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Patient involvement in surgical wound care research: A scoping review

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Abstract

Active involvement of patients in planning, conducting, and disseminating research has been adopted by many organisations internationally, but the extent to which this occurs in surgical wound care is not evident. This scoping review aimed to identify how patients have been involved in surgical wound care research and the quality of its reporting. Full-text studies focused on preoperative and postoperative surgical wound care in the acute care setting, published in English between 2004 and 2019, were included in the review. Screening, data charting, and quality assessment were conducted by two reviewers independently, adjudicated by a third, and then reviewed by five others. Thematic analysis synthesised the findings. Of the eight included studies, seven explained the methods for patient involvement and five described aims related to patient involvement and commented on patient involvement in the discussion. None met all of the quality assessment criteria. Three themes emerged: involvement in modifying and refining research processes, connecting and balancing expert and patient views, and sharing personal insights. Recommendations to improve patient involvement in surgical wounds research include the following: using framework and tools to inform future research; training researcher and patients in their respective research roles; and ongoing monitoring of patient involvement.

KEYWORDS

consumer involvement, patient participation, research, surgical wounds, systematic review

Key Messages

- this scoping review aimed to identify how patients have been involved in surgical wound care research in the acute setting and the quality of reporting of this involvement
- of the eight studies that met the inclusion criteria, only three met ≥3 of the five Guidance for Reporting Involvement of Patients and the Public short form reporting checklist and none met all of them
- half of the eight studies met ≥5 or more of the nine critical appraisal criteria none met all of them
- patient involvement in modifying and refining research processes, connecting and balancing expert and patient views, and sharing personal insights emerged as synthesised themes
- using framework and tools to inform future research, training researcher and patients in their respective research roles, and ongoing monitoring of patient involvement may improve patient involvement in surgical wound care research

1 | INTRODUCTION

Active involvement of patients in planning, conducting, and disseminating research has a groundswell of support. Governments and their funding bodies,[1-3] consumer groups,[4] researchers,[5-7] and research groups such as the Cochrane Collaboration[8] have recognised the benefits of patient input. Patient and public involvement in research is defined as research being carried out "with" or "by" patients and members of the public, rather than "to," "about," or "for" them.[9] Several other terms used to capture patient involvement include patient and/or public advisors, representatives or partners, patient and public involvement, and consumers and community involvement.[10-12] Patients can provide valuable insights and positively influence research priorities, study design and conduct, refine research questions, interventions, comparators and study outcomes, and improve broader processes such as recruitment and dissemination.[11,13,14] Nevertheless, optimal ways of obtaining patient input are yet to be ascertained.[15-17]

Patient involvement can be embedded across the research continuum, including within the planning, conducting, and dissemination phases.[18] A recent systematic review identified 65 theoretically diverse frameworks for supporting, evaluating, and reporting patient involvement in research.[10] Other reviews of patient involvement in research have specific foci such as on research priority setting, in clinical trials, and in engaging hard-to-reach patients.[16,19] Work has also been undertaken to assess patient involvement in research undertaken by various specialty groups such as cancer[20] and more broadly on health and social care research.[15,21]

Surgical procedures are a cornerstone of health care systems with an estimated 4511 operations per 100 000 population occurring annually worldwide, equating to one surgical procedure each year for every 22 people.[22] Surgical wounds are created by an incision using sharp cutting instruments, such as a scalpel and may be closed by either primary (ie, sutures, staples) or secondary intention (ie, wound left open).[23] Given the high volume of surgical procedures and the potential burden that wound complications such as surgical site infections have for patients and their families, it seems intuitive that patients will have a vested interest in surgical wound care research. Yet, the extent of their input and involvement in it is not evident. A systematic review explored the quality of reporting of patient and public involvement in surgical research, but it specifically examined surgical procedures exclusively.[5] Thus, we aimed to extend this understanding by synthesising the research evidence on patient input into surgical wound care research.

2 | METHODS

2.1 | Study design

This scoping review was conducted using Arksey and O'Malley's scoping review framework,[24] along with recommendations to enhance these steps.[25] A scoping review systematically synthesises evidence to answer exploratory research questions and identifies gaps in research.[26] They identify the breadth of a body of literature on a topic and can be used to map the nature, features, and volume of existing literature on a topic.[24] Our review process comprised five stages: (a) identifying the research questions; (b) searching for and identifying relevant studies; (c) selecting studies; (d) charting the data; and (e) collating, summarising, and reporting the results. Arksey and O'Malley's[24] optional stage for consulting with patients was an embedded feature of the development and conduct of this review, adding both methodological rigour[25] and an essential patient viewpoint. The review was designed and executed to comply with the PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist.[27]

The Australian National Health and Medical Research Council's and Consumer Health Forum of Australia's definition of a consumer was adopted to define the term patient because it was broad, ensuring the scoping review was not restricted: "patients and potential patients, carers, and people who use health care services"[28] (p. 6). The research process was defined as the steps involved in undertaking research from determining priorities and questions to designing and conducting the study and finally, analysing and disseminating findings. Surgical wound care was defined as any preoperative or postoperative clinical practices associated with a surgical wound, involving a surgical incision and healing by either primary or secondary intention.

2.2 | Research questions

Two questions guided this review: (1) How have patients been involved in the conduct of surgical wound care research? and (2) What is the quality of patient involvement and reporting in surgical wound care research? These questions evolved over time, as is common in scoping reviews.

2.3 | Inclusion and exclusion criteria

To be eligible, articles had to be full-text studies, published in English and focused on care of surgical wounds, defined as wounds involving a surgical incision and healing by either primary or secondary intention.[23] There were no restrictions on study design, but the setting was restricted to acute care hospitals. Surgical wound care includes both preoperative and postoperative clinical practices, such as showering, dressing changes, and so on. We included published studies that reported, described, or evaluated patient involvement in surgical wound care research. We excluded studies that only focused on patients as research participants (ie, the collection of their individual data). Studies related specifically to surgical procedures were also excluded because of a recent review on this topic.[5]

2.4 | Search strategy

A search of five online databases (Ovid MEDLINE, Elsevier Embase, EBSCO CINAHL, Cochrane Central Register of Controlled Trials, and ProQuest) was undertaken in consultation with an expert health librarian. The search covered a 15-year period from January 2004 to September 2019. The year 2004 was chosen because it coincided with the release of a model framework for consumer and community participation in health research,[1] the establishment of the James Lind Alliance in the United Kingdom, and Patient-Centered Outcomes Research Institute (PCORI) funded research.[11] Searches took place on 16 September 2019. The reference lists of included papers were manually searched to identify further relevant articles that might meet the inclusion criteria through "ancestry" searches.[29] For practical purposes, grey literature was excluded.

2.4.1 | Search terms

The search terms were developed and refined in consultation with an expert health librarian. The search strategy captured terms related to (a) consumer, patient, or public (b); participation, involvement, and advice; and (c) surgical wound. More details about these search terms are provided in Table A1. The full search strategy for Ovid MEDLINE was undertaken on 16 September 2019 and is included as an example in Table A2. The references were managed using Rayyan, a systematic review web application.[30]

2.5 | Article selection

Two reviewers (RM and JP) independently screened the articles in two stages using title, abstract, and keywords, then full text. Papers which were clearly irrelevant were excluded in the first stage of title and abstract review, and if the eligibility of the paper was not clear, the full text was then reviewed in the second stage. This second stage included a review of the authors, their titles and affiliations, to try to identify patients who may have been part of the research team. Disagreements were resolved through consensus discussions between the two, with adjudication by a third reviewer (WC) when consensus could not be reached. Decisions about which articles to include in the scoping review was an iterative process,[26] guided by researcher familiarity with the literature and refinement of scoping review questions.[24] Regular meetings occurred between three authors (RM, JP, and WC) to ensure rigour in the study selection process. The PRISMA-ScR[27] flow chart was used to describe the initial search results, studies screened, studies included and excluded, and reasons for exclusion.

2.6 | Data charting

The data charting process evolved during the review as the reviewers refined the specific data to be extracted to help answer the review questions.[24,26] Extraction tables were piloted on three articles,[26] and subsequently refined, followed by a second pilot extraction phase to develop standardised interpretations and improve interrater reliability.[31] As part of this charting, the methods of involving patients, the time points for this involvement, and the levels of involvement were identified. We used a research adaptation of the International Association of Public Participation spectrum that included six levels of engagement (learn/inform, participate, consult, involve, collaborate lead/support)[32] to classify involvement. The data were initially extracted independently by two reviewers (RM and JP) and then reviewed by a third (WC) and then assessed by other reviewers (EH, RW, EM, FL, and SL) to ensure its authenticity and maintain rigour. The data extraction process was an iterative and involved regular meetings among three reviewers (RM, JP, and WC) and included the broader team as required.

Next, the quality of the reporting of patient involvement was assessed using the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) short form reporting checklist.[6] It is comprised of five reporting criteria: aim, methods, study results, discussion and conclusions, reflections and critical perspectives. Finally, the quality and impact of user involvement in published studies tool[33] (referred to as the critical appraisal criteria) was used in a second assessment of the studies to allow a more detailed analysis of the quality and extent of patient involvement. It has nine items focused on the rationale and appropriateness of involvement as well as methodological and ethical considerations.[33] The data for GRIPP2 and Wright and Foster's[33] critical appraisal criteria were initially extracted by two authors (RM and JP) independently and checked by one other (WC). Following training, the data were reviewed and appraised by at least two other authors (EH, RW, EM, FL, and SL).

2.7 | Collating and summarising (data analysis)

Thematic analysis was used to collate and summary the findings.[25] Initial thematic analysis was undertaken by two reviewers (RM and EH), whereby findings from each of the papers were identified, compared, and interpreted inductively until descriptive codes and preliminary themes were generated.[34] Next, an iterative process of collaborative analysis[35] was initiated. Three reviewers (WC, JP, and JC) reviewed the preliminary themes, bringing together analytic perspectives from different disciplines, theoretical traditions and professional/lay expertise, to confirm analytical decisions. A benefit of collaborative analysis is improved intercoder reliability[35] through checking the appropriateness and consistency of coding and preliminary themes.

2.8 | Patient involvement

The chair of the local hospital's consumer advisory group (JC) was invited to join the review team, specifically, contributing to the development of the review protocol and undertaking discrete parts of this review including analysis. The extent of her contribution was recording using the GRIPP2 checklist. Given the focus of this scoping review, patient involvement was considered a crucial aspect of the review.

3 | RESULTS

The initial search yielded 6674 articles. The articles were imported into Rayyan and duplicates removed. After title and abstract screening by two reviewers (RM and JP), further 4584 articles were removed, resulting in 26 articles for full-text review. Following full-text review, further 18 articles were excluded and 8 articles[36-43] included in review (Figure 1).

3.1 | Characteristics of the included studies

Table 1 summarises the eight included studies. Of them, five were conducted in the United States,[36,37,41-43] and three in the United Kingdom.[38-40] All studies were published between 2013 and 2019. The terms “patient” and “patient advisor” were used in both the US and UK studies to refer to those involved in surgical wound care research, whereas “patient representative” and “patient and public involvement member” (PPI member) were

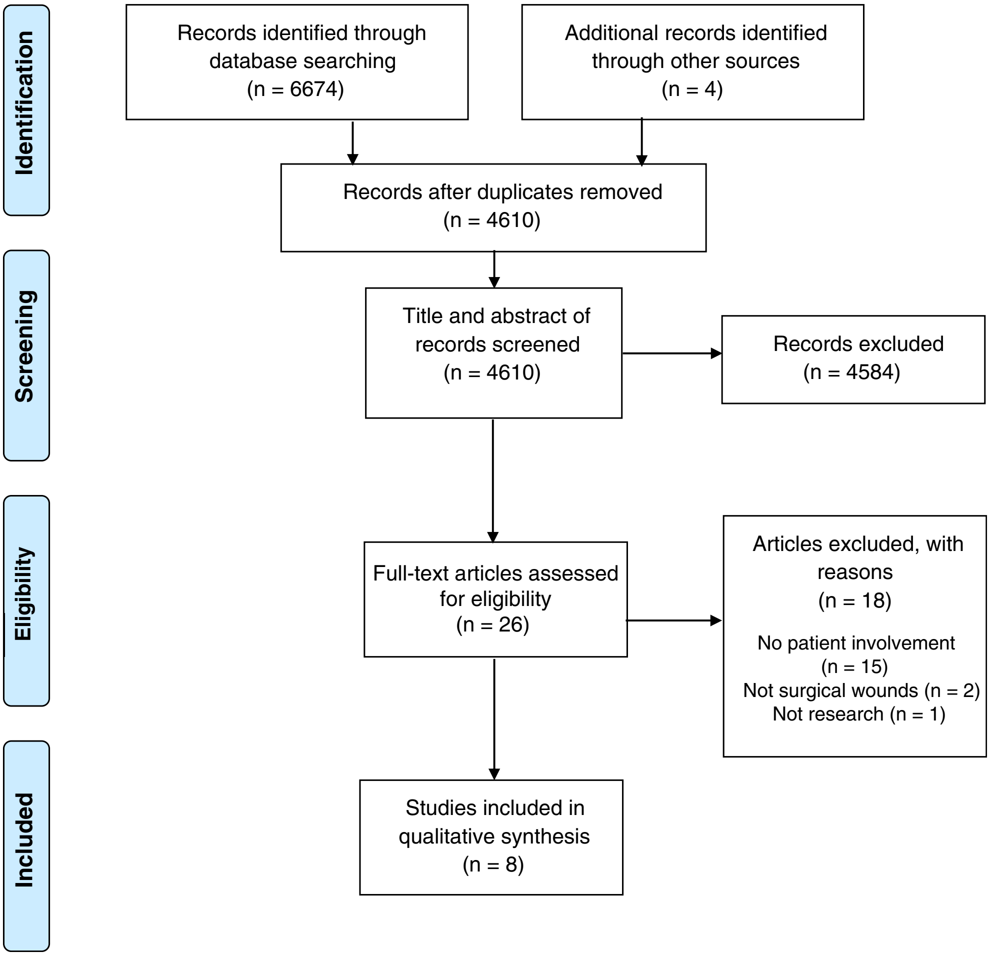

FIGURE 1 PRISMA flow chart of studies[27]

used exclusively in two UK studies,[39,40] and "patient advocate" in one US study.[42] The context of the research reflected a wide variety of surgical procedures. One study was qualitative,[38] two were cross-sectional,[36,43] and the remaining five[37,39-42] were multiple phased, two of which included systematic reviews.

3.2 | Level of involvement and quality of reporting on patient involvement

Table 2 contains an overview of how patients were involved in the conduct of the studies included in this scoping review. Four studies involved patients at more than one time point.[38-40,42] In terms of the involvement spectrum,[32] four studies consulted,[36,37,41,43] one involved,[38] and two collaborated[39,42] with patients. We were unable to determine this information for one study.[40] Based on the GRIPP2, the quality of reporting on patient involvement in the studies was found to be variable (Table 3). Table A3 provides detailed information about each study's adherence to the GRIPP2. All but one study[41] clearly described the PPI methods, five[38-40,42,43] described the PPI aims and four described PPI in the discussion and conclusion.[37,38,40,41] Two criteria were less evident, with only three studies[38-40] describing PPI in the results and two studies providing reflections on and a critical perspective on PPI.[40,42] Table 4 provides a summary of the research in relation to the critical appraisal criteria.[33] Half of the studies[38-40,42] met five of the nine criteria and two studies only met one criterion.[36,41] Table A4 provides more detailed information about this analysis. A summary of consumer involvement in development of our review using the GRIPP2[6] is outlined in Table A5.

3.3 | Thematic analysis

Three themes were generated from the data: involvement in modifying and refining research processes; connecting and balancing expert and patient views; and sharing personal insights.

3.3.1 | Involvement in modifying and refining research processes

Patient involvement was recognised as an important part of refining and modifying discrete elements within the

TABLE 1 Study characteristics (n = 8)

Reference (country)	Study aim	Design	Surgical context	Population and sample	Funding	Conflict of interest
Anderson et al[36] (United States)	To determine patient awareness and knowledge of risks, consequences, and prevention of SSI	Cross-sectional survey	Recent surgical procedure	Convenience sample of 50 adult patients at risk of SSI or who were already diagnosed with an SSI	Unknown	No
Lee et al[37] (United States)	To gain an understanding of the current application of mHealth and PGHD in postoperative incision management and SSI surveillance	Health technology assessment, including a literature review and key stakeholder interviews	SSI surveillance technology and PGHD postoperative care	25 interviews with key stakeholders, including two patients with experience in the field of mHealth and PGHD for SSI	Yes	No
McCaughan et al[38] (United Kingdom)	To explore patients' views and experiences of living with a surgical wound healing by secondary intention	Qualitative, descriptive design, using semi-structured, individual interviews	General, vascular, and orthopaedic surgery	20 patients with open surgical wounds, 11 women and nine men	Yes	No
McNair et al[39] (United Kingdom)	To define a core outcome set for studies in colorectal cancer surgery	Consensus methodology—including systematic review, patient interviews, survey, Delphi methods	Rectal (33, 35%), left (34, 35%), and right (30, 29%) colonic tumours	81 colorectal cancer centres were invited; 63 (78%) responded, including 90 surgeons and 8 clinical nurse specialists Patient response rate was 97 out of 267 invited (36%)	Yes	Yes[a]
Reeves et al[40] (United Kingdom)	To establish feasibility of an RCT to compare the effectiveness of different dressings or no dressing on SSI following elective surgery and to develop a valid method for the assessment of SSI to be used in the main trial	Phase A: Case studies with interviews and various surveys Phase B: Pilot RCT, interviews, validation of surveys, health economic analyses	Elective and unplanned (emergency) abdominal surgeries, healing by primary intention	Phase A: Interviews: 102 participants (69 HCPs and 33 patients Survey: 727 patients in 20 hospitals Questionnaire refinement: participants, n = 37; HCPs, n = 24 Phase B: Pilot RCT: 394 participants. Acceptability interviews: 55 participants	Yes	No

(Continues)

TABLE 1 (Continued)

Reference (country)	Study aim	Design	Surgical context	Population and sample	Funding	Conflict of interest
Sanger et al[41] (United States)	To explore patient experience of SSI and openness to a mobile health wound monitoring "app" as a novel solution	Mixed method design with semi-structured interviews and surveys	Abdominal surgery	13 English speaking adult patients who had postdischarge wound complications after undergoing an intra-abdominal operation	Yes	No
Sanger et al[42] (United States)	To examine conflicts, tensions, and agreements in the course of designing a novel, patient-centred data collection technology tool for mobile postdischarge surgical wound monitoring	Iterative design process, including semi-structured interviews, surveys, critical incident technique, and "think-aloud" approach	Patients who had recently experienced postdischarge SSI in a tertiary academic medical centre and trauma centre	13 patients who experienced a postdischarge SSI; 6 patient advocates who volunteered to advise the hospital on matters affecting patients; 11 health professionals who had experienced routinely managing postdischarge infections	Yes	No
Wiseman et al[43] United States	To explore the feasibility of a mHealth smartphone-based intervention for wound monitoring to promote early recognition of wound complications after discharge	Cross-sectional survey	Vascular surgery	50 adult patients undergoing vascular surgery, not in in intensive care unit	Yes	No

Abbreviations: HCPs, health care professionals; MDs, medical doctors; mHealth, mobile health; PGHD, patient-generated health data; RCT, randomised control trial; RNs, registered nurses; SSI, surgical site infection.

[a] Competing interests declared.

TABLE 2 Summary of consumer involvement in the research

Reference	Consumers	Involvement methods	Time points	Level of involvement[32]
Anderson et al[36]	HCWs and 8 patients	Preliminary drafts of the questionnaire were refined with input from HCWs and patients	Single time point, before participant data collection	Consult
Lee et al[37]	2 patients	Key informant interviews with patients. Interviews included in the final evidence synthesis	Single time point, after literature review, before a Health Technology Assessment report finalisation	Consult
McCaughan et al[38]	3 patient advisors	Patient adviser involvement throughout the research. Topic guide for interviews developed and piloted with input from patient advisers. Contribution from patient advisors on data analysis and comments on early draft of study findings	Multiple time points, development, pilot, and results interpretation	Involve
McNair et al[39]	2 patient representatives acknowledged in the paper, and one coauthor appears to be a consumer	Phase 1: patient representatives were involved in questionnaire domain generation—interviews with patients to inform domains PROMS verified with involvement of one patient questionnaire piloted by patients for face validity, understanding, and acceptability and modified as a result of the feedback Phase 2: patients' essential stakeholders in second Delphi phase Phase 3: consensus meetings with patients, caregivers, and surgeons to finalise the core set	Multiple time points through research phases 1, 2, and 3, development, pilot, and results interpretation	Collaborate
Reeves et al[40]	1 patient representative	Patient representative on steering committee: two PPI meetings to discuss RCT design and protocol elements. One PPI member also read and commented on lay summary of report	Multiple time points through research process: inception, design, and results dissemination	Unable to assess
Sanger et al[41]	The research team included a patient who experienced a postoperative infection—no further details provided	Not reported	Not reported	Consult
Sanger et al[42]	The research team included 1 patient advisor who previously experienced a postdischarge SSI. A second group of 6 patient advocates	The patient adviser was involved in "all aspects," including study design, data analysis, technology development, and manuscript preparation. The patient advisor represented	Multiple time points through research process; design, analysis, and results dissemination	Collaborate

(Continues)

TABLE 2 (Continued)

Reference	Consumers	Involvement methods	Time points	Level of involvement[32]
		the patients' perspective at weekly team meetings A second group of 6 patients were interviewed as part of the design refinement. This group of patients were patient advocates who had previously volunteered to advise the hospital on matters affecting patients		
Wiseman et al[43]	A community-based research advisory focus group	A preliminary draft of the survey was developed and informed by a community-based research advisory focus group: CARDS. CARDS are trained patient advisors who advise researchers and reflect the views of racial, ethnic, and socioeconomic groups seldom represented in research planning and activities. The CARDS input and feedback provided a “patient's perspective” that informed survey development	Single time point during the preliminary drafting of the survey	Consult

Abbreviations: CARDS: Community Advisors on Research Design and Strategy; HCW, health care workers.

TABLE 3 Compliance of studies with the GRIPP2 checklist[6]

Reference	PPI aims	PPI methods	PPI results	PPI discussion and conclusion	PPI reflections and critical perspective
Anderson et al[36]		✓✓			
Lee et al[37]		✓✓		✓	
McCaughan et al[38]	✓✓	✓✓	✓✓	✓✓	
McNair et al[39]	✓	✓✓	✓✓		
Reeves et al[40]	✓✓	✓✓	✓✓	✓✓	✓✓
Sanger et al[41]				✓	
Sanger et al[42]	✓✓	✓✓			✓✓
Wiseman et al[43]	✓✓	✓✓			

Abbreviations: GRIPP2, Guidance for Reporting Involvement of Patients and the Public; PPI, patient and public involvement.
Note: ✓ partial compliance; ✓✓ full compliance.

research process, such as patient information leaflets,[40] protocol development,[40] designing and piloting questionnaires,[36,39,43] developing topic guides for interviews,[38] and manuscript preparation.[38,42] In three studies, patients made wider contributions across multiple phases of three studies.[38,40,42] The authors reported a “collaborative” approach in the four studies involving patients at multiple time points,[38-40,42] suggesting embedded involvement beyond discrete one-step modification and refinement processes, although descriptions were scant.

TABLE 4 Compliance of studies with Wright and Foster's Critical Appraisal Criteria[33]

Reference	Is the rationale for including users clearly demonstrated?	Is the level of user involvement appropriate?	Is the recruitment strategy appropriate?	Is the nature of training appropriate?	Ethical considerations of managing user involvement?	Methodological considerations of managing user involvement?	Have there been any attempts to involve users in the dissemination?	Has the added value of user involvement been clearly demonstrated?	Evaluation of the user involvement component of the research?
Anderson et al[36]		✓							
Lee et al[37]		✓✓	✓					✓	
McCaughan et al[38]	✓✓	✓✓	✓✓				✓	✓✓	
McNair et al[39]	✓	✓✓	✓✓		✓	✓✓	✓	✓✓	
Reeves et al[40]	✓✓	✓✓	✓✓	✓			✓✓	✓✓	✓✓
Sanger et al[41]								✓	
Sanger et al[42]	✓✓	✓✓	✓✓			✓✓	✓	✓✓	
Wiseman et al[43]	✓✓	✓✓	✓✓						

Note: ✓ Partial compliance; ✓✓ Full compliance.

3.3.2 | Connecting and balancing expert and patient views

Balancing differences in expert and patient views was considered important in two studies[37,42] and recognised as a challenge in one other.[42] Tensions between different patients and providers, including patient advisors, were identified,[42] leading to conflict that was reported to impede the research. These authors recommended that iterative engagement with ongoing patient input should be adopted.[42] This suggests not only a degree of underlying and unresolved conflict but also implies an attempt to authentically engage with patient advisors as decision makers, beyond simple feedback loops and information giving.

3.3.3 | Sharing personal insight

Patients were valued as advisors and regarded as an expert source of information. They were reported to have a “unique perspective”[38] and insights through various personal experiences.[37,38,41-43] In one study,[38] three patient advisors were positioned as “key informants” with involvement at multiple time points. Their contributions and insights were considered crucial to the research.[38] Although two of the eight studies briefly referred to the characteristics of patients,[42,43] a range of ethnic, racial, and socioeconomic groups were recruited to the research team in one study.[43] Overall, it was evident that patients shared their personal insights and that these insights influenced the research endeavour.

4 | DISCUSSION

Research shows patient involvement has benefits for the both the health system and the community,[44] but to the best of our knowledge, this is the first review to examine the involvement of patients in the conduct of surgical wound care research. The eight studies involved patients in a variety of ways but not comprehensively throughout the planning, conducting, and disseminating processes. There was limited geographical and temporal diversity in the studies identified in our review, which were undertaken in the United States and the United Kingdom and published between 2013 and 2019. In their reviews, both Fergussen et al[16] and Jones et al[5] also found relatively few studies reporting on patient involvement in research. This contrasts markedly with the findings of a recent survey of surgical trial staff and patient stakeholders in UK surgical trials that found over 90% of surveyed trials reported their research being carried out either with or by patients.[45] This may suggest inconsistent development in patient involvement across and between geographical locations, or a potential lag or disconnection between the international rhetoric and the views and expectations of those involved in surgical wound research in the United Kingdom and the United States.

This review found variability in the extent to which patients have been involved in surgical wound care research; however, there are suggestions for how this might occur. For example, Kauffman et al[19] provide 10 recommendations for meaningful engagement of patients in patient-centred outcome research, such as bringing the research to the communities where patients live, using a period of pre-engagement to recruit patients to the research team and providing a lay summary of findings at an end-of-study celebration. Three additional broader approaches that may assist researchers to enhance patient involvement in surgical wound research are as follows: using a framework and/or toolkit to inform patient participation; undertaking targeted training on the roles that patients may play as coresearchers; and monitoring this participation.

Using a framework to inform the patient's role on the research team is one approach to promoting active involvement. The International Association for Public Participation[46] is one such framework, but there are a huge array of other frameworks that can be used.[10] Various organisations have also developed comprehensive resources and toolkits to promote patient participation[2,4,13] and other freely available resources. The use of these resources may help guide researchers in developing their competence in engaging with consumers.

Once the extent of this participation has been determined, a second approach is to train patients and researchers about the functional and interactional components of patients' roles in the research project.[47] Functional aspects could reflect the extent of expected participation (ie, where on the spectrum the desired participation sits). The interaction component acknowledges the social interactions, relationships, and contextual demands. Clear documentation of the functional expectations and consideration of the interactional aspects of the role can then be used to develop training for both patients and the wider research team. Educating patients about the functional aspects of their role, and training the research team in shared decision-making and good communication techniques, may promote more effective patient involvement in the research process.[48]

Monitoring patient involvement throughout the research process is a third approach to assist researchers to incorporate patients into health research. Tools such as the *patient engagement quality guidance tool*[49] can be used to promote authentic patient participation. This tool provides a tangible process to outline the project plan and the expectations for both the patients and academic researchers. Other tools like critical appraisal criteria,[33] which we used in this scoping review, can also help researchers recognise and prioritise patient input, promoting authentic patient participation.

The quality of reporting on patient involvement in included studies was suboptimal. Several other reviewers noted reporting issues.[5,6,16,21,50] It is difficult to determine if this relates to the country the study was conducted with the US studies generally appearing to have poorer reporting than the UK ones, or if this is related to the years the papers were published, because excluding Lee[37] the less well reported papers were older. We were also unable to determine if suboptimal reporting was linked to low levels of patient involvement, a lack of awareness about the importance of documenting involvement, or other potential reasons. A notable gap in the quality of reporting was related to recruitment and training, and attempts to involve those with a wide cross-section of interests in terms of ethnic background, gender, and age, Approaches to patient involvement have been criticised for “exclusivity, tokenism, and a lack of diversity,” with a tendency to select “well-behaved” white middle class patients who are deemed “appropriate” and “acquiescent.”[7,15] This is also a challenge for surgical wound care researchers, particularly being able to identify representative and diverse patients and patients including “hard to reach” minority groups.[19]

5 | LIMITATIONS

There were several limitations to this review. First, the small number of studies identified may have limited our interpretations and thematic synthesis. Second, although broad search terms were used, we may still have missed articles because of variations in terminology. Third, articles were limited to those in English, so we may have missed potentially important contributions in other languages. A final limitation was that the papers did not provide detailed data on how patient involvement was enacted. Thus, while we used a rigorous process in our review, our findings reflect only what has been reported in the primary research.

6 | CONCLUSION

Patient involvement in surgical wound care research appears to be limited, and the reporting of involvement is suboptimal. This scarcity of reporting may indicate the considerable challenges of involving patients in research, particularly those found in wound care research. In addition, the system disconnect in hospitals may also act as a barrier to meaningful patient involvement in research projects. The findings from this study suggest that when patients are involved in surgical wound care research, their contributions and insights are considered an important aspect of shaping, refining, and modifying elements of the research process. This is despite concern about balancing differences in expert and patient views and possible tensions. As suggested earlier, the use of frameworks and guidelines for effective involvement practices can lead to more effective engagement practices. Researchers can also draw on the wider body of literature on patient involvement in health care to help direct them in their future endeavours.[12] However, developing meaningful patient–researcher relationships is pivotal to achieving long-term sustainable patient involvement. The strategies suggested to include patients in surgical wound care research can be tailored to various research contexts. Additionally, research is required to develop methods and processes to assist both researchers and patients on their involvement in surgical wound care research.

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CONFLICT OF INTEREST

The authors declare no potential conflict of interest.

AUTHOR CONTRIBUTIONS

W.C. conceived of this study. All authors except J.P. contributed to writing the protocol. All except B.G. and H.T. were involved in data extraction. All authors were involved in data analysis, interpretation, and writing the manuscript.

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APPENDIX A.

TABLE A1 Search terms

Consumer	Involvement	Surgical wound
patient* consumer* lay OR communi* famil* OR carer* citizen* OR relative* representative* stakeholder* "advisory group" OR "advisory board" public OR user* client* OR knowledge-user*	engagement OR involve* view* OR centred centred OR participat* input OR design* collaborative OR partnership consult* OR "lay control" lay-controlled OR co-design co-operative OR co-creation co-production preference	surg* OR postop* post-op* OR periop* peri-oper* OR operat* wound* OR infect* site* OR incis* OR dehisc* Primary intention OR secondary intention

TABLE A2 Ovid MEDLINE search

1	((patient* or consumer* or lay or communi* or famil* or carer* or citizen* or relative* or representative* or stakeholder* or advisory group or advisory board or public or user* or client* or knowledge-user*) adj5 (engagement or preference* or involve* or view* or centered or centred or participat* or input or design* or collaborative or partnership or consult* or lay control or lay-controlled or co-design or co-operative or co-creation or co-production)).mp
2	Patient participation/
3	Community participation/
4	Stakeholder participation/
5	2 or 3 or 4
6	1 or 5
7	((surg* or postop* or post-op* or periop* or peri-oper* or operat*) adj3 (wound* or infect* or site* or incis* or dehisc*)).mp
8	(primary intention or secondary intention).mp
9	7 or 8
10	Surgical wound/or surgical wound infection/
11	Surgical wound dehiscence/
12	10 or 11
13	9 or 12
14	6 and 13
15	Limit 14 to case reports
16	14 not 15
17	Limit 16 to year = "2004-Current"
18	Limit 17 to English language

TABLE A3 Detailed information on compliance of studies with the GRIPP2 checklist[6]

Reference	1. Aim: report the aim of PPI in the study	2. Methods: provide a clear description of the methods used for PPI in the study	3. Study results: outcomes—report the results of PPI in the study including both positive and negative outcomes	4. Discussion and conclusions—outcomes on the extent to which PPI influenced the study overall. Describe positive and negative effects	5. Reflections/critical perspectives comment critically on the study, reflecting on things that went well and those that did not, so others can learn from this experience
Anderson et al[36]		Preliminary drafts of the questionnaire were refined with input from a sample of 8 patients.			
Lee et al[37]		Included in key informant interviews on experiences and perspectives of using PGHD in the postoperative SSI setting, which was included in the final data synthesis		Highlights importance of having a broad stakeholder group involved in design process, although does not provide examples specific to consumer involvement	
McCaughan et al[38]	Three patient advisors to act as key informants throughout study	Design and piloting of interview guide and feedback on study findings and early drafts	Involvement in research process was a key strength, which helped to shape interview methodology and interpretation	Contributions were crucial to reflection on the meaning of the interview data and its interpretation	
McNair et al[39]	To define a COS for use in trials and other studies, agreed upon by patients	Patient representative involved grouping patient-related outcomes into different domains. Patients and carers involved in consensus meetings to vote on final list of the COS	As a result of the consensus meeting, patients identified domains, which had overlapping content or themes and voted for them to be combined to prevent confusion		
Reeves et al[40]	To work with a PPI group to inform the conduct and design of a future RCT	Patient representative on steering committee. Two PPI meetings to discuss RCT design elements and how to best engage with future participants	PPI involvement influenced the design of a patient information leaflet to be more user-friendly, the design and delivery of a wound-experience questionnaire, strategies for improving adherence to trial allocation in future RCT and ways to incorporate PGHD	PPI meetings changed RCT protocol and design elements including considerations for adherence, reducing participant dropout, and completion time for questionnaires	To ensure clarity about the role of PPI work, to make the best use of PPI panel members' and researchers' time

(Continues)

TABLE A3 (Continued)

Reference	1. Aim: report the aim of PPI in the study	2. Methods: provide a clear description of the methods used for PPI in the study	3. Study results: outcomes—report the results of PPI in the study including both positive and negative outcomes	4. Discussion and conclusions—outcomes on the extent to which PPI influenced the study overall. Describe positive and negative effects	5. Reflections/critical perspectives comment critically on the study, reflecting on things that went well and those that did not, so others can learn from this experience
			including digital photos of wounds		
Sanger et al[41]				Including patient as part of multidisciplinary team was a core strength of the study, although did not report what specifically they contributed	
Sanger et al[42]	To represent the patients' perspective contributing to the development of a paint-centred data collection tool (mPOWER)	Patient advisor and patient advocates involved in study design, data analysis, technology development, and manuscript preparation. "Think-aloud" approach utilised		Agreement and conflict between patient advisors/ advocates and providers impeded design and adoption of mobile technology interface	Highlights importance of an iterative design process, to ensure ongoing input and preventing overshadowing of ideas. Acknowledgement of potential self-selection bias with recruitment of patient advisors from a pre-existing panel
Wiseman et al[43]	A community-based research advisory focus group was used to provide feedback and a patient's perspective	To develop and inform a preliminary survey draft to assess smartphone capability in outpatient wound assessment			

Abbreviations: COS, core outcome set; GRIPP2, Guidance for Reporting Involvement of Patients and the Public; PGHD, patient-generated health data; PPI, patient and public involvement; RCT, randomised control trial; SSI, surgical site infection.

TABLE A4 Detailed compliance of studies with Wright and Foster's Critical Appraisal Criteria[33]

Reference	Rationale for including users shown	Appropriate level of user involvement	Appropriate recruitment strategy	Appropriate training	Ethical considerations of user involvement	Methodological considerations of user involvement	Users involved in dissemination	Added user value shown	Evaluation of the user involvement component of the research
Anderson et al[36]		A sample of 8 patients provided feedback on a preliminary questionnaire draft							
Lee et al[37]		Patients were consulted in a second round of interviews after feedback from stakeholder groups to discuss their experience with and perspectives on PGHD use in postoperative SSI detection	Patients who had experience using PGHD for postoperative monitoring					Helped to form the beginnings of a "community of practice" comprising diverse stakeholder perspectives to inform future research on this important topic	
McCaughan et al[38] (United	Kingdom)	Patient advisors included as key informants throughout study	Collaboration with three patient advisors involving design and piloting of topic guide, data analyses, interpretation of study findings, and comments on early drafts	Patient advisors selected with personal experience with an open surgical wound due to their unique perspective on a niche area				Advisors commented and provided feedback on early drafts of the manuscript	Patient involvement at all key stages of the research process was an important strength and crucial to reflection on the meaning of the interview data and its interpretation
McNair et al[39]	Lists patients as essential stakeholders	A patient representative was consulted to help group patient-reported outcomes into domains. Patients were consulted to pilot a survey draft and vote on the final core outcome set. The patient advocate coauthor collaborated throughout research process including	Attendees to the consensus meeting had previously been recruited to complete a questionnaire, where non-probabilistic sampling was used to ensure geographical and caseload variation. The co-author credentials included being a member of various		Patient advocate co-author received travel	reimbursement	With concerns that patients may not fully comprehend the clinical terminology used, the "unsure" category was added to the patient consensus meetings so that the terminology could be explained in more detail	The patient advocate coauthor involved in manuscript writing and agreed with overall results and conclusions	Differences between patient and provider consensus meetings lead to changes in the final core outcome set, with domains considered by patients to have overlapping content or themes combined

(Continues)

TABLE A4 (Continued)

Reference	Rationale for including users shown	Appropriate level of user involvement	Appropriate recruitment strategy	Appropriate training	Ethical considerations of user involvement	Methodological considerations of user involvement	Users involved in dissemination	Added user value shown	Evaluation of the user involvement component of the research
		contributing to manuscript writing and agreeing with manuscript overall results and conclusion	patient advocate groups						
Reeves et al[40]	PPI group to inform the conduct and design of a future main trial	Consultation via PPI meetings to discuss RCT design and protocol elements. One PPI member also read and commented on lay summary of report. One patient representative collaborated throughout study as part of the steering committee	Participants had previously been recruited for semi-structured interviews, where sampling became increasingly purposeful to achieve maximum variation according to age, sex, and type of surgery. Patients recruited were undergoing elective or unplanned (emergency) abdominal operations, including caesarean section, with a primary closed surgical wound	In the PPI meeting, a brief overview of the purpose of a patient information leaflet was presented including structure and type of information reported			PPI group member commented and gave feedback on the plain English summary. Findings from Bluebelle study have been presented at conferences including outside conventional academic circles or generic audiences	PPI meetings influenced study design including questionnaire and PIL refinement and strategies for future participant retention, including increasing the font size of the PIL, making the instructions for completing the Wound Experience Questionnaire more prominent and providing more flexibility around the timing of questionnaire completion	Recommend that there is clarity about the role of PPI work,to make best use of PPI panel members' and researchers' time. Written feedback on the PPI meeting was rated as excellent (4/7 response) or very good (3/7 responses). Comments from members included that PPI was regarded as very important and that it had been valuable to meetothers and share experiences
Sanger et al[41]								Highlights that including diverse perspectives from a multidisciplinary team including a patient with previous SSI experience a core strength of study	
Sanger et al[42]	Patient advisor and patient advocates as part of a iterative process	Collaboration with patient advisor involved in study design, data	Patient advisors who had previous personal experience with a			Recruitment from established advocate database could introduce	Patient advisor was involved in manuscript preparation	Highlights the importance of bringing patients into the design	

TABLE A4 (Continued)

Reference	Rationale for including users shown	Appropriate level of user involvement	Appropriate recruitment strategy	Appropriate training	Ethical considerations of user involvement	Methodological considerations of user involvement	Users involved in dissemination	Added user value shown	Evaluation of the user involvement component of the research
	for developing an app to track symptoms of infections after surgery	analysis, technology development, and manuscript development; consultation with patient advocates on design refinement, coding, and design recommendations	postoperative SSI were recruited via email using convenience sampling from a pre-existing database			self-selection bias, although the value of having expert panel outweighs any potential bias introduced		process iteratively and directly on the research team. Key discussions related to agreements and conflicts between providers and patients led to significant implications for app design	
Wiseman et al[43] United States	The use of a community-based research advisory focus group (CARDS) to gain patient's perspectives and help develop and inform a preliminary draft of a survey	Consulted with research advisory focus group to gain patient perspective, which informed and developed preliminary draft of survey to assess smartphone capability in outpatient wound assessment	CARDS are a trained focus group that advise researchers and represent the views of racial, ethnic, and socioeconomic groups that are rarely represented in research						

Abbreviations: PGHD, patient-generated health data; PIL, patient information leaflet; PPI, patient and public involvement; RCT, randomised control trial; SSI, surgical site infection.

TABLE A5 Patient involvement in this wound care scoping review (GRIPP2)

Section and topic	Item
1: Aim: Report the aim of the study	To develop and conduct a scoping review on patient involvement in surgical wound care, with the aim of reporting the quality, transparency, and consistency in wound care research To involve patients as research partners at key stages in the development and conduct of the scoping review
2: Methods: Provide a clear description of the methods used for PPI in the study	One consumer advisor (a term widely used for patient/public advisor in Australia) was initially invited to join the research team to provide oversight and input to all stages of the scoping review. Our consumer advisor was involved in: reviewing the initial grant application for the study, reviewing the draft protocol, setting aims, refining research questions, reviewing the draft publication, and decision making in dissemination. The consumer advisor also assisted with analysis of initial themes and checked comprehension of the draft publication. Our consumer advisor also contributed to edits of this article and is a coauthor.
3: Results: Outcomes; report the results of PPI in the study including both positive and negative outcomes	Patient involvement contributed to the study in several ways, including: • Interpreting results • The consumer advisor checked the comprehension of this article prior to publication and provided feedback and comments from their experiences, which contributed to the write-up of this article
4: Discussion: Outcomes; comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	Patient involvement in this study contributed to a more nuanced understanding of the ways in which patients can contribute to a review study of this type, and provided important guidance in both confirming particular decisions, such as research questions, and raising questions based on their experiences and knowledge. The consumer advisor had received previous training in consumer involvement and was actively involved in leading a consumer advisory group attached to the Gold Coast University Hospital, Queensland. There was a pre-existing relationship between the consumer advisor and academics in the study from previous research, which meant that a level of trust and understanding had already been established from having previously worked together and a mutual appreciation of each other's roles However, there were limitations. The short timeline for completion of the study served to limit potential input from the consumer advisor, and a core team of three researchers (RM, JP, and WC) worked on the literature searches, extraction and initial analysis, and drafting of the paper
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	Patient involvement was an important part of this study, as it focused explicitly on the quality and transparency of patient involvement in surgical wound care research. The key challenge was ensuring that our consumer advisor was involved in a way that was meaningful—for both the researchers and consumer advisor. The pre-existing relationships between the researchers and consumer meant that there was already a level of understanding and trust, which meant that short turnaround times and expectations were negotiated easily. Without pre-existing relationships, the time limitations might have posed difficulties for some consumer advisors and may have limited the extent to which consumer advisors could be involved. A single consumer was involved in the study, which meant limitations in terms of a diversity of views relating to gender, socioeconomic, cultural, and ethnic backgrounds within the study, which requires further consideration in the future

Abbreviations: GRIPP2, Guidance for Reporting Involvement of Patients and the Public; PPI, patient and public involvement.