different audiences of different educational backgrounds or language
- **Exciting** and engaging, showing the importance of the research

Lay summaries can also take form as recordings, interviews or videos - accessibility is key!



Spreading the Word

Present with Community Members



Present research outputs with lived-experience community members

Presenting research with peer researchers or members of the lived-experience community provides opportunities:

To showcase the importance of the research



For members of the lived experience community to gain skills in presentation design and delivery



Co-design presentations with lived-experience community members, and see if there would be interest in presenting alongside you



Consider what the individual would be **most keen to present on**, and if they would like to share their **personal experience** (providing the individual is comfortable to do so)

Spreading the Word

Network for Future Research



Take steps to create a lived-experience network for future research

Finally...

Co-producing and co-designing research **builds trust** between members of the lived experience community and academics/researchers

Keeping the momentum going not only benefits **community members** by providing them with agency during the research process, but also benefits academics by establishing a group of individuals **willing to partake in future research**

*Ask for permission to retain **contact information***



*Create a **mailing list** or **newsletter***

*Create a **shared space** for lived experience collaborators, such as LinkedIn Group or Padlet space*

*By retaining a **research participant group**, the process of co-production becomes an accumulative and iterative process, and **takes less time** to set up for future research*

Other Tips & Tricks: Co-Production



How Do We Identify Effective Co-Production?

Effective co-production can be identified through **one or more** of the following factors¹³:

All points below act as **stepping stones** for this goal!

Testimonials?

Quotes?

Advances evidence to support policymaking

Socioculturally competent outputs

Strengthened social relations and trust

Acknowledgement of lived experience

Clear outcomes:

New approach? Updated intervention?

Essential for any co-production!



Take a look at some co-production **case studies**:

[Improving Dementia Services in Broxtowe¹⁴](#)
[Nottingham West Primary Care Network](#)

[Norfolk and Suffolk Recovery College¹⁵](#)
[Norfolk and Suffolk NHS Foundation Trust](#)

[Exchanges: Inspiring Parkinson's Conversations¹⁶](#)
[MRC Protein and Phosphorylation Unit & University of Dundee](#)

[Eating Disorders and Autism Collaborative¹⁷](#)
[University of Edinburgh, University of Aberdeen, King's College London](#)

[Our Cancer Our Way - Always¹⁸](#)
[Involving children and young people in developing cancer care specification](#)
[Wessex Cancer Alliance](#)

Conveying Key Information

Information



Let's review some key information that you should provide to members of the public, and the lived experience community

Information on Research

- Area of research
- Research aims
- Research relevance
- Research team size
- Ethics of research
- Research Roles (role of the public, role of researcher, role of lived-experience community member)
- Research output (clinical use of research, data outcomes)
- Potential conflicts of interest

Information for PPI

- Purpose and level of co-production for research
- Compensation methods
- Role of lived-experience community member vs. researcher
- PPI-based condition (treatment options, diagnostic options)
- Signposting (Research team contacts, relevant resources and services)
- Expectations of role (role duration, introduction to research)
- Research training opportunities
- Options to withdraw from the role

Information on Accessibility

- Use of lay language
- Equality & inclusivity measures incorporated into research
- Disability information for online and in-person research sites (e.g., accessing the research site)
- Expectations of role (role duration, introduction to research)
- Dissemination of findings & output modalities (e.g., animations, lay summaries, videos, infographics, etc.)

Overcoming Challenges in Co-Production

Allocate Time and Resources From the Get-Go

- Without ample planning time, co-production can quickly become faux-production!
- Time allocation includes considering research steps such as ethical approval, where more time may be required to rationalise your approach

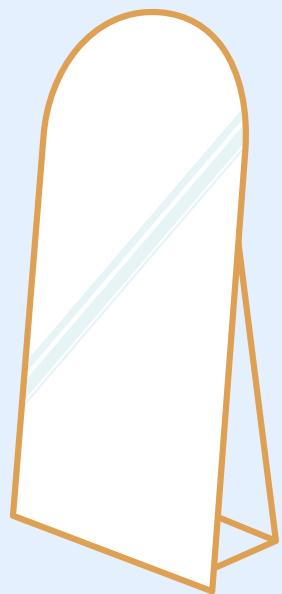


Strike a balance between accessibility and scientific integrity

- Sometimes feedback does not reflect what is currently feasible for you or your research - **clear communication is essential!**
- Different communities may not agree on what ethical research practice looks like. Talking out these differences while keeping shared goals in mind is fundamental

Flexibility and reflection is key!

- It can be easy to feel defensive if traditional research approaches are challenged; **reflection and open communication is fundamental for true co-production**
- Sometimes we can lose track of decisions made during co-production, so allocate time to revisit previous thoughts and decisions, and keep a log of decisions made for the group!



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Compensation Recommendations

Cost	Level of Involvement
£12.50	<i>For involvement in a task or activity such as reading and commenting on an abstract which equates to less than half an hour. For example, reviewing papers for the development of Alerts.</i>
£25.00	<i>For involvement in a task or activity requiring little or no preparation and which equates to approximately one hour of activity or less. For example, participating in a focus group to provide feedback on a proposal.</i>
£50.00	<i>For involvement in a task or activity likely to require some preparation and which equates to approximately two hours of activity. For example, a teleconference with related papers to read or review a few short documents.</i>
£75.00	<i>For involvement in a task or activity where preparation is required and which equates to approximately half a day's activity. For example, participating in a meeting to interview a small number of candidates who have applied to join a committee or panel, participating in a focus group, or delivering training.</i>
£150.00	<i>For involvement in all-day meetings. For example, attending a committee or panel meeting as an observer prior to becoming an active public member of a committee/panel.</i>
£300.00	<i>For involvement in all-day meetings that require substantial preparation. For example, when chairing or co-chairing a meeting or when carrying out other discretionary work, which requires additional responsibilities.</i>

Adapted from NIHR's Guidance on compensation rates.

Appendix B.

Charities & Groups with PPI Experience

Research Area	Charity or Research Network	Contact Information
Alzheimer's & Dementia Research	<ul style="list-style-type: none"> Alzheimer's Research UK Join Dementia Research Partners in Research 	infoline@alzheimersresearchuk.org Contact Us Form TAY.ppipartners@nhs.scot
Cancer Research	<ul style="list-style-type: none"> MacMillan Cancer Voices The Involvement Network (Cancer Research UK) 	cancervoices@macmillan.org.uk involvement@cancer.org.uk
Parkinson's Research	<ul style="list-style-type: none"> Parkinson's UK Research Interest Groups (RIGs) 	Dundee RIG: secretary@drig.org.uk West of Scotland RIG: hello@wosrig.org.uk North of Scotland RIG: lnash@parkinsons.org.uk
Psychology & Social Care Research	<ul style="list-style-type: none"> Eating Disorders and Autism Collaborative Service User Research Enterprise (SURE) - KCL 	EDAC@ed.ac.uk Dr Angela Sweeney, Director of SURE angela.sweeney@kcl.ac.uk
Stroke Research	<ul style="list-style-type: none"> Stroke Association - External Involvement Toolkit 2025 Stroke Association - Stroke Voices in Research 	research@stroke.org.uk involvement@cancer.org.uk
Misc. or Other Research	<ul style="list-style-type: none"> People in Research (NIHR) Be Part of Research (NIHR) 	

* If your area of interest has not been included as an example, search for research interest groups or charities associated with your project

Appendix C.

Training for Researchers & Peer Researchers

Course Name	Information & Details
Introduction to Data & Research	<p>UKRI UK Data Service: New to Using Data</p> <p>King's College London: Research Methods</p> <p>Imperial College London: Peer Research Training Resource</p> <p>NIHR: Reviewing Research</p>
Data Management	<p>University of Edinburgh: MANTRA</p> <p>Courses on data management, safety and handling; includes Python and R tutorials</p> <p>UKRI UK Data Service: Research Data Management</p>
Statistics and Quantitative Data Analysis	<p>Stanford University: Introduction to Statistics</p> <p>University of London: Probability and Statistics</p> <p>UKRI UK Data Service: Computational Social Science</p>
Qualitative Research	<p>UKRI UK Data Service: Qualitative data</p> <p>Griffith University: Why Experience Matters: Qualitative research</p>
Software & Tools	<p>UKRI UK Data Service: Software and tools</p> <p>University of Helsinki: Data Analysis with Python</p> <p>University of Edinburgh: MANTRA: Data Handling in Python, R or SPSS</p>

Appendix D.

Before & During Your Research

Before Your Research

During Your Research

- Allocate Time & Resources**

For Co-Production

- Develop or connect with an**

existing lived experience

network

- Engage with or add peer**

researchers to the team

- Establish roles, shared**

goals and expectations

from the outset

- Identify important research**

questions

- Ensure that your research**

incorporates accessible

recruitment & approach

- See if you can use adapted**

measures in your research

- Implement iterative**

adjustments during

research co-production

Appendix D.

Finishing Up & Disseminating Your Research

Finishing Up Your Research

Have Peer Researchers

Analyse Data

Have community members or
peer researchers review

your research output

Think about how to report

PPI involvement

Disseminating Research

Identify important research

questions

Ensure that your research

incorporates accessible

recruitment & approach

See if you can use adapted

measures in your research

Implement iterative

adjustments during

research co-production
