

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

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Why preconception care?



The World Health Organisation defines preconception care as a series of promotive, preventive, and curative health interventions to maximise maternal and child healthcare.



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Why preconception care?

MHRA/CHM updated advice following a comprehensive safety review (January 2021)



- 11 medicines reviewed
- 2 found safer lamotrigine and levetiracetam
- 9 found to have increased risks and uncertainty of risk
- 10 were listed as not having enough information on their use in pregnancy
- 6 medicines available for prescription in the UK not included in the review



Why preconception care?



Public Health England (2018) “Making the Case for Preconception Care” promote a life-course approach due to frequent missed opportunity to intervene ahead of pregnancy.

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Why preconception care?

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.



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Why preconception care?



MMBRACE-UK 2016-2018 reported deaths related to SUDEP had almost tripled, finding few of those who died had received preconception care.

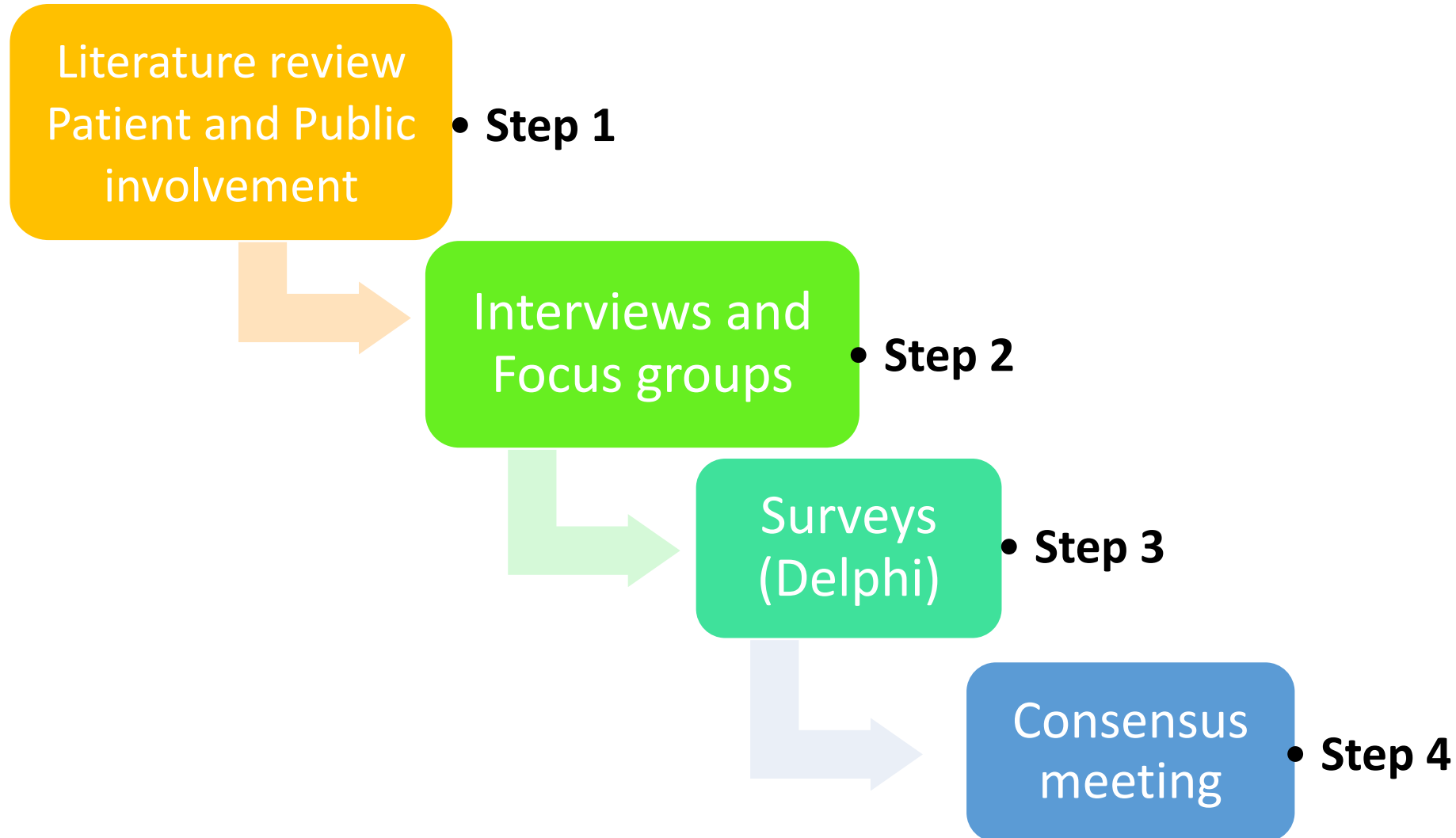
This study set-out to answer

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?

- **Achieved by:**

1. Focus group and interviews with women their partners and family to explore experience
2. Multi-stakeholder online Delphi survey and consensus meeting

This multi-stakeholder Delphi study aimed to gain consensus on the content of preconception care for women with epilepsy



Data collection and analysis

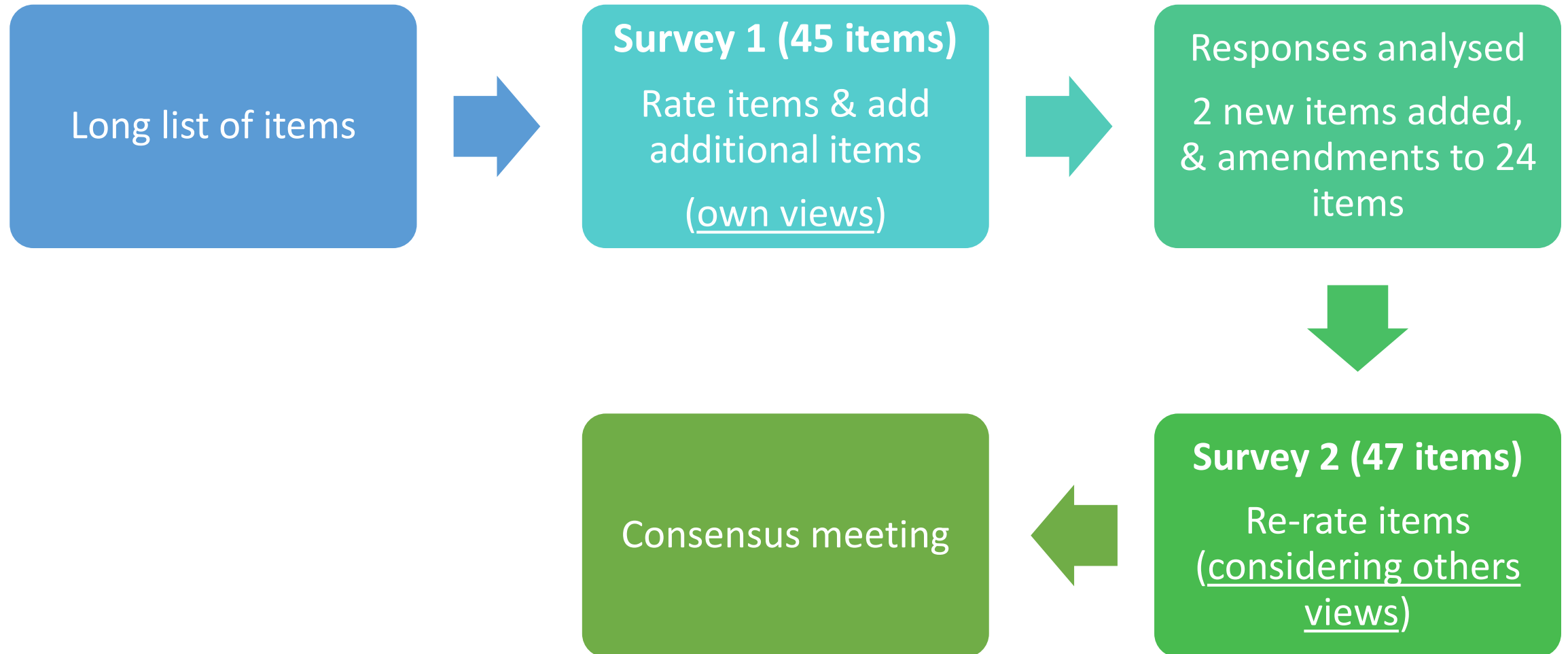
Study stage 2 – interview and focus group

- 58 participants
- 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
- Thematic analysis

Stage 3 – Survey development

- Pilot test survey & refining survey item list
- 10 pilot interviews
- PPI
- Young persons advisory panel
- Professional and voluntary stakeholder representatives

The process of developing the epilepsy preconception care Delphi survey?



Delphi survey results

- 316 participants registered to take part in the Delphi survey
- 296 completed Round 1
 - 153 Patient stakeholders
 - 128 Healthcare professional/researcher stakeholders
 - 15 Voluntary stakeholders
- 248 completed Round 2
 - 126 Patient stakeholders
 - 110 Healthcare professional/researcher stakeholders
 - 12 Voluntary stakeholders
- 2 new items included from the free text responses in round 1

Domains

- Access and Availability of Preconception Care
- Contraception Review
- Information Needs
- Managing pregnancy and seizure related risk
- Optimising seizure control
- Preconception care pathway
- Support for planning

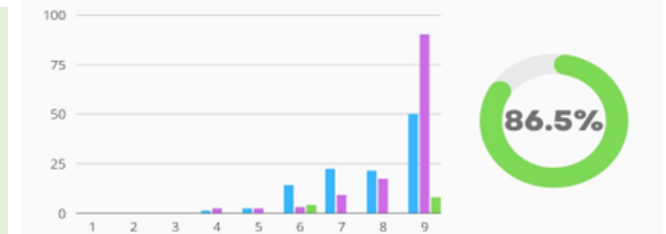
Essential items of preconception care

- 31 items were rated as being essential by over 80% Delphi participants scoring 7-9 (essential).
- **Automatic inclusion** in the final list of essential items preconception care.
- 4 items rated essential at consensus meeting
- 2 items rated as optional for inclusion at consensus meeting

Access and Availability of Preconception Care

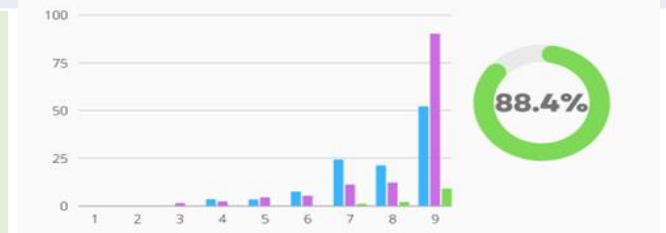
Items

Additional education and training of healthcare professionals about preconception care for women with epilepsy

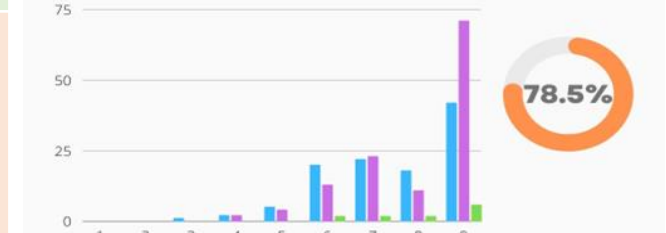


Notifications and reminders for appointments and follow-up services

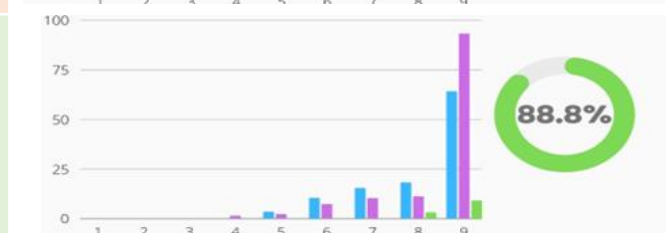
Providing an individualized, person-centred, flexible needs-led service



Services to support continuity of preconception care



Straightforward and timely referral process to access support when planning a pregnancy and when pregnancy intentions disclosed

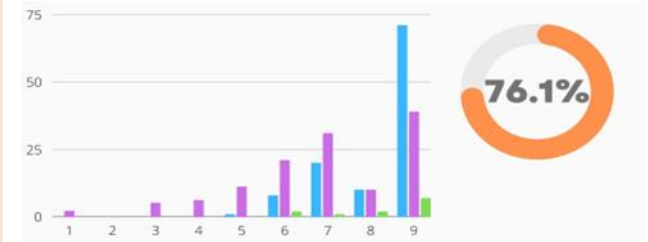


To increase awareness of preconception care services through advertisement

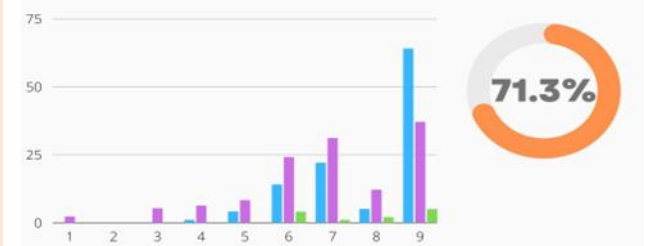
Contraception Review

Items

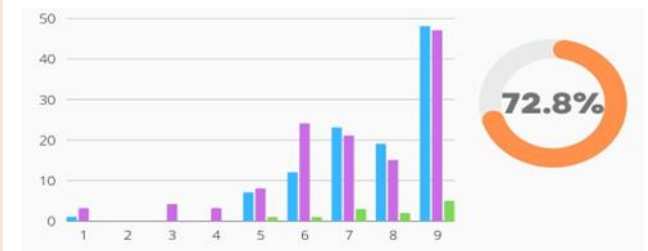
Discussion about preference and need for and use of contraception



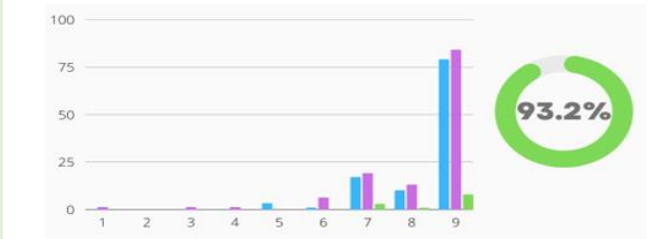
Discussions about the opportunities for long-acting reversible contraception when preparing for pregnancy, in between, and after pregnancy



Discussions to support planning for the withdrawal of contraception



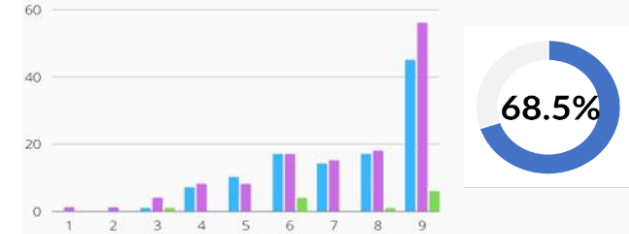
Information regarding contraception and anti-seizure medication



Information Needs (I)

Items

Information about future parenting and childcare (comment from Consensus meeting for post-natal care plan)

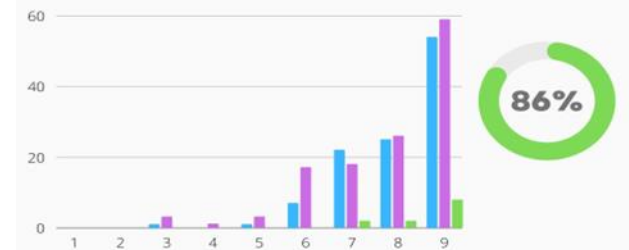


Information about inheritance and epilepsy

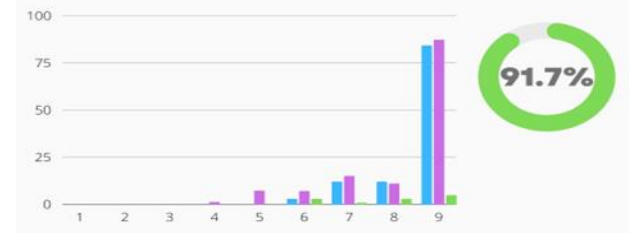
Information about interactive web-based programs for planning a pregnancy

Information about the benefits of improving physical health before and in between pregnancy

Information about the benefits of planning pregnancy for the patient and her partner as future parents, and for the future baby



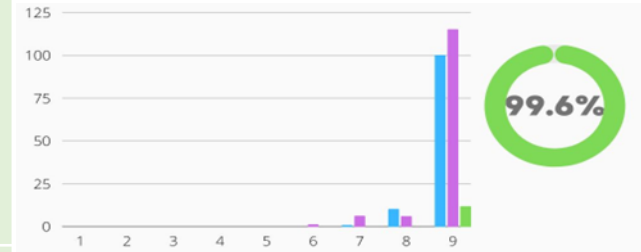
Information about the benefits of taking the vitamin supplement Folic Acid before and in between pregnancy



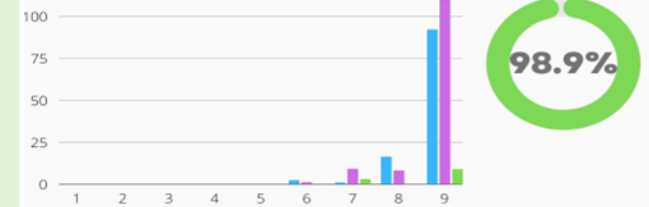
Information Needs (2)

Items

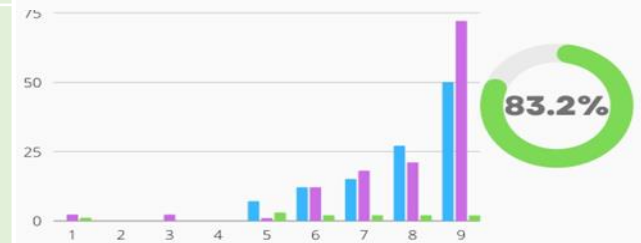
Information about the consequences of taking anti-seizure medication in pregnancy and the risk of disabilities in the future baby and child



Information about the long-term effects of anti-seizure medication on child development

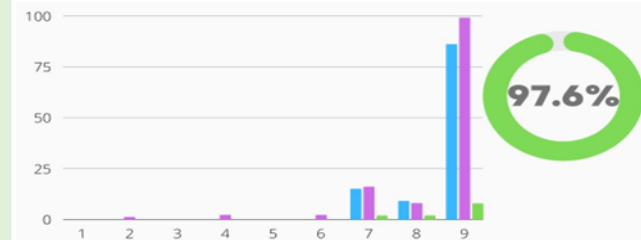


Information about the opportunity of breastfeeding with epilepsy



Information about the UK Epilepsy and Pregnancy Register

Information about what to do on the discovery of pregnancy



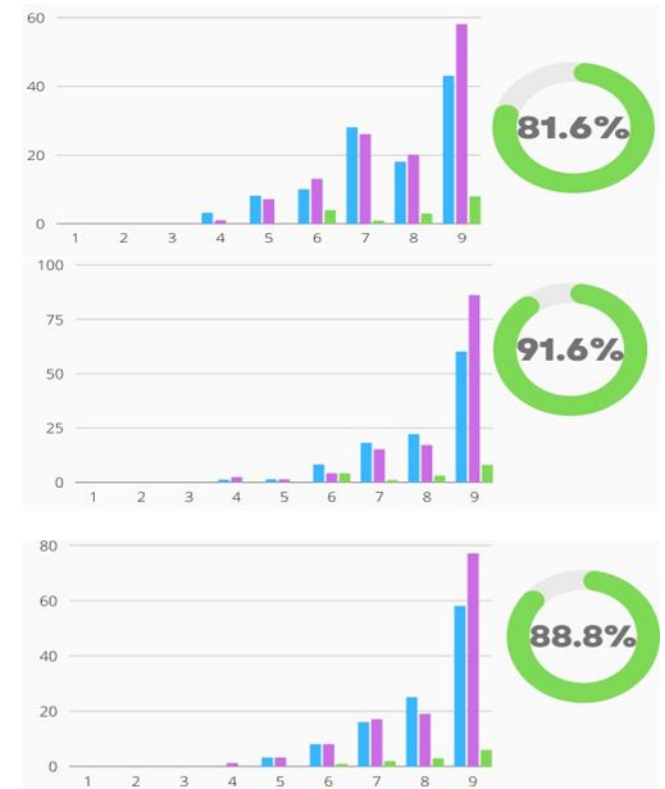
Managing pregnancy and seizure related risk

Items

Recognition of the sensitive content of risk information with the potential to cause distress

Supporting personalized risk assessment of treatment and seizure-related risks for the woman and a future baby in preparation for pregnancy

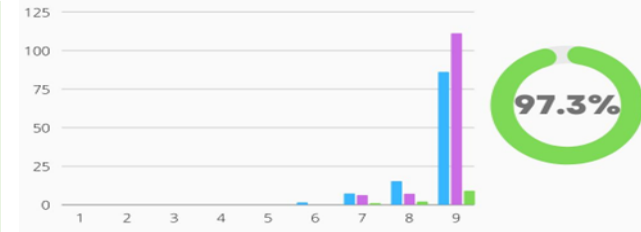
Supporting person-centred communication of risk information for the patient and her partner (and, as felt appropriate, parents, extended family, friends and carers)



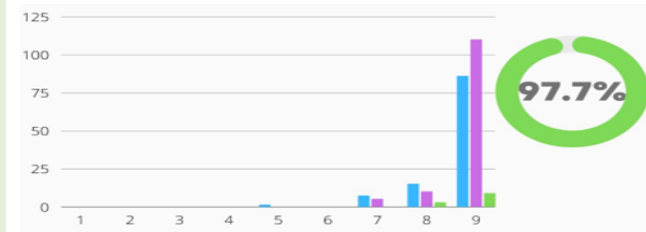
Optimising seizure control (I)

Items

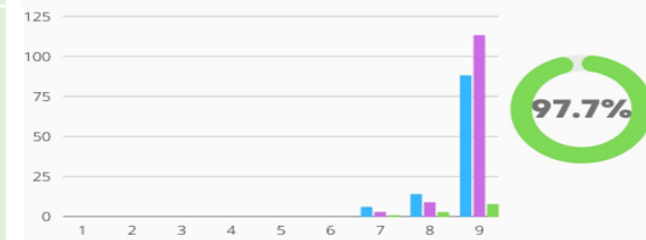
Address anti-seizure medication concerns for future baby



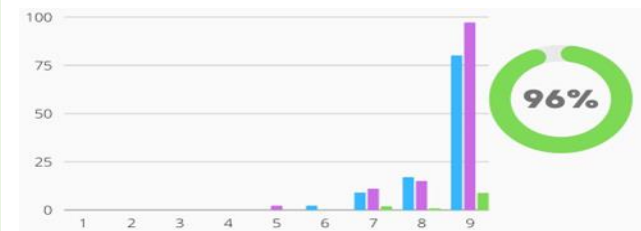
Address concerns about seizures occurring before, during and after pregnancy



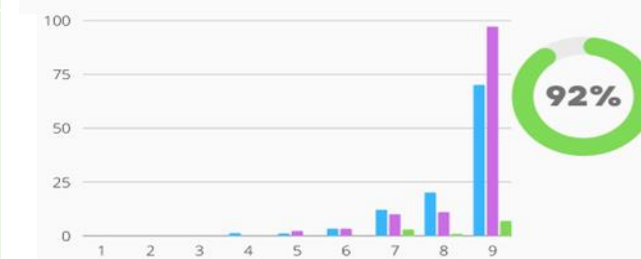
Address concerns about the need for anti-seizure medication changes in pregnancy



Assess opportunities to optimize epilepsy management ahead of first and in between pregnancy



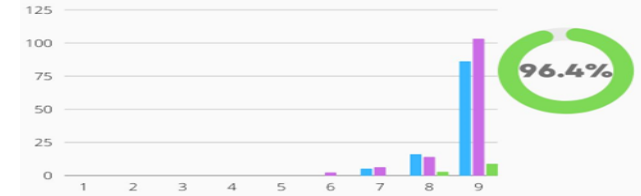
Assess opportunity for planned anti-seizure medication withdrawal ahead of pregnancy



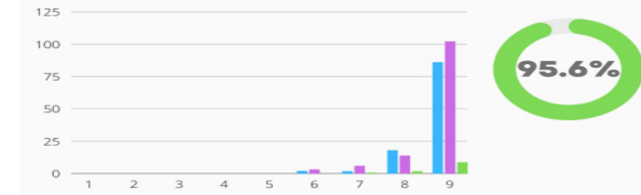
Optimising seizure control (2)

Items

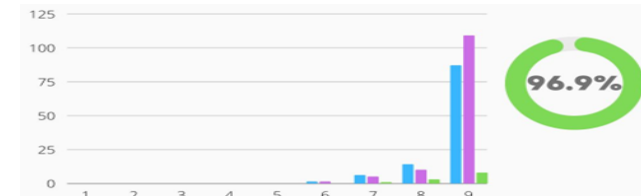
Assess patient need for anti-seizure medication before, during and after pregnancy



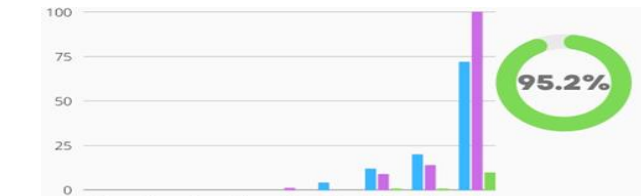
Assess the need to change anti-seizure medication in preparation for the first or subsequent pregnancy



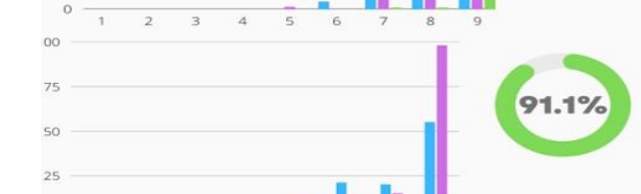
Review of the effectiveness of anti-seizure medication to maintain seizure control before, during and after pregnancy



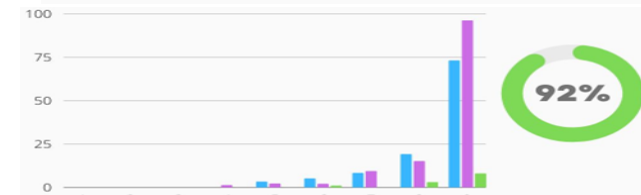
Review tolerance of current anti-seizure medications before, during and after pregnancy



Explore the safety of other medicines used to manage conditions commonly associated with epilepsy



To offer opportunities to explore pregnancy goals of optimizing seizure control before, during and after pregnancy



Preconception care pathway

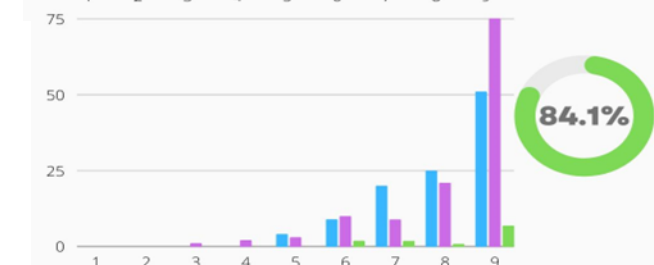
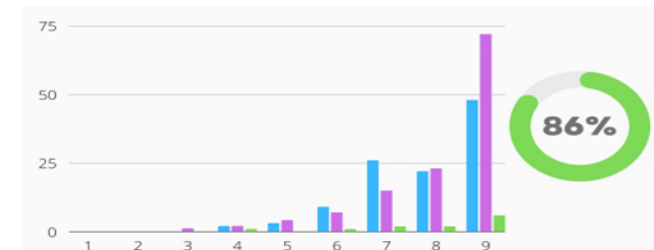
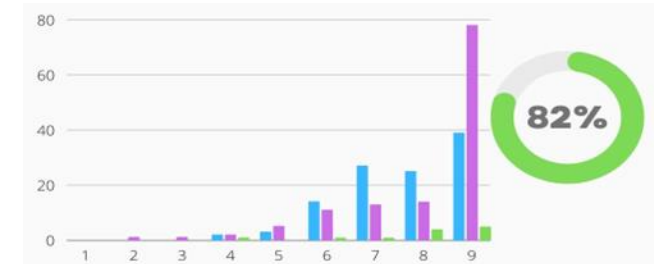
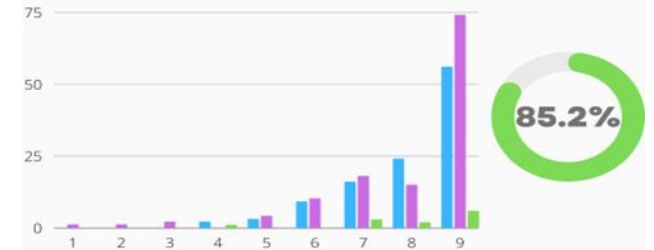
Items

Advanced planning for pregnancy, to start planning the stages of intervention for pregnancy ahead of time, in advance of formal plans to start trying for pregnancy

Personalized pregnancy pathway identifying the steps to prepare for pregnancy and steps in between subsequent pregnancy, setting out the stages of interventions to optimize pregnancy outcomes

Supporting flexible plans for pregnancy through shared decision-making and discussions about acting in response to changing circumstances

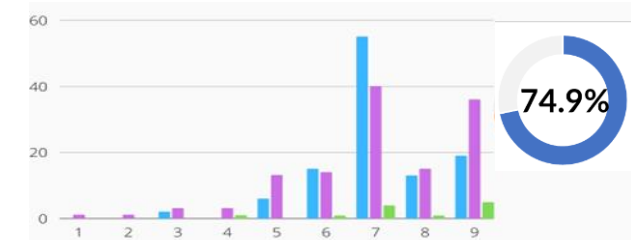
Multidisciplinary team approach to preconception care



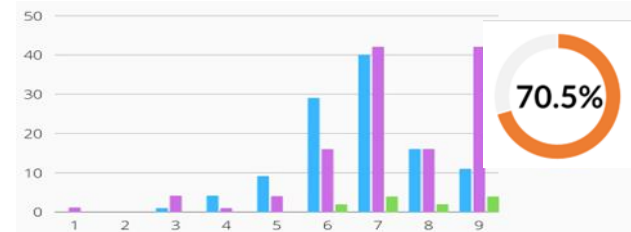
Support for planning

Items

Assess information needs and explore prior knowledge



Assess psychological and emotional support needs in preparation for pregnancy

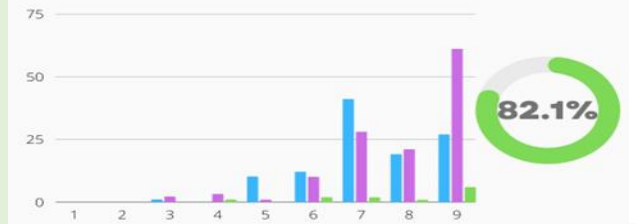


Assessment of the support needed to increase confidence to plan for pregnancy
Discussion of pregnancy expectations and access to lived experiences

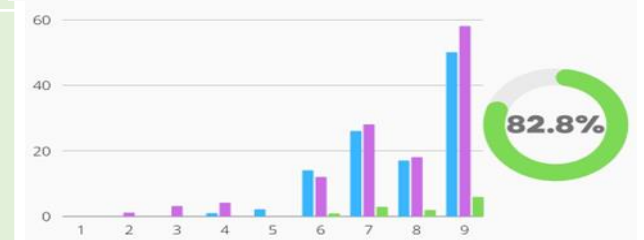
Support for planning

Items

Promoting the opportunity for the patient to attend clinic appointments with those involved in her plans for pregnancy

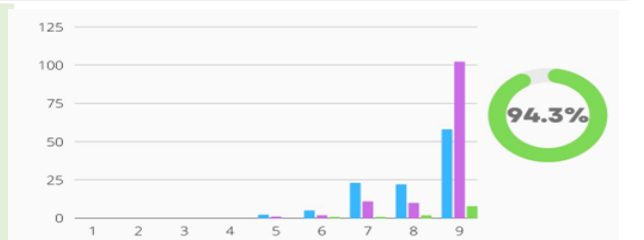


Opportunities for shared decision-making in preparation for pregnancy



Opportunities to assess the support needs in preparation for the transition to becoming a mother and family building

Opportunity to explore concerns relating to pregnancy with epilepsy (include concerns of inheritance – comments from Consensus meeting)



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.
- Findings highlight the need for emotional and psychological support.

Conclusions

- Barriers to planning pregnancy include misunderstandings about what preconception interventions entail and the timing of implementation.
- The identification of the essential items of preconception care can inform targeted health messaging.
- We will review ways to test feasibility of the preconception care pathway.
- We will explore the use of a measure of pregnancy intention to support targeted interventions for women at risk of poor pregnancy outcomes

Acknowledgement of collaborators

- Fife NHS Trust (Fiona MacPhie)
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 - SUDEP Action
 - INFACT
 - Valproate Victims
 - Epilepsy Scotland
 - Epilepsy Wales
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A special thank you
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