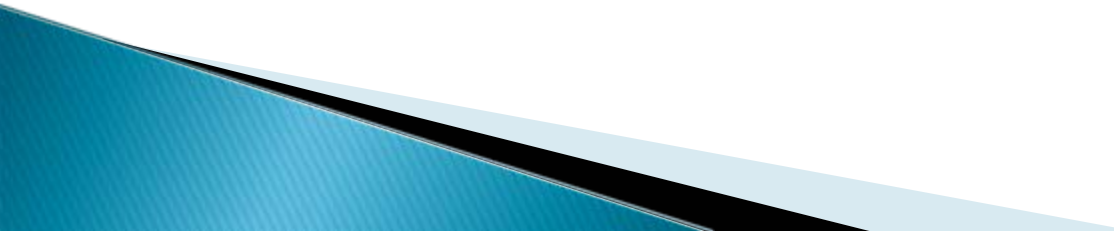


A Lay Member's View on PPI in RfPB Applications

Rosemary Humphreys
SEC RfPB Regional Committee

Start before the beginning

- ❖ Section 12 *Please provide details of public involvement in the research*
 - ❖ ‘We will’ ‘We shall’ ‘We aim to’ ‘We will talk to’
 - ❖ Too late – the application has already been submitted
- 

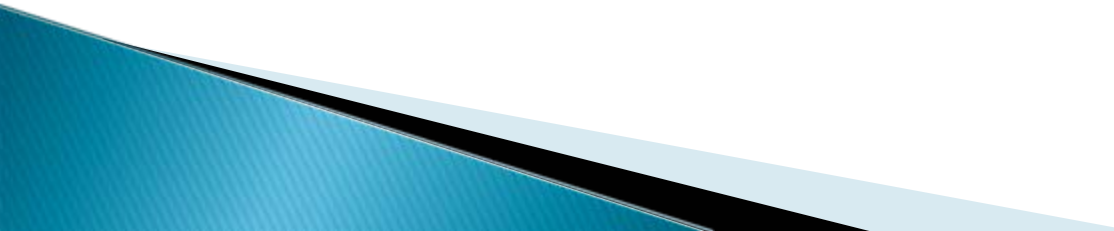
Where do we find people?

- ❖ Home grown are best!
- ❖ Poster in waiting room
- ❖ National support group → Local support group
- ❖ Local Directory of Voluntary Organisations
- ❖ Ask the Research Design Service
- ❖ Contact local GPs / Advertise in practices
- ❖ Get an article in the local paper – *Researchers want to involve local people in their work.*

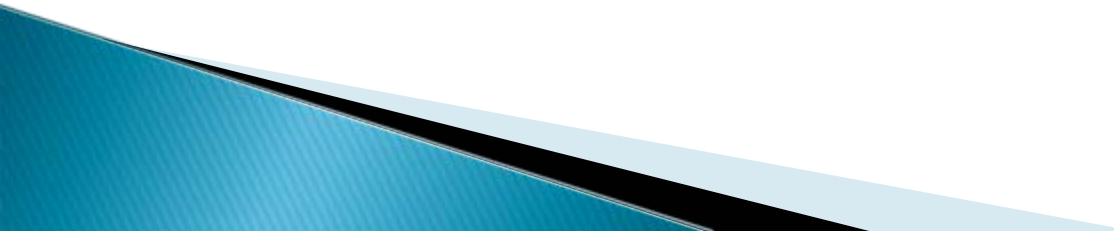
Do you really mean it?

- ❖ A service user as a co-applicant?
- ❖ Representation on the Steering Group – ideally more than one person
- ❖ An advisory group of service users?
- ❖ Are they a cross-section of your community?
- ❖ Costs for lay involvement in the budget
- ❖ User-friendly venue for meetings

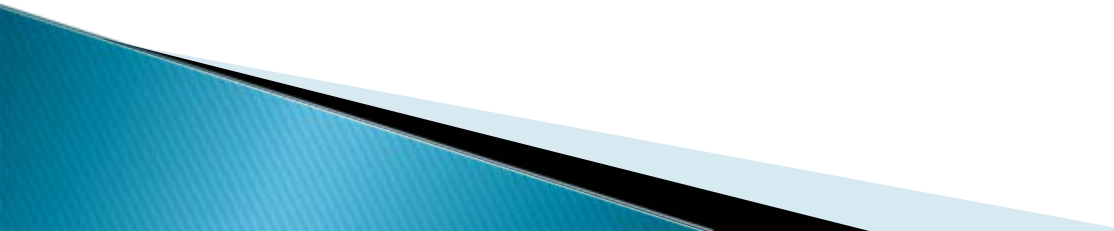
Research Design

- ❖ The doctor knows the condition, the patient knows the impact
 - ❖ Involve the patients from the beginning
 - ❖ They have a different perspective
 - ❖ Suggest outcomes you might not have thought of
 - ❖ Suggest ways in which the research can be conducted to encourage participation
- 

Patient Information Leaflet

- ❖ Not a fait accompli!
 - ❖ Produce a draft, patients can read and comment
 - ❖ If it's not clear to them – it won't be to study participants either
 - ❖ Think about making it accessible
- 

Watch your Language!

- ❖ Section 6 Plain English Summary – They are really hard to write so they make sense to the non-specialist
 - ❖ Jargon!
 - ❖ Acronyms!
 - ❖ Involve your patient group
- 

Dissemination

- ❖ Send all study participants thanks and a copy of the journal article/lay summary of the report
 - ❖ Ask them and other service users about wider dissemination – they may know of outlets that you are not aware of
- 