

# Involving Experts by Experience in identifying mental health research topics and priorities

Iliana Rökkou<sup>1</sup>, Phil Alsop<sup>2</sup>, Chris Carling<sup>2</sup>, Holly Davies<sup>2</sup>, Sarah Rae<sup>2</sup>, Robbie Duschinsky<sup>3\*</sup> and Elspeth Mathie<sup>4,5\*</sup>

1: Cambridgeshire and Peterborough NHS Trust, 2: Lived Experience Advisory Group, 3: University of Cambridge, 4: CLAHRC East of England, 5: University of Hertfordshire

\* Equal contribution

**Involving Experts by Experience (EbEs) in identifying health research topics and priorities is important to improve the quality and relevance of the research undertaken and the potential for implementation into practice** [1-3].

**Despite growing interest and emerging evidence of EbE involvement in health research agenda setting** [4-6], **little is known about initiatives in the context of mental health research.**



## Aim

- To review the literature to find examples of EbE involvement in identifying mental health research topics and priorities. This poster describes how EbEs were involved at this key decision making stage in research development.

## Method

- A scoping review was conducted based on methodologies developed by Arksey & O'Malley [7] and Levac [8].
- Searches were undertaken from January 2007 to April 2018 in the electronic databases MEDLINE, EMBASE, PsycINFO and CINAHL. The search resulted in 368 citations of which 11 satisfied the inclusion criteria.
- Five EbEs were recruited to this study's Lived Experience Advisory Group (LEAG). Members were involved in refining the review questions, selecting keywords and inclusion/exclusion criteria for the search strategy and providing input on article inclusion and type of information required. They reviewed selected papers and worked on the analysis and interpretation of preliminary findings. Feedback was provided on dissemination material outlining preliminary findings.

## Preliminary findings

- The majority of studies were from the UK (n = 7), but evidence was also reported from the US (n = 2), Australia (n = 1) and Chile (n = 1).
- Most of the studies reported common practices around identification of EbEs (e.g. use of existing relationships to gain access to relevant networks and organisations, community outreach, the use of advertisements and snowballing based approaches).
- Five studies described the use of consultation models to engage with EbEs. In the majority of these studies EbEs were invited to take part in stakeholder consultation exercises mostly amalgamating different groups within a single research agenda-setting exercise. Five studies described a more collaborative and inclusive approach where EbEs and researchers worked together as equal partners to identify local research topics. One EbE driven approach was reported. Information about the way people were involved at different stages of identifying research topics and priorities is presented in Table 1.
- The numbers of EbEs involved in consultations exercises ranged from 6 to 83.
- Consultations resulted in the identification of research themes/questions but only one study generated a list of specific implementable research projects that could be undertaken.
- Two studies reported plans to continue working with EbEs and/or key stakeholders to implement priorities but in general no specific implementation strategies were identified.
- In the less structured approaches research questions led to the development of new research.

	Consultation	Collaboration		User-Led
		Mixed Methods	Team working	
<b>Planning</b>		Service user researchers were part of a research team	EbEs were members of research networks/user groups	Service user researchers were principle investigators
<b>Identifying research questions</b>	Stakeholder consultation exercises including EbEs  Methods: Focus Groups, Delphi method, facilitated workshops/ face to face and online group based meeting	Consultation exercises with EbEs  Methods: Surveys, facilitated workshops and group based meetings	Dialogue between professionals and EbEs  Methods: group based meetings/ steering group membership	Working in partnership with service user steering group  Methods: Meetings
<b>Selecting priorities</b>	Methods for decision making: Nominal Group Technique (NGT), Delphi technique, ranking, rating, facilitated workshop	Methods: facilitated workshops; frequency that each category was mentioned in the transcripts.	Methods: collaborative shared decisions approach	
<b>Outputs/ Dissemination</b>	<ul style="list-style-type: none"> <li>Research topics/priorities</li> <li>Implementable research agenda</li> <li>Publications/Reports</li> </ul>	<ul style="list-style-type: none"> <li>Research themes/priorities</li> <li>Publications/Reports</li> <li>Local feedback</li> <li>Wide dissemination to user networks and NHS community</li> </ul>	<ul style="list-style-type: none"> <li>Topic generation</li> <li>Research question identified</li> <li>Publications</li> </ul>	<ul style="list-style-type: none"> <li>Topic generation</li> <li>Research question identified</li> <li>Publication</li> </ul>
<b>Implementation</b>	<ul style="list-style-type: none"> <li>Agenda translated into funding programme</li> </ul>	<ul style="list-style-type: none"> <li>Priorities fed into research programme</li> <li>Resource material produced</li> </ul>	<ul style="list-style-type: none"> <li>New research</li> <li>Changed focus of funding application</li> </ul>	<ul style="list-style-type: none"> <li>Conducted research</li> </ul>

Table 1: Degree of EbE involvement in identifying research topics and priorities. Consultation refers to EbEs providing opinion and advice; Collaboration refers to active, ongoing and equal partnership between researchers and EbEs; User-led refers to EbEs leading and making decisions about their own research. Activities that EbEs were not involved in are added in italics.

## Next steps

Work with LEAG to:

- Complete synthesis of information – focus on the strengths and weaknesses of the above models, the impact of involvement and what might have influenced its effectiveness.
- Carry out an expert seminar to discuss findings and to add experts' interpretations and perspectives.
- Share conclusions with local R&D, NHS leads and discuss ways to inform future work in Cambridgeshire.
- Share conclusions with national and regional PPI networks.

**References:** 1. Chalmers I, et al. Avoidable waste in the production and reporting of research evidence. *Lancet* 2009;374:86–9. 2. Brett J, et al. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect*. 2014;17:637-650. 20. 3. Brett J, et al. A systematic review of the impact of patient and public involvement on service users, researchers and communities. *Patient*. 2014;7(4):387-395. 4. Manafa E, et al. Patient and public engagement in priority setting: a systematic rapid review of the literature. *PLoS One*. 2018; 13:3. 5. Madden M, Morley R. Exploring the challenge of health research priority setting in partnership: reflections on the methodology used by the James Lind alliance pressure ulcer priority setting partnership. *Res Involv Engagem* 2016; 2:12; 6. Tineke et al, Patient participation as dialogue: setting research agendas. *Health Expect*. 2010; 13(2):160–173. 7. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005; 8:19–32. 8. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci*. 2010;5:69.

Acknowledgements: Ms Isla Khun, and the CLAHRC Fellowship programme.

This is a summary of independent research funded by the National Institute for Health Research (NIHR)'s Collaboration for Leadership in Applied Health Research and Care East of England (CLAHRC EoE) Programme. Views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.