BMJ Editorial

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Patient and public involvement in research reporting: Are we nearly there?

Patient and public involvement (PPI) has become a key part of health and social care research in many countries with a focus on working ‘with’ or ‘by’ patients rather than ‘to’ ‘about’ or ‘for’ them, aiming to co-produce knowledge that is relevant, appropriate and acceptable for patients (1,2). Patient and public contributors can and should be included at all stages of research, including identifying key questions, designing, recruiting, selecting outcomes and implementing findings (1).

Patient involvement in a study should be reported within a paper to ensure that this knowledge contributes to building the PPI evidence base for practice. While this may seem obvious, the reporting of PPI in research remains more elusive than we might expect. Past studies have identified poor and inconsistent reporting (3,4), which resulted in development of the GRIPP2 reporting guidance specifically for PPI (5, 6). GRIPP2 is supported by journals that request authors to report PPI, including the BMJ and BMC Research Involvement and Engagement (7,8).

Despite highlighting the problem of poor PPI reporting and the availability of reporting guidance, Vanneste and colleagues (9) have identified a worrying lack of progress in reporting PPI in randomized controlled trials (RCTs). They used a meta-epidemiological evaluation to systematically review PPI reporting in highly influential RCTs, drawing on four major medical journals since 2015. With the focus on PPI encouraged by many funders, we might assume some of these trials included patients collaborating with research teams to co-produce the studies.

Vanneste and colleagues (9) extracted data on a range of parameters, including the involvement of patients/communities, description and extent of PPI activities/ processes, and recognition of PPI contributions. The findings provide a very disappointing assessment of PPI reporting. Of the 360 articles, PPI was only reported in 64 articles (17.8%) and 56 protocols (18.7%). Overall, 84 out of 360 trials (23.3%) reported PPI in the article and/ or protocol. The narrative analysis provides an even gloomier picture about the depth of reporting. Most articles (n=15, 23.4%) and protocols (n=16, 35.0%) described one single study activity/process involving PPI. Compared to the protocols, the PPI information

provided in the articles was often vague or moderately detailed. The most common study activity was participation in trial committees, with generally broad descriptions of the specific roles and contributions but without detailed information on specific outcomes and the impact on decision-making.

We might ask ourselves why poor PPI reporting continues, despite the obvious commitment to PPI expressed internationally by patients, funders, and the research community. One possibility is that PPI is still not fully embedded as a core part of research practice (10). Perhaps PPI is not planned for in as much detail as other parts of a research study, which can make reporting difficult as activity can feel vague, or it may not be captured or evaluated in ways that can lead to high-quality reporting. Or word length restrictions in journals impact on what teams can report.

Whatever the reason for poor PPI reporting, there are several implications we should consider. From the patient's perspective, poor PPI reporting means their contributions to a study are not publicly acknowledged, remaining only within the team. It may also mean that other patients view the study as being less credible or trustworthy. For clinicians who draw on an evidence base, it may be unclear to what extent patients have shaped the evidence; for example, they may not know if the outcomes measured in a study are important to patients. For researchers attempting to identify good practice, attempts to synthesise studies can be severely limited, leading to a fragmented evidence base that doesn't inform practice. From the funder and policy perspective, this represents a form of research waste, when activity is undertaken, but lost (11).

While providing a disappointing picture of PPI reporting, Vanneste and colleagues (9) offer a ray of hope: the highest levels of PPI reporting were observed in the last two years, which may suggest the beginning of an upward trend. Key reporting guideline updates, such as CHEERS 2022 for health economic evaluation (12), now include PPI items. For RCTs, the updated CONSORT 2025 checklist for trials and SPIRIT 2025 checklist for trial protocols will include one item on PPI (13,14), addressing one of the recommendations made by Vanneste and colleagues (9). We hope that this sends a new powerful signal to the international research community: plan well-funded PPI in your protocol, do it using evidence to inform your practice, capture/evaluate it and then report it in your paper, ideally with patients as co-authors. With this approach, we will grow the international PPI evidence base, support excellence in PPI reporting and

practice, and contribute to more efficient and relevant RCTs that address patient needs and preferences.

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