



# **PPI and the CLRNs**

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# Who am I?

- Sheila Parker
- Job title “PPI co-ordinator”
- I work for West Anglia Comprehensive Local Research network
- My role is “to leverage existing organisations and activities to promote PPI and inform, educate and guide both researchers and patients/members of the public.”

# PPI - what is it ?

- **Patient Involvement** is about involving people who have used health services in the planning management or review of health research.
- **Public Involvement** is about involving people as citizens to ensure public accountability.

*House of commons health committee 2007*

# Why PPI ?

- **To improve the quality of research**
- There are many other benefits, but let us not lose sight of the main purpose. The aim here is to have health research that is of good quality, relevant and successful.

# Why should CLRNs get involved in PPI?

- Surely our portfolio projects are already fully formed?
- Isn't this the job of the RDS?
- Isn't this the job of the R&D departments?
- Where is the benefit to us?

## Why should CLRNs get involved in PPI? - answers

- We want the highest quality projects on our portfolio. PPI, well done, improves the quality of the projects.
- RDS and R&D departments have a role to play in introducing PPI to projects, but only the CLRNs have the ability to coordinate all the various agencies
- PPI can help with recruitment to projects – a key measure for CLRNs

# Nationally, what are CLRN's doing about PPI?

## Overview

Overall there is no consistency in how each CLRN is tackling the issue of PPI.

All CLRN's acknowledge that they **should** be involved in PPI. The NIHR tells us to do PPI. CLRN's vary wildly in their approaches and level of commitment.

# Nationally, what are CLRNs doing about PPI?

## - detail

- Strategy
  - Most describe themselves as “forming a strategy” or “undertaking a scoping exercise”
- Board Membership
  - 4 CLRNs have recruited lay members to their full boards
- Staffing
  - A few have dedicated PPI officers Peninsular – full-time, West Anglia half-time, Kent 10hrs/week
  - Some have allocated responsibility for PPI to a staff member, tacked on to the day job,
  - Some jointly fund a post with other organisations, eg with the DRN and PCRN; with CLAHRC and RDS
  - Some use lay volunteers eg Sussex and Surrey, Hampshire and Isle of Wight

*Source – NIHR “PPI Plans in Comprehensive Local Research Networks from CLRN business plans 2010”*

# What is West Anglia CLRN doing? - strategy

- West Anglia CLRN aims to act as a central information and co-ordination organisation for PPI in our area.
- The CLRN will not have a controlling role. Our aim is to facilitate.
- The CLRN will actively promote PPI in health research.
- The CLRN will seek to identify and disseminate best practice in PPI in health research.



# Formal PPI in the West Anglia region



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Service Users group



Cambridge University Hospitals   
NHS Foundation Trust

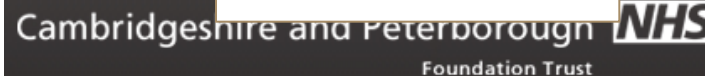
Patient and Public  
Involvement group




Lay members of  
PCR N board



Active service  
user involvement

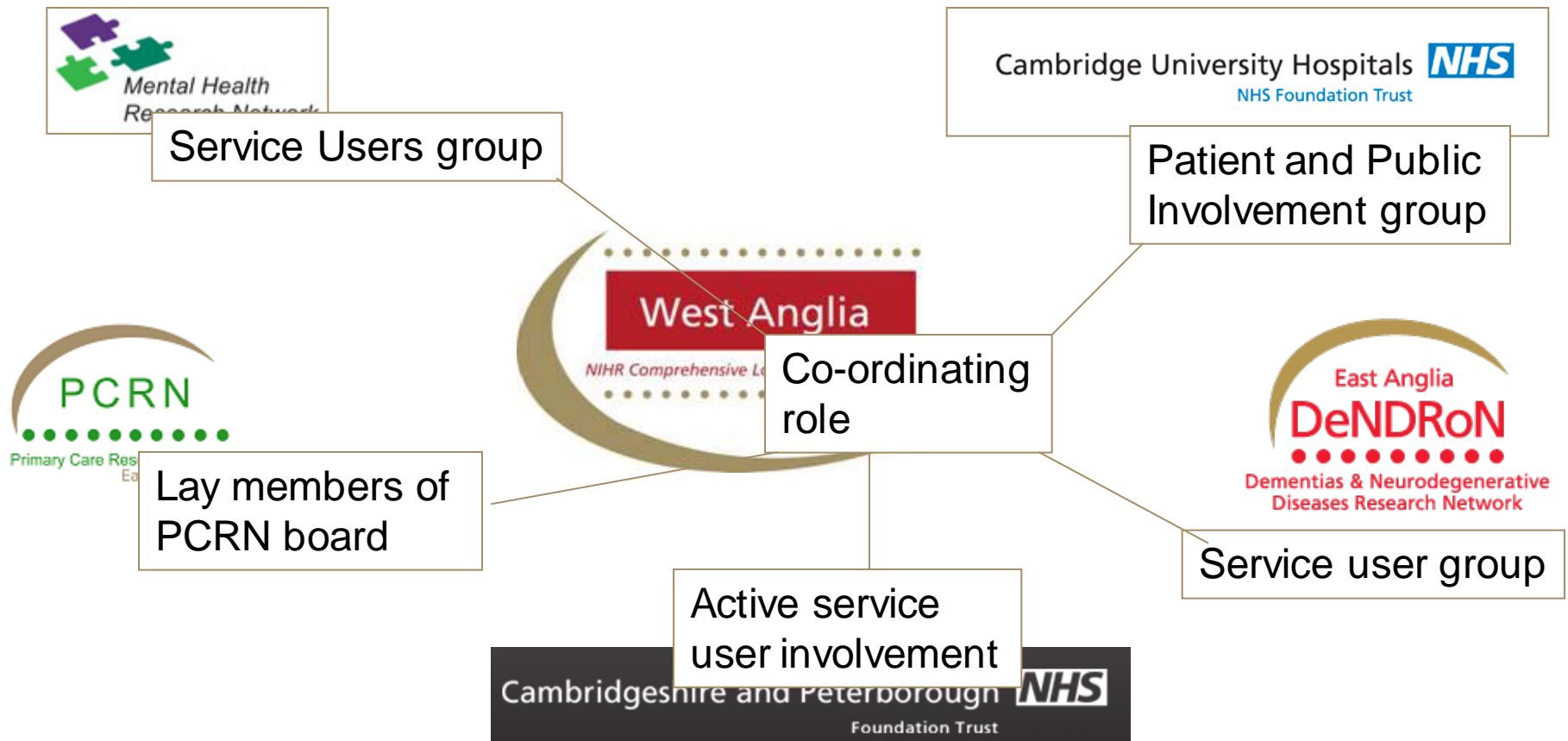


Cambridgeshire and Peterborough   
Foundation Trust



Service user group

# Formal PPI in the West Anglia region



# Informal PPI arrangements in West Anglia

- PPI does not have to be done through formal groups
- Many researchers, hospital departments and organisations in our area have recruited individuals to help with research project.
- Our role in this case is identify these cases and offer any help, training or support that is required.
- Other departments work with PALS or LINKs, taking the view that PPI in research is no different to the established PPI in the rest of the health service.

# What is West Anglia CLRN doing? - actions

- We have recruited a lay representative to the board, from Bedfordshire LINKs
- We have worked with R&D at CUH to resurrect their Patient and Public Involvement Panel. That group is now active and taking on projects.
- Our PPI co-ordinator acts as a source of information, responding to enquiries by email and phone.
- We promote PPI to researchers and the general public by short presentations on PPI in research workshops and seminars, by displays, newsletter articles and a website presence.
- We promote links between the other organisations in our area TCRNs, PCRNs, RDS, R&D departments, ensuring that resources and information are shared.

# Example enquiries about PPI received by WACL RN

- 1 – The researcher
  - Help requested in setting up a the TRAC study
  
- 2 – The member of the public
  - Asking how to become involved.
  
- 3 The public workshop
  - Help requested in publicising the event.

# 1 - Help requested in setting up the TRAC study

- The TRAC study is a proposed longitudinal study of the needs of patients with advanced chronic obstructive pulmonary disease, (COPD). It aims to follow 200 patients for 2 years and identify needs and changing needs of patients and carers.
- The researcher, Morag Farquhar, asked Sheila for help in finding COPD patients and their carers to become involved in their project.
- Sheila approached two local “Breathe Easy” groups. These are patient support groups for COPD.
- Morag met with individuals from one of the groups, and had a group meeting with the other to examine the project’s feasibility from the patient point of view.

## 2 – The member of the public.

- Sheila was contacted by one of the Oncology consultants, Pippa Corrie. Pippa knew a recently bereaved carer, "John", who wanted to get involved in health research. Pippa had already recruited John to one of her projects, but John was keen to do more.
- Sheila met with John to discuss what he wanted to do.
- Sheila put John in touch with the CUH R&D Patient and Public Involvement group. John joined the group and was recruited on to a urology project.
- Also, at the time, the National Cancer Research Institute was recruiting for their clinical studies group. I suggested that John consider this, he applied and was accepted onto one of the groups.

## 3 - The public meeting

- The East of England Mental Health Research Network had arranged a free drop-in workshop for members of the public in Bedford hospital –  
  
*"Mental Health research - why is it so important, what does it entail and how can you get involved?"*
- The organiser, Muireann McSwiney asked for help with publicity.
- Sheila put a piece on the WACLRN website about the workshop and circulated details to all known contacts, in particular, contacting Bedfordshire LINKs. In total 40 members of the public attended the workshop, including several members of LINKs.

# PPI and WACLRN – the future

At present, in our region, most research projects do not have a PPI component. Our aim in the next few years is to change that.

We need to make it easy, and clearly beneficial, for researchers to welcome patients and members of the public on to their projects.

So the top-level aims are

1. Provide good quality PPI, ensuring that the right people are available for research projects.
2. Convince researchers that PPI is beneficial.

Secondly, we have a role in promoting health research to the general public as a public good.

# PPI and WACLRN – specific plans

- Promote PPI to researchers through specialty groups, by newsletters, website, presentations and displays at seminars and conferences.
- As demand for PPI builds, facilitate recruitment of members of the public to get involved in health research.
- Facilitate the provision of training courses for both researchers and members of the public.
- Promote health research to the general public.



# Questions?

*The West Anglia Comprehensive Local Research Network is part of the National Institute for Health Research and the UK Clinical Research Network*



# Spare slides

# The immunological basis of inflammatory arthritis, particularly spondyloarthritis.

- Biomedical project investigating whether the mode of action of HLA-B27 is principally at the level of the dendritic cell influencing cytokine output.
- PPI Involvement ?

<http://www.arc-research.org.uk/arcBacktobasics-thespondyloarthritisstory.asp>

*Funded by Arthritis Research Campaign*

# Arthritis Research Campaign (ARC)

## Lay case for Grant support

- **ARC** requires a lay case for support with all applications. The main purpose of the lay summary is to allow assessment of the application by representatives of **ARC's** stakeholders, patients and healthcare providers
- The lay case will be reviewed by the **USER** committee, comprising front-line healthcare professionals and informed lay members

<http://www.arc-research.org.uk/documents/LayCaseforSupport.asp>