

GRIPP2-SF Item	Description
1.Aims: Report the aim of PPI in the study	<p><i>i) Ensure there is a patient voice included at all stages of the EURIPIDES study</i></p> <p><i>ii) WP3: To participate meaningfully in all areas of the research activity from design, to data collection, to analysis and writing</i></p> <p><i>iii) WP3: To develop and discuss the themes and sub-themes identified in the data collected to ensure face and content validity</i></p>
2.Methods: Provide a clear description of the methods used for PPI in the study	<p><i>Both the Survivor Researchers (SRs) and the Patient and Public Involvement Team (PPIT) were involved extensively throughout WP3 from inception to completion. The SRs were involved in designing the recruitment materials and instruments, in conducting research interviews, and in defining coding frameworks alongside the research team. The SRs were also involved in co-authoring the PPI chapter of the final report.</i></p> <p><i>The PPIT helped develop the vignettes used in interviews with patients, carers and staff. In particular, they designed and approved 'flashcards' for use in interviews with service users and carers across six case sites. They were involved in developing the initial coding frameworks used to analyse the data. After data collection we presented some transcripts through role play and the group discussed emerging themes and expressed their thoughts and understanding of the transcripts. They provided detailed feedback in sub-groups both verbally which was recorded and on mind-maps. The PPIT met regularly and at key points during the study. The group were facilitated by DCK who ensured they felt able, and were supported, to contribute and challenge.</i></p>
3.Study results Outcomes: Report the results of PPI in the study, including both positive and negative outcomes	<p><i>The PPIT and SRs combined provided a strong user and carer perspective but each drawing on their unique expertise to lend support to the study in different ways. They all critiqued the content of the emerging themes in service user and carer interviews. They provided content and face validity of the themes and sub-themes identified. The PPIT provided real life examples of the themes from their own experiences. The SRs used their research skills to carry out research activity. The PPIT and SRs also provided an opportunity to check the themes from studies resonated in a UK context.</i></p>
4. Discussion and conclusions Outcomes: Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	<p><i>The PPI was important for iterative design of the interview schedules and flashcards, in gathering and analysing the data, and in reaching conclusions from the analysis. Feedback from participants in the study was that the flashcards were very helpful, and interviewees also found them extremely beneficial when identifying context, mechanisms and outcomes with participants.</i></p> <p><i>The Group agreed on the final themes and felt they had been strongly involved and listened to and overall had an enjoyable experience.</i></p>

5. Reflections/critical perspective: Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience

*The Patient and Public Involvement Reference Group worked well in the study. As the study progressed they became more confident in their involvement. As the study progressed we learnt the PPIT did not like presentations or a lot of paper but preferred more involved ways of information gathering, hence the role plays, sub-group discussions, and use of mind-maps to gather their individual thoughts, feelings and experiences. Our working together developed over the course of the study.*