

PPI Training in DeNDRoN: Draft examples of DeNDRoN training sessions. I am extremely grateful to **Ruth Chandler** for drafting this example for us to discuss at the November 2010 PPI Working Group. Terry

Session 1:

Understanding involvement roles in research processes

Duration 90 minutes

Participants 20 people

Learning outcomes By the end of this session, participants should be able to:

- Describe a range of involvement role(s) for lived experience experts in research processes.
- Give examples of how a range of lived experience expertise can add quality and relevance to research

Outline

1. Introduction. Give overview of session aims and structure and set boundaries around safe working (5 mins)
 - In pairs, ask everyone to introduce themselves to each other and briefly describe their interest in research as) a) a person living with an illness and b) as family or friend who has or has held a caring role. Ask each pair to introduce their partner to the group (15 mins)
2. Present **Learning Material 1:** Public Involvement in Health Research-why bother? (15 mins)
 - Ask pairs to complete **Teaching Aid 1:** Involvement Quiz (10 mins)
3. Introduce **Learning Material 2:** Overview of Involvement in DeNDRoN Research Network (10 mins)
 - Divide into four disease specific topic groups. Ask each topic group to discuss: “How does/can experience of living with an illness or being a family member or friend with a caring role add to the quality and relevance of research in the network?”

Ask groups to give examples where possible and record answers on flipchart (25 mins):

- Take feedback.(10 mins)

Session 2

Involving lived experience in decision-making

Duration 90 minutes

Participants 20 people

Learning outcomes By the end of this session, participants should be able to:

- identify similarities and differences between individual experiences and the experiences of others
- use lived experience expertise to inform decisions about research quality and relevance to people living with a degenerative illness and their family and friends.
- use lived experience to advise on likelihood of recruitment and retention to research

Outline

1. Represent **Learning Material 2: Overview of Involvement in DeNDRoN Research Network** to recap previous session. Draw out themes from topic group feedback and recap different kinds of involvement activity in the network- take questions (10 mins)
2. Divide into four groups making sure that all groups contain at least one member from each topic group.
 - Ask groups to list similarities and differences between topic groups (20 mins).
 - *Do some similarities cut across all topics? Which are harder to share?*
3. Present **Teaching Aid 2: Role Play** (30 mins total)

- Give each group two lay summaries of fictional research proposals explaining that they are the PPI representatives on the selection committee of a prestigious grant awarding body.
- The committee can only afford to choose one of them. The decision is based on the following criteria:

Is the research question important or relevant to people living with a degenerative illness and/or caring for a family member or friend?

Are the research outcomes important or likely to be of positive use to people living with a degenerative illness and/or caring for a family member or friend?

Would people living with a degenerative illness and/or caring for a family member or friend be willing to take part in the research? Or is it so burdensome that they are either unlikely to agree to take part or stay in the project?

Did the research team consult people living with dementia and/or caring for a family member or friend when they designed the research? Are plans for continued involvement appropriate and sufficiently resourced?

Does the study plan to report findings back to study participants and to the public? Are experts by lived experience involved in this? If not are the reasons for exclusion appropriate?

- Ask groups to score their answers and place them in order of importance to come to a decision. In the event of a tie, what other considerations would influence the decision?
4. Ask groups to announce their decision with the option of giving suggestions for improvement to the loser. (10 mins)
 5. Whole group discussion. Which parts of the role play were easier to assess from individual experience and which needed an understanding of shared experiences? (20 mins)