

Lived experience matters:

An introduction to service user and carer involvement in research.

Iliana Rokkou, User and Carer R&D Manager, CPFT

iliana.rokkou@cpft.nhs.uk

01223 465182

What we will cover...

PPI – Patient and Public Involvement

- What is PPI (Service user and carer involvement in research)?
- Why is it important?
- Support that you can access
- Panel discussion

Involvement or Participation?

- 1) An Expert by Experience (EbE) attends a focus group discussing his/her experiences of receiving services from a community psychiatric nurse (CPN).
- 2) An EbE reviews a protocol, patient information sheet and consent form that has been prepared by a researcher as part of their application to get ethical approval.
- 3) An EbE attends the Wolfson Brain Imaging Centre in Cambridge to have an MRI Scan and complete a set of questionnaires.
- 4) An EbE comes to Douglas House in Cambridge to meet with a researcher to give them an opinion about how they plan to design a study.
- 5) An EbE comes to Douglas House to complete a computer-based activity testing his/her ability to remember faces.
- 6) An EbE meets with a research team to look at interview transcripts and pick out key themes mentioned by the participants.
- 7) An EbE meets with a research team to discuss how they will communicate the findings of their research to the general public.
- 8) An EbE conducts interviews with people who have used CPFT services alongside a researcher.
- 9) An EbE comments on a plain English summary explaining a research project which has been prepared as part of an application for funding.
- 10) An EbE makes links with a nationwide charity – such as Mind – and submits a research idea to the Patient Led Research Hub based at Addenbrookes Hospital. He/She then meets with a researcher to discuss how this idea could be put into action.

Language and terminology

Involvement - Involvement in research refers to **active partnership** between people who use services, carers and researchers, rather than the use of people as participants in research (or as research 'subjects').

Many people describe involvement as **doing research with or by people who use services** rather than to, about or for them.

Patients and the public have a **decision-making impact** on one or more stages of the research process

Participation - Taking part in a research study, for example people being recruited to take part in a clinical trial or another kind of research study, joining in a focus group or completing a questionnaire.

Engagement - Where information and knowledge about research is provided and disseminated.

<http://www.invo.org.uk/resource-centre/jargon-buster>, INVOLVE, 2016

Why lived experience matters?

- **access to *privileged knowledge***: patients and the public have **knowledge** of their own mental health condition that can be of benefit to researchers, who may not have first-hand experience themselves of the issue they are researching
- **democratic principle**: patients and the public have the **right** to be involved in any publicly-funded research that may impact on their health status or the services that they receive

Why lived experience matters?

- **Benefits to research:** PPI has the potential to **improve the quality, relevance and impact of health research**, whilst also improving the transparency of the process and the accountability to the wider community of the researchers themselves
- **The policy imperative:** PPI is currently **Department of Health and NIHR policy**, so funding often depends on getting PPI right at the grant application stage

User Involvement in Research Policy



“Principle 4: Patient, Service User and Public Involvement

Patients, service users and the public are involved in the design, management, conduct and dissemination of research, unless otherwise justified.”

Interest of research funders and research organisations

- Research Funders
 - *National Institute of Health Research*
- Research Ethics Committees
- National Institute for Health and Care Excellence (NICE), Social Care Institute for Excellence (SCIE) , Association for Medical Research Charities (AMRC)

How might people be involved?

Consultation

Collaboration

Control



Researcher-led

Joint

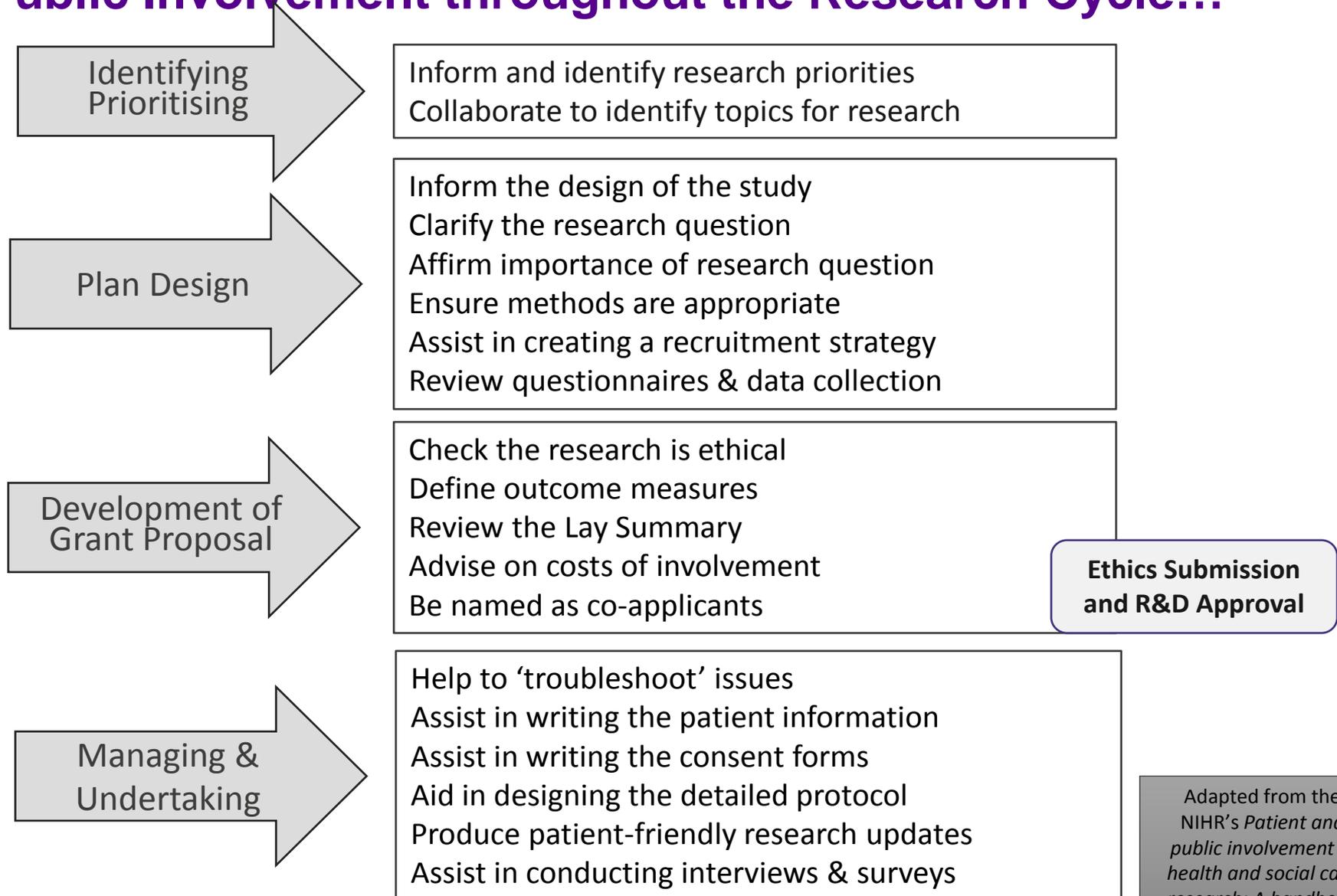
User-led

Consultation: Service users/carers are asked for their opinions or views on an aspect of research.

Collaboration: Service users and/or carers are active partners in the research which includes sharing some of the responsibilities for running the process.

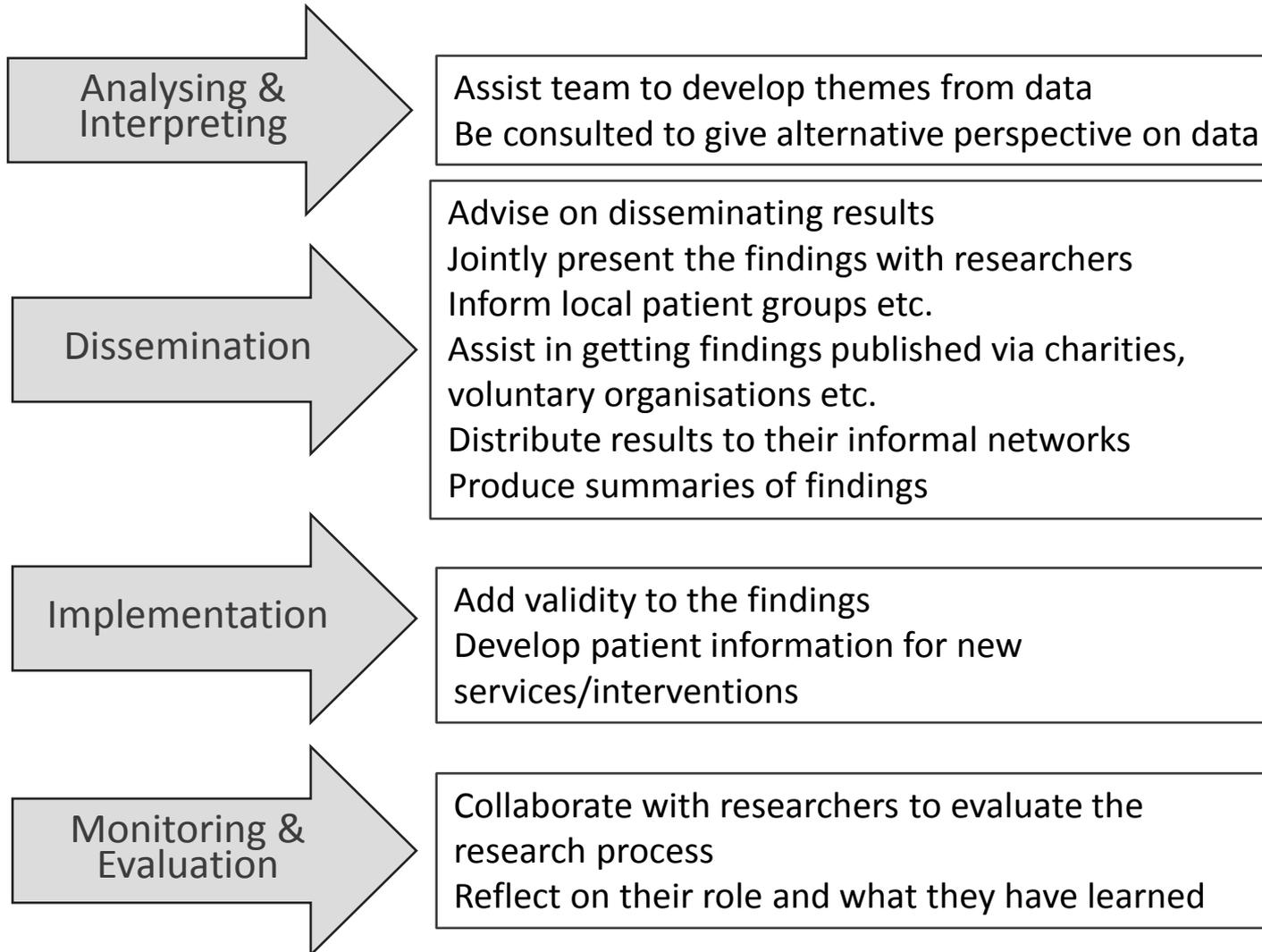
Service User or Carer led Research: Service users and/or carers identify an issue and work with a team to seek funding and lead the research themselves.

Public Involvement throughout the Research Cycle...



Adapted from the
NIHR's *Patient and
public involvement in
health and social care
research: A handbook
for researchers*

Public Involvement throughout the Research Cycle...



Adapted from the
NIHR's *Patient and
public involvement in
health and social care
research: A handbook
for researchers*

CPFT support for PPI

*We have a commitment to ensure **meaningful** service user and/or carer involvement at the early stages of project design and bid development and throughout the research project to improve research and maximise its benefits to service users and/or carers (CPFT R&D PPI Strategy)*

- **PPI Lead** within Research and Development team
- Access to the **CPFT Service User and Carer Research Group** and close links with other patient/lay advisory groups
- Provide **advice and support** to researchers, service users and carers
- Provide **learning and development** opportunities to researchers, service users and carers
- Support user involvement from an **early stage** of the research process
- **Promote and disseminate** local examples of good practice or change

CPFT Service User and Carer Research Group

- People with personal experience of mental health issues or dementia or who care for someone who has.
- Interested in providing input into studies which will take place in the Trust
- Have a range of experience advising and working on projects as advisors/reviewers
- Willing to contribute and work as part of a team
- Training & support

What does the group do?

- Members are invited to get involved in research projects that are relevant to their lived experience
- Service user/Carer advisory groups are set up to discuss with researchers specific studies and provide advice and support
- Members occasionally provide feedback to researchers in between meetings
- At least two people with relevant lived experience review mental health and dementia research projects as part of the R&D Approval Process
- Members are involved in training for researchers
- Members are involved in promoting research

Questions?

- 1) What makes involvement meaningful & effective?**

- 2) What stops meaningful involvement: what might be some of the challenges and frustrations?**

Tips for success

As early as possible...

- **Plan well in advance**
- Factor PPI into **funding applications**
- Involve people as **early in your project** as possible
- Allow **time** for positive working relationships to develop
- Identify **resources** to support involvement activities (e.g. involvement of R&D office, staff time, training opportunities)

INVOLVE website <http://www.invo.org.uk>

Iliana Rokkou, User and Carer R&D Manager, CPFT

Iliana.rokkou@cpft.nhs.uk

Access training opportunities e.g. *Building Research Partnerships*

Training Opportunities

- **Introduction to PPI, Addenbrookes, 5th December 2017**
- **“Conversations with Experts by Experience” – for non-clinical researchers**
- **“Recovery Language in Research”, Jan 2017**
- **“Informed Consent Training”, December 2017**

Tips for success

During the project...

- Be **clear** about roles, responsibilities and approach
- Make **communication** as easy as possible and avoid jargon
- Ensure meeting date/time/format is appropriate
- Offer/signpost to advice, **training and support**
- Be **open to change** - ask what is working and what needs to be changed and make appropriate changes
- Keep people informed throughout and provide **feedback**
- Ensure **on-going** involvement
- Provide **payment** for people's time and expenses – on time
- **Acknowledge** people where possible
- **Evaluate** service user involvement in your research
- Be **flexible!**

Thank you for listening!

Useful resources...

- Hayes, H. et al. (Ed) (2012) Involving the Public in NHS, Public Health, and Social Care Research: Briefing Notes for Researchers, Eastleigh, Involve, <http://www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEBriefingNotesApr2012.pdf>
- <https://www.parkinsons.org.uk/content/patient-and-public-involvement-ppi-your-study>
- INVOLVE (2013) Exploring the impact of public involvement on the quality of research: examples, Eastleigh: INVOLVE, <http://www.invo.org.uk/wp-content/uploads/2013/08/invoNETexamples2013.pdf>
- <http://www.invo.org.uk/resource-centre/libraries/publications-by-involve/>