



Vanessa Pinfold, Ruth Sayers, Elizabeth England, Thomas Keeley and Partners2 study team

## Putting lay voices into primary care research : PPI strategies and early steps in the PARTNERS2 study

### Aims

1. To understand current care for people with schizophrenia or bipolar in secondary and primary care services.
2. To assess key components of collaborative care for people with schizophrenia or bipolar.
3. To explore barriers and enablers to implementing this model of care.
4. To investigate the feasibility of collaborative model of care
5. To assess the impact of primary care based collaborative care for people with schizophrenia or bipolar.

### Background

PARTNERS2: development and pilot trial of primary care based collaborative care for people with severe mental illness is funded by the NIHR Applied Health programme grant (RP-PG-0611-20004). The program, developed by the late Professor Helen Lester and led by Professor Max Birchwood from University of Warwick, is running from March 2014 until February 2019. It is a collaboration between members of the NIHR School for Primary Care Research (SPCR) in Primary Care Clinical Sciences at the University of Birmingham, and several Universities as well as the McPin Foundation, which provides PPI (Public and Patient Involvement) expertise. PARTNERS2 developed directly out of the findings from PARTNERS1 (NIHRSPCR funded in 2009), which found that although primary care is central to the care of people with severe mental illness, consultation rates were lower than previously reported and cross-boundary and informational continuity between sectors was poor<sup>1</sup>. PARTNERS1 concluded that research was needed to determine whether, and how, a collaborative model of care at the primary-secondary interface can lead to improved health and service delivery.

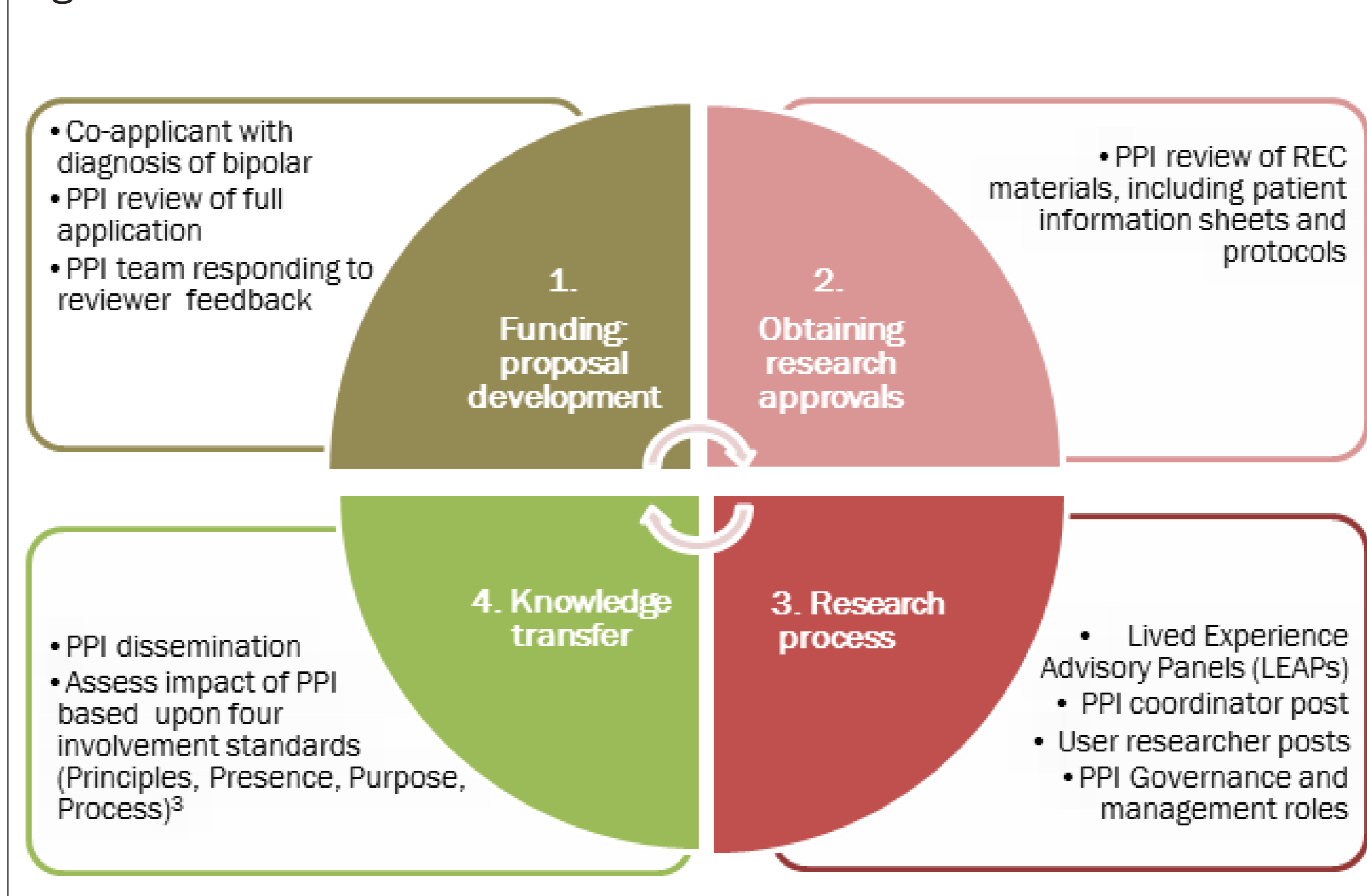
### Collaborations

McPin Foundation, University of Exeter, Plymouth University, University of Manchester, University of Warwick, Lancaster University

### What will PPI contribute to PARTNERS2?

High quality research and service development needs to combine excellent research expertise with insights gained from direct personal experience of the study topic<sup>2,3</sup>. Feedback from reviewers of the PARTNERS2 proposal stated: "PPI is a strong element in this work". The identification of the research topic came from the applicants' prior research and experience of working with the target group. Service user input has been built into all sections of the research. User researchers, and consultants on each of the work streams, are a notable feature." PPI must be active in all stages of the research. Figures 1 and 2 show this within PARTNERS2.

Figure 1: An overview of PPI in PARTNERS2

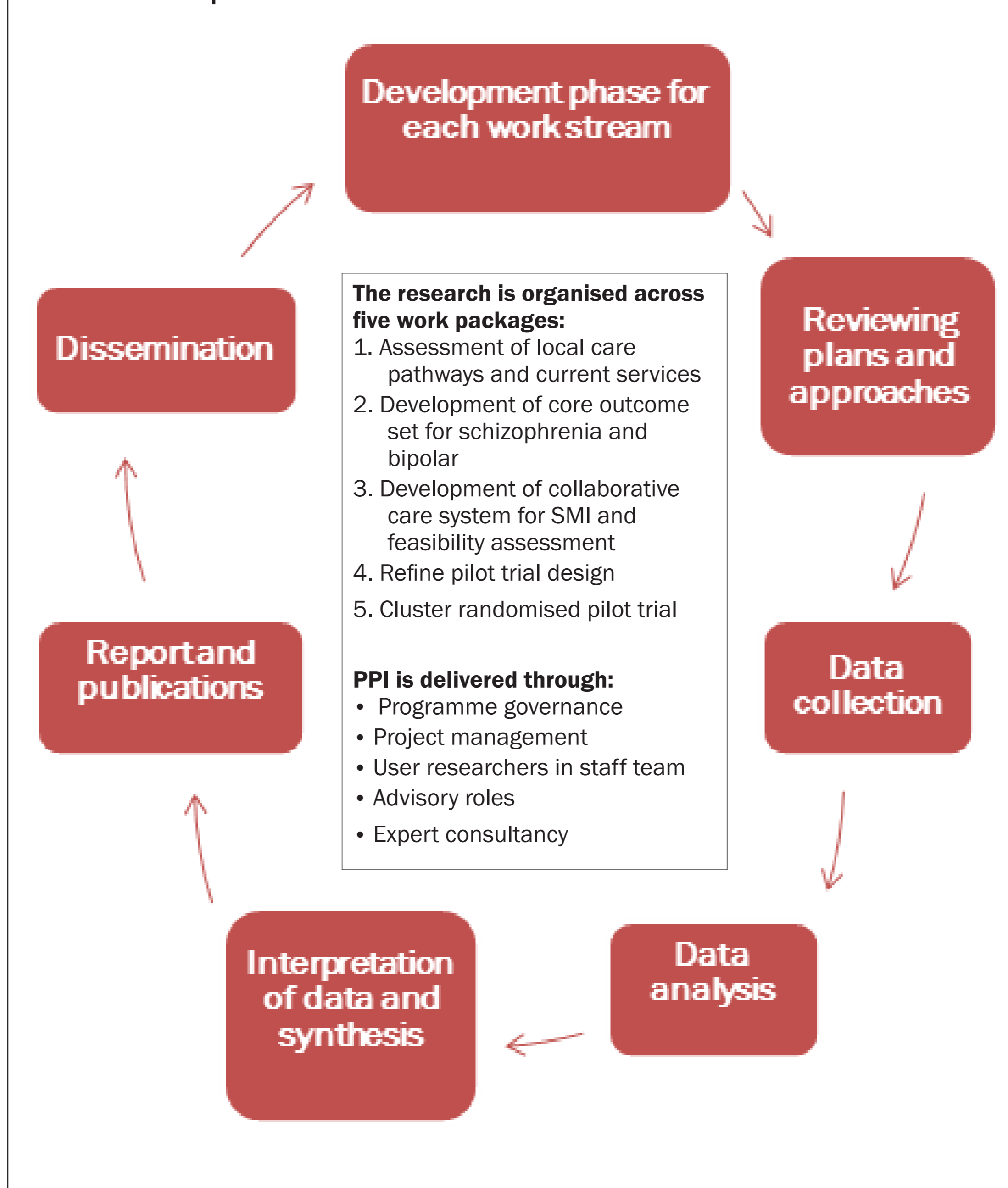


### LEAP structures explained

A Lived Experience Advisory Panel (LEAP) is a group of people with personal experience of mental health problems as a service user or a carer (for PARTNERS2, living with schizophrenia or bipolar), which combines expertise from lived experience with insights into research. Members of the public apply to join a LEAP; selection is based on their experiences, interests and skills to support PARTNERS2. A LEAP in each of the three study sites will meet regularly to promote the study

locally, problem-solve, ground interpretation and develop the intervention.

Figure 2: Where is PPI within the PARTNERS2 research process?



### Essential features of PPI in PARTNERS2

- A paid PPI coordinator working across the 3 study sites to harness lived experience expertise to benefit the study
- Embedding PPI in every work stream through advisory and PPI researcher roles
- Assessing the impact of PPI to know, and to show, how our approach to using insights from lived experience makes a difference, and why<sup>4,5</sup>.

### References:

- <sup>1</sup> Reilly S, et al. (2012) The role of primary care in service provision for people with severe mental illness in the United Kingdom. *PLoS one* ;7(5):e36468.
- <sup>2</sup> INVOLVE (2012) Briefing notes for researchers: involving the public in NHS, public health and social care research. INVOLVE, Eastleigh
- <sup>3</sup> The National Survivor and User Network (2013) National Involvement Partnership 4PI National Involvement Standards. NSUN, London.
- <sup>4</sup> Staniszewska S, et al. (2011) The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research. *International Journal of Technology Assessment in Health Care*, 27:4, 391–399.
- <sup>5</sup> Popay, J and Collins, M (editors) with the PiiAF Study Group (2014) The Public Involvement Impact Assessment Framework Guidance. Universities of Lancaster, Liverpool and Exeter.

### Contacts:

PPI coordinator: Ms Ruth Sayers. Email: ruthsayers@mcpin.org  
SPCR lead: Dr Elizabeth England. Email: e.j.england@bham.ac.uk

### School for Primary Care Research

The National Institute for Health Research School for Primary Care Research (NIHR SPCR) is a collaboration between the Universities of Birmingham, Bristol, Keele, Manchester, Nottingham, Oxford, Southampton and UCL.

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