

Reporting the Impact of Public and Patient Involvement in Midwife-led Care Study on Reproductive Age Group Women in India

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Abstract

Patient and public involvement (PPI) is an interaction with researcher, patient, and members of public. Involving patients and the public is considered to influence health research. However, the impact of PPI is not clear due to limited reporting. This study aimed to report on how PPI members were actively involved in research decisions and the impact it had on midwife-led care study conducted on reproductive age group women in India. PPI members were consulted from onset of the research study. Four women from two states of India were involved as PPI members. The meetings with the women took place online lasting for an hour. Meeting notes and activity log was recorded and maintained. The impact of PPI was reported using the GRIPP2-Short Form (SF) reporting checklist. The impact is presented under two parts 1. Research impact and 2. Personal impact. The research impact outlines the impact of PPI on designing the research proposal and methods. Further, it also highlights how PPI influenced the preparation of participant-centred research documents including the midwife-led care poster. The personal impact indicates significance of PPI event on PPI members and researcher.

The interaction between researcher and PPI contributors was rewarding and benefitted the research project. The PPI members were active and had strong interest in contributing to the design of the study. The impact reported in this paper will enhance involvement of PPI members in future nursing and midwifery research conducted in India.

Key words: Patient and public involvement, PPI impact, Midwife-led care

Patient and public involvement (PPI) refers to several ways of interacting with the public and involving them in research (National Institute of Health and Care Research /NIHR, 2021). The word “Public” includes patients, caregivers as well as all individuals using and representing health and social care services (NIHR, 2021). The NIHR, UK defines “public involvement” as research conducted ‘with’ or ‘by’ member of public rather than ‘to,’ ‘about’ or ‘for’ them (NIHR, 2021). Involving the public and making research decisions with them enhances the value of research (Jackson et al, 2020). Hence, currently involving patient and public in health and social care has increased internationally (Staniszewska et al, 2017).

Need of the study

For the past decade PPI has progressed efficiently and its contributions are well received in health-

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care research (Staniszewska et al, 2017). Involving public in research is widely recognised because it enables investigators to include public perspectives and ensures research focuses on the needs of the public (NIHR, 2021). PPI provides better understanding of what would work for the research participants in a particular context (Staniszewska et al, 2017). Further, the views of PPI members may differ from a researcher and thereby have the potential to improve the research design and methodology (Muller et al, 2019). Against this background, the researcher attempted to include PPI to know the views of public about the proposed midwife-led care research.

Despite advancements in PPI, it is obvious from previous studies that researchers have difficulty in understanding about what PPI is and how to approach public to involve in research (Crawford et al, 2002). Likewise, awareness about PPI and the opportunity to get involved in research among public is also less (Jackson et al, 2020). Additionally, research studies’ reporting about PPI and its impact is limited. This paper explains the

involvement of public that occurred at all stages of research starting from proposing the study, developing instruments for data collection, recruiting participants for the study, disseminating research documents and follow-up action. Besides describing the process of PPI, the paper also reports the impact of PPI using a standard checklist.

Objectives

The main objective of this paper is to report the involvement of PPI and its impact on midwife-led care research study conducted on reproductive age group women in India using the GRIPP2 - SF (Short Form) reporting checklist (Staniszewska et al, 2017).

Review of Literature

A study by Mann et al (2018) states that involving public in research resulted in personal benefits and satisfaction for the researchers. Public involvement increased the interest of researchers towards the research topic. The study highlights 'increased confidence,' 'feeling valued and enthusiastic' as benefits attained by PPI contributors. Similarly, another study by Muller et al (2019) demonstrated that involving public in all stages of research was beneficial to acquire funding, develop protocol and interview guides, analyse data and disseminate research findings.

A review done by Brett et al (2012) identified challenges in maintaining relationships between researcher and the public. The review specified that on certain occasions researchers could not accept all suggestions from PPI members and this made the contributors feel devalued leading to disagreements between the two (Brett et al, 2014). Another concern of involving public was time. A review by Domecq et al (2014) informed that involving patient and public in research is time consuming both for researchers and public. For instance, the review explains that incorporating PPI increased the need for extra time to complete investigation.

Methods

The patient and public involvement can occur at various stages of research (NIHR, 2021). However, to assure the appropriateness of research methods to the needs of the target population the PPI members were involved from the research proposal stage (Turk et al, 2016). The global pandemic Covid-19 caused an impediment for in-person interaction. As social

media provides good opportunity for investigators to connect research work with public (NCCPE, 2018) WhatsApp was selected to contact the relevant PPI members. A gatekeeper familiar about pregnancy support group run through WhatsApp in Chennai and Telangana was approached to advert on the requirement of PPI members. In response to the advert, two women accepted who later referred one woman each from their state. So, totally four women from two states of India, Tamil Nadu and Telangana formed as the PPI group in May 2021. The recruitment of PPI group members was based on two essential criteria (1) women in reproductive age 16-49 years and (2) women who were either pregnant or having a child less than 3 years. Participation was completely voluntary; and the women interested and willing to contribute were only included. The characteristics of women involved as PPI contributors are given in Table 1.

The approach utilised for PPI was more of "consultation" wherein the PPI members were asked to give their views on the proposed study and the relevance of the research design to the context. The first consultation with the PPI members was held in June 2021. Prior to the first formal meeting, the researcher called and briefed about the concept of PPI to the members, so they were informed about what was expected from them.

Additionally, a lay summary of the research proposal and relevant documents such as survey questionnaire, interview schedule and participant information sheet were e-mailed to the group members. The meetings were held individually lasting for 40-60 min with each member and at a preferred date and time of the members. During each meeting, the researcher was aware that no personal information was disclosed by any PPI members. On completion of each meeting feedback



Research in developed countries like UK and Australia show midwife-led care promotes health of mother and child through safe normal delivery



Our neighbouring countries like Bangladesh, Pakistan and Nepal introduced midwife-led care and found it reduced pregnancy and childbirth deaths



Fig 1: The poster developed after receiving inputs from PPI members.

about any changes made were informed to each participant in the subsequent meetings.

Results

This paper outlines the impact of a PPI event and is not a study. Hence the results are based on the meeting notes and activity log recorded and maintained by the researcher. The impact log used to evaluate the impact of PPI is presented in Table 2. The impact is presented under two main headings: 1. Research impact and 2. Personal impact.

Research Impact

Research proposal

Midwife-led care refers to the care given by a lead midwife to childbearing women throughout pregnancy starting from the initial booking to the post-natal period (International Confederation of Midwives, 2017). To provide standard midwifery care to women the Government of India had initiated the new Guidelines on Midwifery Services in India, 2018 nationwide (Guidance Note: Planning of Midwifery Initiative, 2019-20). This initiative aims to bring in a new cadre of midwives entitled “Nurse Practitioners in Midwifery” (NPM). In this context, the researcher proposed a study to determine the attitudes and beliefs of women about the implementation of midwife-led care in India. To ascertain the significance of proposed research and to determine whether the research topic would be of interest to target audience suggestions from PPI were obtained.

The PPI group members had different opinions about midwife-led care study. As the term ‘midwife’ and ‘midwife-led care’ was not familiar among women in India the group questioned the contextual realities of conducting research in the target group. Concurrently, the contributors believed that this study on midwife-led care would also give a clear definition and understanding for women about: Who is a midwife? What is midwife-led care? and, Why is it important to implement midwife-led care in India?

Subsequently, the PPI members felt the study would communicate about the initiative of midwifery care in India among women and therefore acknowledged that the study was important. The interaction with PPI members indicated that the research topic was interesting and essential to be conducted in India. The positive feedback from PPI members increased the significance of the proposed research study.

Research methods

The proposed research was planned to be con-

Table 1: Characteristics of PPI group members

| PPI Group Member | State | Age in years | Area | Native language | Education status | Pregnant | Number of children (< 3 years) |
|------------------|------------|--------------|-------|-----------------|------------------|----------|--------------------------------|
| W1 | Telangana | 29 | Urban | Telugu | Graduate | Yes | 2 |
| W2 | Telangana | 27 | Urban | Telugu | Graduate | Yes | 1 |
| W3 | Tamil Nadu | 32 | Urban | Tamil | Graduate | No | 1 |
| W4 | Tamil Nadu | 26 | Rural | Tamil | Graduate | Yes | 1 |

Table 2: Impact log

| Discussion | Impact |
|--------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Commented on the study proposal and the relevance to context | <ul style="list-style-type: none"> The PPI group members had a different opinion about midwife-led care and acknowledged that they had thought midwife-led care was like 'doulas' or 'staff nurses caring in maternity wards.' As women themselves had varied ideas and understanding, they all felt that the study was important as it would communicate about midwife-led care to other women. The interaction among group indicated that the research topic was interesting and essential to be conducted in India. |
| Gave feedback on supporting documents such as participant information sheets, consent forms and letters to participants. | <ul style="list-style-type: none"> Modified terminologies in the participant information sheet and consent forms by simplifying terms. For example, the term 'caesarean or c- section' was difficult to understand and hence changed to 'operation delivery'. The content used in inviting participants to research study was kept to the point, so it was easy to recruit potential participants through social media. |
| Gave suggestions on cross-sectional survey questionnaire | <ul style="list-style-type: none"> The survey questionnaire options were added based on the PPI group suggestions. The duration of survey questionnaire was designed to last for 15-30 min to avoid incomplete surveys. Sensitive questions were rephrased and order changed. |
| Advised on conducting qualitative interviews with potential participants | <ul style="list-style-type: none"> The online meetings for qualitative study using 'Zoom' was added as an option as PPI group made it clear that Zoom worked better than MS Teams. As per PPI members' feedback, all interviews took place on a date and time convenient to potential participants. |
| Contributed to design and content of poster on midwife-led care | <ul style="list-style-type: none"> Based on the PPI group comments the poster had certain additions and simplification of some terminologies. Poster was modified by adding few sentences on why midwife-led care is implemented and the details of who is implementing the programme. The sentences used in poster were kept simple, easy and clear. As per PPI group members suggestions it was ensured the sentences in poster represented one idea only. As per request of PPI negative sentences in poster were removed. As suggested the definition of midwife was simplified for better understanding of the target group. |
| Dissemination | <ul style="list-style-type: none"> The group suggested ways to disseminate the research findings and the poster to target groups Incorporated in the dissemination plan. |

ducted as a mixed-methods study to demonstrate the feasibility of the research and to confirm whether the research methods adopted were relevant to context the PPI group.

PPI members indicated that conducting online research would be more practicable as many women would take up the survey. The PPI group also listed the social media platforms that were popular among women in India. Further, the PPI contributors expressed the need to keep up the timing and duration while collecting research data from participants. For example, it was suggested by PPI members to send links and collect data from respondents by early afternoons rather than early mornings.

The input given by PPI helped to choose the appropriate social media platform such as Facebook, WhatsApp, as well as Zoom and aided in recruitment of appropriate participants. Further, the suggestions given by PPI on timing and duration of data collection assisted in conducting the study within the specified period. The PPI idea to simply terminologies in information sheets supported researcher in producing simple and easily readable research documents such as participant information sheets, survey questionnaire and interview schedule.

Poster on midwife-led care

To emphasise the significance of midwifery care and to disseminate information about it among women in India the researcher designed an infographic poster on midwife-led care and invited suggestions from PPI group members.

PPI group reviewed the poster on midwife-led care and gave valuable suggestions that included certain additions and modifications of contents. For example, the PPI contributors highlighted the importance of adding a sentence on 'why and who is bringing in midwife-led care in India?' As per PPI suggestions the medical terminologies used in poster was removed and all wordings and phrases were kept short and simple.

The contributions given by PPI resulted in designing a simple infographic poster on midwife-led care. The

Table 3: GRIPP2 Short Form

| Topic | Description | Reported on page |
|----------------------------|--------------------------------------------------|------------------|
| Aim | State the aim of PPI | 2 |
| Methods | Clear explanation of methods used for PPI | 3-4 |
| Study results | Report the results of PPI | 4-9 |
| Discussion and conclusions | Comment on the influence of PPI | 9-11 |
| Reflections | Comment critically on what went well and did not | 11-12 |

GRIPP: Guidance for Reporting Involvement of Patients and the Public; PPI: Patient and public involvement.

PPI group considered that the infographic poster would increase awareness about midwife-led care among women in all settings in India. The final infographic poster after adding the input from PPI group members is in Figure 1.

Personal Impact

PPI members

The group members expressed that it was their first time to get involved in PPI activity and felt more valued while contributing their ideas to development of the research. The PPI group felt that participating as a member was a new experience and promoted their personal development. The members believed that their confidence and communication skills improved in due course because of participating in the PPI event. The members also acknowledged that with each meeting with the researcher, their overall knowledge about research and the understanding of midwife-led care advanced. The group reported that they had gained good understanding on how healthcare research is conducted.

The beneficiary members also reported certain limitations especially with time. PPI members felt that they had to restrict their involvement timing due to family obligations such as household works and childcare. Contributors expressed that it was difficult to engage in topic initially as they felt it was new and unknown. Some members said they hesitated to express suggestions in the first meeting due to unfamiliarity with research and the researcher. However, they acknowledged that receiving lay summary and adequate explanation about the study from the researcher enhanced their understanding about the topic of research and influenced their participation in subsequent meetings. Despite these limitations the PPI members overall felt respected and happy to get involved in all stages of the PPI event.

Researcher

The PPI event aided researcher to gain a deeper understanding of the challenges in executing the research relevant to the context. Through the PPI

meetings the researcher learnt about the expectations of the public while conducting research. The PPI also helped researcher gain insight on the target population's culture that influenced producing participant-centred research documents. The researcher understood that developing trust among participants and treating them respectfully was a requisite. Further, the researcher attained more knowledge and skills on involving public that will be incorporated in future research studies.

However, researchers also experienced few negative impacts. For example, some PPI members cancelled and rescheduled appointments at the last moment, which negatively impacted the researcher. Due to rescheduling of appointments executing PPI activities as planned was difficult for the researchers. As there was lack of funding, PPI members had to participate voluntarily, so researcher was more conscious about the members' time and effort during the event.

Discussion

This paper reports on how PPI members were involved and what impact it had on designing the midwife-led care research conducted on reproductive age group women in India.

Findings from this paper showed that involving public aided in improving the research methods in relevance to the context thereby enhancing the significance and quality of the study. Besides, the frame of reference given by PPI members enabled the researcher to design the participant-centred research documents and choose the social media platform appropriate for the setting. The NIHR also emphasises that involving public as contributors promotes relevance and excellence of research (NIHR, 2015).

Another outcome of this paper stated that the PPI group was interested in getting involved and contributing to research. However, it was also evident that some members were reluctant and had difficulties engaging in new topics. Earlier, Jackson et al (2020) reports that lack of awareness about PPI, cultural context of members, power dynamics existing between researcher and the public, inadequate funding and resources were some of the major causes for PPI refraining from the event. This paper suggests introductory meetings, sending lay language summary about research prior to meetings, using precise language while communicating with members, listening to the needs of group, providing equal opportunities to each member in the group and giving adequate feedback after each meeting as key to involve PPI

members more actively in research.

This study found that PPI had challenging impacts on researchers especially due to limitations in timescale of proposed research. Previous research studies and review findings also show that restrictions in time, limited resources and funding demotivate researchers from involving in PPI activities (Brett et al, 2014). Also thorough planning, training, education and additional courses on PPI for researchers and supportive frameworks would enhance effective implementation of PPI activities within a period (Biggane et al, 2019).

Implications

Health knowledge and wellness of patient and public improves when they are involved in healthcare research. Therefore, adequate PPI training and supportive environment to be considered for researchers. Further, it is suggested that researchers report the impact of PPI using standard checklists (Table 3: GRIPP2).

Recommendations

PPI in future nursing and midwifery research employing different approaches is recommended.

Conclusion

The PPI activities had several positive impacts on research study as well as on PPI members and researcher. The involvement of PPI members contributed to modify the research methods in accordance with the context and to design a poster on midwife-led care. The contributors felt participating in PPI increased their value and esteem. Further, the researcher benefitted by learning about the ways to include public in research.

All PPI meetings between the group and the researcher happened online due to the pandemic. Although the interaction through social media was successful, the researcher personally felt that a face-to-face meeting would have enhanced the involvement and contribution of PPI members more effectively. Restrictions in timeframe of research was another limitation encountered. Regardless of these limitations the researcher personally felt contented with the contributions received from the PPI members as it redesigned the research methods to steadily reach the target population.

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