UK Epilepsy Preconception Study Delphi - developing consensus on the content of care for women with epilepsy planning a pregnancy

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Key findings

- Patient co-research and patient and public involvement in epilepsy research is achievable.
- 33 items of preconception care were identified as essential through a consensus Delphi process.
- Evaluation of preconception care interventions for women with epilepsy and health professionals involved in their care is warranted.
- Our findings highlight the need for targeted messaging to raise awareness of the importance of preconception care, encourage health professional engagement and direct women to appropriate evidence-based resources and support.

I. Introduction

The study rationale to investigate preconception care for women with epilepsy was a response to the recommendations made in three governmental publications:

- The Confidential Enquiry into Maternal Deaths
- The most recent MMBRACE-UK 2016-2018¹ reported deaths related to SUDEP had almost tripled, and few had received preconception care.
- The Medicines and Healthcare products Regulatory Agency Valproate guidance
 - The Valproate scandal has raised new challenges for women who may experience poor seizure control due to avoiding valproate, or due to stopping it prior to or during pregnancy.
- Public Health England (2018)² "Making the Case for Preconception Care Planning and preparation for pregnancy to improve maternal and child health outcomes" recognizing the frequent missed opportunity to intervene ahead of pregnancy.

The WHO defines preconception care as a series of promotive, preventive, and curative health interventions to maximise maternal and child healthcare³.

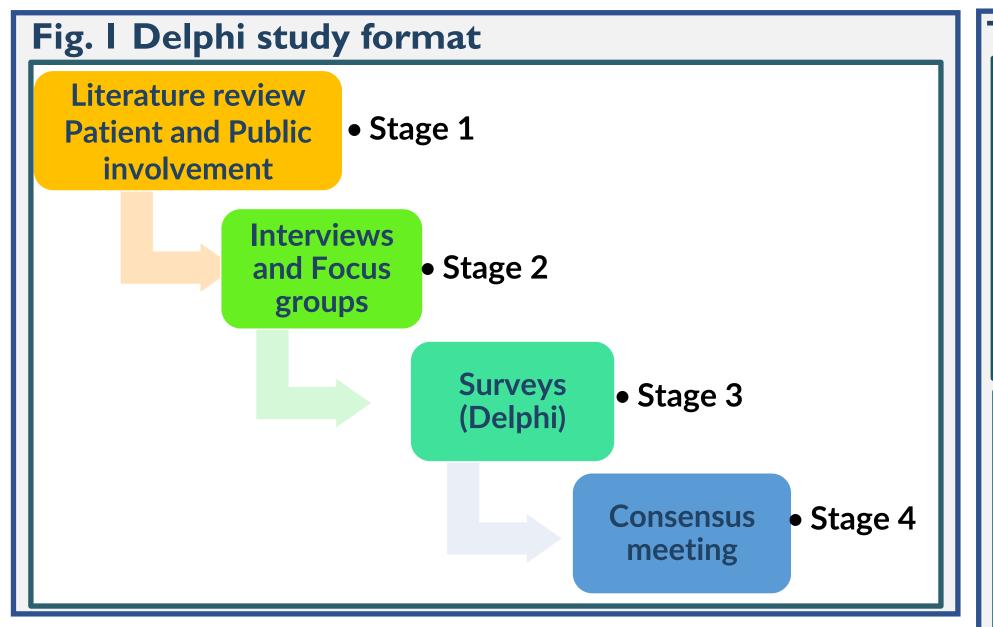
Preconception care interventions to include any educational, health promotion (condition management), or counselling interventions (or a combination of these) targeting women with epilepsy, with the intention of improving preconception health outcomes⁴.

2. Methods

This mixed methods Delphi study with consensus meeting (fig. 1) aims to answer the research question:

For women with epilepsy aged 16-50 years in the UK, what are the essential elements of preconception care that will improve outcomes along their preconception care pathway? The study objectives are to:

- identify the essential preconception care interventions
- identify the key stages in the care pathway that they should be delivered
- gain an understanding of the preconception care outcomes of importance to women with epilepsy
- 1. We engaged in patient and public involvement and collaborated with patient organisations to inform development of the study methods and study materials (including multi-model recruitment via NHS sites, NIHR CRN, social media and snowball techniques).
- 2. We systematically reviewed preconception interventions reported in a mixed methods review to include items important to stakeholder groups reported in qualitative studies⁴.
- 3. We invited women their partners and family to participate in interview and focus group (comoderated with the patient researcher) (table 1). 4. We generated a long list of items of preconception care, process and outcomes (fig. 2) and
- categorised into Domains based on the taxonomy of the COMET initiative⁵ (table 2). 5. We a priori defined consensus and prospectively registered the study on the COMET database.
- 6. We used DelphiManager software to run a two round Delphi online survey.
- 7. We held an online Consensus meeting of 30 participants from all groups, with independent chair to facilitate discussion using consensus methods informed by the James Lind Alliance.



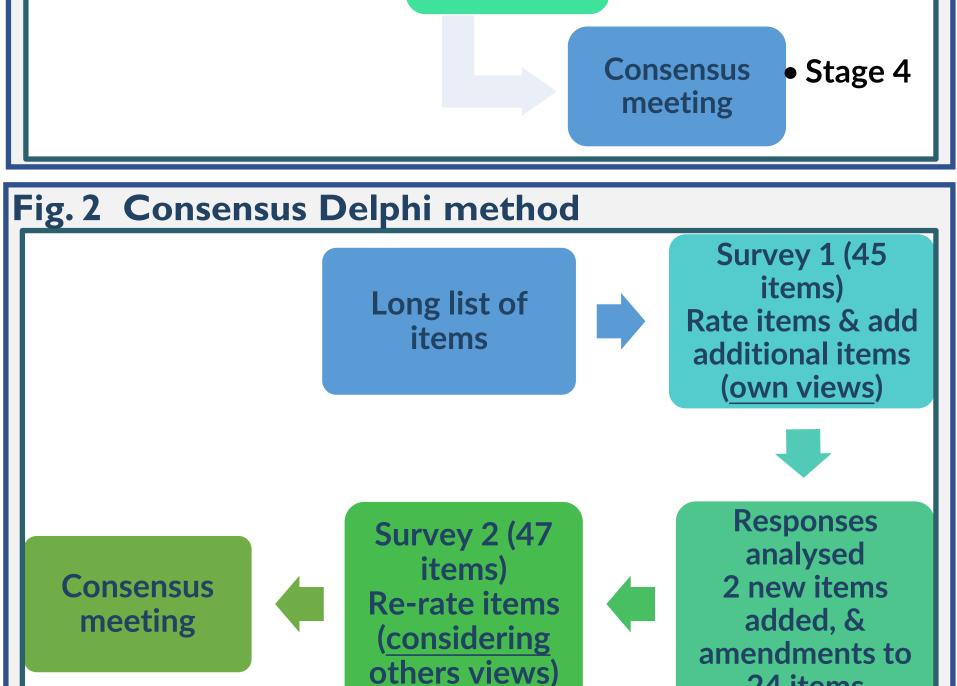


Table I. Delphi survey development Interview and focus groups (n=58) 3 focus groups (n=17) Shared facilitation with the patient co-researcher • 35 interviews (n=41) • 10 women and their partners • 2 bereaved parents • 2 interviews with extended family Pilot test survey & refining survey item 10 pilot interviews Young persons advisory panel

Professional and voluntary stakeholder

Table 2. Preconception Care Domains Access and Availability of

Preconception Care

representatives

- **Contraception Review**
- **Information Needs** Managing pregnancy and seizure related risk
- Optimising seizure control
- Preconception care pathway
- Support for planning

3. Results Preconception care items were identified from systematic review and PPI

24 items

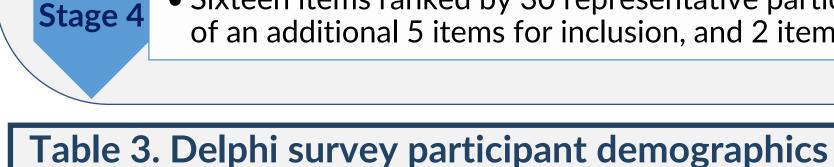
• 23 papers were eligible for review & verbatim items were recorded

• 58 participants shared lived experience in interview and focus group • Thematic analysis identified domains and items and processes of care

• 45 items were selected from results of stages 1 & 2 for Round 1 Delphi

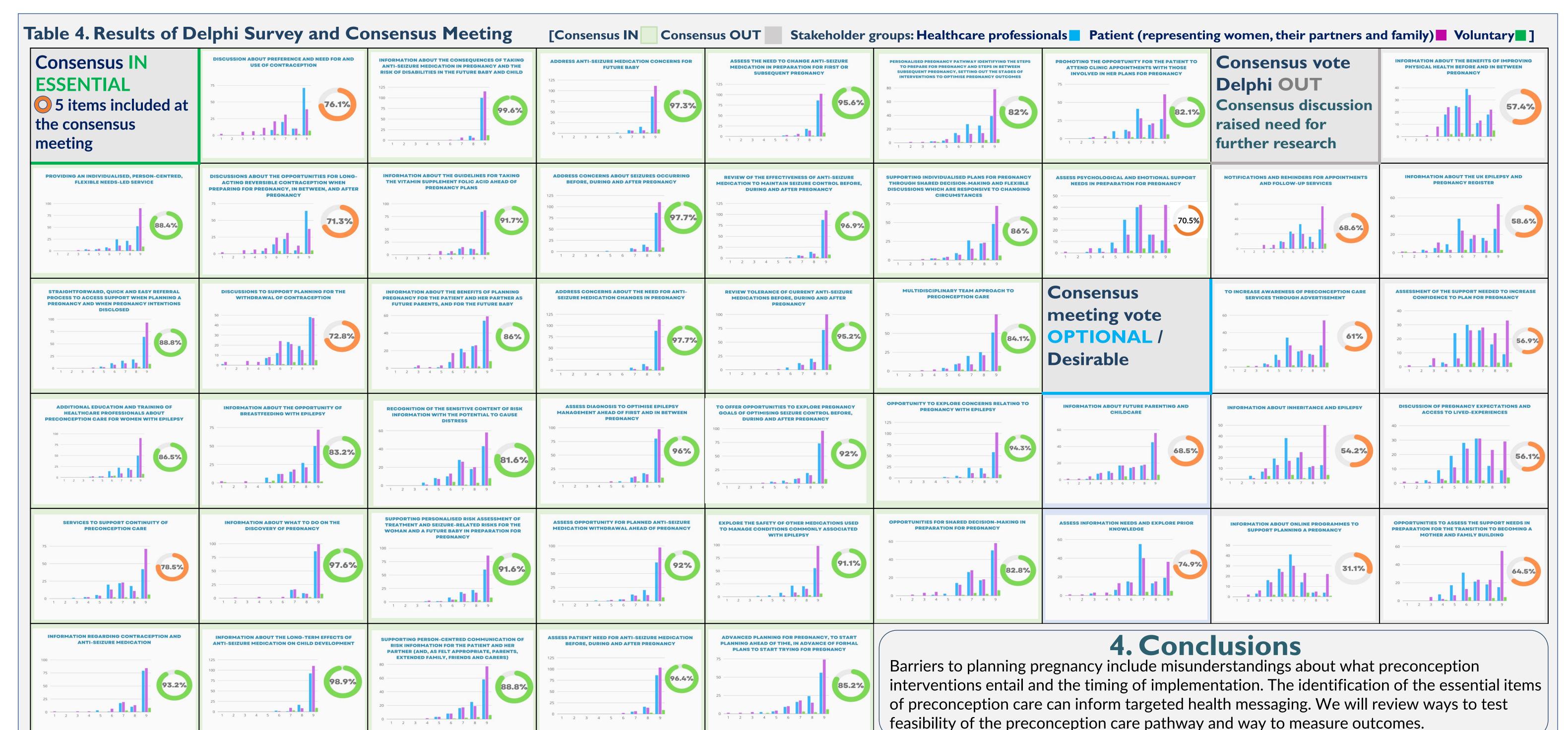
• Consensus sought from 248 participants completing both Delphi Rounds 1 & 2 ranking 47 items (2 new items included from the free text responses in Round 1) (table 3)

• Review consensus and ratify 31 items as essential for inclusion (Table. 4, for consensus discussion) • Sixteen items ranked by 30 representative participants in online Delphi Consensus finding agreement of an additional 5 items for inclusion, and 2 items desirable/optional



Stage 3

Characteristic Round 2, n=248 Round 1, n=296 Male 44 (17) **Female** 207 (83) Stakeholder group 126 (51) **Patients** Healthcare professionals 110 (44) **Voluntary members** 12 (5) Country 215 (86) **England Northern Ireland** 12 (5) **Scotland** 12 (5) 11 (4) Wales



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