

GRIPP 2 Checklist Example: Making an impact: The value added from patient and public involvement in the Life after Prostate Cancer Diagnosis (LAPCD) study

Section 1: Abstract of paper

1a: Aim Report the aim of the study

To explore the impact of PPI in the Life After Prostate Cancer Diagnosis (LAPCD) study and to explore the facilitators and challenges experienced.

1b: Methods Describe the methods used by which patients and the public were involved

Electronic survey and telephone interviews with both UAG members and researchers.

1c: Results Report the impacts and outcomes of PPI in the study

Improved survey design and topic guides for interviews, enhanced clarity of participant facing materials, identification of themes, development of lay summaries for paper.

1d: Conclusions Summarise the main conclusions of the study

Including PPI as an integral component of the LAPCD study, and providing the right context and mechanisms for involving the User Advisory Group (UAG) helped maximise the impact

1e: Keywords Include PPI, "patient and public involvement," or alternative terms as keywords

Patient and public involvement (PPI), User Advisory Group (UAG)

Section 2: Background to paper

2a: Definition Report the definition of PPI used in the study and how it links to comparable studies

Research being carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them (INVOLVE)

2b: Theoretical underpinnings Report the theoretical rationale and any theoretical influences relating to PPI in the study

Informed by realistic evaluation (Pawson & Tilly 2000)

2c: Concepts and theory development Report any conceptual models or influences used in the study

Informed by realistic evaluation (Pawson & Tilly 2000)

Section 3: Aims of paper

3: Aim Report the aim of the study

To evaluate the 'value added' or impact of the UAG on LAPCD study, and to explore the facilitating and hindering factors experienced

GRIPP2 Section 4: Methods of paper

4a: Design Provide a clear description of methods by which patients and the public were involved

For the evaluation study:

Using previous systematic literature reviews describing the impact of PPI on research (Evans 2014, Brett 2014, Brett 2013) a theory of change model developed by one of our service users (HB) to inform the evaluation, an online survey and topic guide was developed in collaboration with the UAG.

UAG members were also involved in the qualitative analysis. ZD conducted the initial analysis, and then the themes with relevant quotes were sent to the UAG to discuss. The UAG either agreed that the quote fitted the theme, moved it to another theme, or created a new theme for the quote.

UAG members assisted in the drafting and editing of this paper, and writing a clear lay summary.

4b: People involved Provide a description of patients, carers, and the public involved with the PPI activity in the LAPCD study

The UAG sample included men from different parts of the UK who had experienced different stages of prostate cancer and experienced different treatments, and representatives from Prostate Cancer UK.

4c: Stages of involvement Report on how PPI is used at different stages of the study Evaluation study:

UAG members were involved in the conception of this evaluation study, the design, the development of the theory of change model that informed the survey and the topic guide for interviews, assisted in the analysis of the qualitative work, wrote the lay summary for the paper and commented on iterations of the paper.

4d: Level or nature of involvement Report the level or nature of PPI used at various stages of the study

Evaluation study:

The evaluation was led by JB (researcher) and HB (Chair of UAG). A collaborative approach between the UAG and researchers (ZD, FM, JB) was adopted throughout the study.

GRIPP2: Section 5: Capture or measurement of PPI impact

5a: If applicable, report the method used to qualitatively capture the impact of PPI in the study

Interviews with patient representatives and researchers

5b: If applicable, report the method used to quantitatively measure or assess the impact of PPI

Online survey with patient representatives and researchers

5c: If applicable, report the robustness of the method used to capture or measure the impact of PPI N/A Not a validated measure of impact

GRIPP2: Section 6: Economic Assessment

6. If applicable, report the method used for an economic assessment of PPI N/A

GRIPP2: Section 7: Study results

7a/7b: Impacts and Outcomes of PPI Report the results of PPI in the study, including both positive and negative outcomes

Within the LAPCD study the UAG improved survey design and topic guides for interviews, enhanced clarity of patient facing materials, informed best practice around data collection for the ethics application, ensured the steering group meetings were grounded in what is important to the patient and ensured dissemination of study findings was patient focussed through talks of patient perspectives at conferences and development of lay summaries for papers.

Personal impacts for UAG members included a 'sense of helping others', enjoying the camaraderie, gaining confidence, and sharing experiential knowledge to inform better services for men with prostate cancer

Personal impacts on researchers included greater understanding and insight into what it is like to have prostate cancer as service users shared valuable experiential knowledge, gaining a rapport with the UAG, gaining knowledge of how to engage service users in research, benefitting from the additional support UAG members provided in the research process, and making the study feel 'real' to them

7c: Context of PPI Report the influence of any contextual factors that enabled or hindered the process or impact of PPI

There was a positive attitude towards PPI among both researchers and UAG members, and enough funding in place to support PPI, providing a good context for involving the UAG

7d: Process of PPI Report the influence of any process factors, that enabled or hindered the impact of PPI

The UAG was embedded early in the study and integral to each work-stream of the study, with a plan of how they would contribute for each work-stream. The UAG had good leadership, supportive camaraderie. The Chair of the UAG would discuss with researchers the involvement needed, then he would discuss with the rest of the UAG group in regular meetings or through email.

7ei: Theory development Report any conceptual or theoretical development in PPI that have emerged

Development of Theory of Change in PPI model, informed by systematic review data on the impact of PPI on health and social care research and informed by Realistic Evaluation.

7eii: Theory development Report testing 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****Gripp2: Section 8: Discussion and conclusions****8a: Outcomes Comment on how PPI influenced the study overall. Describe positive and negative effects**

The contexts that contributed to beneficial involvement from the UAG in the LAPCD study included clear aims and roles, strong leadership from the UAG Chair and committed confident members of the UAG, previous experience and a positive attitude towards PPI from the research team, and supportive relationships between the UAG and researchers.

The mechanisms that contributed to the successful involvement of the UAG in the LAPCD study included embedding PPI into the study early, the collaborative nature of PPI, and time and resources available to allow integration of the UAG into the study, with regular attendance of the UAG members at study research days, teleconferences and social events outside of formal research activities to build relationships

8b: Impacts Comment on the different impacts of PPI identified in this study and how they contribute to new knowledge

Reported impacts of PPI on the LAPCD study were evident throughout the LAPCD study. The reported impacts on improvements in patient facing materials, the design of research tools such as questionnaires, interview schedules and questions for focus groups and recruitment have previously been reported.^{2,20} Studies have also reported the impact of PPI on analysis of data.^{2,20} This can check the validity of study conclusions, correct misinterpretation of data, identify themes that would have otherwise been missed, identify which findings would be most relevant to patients or the public, and improve the way in which results have been described in reports.²⁰ PPI contribution to write up of papers, presentation of results at conferences, and in other dissemination activities has been reported to increase the likelihood of people acting on the findings.^{2,20}

This study also reports the personal impact that PPI has on the patient advisors and the researchers. The UAG members reported a 'sense of helping others', enjoying the camaraderie, gaining confidence, and sharing experiential knowledge to inform better services for men with prostate cancer. These personal impacts have previously been identified.⁸ Other studies have reported the notion of the "good citizen," with PPI in research being a natural extension of their wider civic interests, and how involvement in research helps patient advisors to make sense of living with or recovering from disease, and therefore offering space for the reconfiguration of self and identity.²¹ Researchers in the LAPCD study reported having a greater understanding and insight into what it is like to have prostate cancer as service users shared valuable experiential knowledge. This experiential knowledge has been referred to as 'knowledge in context'.¹⁴

(See paper reference list for references)

8c: Definition Comment on the definition of PPI used (reported in the Background section) and whether or not you would suggest any changes.

The definition of PPI was appropriate for this study

8d: Theoretical underpinnings Comment on any way your study adds to the theoretical development of PPI

The study is informed by Realist Evaluation and identifies how the context, environment, processes and mechanisms influence the impact that PPI has on a research study

8e: Context Comment on how context factors influenced PPI in the study

Contextual factors that contributed to the beneficial impact of PPI on the LAPCD study included clear aims and roles, time to contribute, confidence in contributing and strong PPI leadership, feeling valued and supported by the researchers, and inclusion in study communications

8f: Process Comment on how process factors influenced PPI in the study

The processes/mechanisms that contributed to beneficial impact included incorporating PPI into the study from the start with a planned programme of work dedicated to user involvement activities embedded in each work-stream, the collaborative nature of PPI, having resources available to allow integration of the UAG into the study, and regular attendance of the UAG members at study research days, teleconferences and social events outside of formal research activities to build relationships

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

The PPI in the LAPCD study was pre-planned, organised well, and conducted by a committed UAG and a committed research team. As a separate work-package within the programme of research, the PPI had many meaningful impacts on the separate work packages that improved the study outcomes. In future studies the participants agreed that hearing the voices of a more diverse group of prostate cancer patients may improve the impact of PPI in the studies, with suggestions of having a wider involvement through a Community of Interest Group (through support groups and online charity forums) as well as the core UAG. Distance of travelling to research meeting was a challenge for the UAG members, but the PPI study was well funded to cover their time and expenses for these meetings. Post COVID, where online meetings are more the norm, this may be less of a problem for future studies. Communication is key to overcome any differences in ways of working, and providing the UAG members with sufficient time to input is important.