

# THE INVOLVEMENT OF PEOPLE WITH LIVED EXPERIENCE AND CARERS IN RESEARCH

CNWL Mental Health  
Services Research  
Partnership Group



# INVOLVING PEOPLE WITH LIVED EXPERIENCE AND CARERS IN RESEARCH

*A Vital Role for the Third Sector*



# AIMS AND OBJECTIVES

- **To increase awareness in the Third Sector of the importance of research to the NHS**
- **To increase awareness of the importance of the involvement of people with lived experience and carers in all aspects of research**
- **To enable you to tell the people you work with what to say to people with lived experience and carers who want to become involved with research**



# WHAT IS RESEARCH?

- There are different type of research, but this is probably what the NHS is most interested in.
- *Research is a careful and detailed study into a specific problem, concern, or issue using scientific methods. This is best accomplished by turning the issue into a question or questions: the research is designed to answer the question or questions.*



# Why research is important

- It is essential for creating and delivering better health care services. Without research we might not know what improvement or new changes to make.
- Research is a core part of the NHS. NHS England is committed to working and engaging with patients, carers and the public in a wide range of ways.
- Ensuring that people's views are heard at all levels and across all parts of the healthcare system.



# Why it is vital that people with lived experience and carers are involved in research

- People with lived experience and carers can give invaluable advice to researchers based on their own lived experience and may have ideas researchers have not thought of.
- Researchers:
  - May be intellectuals, but may not be good at talking to people in a way that they can understand
  - May need the advice of people with lived experience about how to get people involved in their research
  - Need to get people with lived experience and carers involved to produce more robust outcomes
  - and* it is vital to get people with lived experience and carers involved for funding purposes



# Different ways in which people with lived experience and carers can be involved in research:

- As participants
- Going on research mailing lists
- Steering / Advisory Group member(s)
- Initial ideas for research
- Design and test information leaflets about the research
- Advising on ethics applications
- Promoting studies / recruiting participants



## Different ways in which Service Users, Carers and the Public can be involved in research:

- Work as a researcher – conducting interviews, focus groups, questionnaires etc.
- Contributing to reports and papers & distributing results
- Research presentations

Not all these opportunities are available all the time, but they all crop up from time to time.....





# How the Third Sector can help

**The Third Sector can tell the people they work with:**

- **about opportunities for health research**
- **why health and care research is important**
- **how getting involved in research can help them**
- **how to get involved in research**



# How Research can help the people you work with

Research can help the people you work with:

- Gain experience, skills, and confidence
- Meet people
- Let their voice be heard and have an opportunity to contribute to the improvement of health services
- Have some opportunities for training and participation in broader PPI work
- Be paid (not a lot) for their time – this varies from project to project



# The next step

People with Lived Experience, or their Carers wanting to get involved in CNWL research should contact Charlotte Green on

[charlottegreen@nhs.net](mailto:charlottegreen@nhs.net)

