

# Co-Production: “The Real PPI”

## The Researcher's Toolkit



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-  [edacresearch.co.uk](http://edacresearch.co.uk)
-  [alzheimersresearchuk.org](http://alzheimersresearchuk.org)

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# Co-Production: An Overview



# What is Co-Production?

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

***lived***



and ***learnt***

experience work together to conceptualise, conduct and disseminate research<sup>1-3</sup>



**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

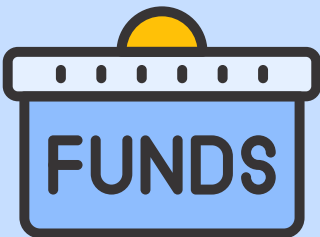


- Highlights the societal importance or nuanced aspects of a condition
- Improves understanding of a condition for parents, carers or loved ones



**Co-Production** strengthens many aspects of the research process:

### Acquiring Funding



Co-production aligns with many funders' priorities.<sup>4</sup> 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-Production<sup>5</sup>** 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**

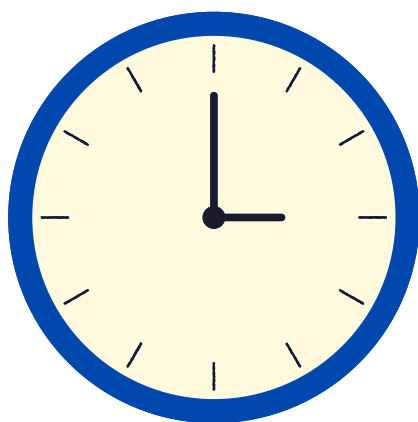


**Establish roles, shared  
goals and expectations  
from the outset**



### 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.<sup>6</sup>

#### 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!



### 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 recommend you **consult recommended salaried or per-meeting rates<sup>6,7</sup>**, and discuss with your local research & development team.

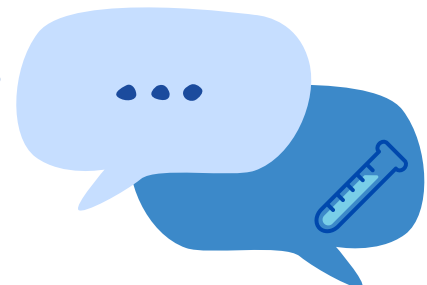


### **Establish roles, shared goals and expectations from the outset**

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:

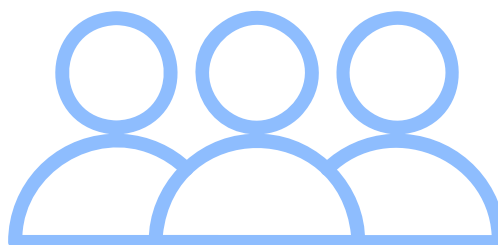
*Think about including the following topics:*

Research priorities for the lived experience community

The general research topic

Individuals' day-to-day experience

A particular research approach (e.g., what do you think about MRI?)



How people feel about their condition or circumstances

### Online or In-Person?



### Conduct Preliminary Research!

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

Demographic survey?

Qualitative?



Quantitative?

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.)<sup>8</sup>





# 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**



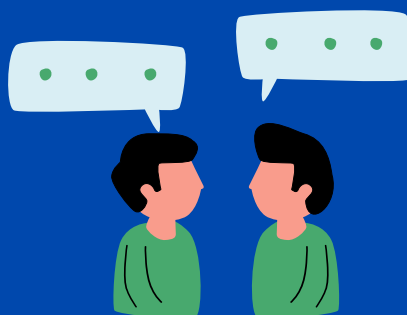
For instance, take a look at the [Generalised Anxiety Disorder-7](#) and [Patient Health Questionnaire-9](#) adapted and **validated** for those with intellectual disability<sup>9</sup>

*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



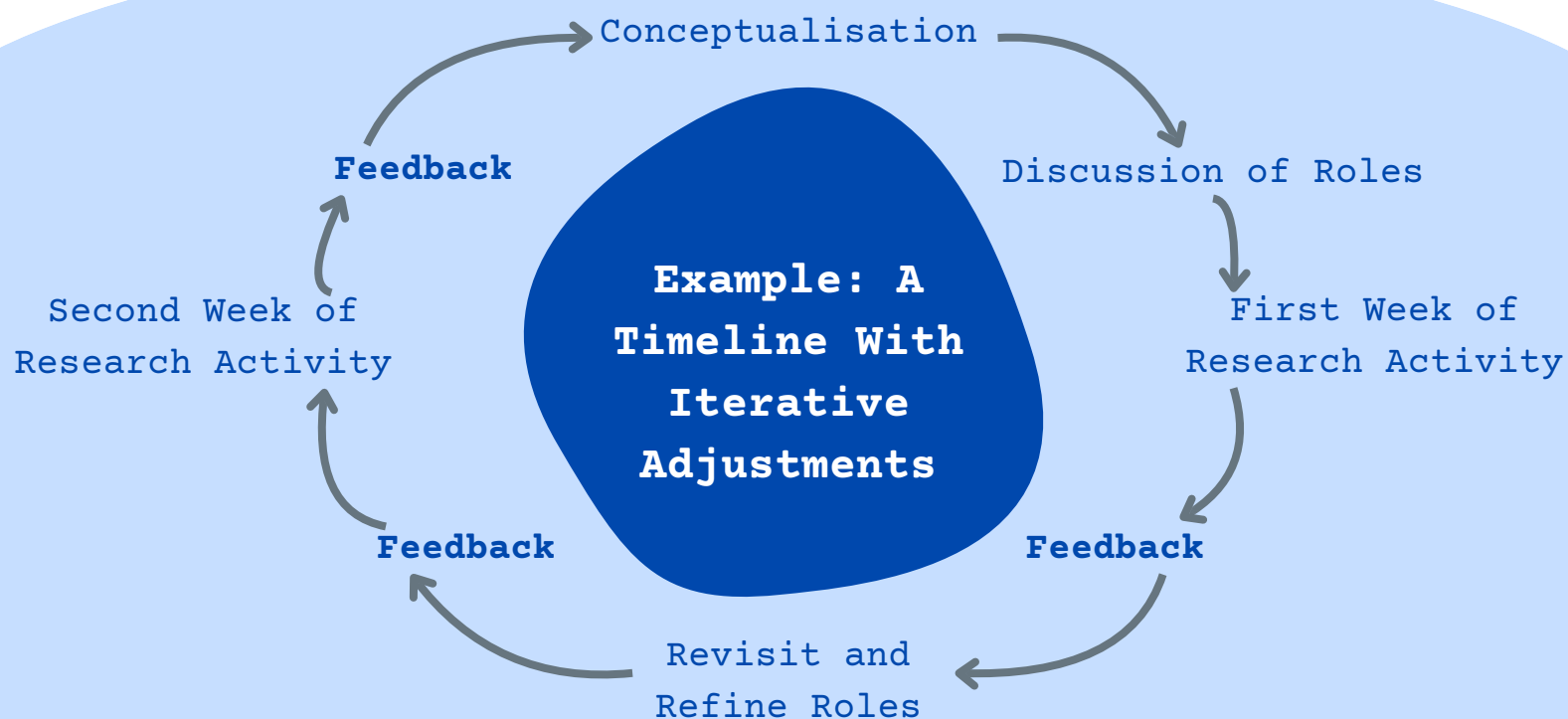
**Implement iterative adjustments during  
research co-production & approach**

**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

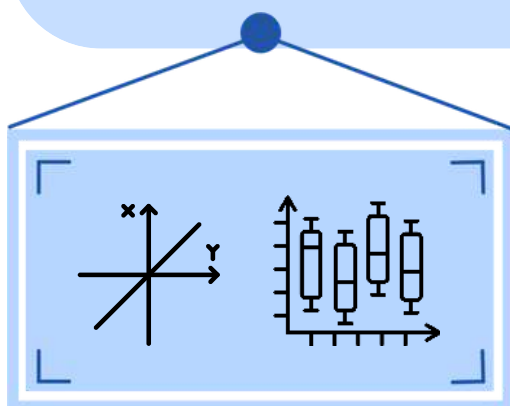
## Have Peer Researchers Analyse Data



### 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 insitutions or reputable research funding bodies



### 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 standards<sup>10</sup>



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 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



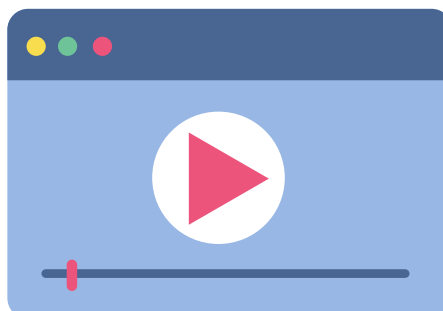
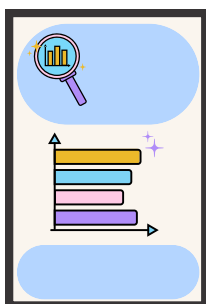
### Provide accessible lay summaries in multiple formats

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)



## 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 factors<sup>13</sup>:

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



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

Improving Dementia  
Services in Broxtowe<sup>14</sup>  
Nottingham West Primary Care  
Network

Norfolk and Suffolk Recovery  
College<sup>15</sup>  
Norfolk and Suffolk NHS Foundation  
Trust

Exchanges: Inspiring Parkinson's  
Conversations<sup>16</sup>  
MRC Protein and Phosphorylation Unit  
& University of Dundee

Eating Disorders and Autism  
Collaborative<sup>17</sup>  
University of Edinburgh, University  
of Aberdeen, King's College London

Our Cancer Our Way - Always<sup>18</sup>  
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



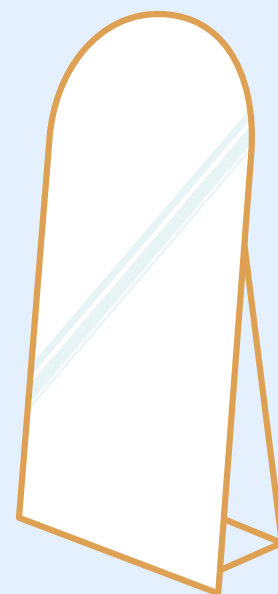
## Strike a balance between accessibility and scientific integrity

- 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.*

Charities & Groups with PPI Experience

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

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

## Training for Researchers & Peer Researchers

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

# Appendix D.

## Before & During Your Research

### Before 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

### During Your 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

# 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