

BMJ Open Patient engagement in the development of best practices for transitions from hospital to home: a scoping review

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To cite: Zhao G, Kennedy C, Mabaya G, *et al.* Patient engagement in the development of best practices for transitions from hospital to home: a scoping review. *BMJ Open* 2019;**9**:e029693. doi:10.1136/bmjopen-2019-029693

► Prepublication history and additional material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2019-029693>).

Received 6 February 2019
Revised 13 June 2019
Accepted 14 June 2019



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ABSTRACT

Objectives To explore the extent of patient engagement in the development of best practice reports related to transitions from hospital to home.

Design Scoping review.

Data sources Electronic databases (MEDLINE, EMBASE, CINAHL, Scopus, Trip Database, DynaMed Plus and Public Health Plus) and multiple provincial regulatory agency and healthcare organisation websites.

Eligibility criteria We included best practice reports related to the transition from hospital to a long-term care facility, community dwelling or rehabilitation centre. We included documents disseminated in English between 1947 and 2019.

Data extraction and synthesis Two independent reviewers screened for eligibility and one extracted and analysed data using a data extraction tool we developed based on established patient engagement frameworks. Only records actively engaging patients were analysed (n=11). The methodological quality of actively engaging patients was assessed using domain 2 (item 5) of stakeholder involvement from the Appraisal of Guidelines for Research and Evaluation II (AGREE II) tool.

Results The search yielded 1921 citations of which 23 met the inclusion criteria and were included for narrative synthesis. These were disseminated between 1995 and 2019, with 18 (78%) published after 2010. Most were conducted in North America (USA 43%, Canada 22%), Europe (UK 30%) and Australia (4%). Eleven (48%) actively involved patients, of which only two involved patients across all stages of development. Most involved patients through direct or indirect consultation. The mean AGREE II domain 2 item 5 score (of those that actively engaged patients) was 5.9 out of 7.

Conclusions Only half of existing best practice reports related to the transition from hospital to home actively involved patients in report development. However, the extent of patient engagement has been increasing over time. More organisations should strive to engage patients throughout the best practice development process and provide patients with opportunities for shared leadership.

INTRODUCTION

Around the world, healthcare systems strive towards patient-centred care.^{1–4} In the UK, patients have been involved in health research for at least 15 years^{5,6} and patient engagement is a prerequisite for many funding bodies

Strengths and limitations of this study

- We conducted a scoping review of both peer-reviewed and grey literature to identify and assess relevant best practice reports including quality standards, clinical guidelines and consensus statements.
- We used existing patient engagement frameworks to develop a data extraction tool that specifically assessed the level of patient engagement from consultation to involvement to shared leadership.
- We used item 5, domain 2 from the Appraisal of Guidelines for Research and Evaluation II reporting checklist to assess the extent to which patient and public perspectives were sought during best practice report development.
- Research was done in partnership with a health quality agency preparing to inform patient engagement in the development of a quality standard on the transition from hospital to home.
- Due to limited documentation, some patient engagement activity may not have been reported which may mask actual level of patient engagement.

and research ethics approval.^{6,7} In the USA, patient engagement was mandated in health research processes once the Patient Centered Outcomes Research Institute was established in 2010.^{5,8} The Canadian Institutes of Health Research created the Strategy for Patient-Oriented Research patient engagement framework in 2014.⁹ Increased involvement of patients in health services research, along with engagement in healthcare delivery and policy-making, has led to a 'patient revolution' in the last few decades.^{4,8,10–12}

Patient engagement in clinical practice guideline development has been recommended by multiple institutions including the National Institute for Clinical Excellence (NICE),¹³ the WHO¹⁴ and the Guidelines International Network.¹⁵ Even guideline appraisal tools, such as the Appraisal of Guidelines for Research and Evaluation II (AGREE II) has a specific section for the evaluation of patient engagement.¹⁶ Despite this increase in patient engagement, there is a lack of consensus on

how and when to optimally engage patients.^{4 7} Further, it is unclear how widely organisations follow the patient engagement guidance in the development of guidelines or other evidence-based recommendations.

The transition from hospital to home is an important, yet vulnerable exchange point that if not properly handled can lead to adverse clinical events and preventable hospital readmissions.^{17 18} Often patients are not involved in their care transitions planning,^{18–21} which can result in unmet needs once home.^{22 23} Understanding the patient's perspective is important in not only meeting their needs postdischarge but also in improving health outcomes.^{18 24} Patient and caregiver involvement in guidance development may address some of these known gaps in care.

Currently, little is known about the extent to which patients and caregivers have been involved in the development of best practice reports related to the transition from hospital to home. Hence, we conducted a scoping review to assess the extent of patient engagement in the development of best practice reports on transitions from hospital to home. We define best practice reports as documents that provide evidence-based recommendations for providing quality care on a particular medical condition or topic. We used Carman *et al*'s patient engagement framework because it examines the continuum of engagement at the policy-making level from consultation or involvement to partnership and shared leadership.²⁴ We focus on active patient engagement, defined here as participation in an advisory or working group and/or direct consultation whereby resultant discussions informed the content of the report.²⁵ Our findings would inform the approach to patient engagement in the development of a quality standard in transitions by the provincial quality agency in Ontario, Health Quality Ontario (HQO).

METHODS

We conducted a scoping review with guidance from the scoping review methodological framework developed by Arksey and O'Malley²⁶ as well as from PRISMA Extension for Scoping Reviews (PRISMA-ScR) guidelines.²⁷ The protocol was developed through consultation with the project team, including a health sciences information specialist, a clinician investigator and quality improvement professionals from HQO who are involved in the development of quality standards. Details of the protocol can be requested from the corresponding author.

Inclusion criteria

We aligned our inclusion criteria to match the anticipated scope of HQO's quality standard on transitions of care. We included best practice reports (ie, clinical guidelines, quality standards, consensus statements, guiding principles, best practice recommendations) related to the transition from hospital to home. Home was broadly defined as a person's place of residence for an extended period of time (ie, long-term care facilities, skilled nursing facilities,

community dwellings (ie, retirement home, house, apartment, shelter) or rehabilitation centres). Note that rehabilitation centres were included because HQO's patient and family advisors had suggested to include this along with complex continuing care centres as part of the broad definition of home. We included all populations (ie, disease/conditions, ages, ethnicity, gender). We included documents disseminated in English between 1947 and 2019 published in either the peer-reviewed or grey literature. We had no exclusion by year of publication as we found that literature on patient engagement in the creation of guidelines is quite limited. Foreign language was excluded because of cost and time involved in translating materials.

Search strategy

We developed a search strategy in consultation with an information specialist (online supplementary appendix A). She devised an initial search strategy which was later refined in light of early results. She searched seven electronic databases covering sources from 1947 to May 16, 2018: MEDLINE (OVID), EMBASE (OVID), CINAHL (EBSCO), Scopus, Trip Database, DynaMed Plus and Public Health Plus. The updated search was conducted on 7 May 2019 (online supplementary appendix B). Electronic search terms included but were not limited to 'transitional care,' 'guidelines,' 'best practices,' 'consensus,' 'guiding principles' and 'standards'. With consultation from HQO, we identified provincial healthcare quality councils and major international organisations that we hypothesised would hold the majority of grey literature on best practice reports. The updated grey literature search was informed by extensive, iterative searches in Google to identify organisations that create or study health guidelines, as well as a federated search in MacPlus, McMaster University's Health information unit. We searched website content using keywords such as 'transition', 'transition care' or transitional care. Each website was searched for primary and secondary literature.

Selection of sources of evidence

We conducted and reviewed peer-reviewed and grey literature searches separately. Search results were imported into an online systematic review software, Rayyan.²⁸ First, titles and abstracts were reviewed to determine eligibility for full-text review. Screening was performed blindly by two independent reviewers, with one reviewer (GZ) reviewing all titles and abstracts. Any discrepancies between reviewers were discussed and consensus was reached. We conducted a pilot screen of 20 articles which were reviewed among all members of the project team to test the reviewer software and address any concerns with the article selection criteria developed a priori. From those selected at title and abstract screening, one reviewer (GZ) further reviewed the full-text records for eligibility owing to resource limitations.

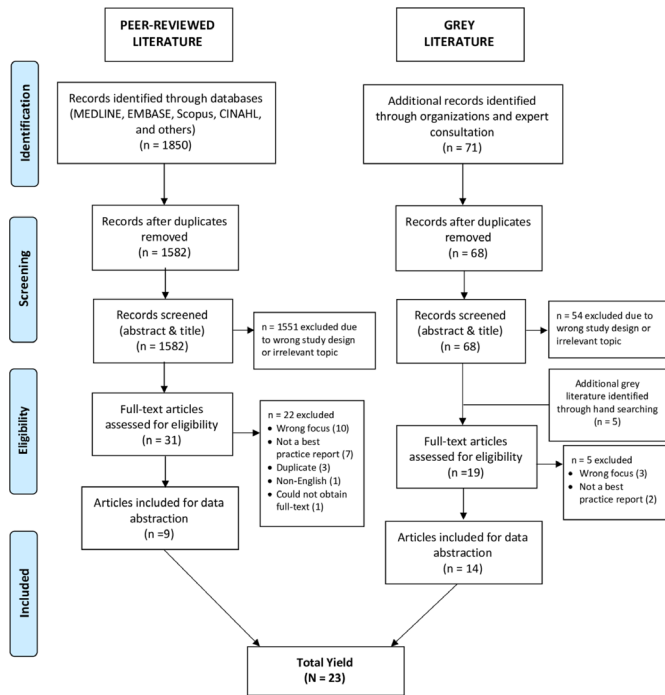


Figure 1 PRISMA flow diagram of literature search and selection process. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Data extraction and synthesis

GZ performed the data extraction using a data extraction tool (online supplementary appendix C). The data extraction tool was developed based on published patient engagement frameworks^{9 24 29} and tested by the team before use. We used Carman *et al*'s patient engagement framework²⁴ to determine the types and extent of patient engagement. We focused on the level of engagement at the policy-making level, and considered the continuum of engagement (*consultation, involvement and shared leadership*). For included articles, GZ extracted report characteristics (ie, year, jurisdiction, literature type), whether patients were involved, terminology, whether consideration was given to marginalised populations, and specifics of when and how patients were involved. For simplicity, here 'patients' refer to patients and caregivers. Particular attention was paid to whether patients were participants of the advisory or working group that developed the recommendations. We restricted our analysis to records actively engaging patients (n=10). Data will be presented in a narrative format with tables and figures.

Quality appraisal

Quality appraisal of the best practice reports was performed using one item from the AGREE II reporting checklist.³⁰ We used item 5 from domain II (stakeholder involvement) to assess whether the perspectives of the target population (ie, patients, public and so on) were sought. The item is scored out of 7, where a score of 1 indicates that there is no information that is relevant to the AGREE II item or if the concept is very poorly reported, and a score of 7 indicates exceptional quality

Table 1 Overview of selected record characteristics

Characteristic (n=23)	Output
Year	1995–2000 (13%, n=3) 2000–2009 (9%, n=2) 2010–2018 (78%, n=18)
Record type	Guidelines document (43%, n=10) Consensus statement (22%, n=5) Best practice recommendations (17%, n=4) Other (17%, n=4)
Geography	USA (43%, n=10) UK (30%, n=7) Canada (22%, n=5) Australia (4%, n=1)
Jurisdiction	Government agency (30%, n=7) Professional organisation (30%, n=7) Non-profit organisation (17%, n=4) Other (22%, n=5)
Topic area	General (52%, n=12) Stroke (17%, n=4) Heart failure (17%, n=4) Neurological (4%, n=1) End of life care (4%, n=1) Chronic obstructive pulmonary disease (4%, n=1)
Active PE	Yes (48%, n=11) No (52%, n=12)

PE, patient engagement.

of reporting and where the full criteria articulated in the reporting checklist have been met.

Patient and public involvement

Patients and the public were not involved in the development of this study.

RESULTS

The systematic search yielded 1582 peer-reviewed and 68 grey literature results after duplicates were removed (figure 1). Overall, 1605 articles were excluded at the title and abstract screen. A further 22 peer-reviewed and 5 grey literature were excluded for the following reasons: 23 did not meet the inclusion criteria, 3 were duplicates within the peer-reviewed searches and 1 full-text article could not be obtained. The remaining 23 relevant reports from peer-review (n=9) and grey literature (n=14) met our relevance screen.

Report characteristics

The included 23 records were published between 1995 and 2018, with 18 (78%) published in 2010 and beyond (table 1). Of these, 10 were guidelines, 5 were consensus statements, 4 were best practice recommendations, 2 were guides, 1 was a discharge care bundle and another was a scientific statement. Most were conducted in North America (n=15; 65%) and the UK (n=7; 30%). Only 10 of the best practice reports considered marginalised populations in their search and/or assessment of recommendations (table 2). Eleven (48%) out of 23

Table 2 Best practice reports on transitions from hospital to home included in review (n=23)

Author, year	Jurisdiction	Country	Type of BPR	Scope of BPR	Method of PE	Active PE	Considered vulnerable populations
Ospina <i>et al</i> , 2018 ^{56*}	Research group	Canada	Other: discharge care bundle	Development of discharge care bundle for acute COPD patients	2-round modified Delphi survey	Yes	No
Miller <i>et al</i> , 2018 ⁵⁷	American Congress of Rehabilitation Medicine	USA	Position paper	Recommendations on transition planning poststroke	Literature review	No	No
Farrahi, 2018 ⁵⁸	Thesis Project	USA	Best practice recommendations	Best practice recommendations for reducing heart failure hospital readmission	Literature review	No	No
AHRQ, 2017 ⁴⁸	Government Agency: Agency for Healthcare Research and Quality	USA	Other: best practice guide	Hospital guide to reducing Medicaid readmissions	Expert opinion from hospital executives or managers	No	Yes
NICE, 2016 ³¹	Government Agency: National Institute for Health and Care Excellence (NICE)	UK	Guideline	Guidelines on the transition between inpatient mental health settings and community or care home settings	Literature review, focus groups, Public Involvement Programme	Yes	Yes
Cameron <i>et al</i> , 2016 ³⁵	Heart and Stroke Foundation	Canada	Guideline	Managing transitions of care following stroke	Literature review	Yes	Yes
Pellett, 2016 ^{41*}	Queen's Nursing Institute	UK	Best practice recommendations	Best practice in transitions of care related to discharge planning	Literature review, two online surveys, focus groups	No	No
Coombs <i>et al</i> , 2015 ^{49*}	Research group	UK	Guideline	Development of clinical guidance document on transferring critically ill patients home to die	1 day national stakeholder event; consensus methodology and nominal group technique	Yes	Yes
Trillium Health Partners and Mississauga Halton CcCAC, 2015 ³⁶	Partnership between Trillium Health Partners and Mississauga Halton Community Care Access Centre	Canada	Other: best practice guide	Guidebook to better integrate care for patients being discharged from hospital to home/community	Interviews, consultations	Yes	Yes
NICE, 2015 ³²	Government Agency: National Institute for Health and Care Excellence	UK	Guideline	Guidelines on the transition between inpatient hospital settings and community or care home settings for adults with social care needs	Literature review, focus groups	Yes	Yes
Albert <i>et al</i> , 2015 ⁴²	American Heart Association	USA	Other: scientific statement+clinical recommendations	Describes transitional care interventions and outcomes and discusses implications and recommendations	Literature review	Unclear/not stated	Unclear
Australian Government, 2015 ⁴³	Government Department of Health	Australia	Guideline	Transition care programme guidelines	Literature review	Unclear/not stated	Yes
Dreyer, 2014 ⁵⁹	Centre for Health Research and Transformation	USA	Best practice recommendations	Best practices and evidence-based programmes in care transitions	Literature review	No	No

Continued

Table 2 Continued

Author, year	Jurisdiction	Country	Type of BPR	Scope of BPR	Method of PE	Active PE	Considered vulnerable populations
RNAC, 2014 ⁴⁴	Registered Nurses' Association of Ontario	Canada	Guideline	Nursing best practice guidelines on assessing and managing client care transitions	Focus groups, literature review	No	No
Cowie <i>et al</i> , 2014 ^{33*}	Research group	Europe and USA	Consensus policy recommendations	Optimising care (including transitions) for acute heart failure patients	Structured discussions, literature review	No	No
Lim <i>et al</i> , 2012 ⁴⁵	Government Agency: Agency for Healthcare Research and Quality	USA	Guideline	Geriatric nursing protocols for best practice on transitional care	Literature review	No	No
SIGN, 2010 ³⁴	Government Agency: Scottish Intercollegiate Guidelines Network	Scotland	Guideline	Guidelines on management of patients with stroke	Literature review, internal and public consultation (website) Patient Involvement Officer	Yes	Yes
AMDA, 2010 ⁴⁶	American Medical Directors Association	USA	Guideline	Practice guideline on transitions of care in the long-term care setting	Expert opinion of practitioners in long-term medicine, literature review	No	No
Snow <i>et al</i> , 2009 ^{40*}	Transitions of Care Consensus Conference	USA	Consensus policy statement	Recommendations for standards concerning the transitions between inpatient and outpatient settings	Literature review, multistakeholder consensus conference: breakout sessions	Yes	Yes
Malcom <i>et al</i> , 2008 ⁴⁷	Canadian Cardiovascular Society	Canada	Consensus statement	Best practices for the transition of care of heart failure patients	Literature review	No	No
Davies and Hopkins, 1997 ^{37*}	Royal College of Physicians Working group	UK	Guideline	Guidelines on management of adults with malignant cerebral glioma	Patient interviews, workshops, literature review	Yes	No
Ball <i>et al</i> , 1997 ^{38*}	Government Agency: Emergency Medical Services for Children, National Task Force on Children With Special Healthcare Needs	USA	Consensus statement	Recommendations for coordinating care for children with special healthcare needs	Consensus process	Yes	Yes
Gresham and Stason, 1995 ³⁹	Government Agency: Agency for Healthcare Research and Quality	USA	Guideline	Guidelines on poststroke rehabilitation	Literature review, external review	Yes	No

Active patient engagement (PE) is defined as in-person patient participation and or consultation whereby resultant discussions inform recommendation content.

*Peer-reviewed articles.

BPR, best practice report; COPD, chronic obstructive pulmonary disease.

records actively engaged patients in the development of the best practice reports.

Types of patient engagement

Using Carman *et al's* patient and family engagement framework,²⁴ we found that when patients were engaged, most were engaged in the *consultation* (direct and indirect) stage, some in *involvement*, and a few in *shared leadership* (table 3). *Direct consultation* included surveys, an open forum, patient interviews, workshops, conference breakout sessions, focus groups and peer review of provisional guidelines. *Indirect consultation* included four instances where patient preferences and values informed the literature search.^{31–34} *Involvement* activities included eight instances where patients were involved in the guideline developing group.^{31–33 35–39} *Shared leadership* included one instance where a patient was acknowledged as a coauthor³⁵ and two instances where patients were involved from the outset.^{34 36}

Item 5 assesses whether the views and preferences of the target population were considered. Score ranges from 1 (no patient engagement (PE)) to 7 (maximum PE).

Quality appraisal

Of the records that actively engaged patients (n=11), the mean quality score for reporting of patient engagement was 5.9 out of 7 based on the AGREE II tool (domain 2, item 5) (table 4). The quality scores ranged from 4 to 7 (SD=1.04), with the best practice reports from 2010 onwards scoring either 6 or 7 (SD=0.53). Two of the four rating criteria—statement of patient engagement strategy type and methods by which preferences and views were sought—were met by all eleven of those reports that included patient engagement in their development. The type of information gathered and how it was used to inform the development process was less often addressed in records published between 1995 and 2009.

Level of patient engagement

In earlier years (1995–2009), patient engagement primarily occurred in the post-development stage, after provisional guidelines had been drafted. In three reports within this time period, patients discussed and debated provisional guidelines either at a conference breakout session, a workshop, or an open forum.^{37 39 40} During this period, patients were minimally represented in the working group that writes the guidelines (developing stage), oftentimes having as little as one patient representative on a committee of up to 33 professionals.^{38 39} Many of the recommendations were developed by experts and medical professionals only and did not involve patients.^{33 40–47} Starting in 2010, a greater proportion of the working group was comprised of people with lived experiences^{31 32 34–36} and considered the patient perspective when searching the literature.^{31 32 34}

Within each stage of development, the precise contributions of patients and caregivers were unclear.

In one paper,³⁸ there was little information on how the consumer representative (1 of 33 professionals) was involved in the task force as the authors did not elaborate on the methodology of developing the recommendations. For the development of the Transitions of Care Consensus Policy Statement,⁴⁰ a consensus conference was convened which had attendees representing patient groups. However, it was not stated how many participants represented the patient groups nor were individual patients acknowledged in the manuscript.

UK government agencies did better

The best practice reports developed in the UK, SIGN and NICE involved patients at all stages of the development process and had a greater proportion of patients sitting in the working group.^{31 32 34} Furthermore, more UK best practice reports considered marginalised populations. Of the 10^{31 32 34–36 38 40 43 48 49} reports that had considered this, 4^{31 32 34 49} were developed from the UK.

As part of the National Health Service, both SIGN and NICE have to complete an 'equality impact assessment' to identify and address any equality issues regarding age, disability, gender, race, religion and/or sexual orientation.⁵⁰ For example, NICE's 2015 guideline on the transition between inpatient hospital settings and community settings for adults with social care needs had special considerations for the homeless and lesbian, gay, bisexual, trans and queer (LGBT) populations.

DISCUSSION

We found that only half of best practice reports related to the transitions from hospital to home actively involved patients in report development. The reporting on the level of patient engagement was generally good, although some reports lacked detail about the exact contributions of patients. Overall, there has been an increase over time in the amount of patient engagement in the development of best practice reports for the transition from hospital to home. Since 2010, patients have been engaged earlier in the planning stages and also have been more involved as participants of working groups and advisory committees. Few organisations involved patients in shared leadership with only two organisations that involved patients at every stage of development from guideline topic proposal to peer review.

Overall, UK government agencies, such as the NICE and SIGN, were more advanced at engaging patients throughout the development process, had clearer documentation of their involvement and did better at considering marginalised populations. This is unsurprising as reporting of patient engagement has been required in the UK for over 15 years, much longer than other countries, and also reflects the cultural shift towards the importance of engaging and reporting patient engagement.^{6 51} UK government agencies deliberately factor patient engagement in the development of these reports by having 'patient involvement officers' or a 'public involvement

Table 3 Reporting of patient engagement for included studies with active patient engagement (n=11)

Reference	Consultation	Involvement	Shared leadership
Ospina <i>et al</i> , 2018 ⁵⁶	<ul style="list-style-type: none"> ▶ 34 COPD patients were involved in survey to inform the development of the COPD discharge bundle. 	None.	None.
NICE, 2016 ³¹	<ul style="list-style-type: none"> ▶ Public and Patient Involvement Programme (PPIP) provides input on provisional guidelines. ▶ Mental illness advocacy organisations provided input on the scope. ▶ Patient preferences and values considered in developing research questions. 	<ul style="list-style-type: none"> ▶ 2 patients and 2 caregivers were part of the guideline committee (4/15). ▶ 1 PPIP member sits on the scoping group. 	None.
Cameron <i>et al</i> , 2016 ³⁵	<ul style="list-style-type: none"> ▶ At least 2 patients or caregivers were external reviewers. 	<ul style="list-style-type: none"> ▶ Stroke survivor(s) were part of the writing group which discussed and debated the value of evidence of recommendations. 	<ul style="list-style-type: none"> ▶ One stroke survivor was made a coauthor of the journal article.
Ccac, 2015 ³⁶	<ul style="list-style-type: none"> ▶ 50 patients were interviewed to develop scope. ▶ Members of a patient and family advisory forum (Mississauga Halton Share Care Council) were consulted to develop the scope. 	<ul style="list-style-type: none"> ▶ 50 patients were involved in postdischarge interviews after implementation of new approach. ▶ Design team had a patient and a caregiver to help build a patient-centred approach to transition planning. 	<ul style="list-style-type: none"> ▶ Patients were engaged at every stage, including creating the scope of the problem.
NICE, 2015 ³²	<ul style="list-style-type: none"> ▶ Public and patient involvement programme (PPIP) provides input on provisional guidelines. ▶ Patient preferences and values considered in developing research questions. 	<ul style="list-style-type: none"> ▶ 4 patients and caregivers were part of the guideline committee (4/14). ▶ 1 PPIP member sits on the scoping group. 	
Coombs <i>et al</i> , 2015 ⁴⁹	<ul style="list-style-type: none"> ▶ Patients (unclear how many) engaged in focus groups that developed questions to be used in the national stakeholder meeting to inform the development of a clinical guidance document on transferring critically ill patients home to die. ▶ At the meeting, these patients were also involved in informing guidance content by participating in the event's activities. 	None.	None.
Network, 2010 ³⁴	<ul style="list-style-type: none"> ▶ Patient involvement officer provided support and facilitation for the guideline development group (GDG). ▶ Draft guideline was available on the SIGN website for a month to allow the public to comment. ▶ At least 2 peer reviewers were patients or caregivers. ▶ Members of the SIGN patient network were also invited to comment on the draft guideline. 	<ul style="list-style-type: none"> ▶ 4 lay representatives were part of the GDG; at least 2 were patient representatives selected from national and/or local patient-focused organisations in Scotland (4/26). ▶ Representatives participated in informal consensus. 	<ul style="list-style-type: none"> ▶ Patients were engaged at every stage. Individuals or patient groups may propose a guideline topic through an application.
Snow <i>et al</i> , 2009 ⁴⁰	<ul style="list-style-type: none"> ▶ Patient groups from the Institute for Family Centred Care attended the Transitions of Care Consensus Conference (unclear how many). ▶ Patient groups were involved in breakout sessions focused on discussing the principles and standards already drafted for revision. ▶ Revision, refinement and prioritisation of standards were done through a group consensus voting process. 	None.	None.
Ball <i>et al</i> , 1997 ³⁸	None.	<ul style="list-style-type: none"> ▶ One patient representative was a part of the multidiscipline task force that developed the transitional care plan (1/33). ▶ Unclear on the consensus process. 	None.

Continued

Table 3 Continued

Reference	Consultation	Involvement	Shared leadership
Davies and Hopkins, 1997 ³⁷	<ul style="list-style-type: none"> ▶ Patients were interviewed to inform guideline for patient management concerning communication and support. ▶ Patients were involved with approval of final guidelines. 	<ul style="list-style-type: none"> ▶ Patient and relative groups (unclear how many) were a part of the working group, which reviewed and debated provisional guidelines derived from research literature. 	None.
Gresham and Stason, 1995 ³⁹	<ul style="list-style-type: none"> ▶ The public was consulted through an open forum where professional and provider organisations, manufacturers, pharmaceutical firms and individuals can present written or oral statements. ▶ Patient organisations reviewed the patient and family guide. 	<ul style="list-style-type: none"> ▶ Guidelines are developed by a multidisciplinary panel of experts with one patient representative who provided the patient perspective (1/16). 	None.

programme'.^{31 32 34} Additionally, SIGN allows any patient or group to propose a guideline topic and writes to various patient organisations and National Health Service organisations prior to the first meeting of the guideline development group to solicit input. The patient engagement officers encourage patient participation throughout all stages of development and provide training for all stakeholders involved. This addresses some of the barriers to patient engagement implementation, such as lack of organisational support, limited resources (space and time), resistance to the idea of power sharing, and perceived importance of patient engagement.^{4 8 13 51–54} However, Canadian jurisdictions have more recently been engaging patients earlier, notably in the example of the *Seamless Transitions: Hospital to Home* initiative where patients were engaged throughout the design process.³⁶

While recent literature on patient engagement focuses on hospital service improvement⁵³ or health services research,^{6 12} our paper highlights the extent of patient engagement in best practice reports focused on transitions from hospital to home. The findings of this review are consistent with earlier studies on patient engagement in health services research, planning and design. More often than not, there was little detail on the precise contributions of the patient representatives within the working group, which seems to be consistent with the literature.^{6 53 55} Some reasons for this include the complexity of patient engagement being a multifaceted social process⁷ and that journals and peer reviewers do not usually request patient engagement information within manuscripts until more recently.⁶ However, we found that in recent years, patient engagement documentation has become clearer and easier to find with respect best practice reports, particularly those developed by government agencies in the UK.

The strengths of this review include a comprehensive systematic search which included searching the peer-reviewed and grey literature, the use of several patient engagement frameworks to develop our data extraction tool, and compliance with standards for the conducting and reporting of reviews (Preferred Reporting Items for

Systematic Reviews and Meta-Analyses). There were also some notable limitations. With respect to article selection, an additional reviewer to screen the full-text articles could have increased the rigour of the selection process. This was mitigated by sharing all included and excluded articles with documentation of reasons for exclusion to the project members. Owing to resource limitations, only one reviewer performed the data extraction, and thus it is possible that some information may have been missed. Some patient engagement activity may not have been reported in the publication. Further, we did not solicit information from authors of the best practice reports to confirm. Although the type of patient engagement was captured in all of the studies, we do not know how influential their contributions were.

Our findings highlight the opportunity for organisations to better engage patients in any quality improvement initiative. Five strategies that organisations can consider are (1) engage patients in developing the scope of the problem, (2) involve patients in the writing of recommendations, (3) consider the needs of vulnerable populations, (4) use a patient engagement officer to recruit patients to participate across all stages of development and (5) document patients' precise contributions. Many of these strategies are lessons learnt from UK organisations that have engaged patients across the spectrum. In a report commissioned by the UK's National Institute for Health Research to evaluate the impact and outcomes of patient engagement in funded research, one case study reported rises in recruitment rates once patient engagement officers were involved.⁷ Allowing patients to participate in all or most stages of the planning, administration and evaluation can reduce patient engagement barriers, reduce the risk of tokenism, and lead to improved quality of outcomes.^{8 53 54} The earlier the patient engagement, the greater the reduction in research 'waste' by focusing on the topics that matter to patients.⁶

Our work will inform patient engagement in the development of a quality standard on the transition from hospital to home in Ontario, Canada. Our intent is to engage patients throughout the development process

Table 4 Stakeholder involvement methodological quality assessment (AGREE II, domain 2, item 5 stakeholder engagement): on best practice reports with active patient engagement (n=11)

Author, year	Rating criteria				Additional considerations			Overall Stakeholder Involvement Quality Score Item 5 AGREE II (1=poor to 7=exceptional)
	Statement of type of strategy used to capture patients'/ public's views and preferences in the guideline development group, literature review of values and preferences)	Methods by which preferences and views were sought (eg, evidence from literature, surveys, focus groups)	Outcomes/ information gathered on patient/public information	Description of how the information gathered was used to inform the guideline development process and/or formation of the recommendations	Is the item well written? Are the descriptions clear and concise?	Is the item content easy to find in the guideline?	Did patients take part in writing recommendations/ guidelines?	
Ospina <i>et al</i> , 2018 ⁵⁶	✓	✓	✓	✓	✓	✓	✓	6
NICE, 2016 ³¹	✓	✓	✓	✓	✓	✓	✓	7
Cameron <i>et al</i> , 2016 ³⁵	✓	✓	✓	✓	✓	✓	✓	6
Trillium Health Partners and Mississauga Halton Ccac, 2015 ³⁶	✓	✓	✓	✓	✓	✓	✓	7
NICE, 2015 ³²	✓	✓	✓	✓	✓	✓	✓	7
Coombs <i>et al</i> , 2015 ⁴⁹	✓	✓	✓	✓	✓	✓	✓	6
SIGNN, 2010 ³⁴	✓	✓	✓	✓	✓	✓	✓	7
Snow <i>et al</i> , 2009 ⁴⁰	✓	✓	✓	✓	✓	✓	✓	5
Ball <i>et al</i> , 1997 ³⁸	✓	✓	✓	✓	✓	✓	✓	4
Davies and Hopkins, 1997 ³⁷	✓	✓	✓	✓	✓	✓	✓	5
Gresham and Stason, 1995 ³⁹	✓	✓	✓	✓	✓	✓	✓	5
Average score								5.9
SD								1.04
Range								4-7

starting with a province-wide patient consultation using concept mapping to help prioritise topic areas for the standard. Lessons that we can learn from patient engagement practices in the UK include clearer documentation of patient engagement and involving patients in writing best practice recommendations.

CONCLUSION

Patient engagement has steadily increased over the last decade; however, a standardised protocol for reporting patient engagement is needed. We can learn from UK government agencies to better engage and document patient engagement as well as to consider the needs of marginalised populations in the development of best practice reports related to transitions from hospital to home. Our work will inform patient engagement in the development of a quality standard on the transition from hospital to home in Ontario, Canada.

Acknowledgements We would like to thank our information specialists from St. Michael's Hospital, Nazi Torabi, Glyneva Bradley-Ridout and David Lightfoot for their expertise and support in conducting the search strategy. We would also like to acknowledge Kim Devotta for her support in facilitating this project.

Contributors Each named author has provided substantial contributions to the design, collection, analysis, drafting and revision of this manuscript. The final version was approved by all named authors. Additionally, to the best of our knowledge, the named authors have no conflict of interest, financial or otherwise.

Funding Dr. Kiran is the Fidani Chair of Improvement and Innovation at the University of Toronto. She is supported as a Clinician Scientist by the Department of Family and Community Medicine at St. Michael's Hospital and at the University of Toronto. She is also supported as an Embedded Clinician Researcher by the Canadian Institutes of Health Research and Health Quality Ontario. This research was supported by Dr. Kiran's Embedded Clinician Researcher award.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The protocol and data analysis of included articles can be accessed upon request by emailing the corresponding author (grace.zhao@mail.utoronto.ca). Reuse only with permission and with citation.

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