GRIPP 2 Long Form

We have followed the GRIPP2 (Guidance for Reporting Involvement of Patients and the Public) methodology, and report using the long form. For some sections below, the relevant material is not contained in the report itself but instead further detail is provided here.

Section and topic	**Item**	**Reported on page No**
Section 1: Abstract of paper		
1a: Aim	Report the aim of the study	2
1b: Methods	Describe the methods used by which patients and the public were involved	4
1c: Results	Report the impacts and outcomes of PPI in the study	79
1d: Conclusions	Summarise the main conclusions of the study	85
1e: Keywords	Include PPI, “patient and public involvement,” or alternative terms as keywords	i
Section 2: Background to paper *(this is Chapter 1)*		
2a: Definition	Report the definition of PPI used in the study and how it links to comparable studies *Note*: We approached the involvement of patients in the study design and implementation in accordance with the accepted INVOLVE definition. INVOLVE was established in 1996 and was part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research. INVOLVE defines public involvement in research as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them (https://www.invo.org.uk/public-involvementparticipationengagement-in-research/). Its role transferred in April 2020 to the NIHR's Centre for Engagement and Dissemination.	See note
2b: Theoretical underpinnings	Report the theoretical rationale and any theoretical influences relating to PPI in the study *Note*: Our patient panel met across four occasions, all of those on-line due to Covid-19 restrictions on face to face meeting. Being obliged to interact with patients online we adopted an approach conforming to the Accessible Information Standard (https://www.gov.uk/guidance/accessibility-requirements-for-public-sector-websites-and-apps). This standard says that all publicly funded adult health care providers, so including NIHR funded research teams, must identify and meet the information and communication needs of those who use their services. We	See note

Section and topic	Item	Reported on page No
	made our online content and design clear and simple enough so that most people could use it without needing to adapt it, and supported those who did need to adapt things.	
2c: Concepts and theory development	Report any conceptual models or influences used in the study *Note*: Dawson et al advise the need to adopt flexible approaches rather than a one-size-fits-all model when working with PPI contributors. (See: Dawson, S., Ruddock, A., Parmar, V. *et al.* Patient and public involvement in doctoral research: reflections and experiences of the PPI contributors and researcher. *Res Involv Engagem* 6, 23 (2020). https://doi.org/10.1186/s40900-020-00201-w). Our patient panel met on four occasions, all of those online. We adapted our approach by creating an extensive background document set using the Microsoft Sway newsletter format. This newsletter incorporated video as well as text. Two of the patient panel members were sight impaired. Adaptations to support equality of involvement included an accessibility view in the Microsoft Sway pre-meeting materials and pre-panel invitations to those members to speak with the study team patient involvement lead to personalise communication at the panel. This was taken up by one of the panel, and all of the materials materials were reviewed using a screen reader in advance of the meeting. The patient involvement on-line material was assured as suitable for screen reader technology. We additionally created an Easy Read document describing the study to sit on the study website as an intentional approach to broadening the study's public engagement reach. This was co-produced with specialist graphic design input and with adults with learning disability and/or autism. The Easy Read document was also adapted for screen reader use by involvement of one of the sight impaired patient panel members. Chinn and Homeyard's meta analysis interrogates the benefit of an Easy Read format. They advise that *individually tailored information is more likely to meet personalized health information needs for people with intellectual disabilities. The emergence of different social formations in the creation of accessible information has potential for advancing engagement of diverse groups* (see: https://onlinelibrary.wiley.com/doi/full/10.1111/hex.12520)	See note
Section 3: Aims of paper		
3: Aim	Report the aim of the study	xiii

Section and topic	**Item**	**Reported on page No**
Section 4: Methods of paper		
4a: Design	Provide a clear description of methods by which patients and the public were involved	4
4b: People involved	Provide a description of patients, carers, and the public involved with the PPI activity in the study	5
4c: Stages of involvement	Report on how PPI is used at different stages of the study	5
4d: Level or nature of involvement	Report the level or nature of PPI used at various stages of the study	4
Section 5: Capture or measurement of PPI impact		
5a: Qualitative evidence of impact	If applicable, report the methods used to qualitatively explore the impact of PPI in the study	n/a
5b: Quantitative evidence of impact	If applicable, report the methods used to quantitatively measure or assess the impact of PPI	n/a
5c: Robustness of measure	If applicable, report the rigour of the method used to capture or measure the impact of PPI	n/a
Section 6: Economic assessment		
6: Economic assessment	If applicable, report the method used for an economic assessment of PPI	n/a
Section 7: Study results		
7a: Outcomes of PPI	Report the results of PPI in the study, including both positive and negative outcomes	79
7b: Impacts of PPI	Report the positive and negative impacts that PPI has had on the research, the individuals involved (including patients and researchers), and wider impacts *Note*: we did not feel there were any negative impacts that PPI had on the research.	79
7c: Context of PPI	Report the influence of any contextual factors that enabled or hindered the process or impact of PPI	79
7d: Process of PPI	Report the influence of any process factors, that enabled or hindered the impact of PPI	79
7ei: Theory development	Report any conceptual or theoretical development in PPI that have emerged	See note

Section and topic	**Item**	**Reported on page No**
	Note: By adopting our approach in accordance with the Accessible Information Standard we demonstrated clear gain in a broader inclusion to patient involvement via the patient panel. The patient panel praised the Sway newsletter as a successful and a pleasing support to their informed involvement. The Easy Read study document ensured a broader public engagement principle. These developments have resonance beyond a Covid-19 obligation into all patient involvement in and public engagement with health research.	
7eii: Theory development	Report evaluation of theoretical models, if any	n/a
7f: Measurement	If applicable, report all aspects of instrument development and testing (eg, validity, reliability, feasibility, acceptability, responsiveness, interpretability, appropriateness, precision)	n/a
7g: Economic assessment	Report any information on the costs or benefit of PPI	n/a
Section 8: Discussion and conclusions		
8a: Outcomes	Comment on how PPI influenced the study overall. Describe positive and negative effects	79
8b: Impacts	Comment on the different impacts of PPI identified in this study and how they contribute to new knowledge	n/a
8c: Definition	Comment on the definition of PPI used (reported in the Background section) and whether or not you would suggest any changes	4
8d: Theoretical underpinnings	Comment on any way your study adds to the theoretical development of PPI	79
8e: Context	Comment on how context factors influenced PPI in the study	79
8f: Process	Comment on how process factors influenced PPI in the study	79
8g: Measurement and capture of PPI impact	If applicable, comment on how well PPI impact was evaluated or measured in the study	n/a
8h: Economic assessment	If applicable, discuss any aspects of the economic cost or benefit of PPI, particularly any suggestions for future economic modelling.	n/a
8i: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so that others can learn from this study	79