








SCOPING REVIEW

Reporting and conducting patient journey mapping research in healthcare: A scoping review

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Abstract

Aim: To identify how patient journey mapping is being undertaken and reported.

Design: A scoping review of the literature was undertaken using JBI guidance.

Data Sources: Databases were searched in July 2021 (16th–21st), including Ovid's Medline, Embase, Emcare and PsycINFO; Scopus; Web of Science Core Collection, the Directory of Open Access Journals; Informit and; ProQuest Dissertations and Theses Global.

Review Methods: Eligible articles included peer-reviewed literature documenting journey mapping methodologies and studies conducted in healthcare services. Reviewers used Covidence to screen titles and abstracts of located sources, and to screen full-text articles. A table was used to extract data and synthesize results.

Results: Eighty-one articles were included. An acceleration of patient journey mapping research was observed, with 76.5% ($n = 62$) of articles published since 2015. Diverse mapping approaches were identified. Reporting of studies was inconsistent and largely non-adherent with relevant, established reporting guidelines.

Conclusion: Patient journey mapping is a relatively novel approach for understanding patient experiences and is increasingly being adopted. There is variation in process details reported. Considerations for improving reporting standards are provided.

Impact: Patient journey mapping is a rapidly growing approach for better understanding how people enter, experience and exit health services. This type of methodology has significant potential to inform new, patient centred models of care and facilitate clinicians, patients and health professionals to better understand gaps and strategies in health services. The synthesised results of this review alert researchers to options available for journey mapping research and provide preliminary guidance for elevating reporting quality.

KEYWORDS

health journey, patient journey mapping, reporting guidelines, scoping review, touchpoints, patient experience, health service, nursing

1 | INTRODUCTION

Health systems and services are complex, inter-related and, for many, intimidating and challenging to navigate (Griese et al., 2020). Clinicians and researchers have adapted a research approach from the marketing industry to gain insight into how individuals navigate and experience these health systems (Crosier & Handford, 2012). This approach has become known as 'patient journey mapping' (Davies et al., 2022).

Patient journey mapping is an increasingly popular approach to evaluating the experiences of individuals as they navigate complex and dynamic health services and systems (Sijm-Eeken et al., 2020). Projects where patient journey mapping methods are used almost always place individuals at the centre of the research in attempts to both understand and improve the experience of the individual and the systems that they navigate (Kelly et al., 2016, 2017; Kushniruk et al., 2020). One specific advantage is the capacity of this type of research to provide nuanced clarity about peoples' experiences as they traverse health systems rather than only capturing single episodes of care. In this scoping review, the nature of these projects is considered, with a particular focus on how patient journey mapping research is being reported in published literature (Davies et al., 2022).

1.1 | Background

The terminology used to describe patient journey mapping projects varies, and includes; process mapping (Barton et al., 2019; Frew et al., 2020; Trebble et al., 2010), patient journey modelling (Curry et al., 2007), journey mapping (Bearnot & Mitton, 2020), and client journey mapping (Dawson et al., 2017; Schildmeijer et al., 2019). Several definitions for patient journey mapping approaches to research have been provided in the literature. Barton et al. (2019, p. 1) describe it as "a map of the steps a client takes as he or she progress (sic) through different stages of a disease, often capturing diagnosis and management and interactions with health professionals". Curry et al. (2007, p. 905) define this process as "a patient-centric activity that details a patient's progress through a healthcare system for a given service". In this review, patient journey mapping is viewed as a patient-oriented project that has been undertaken to better understand barriers, facilitators, experiences, interactions with services and/or outcomes for individuals and/or their carers and family members as they enter, navigate, experience and exit one or more services in a health system by documenting elements of the journey to produce a visual or descriptive map.

The reasons for undertaking patient journey mapping vary and have included improving the quality of care provided through understanding patient experiences with greater detail; better understanding the relationship that develops dynamically between patients and service organizations, and exploring the lived experiences of people from stigmatized or disadvantaged populations who may have additional challenges or barriers to accessing and remaining in contact

with health services (Bearnot & Mitton, 2020; Lawrence et al., 2021; McCarthy et al., 2020; Richardson et al., 2007).

Patient journey mapping projects have been undertaken using a variety of data collection and analytical approaches that have included physically tracking patients' movements through health services (Barton et al., 2019), interviewing or surveying patients, family members and healthcare workers about experiences of navigating a health system or health services (Barton et al., 2019, p. 1), auditing case notes (Epstein et al., 2007), identifying and tracking key touch-points in the journeys of individuals or groups of people accessing health services or through a combination of methods (Gualandi et al., 2019).

Not only is there variability in how researchers and clinicians approach patient journey mapping projects, but there is also variety in what is reported in publications. As recently noted by Sijm-Eeken et al., there is no standardized approach for how to perform patient journey mapping, and there is significant variability in the quality of the methods used for these projects (Sijm-Eeken et al., 2020). In some instances, traditional qualitative or quantitative methodologies have been adapted to describe a patient's experience with a linear approach (Jackson et al., 2012; Mohr et al., 2018; Momen et al., 2013); in others, newly developed mapping tools integrate information from different perspectives and from multiple dimensions (Kelly et al., 2016; Sijm-Eeken et al., 2020).

In addition to highlighting methodological variability, Sijm-Eeken et al. (2020) also identify significant variability in the quality of reporting of patient journey mapping research as problematic. With significant concerns raised across disciplines, and indeed the spectrum of research methods, issues regarding transparency, rigour and trustworthiness are certainly not limited to patient journey mapping research (Kazak, 2018; Sijm-Eeken et al., 2020; Tong et al., 2007; von Elm et al., 2008). Investigating the areas of concern that exist in this body of literature may be of value for elevating the quality of reporting in future publications and provide direction to appropriate reporting guidelines. Given the array of approaches to both the mapping process and the quality of the reporting of this type of research, this scoping review sought to map the literature that documents or utilizes patient journey mapping methodologies in health care and to document and describe the methods and approaches used to report these projects.

2 | THE REVIEW

2.1 | Aim

The aim of this scoping review was to identify how patient journey mapping research is being undertaken and how it is being described and documented in academic literature. The overarching questions being addressed were: "what approaches are being adopted to map patient journeys through health systems"; "what justifications are provided for undertaking patient journey mapping research" and "how are studies that use a patient journey mapping methodology

in health services described and documented in the academic literature?" These aims and questions have been altered from the original protocol to allow a broader exploration of the included articles (Davies et al., 2022). The alterations in aims and review questions did not necessitate changes to the eligibility criteria or search strategy for the review.

2.2 | Design

This review was conducted according to the JBI guidance for scoping reviews (Peters et al., 2020) and is reported in accordance with the PRISMA extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). An a priori protocol was developed and published (Davies et al., 2022) and the review title was registered on the JBI systematic review register.

The Participant, Concept, Context (PCC) approach for developing eligibility criteria was adopted and is outlined in detail in the review protocol (Davies et al., 2022). In brief, there were no eligibility criteria relating to participants, including, but not limited to their age, gender, diagnosis, treatment or location. The concept being explored was the mapping of patient journeys through health care systems and services as a method of collecting, analysing and presenting data for research or quality improvement projects. The context included all settings where patients are provided with healthcare services (Davies et al., 2022). Types of sources eligible for inclusion included peer-reviewed primary research articles that used or described a patient journey mapping methodology, limiting the search to published peer-reviewed journal articles, theses and dissertations (Davies et al., 2022). There were no date restrictions for the evidence sources.

In clearly defining the types of research and methodology papers that were to be included in this review, a list of methodological approaches that could be considered relevant or adjacent to patient journey mapping was collated and contributed to an expanded exclusion criteria for this review. These excluded methodologies included auto-ethnographies; time-to-treatment studies where two data points were used to evaluate delays to treatment or management of illness; consensus papers where a 'typical' patient journey is described by medical experts; patient flow studies, where large data sets of touch-points are used to describe issues and challenges with patient flow through systems, without focusing on individual experiences and; process mapping studies where the productivity and efficiency of service delivery are being measured.

2.3 | Search methods

A search strategy was devised in consultation with VL (academic librarian) and can be viewed in Appendix S1. Examples of key words and phrases included patient journey, journey map and healthcare journey. Keywords and controlled vocabulary were used in a search

strategy that was manually adapted for the following online databases and collections: the Directory of Open Access Journals (DOAJ); Ovid's Embase, Emcare, Medline and PsycINFO; Scopus; Web of Science Core Collection; Informit and; ProQuest Dissertations and Theses Global. The search strategy was used to search these platforms between July 16th and July 22nd 2021. The reference lists of all included articles were perused for any additional eligible articles that were not captured in the initial database search. This process involves reviewing the reference lists of all included articles for eligible articles that were not screened in the primary search (Louw et al., 2011).

Articles were initially imported into EndNote X9.3.3 (Clarivate Analytics, PA, USA). Duplicates were removed before articles were imported into Covidence (Veritas Health Innovation, Melbourne, Australia) where they could be screened by reviewers. Reviewers (ED, LB, DP, JK, RL, AG, VL) undertook pilot testing by screening the title and abstract of the same 10 articles independently, before coming together to discuss each article and clarify doubts and uncertainties. Consensus was reached regarding the eligibility status of each of these articles, and screening proceeded. Each title and abstract were screened independently by two of the reviewers (ED, LB, VL, AG, RL, MA-C and AW). All reviewers pilot-screened the same six full text articles, and all reached the same conclusion regarding the eligibility of these articles. Full-text screening proceeded, with each article independently reviewed by two reviewers (LB, ED, AW, MA-C, DP, VL, RL, JK and AG). Conflicts arose in both the title and abstract and full-text screening processes, as the central concept of the review is not well defined or articulated in literature, and there was some ambiguity in definitions provided in screened articles. All conflicts were arbitrated by either the lead author or a third reviewer and resolved by returning to the definition of patient journey mapping that has been provided in the background section of this review.

2.4 | Data extraction

An extraction spreadsheet was developed in Microsoft Excel and used to extract data from the included studies (see [Supporting Information File 2](#)). All reviewers extracted data from five studies to pilot the extraction tool and to ensure consistency and accuracy. The data extraction tool was modified iteratively throughout this process. Alterations included additional columns to facilitate the extraction of data relating to the justifications provided for undertaking patient journey mapping research, and a process for extracting details relating to the quality of reporting when rated against established reporting guidelines (COREQ and STROBE). Data were extracted from included articles by one reviewer (LB, AW and VL), and a second reviewer (ED and JK) checked for completeness and accuracy of the extracted data. Data regarding study characteristics, methodological approaches, data collection and data analysis were extracted. Key findings relevant to the review questions, such as journey mapping tools, the purpose of the journey mapping, type of healthcare where journeys were mapped, disease processes for

and the perspectives presented in the reporting of studies, were extracted.

2.5 | Data analysis and presentation

Descriptive statistical analysis was conducted for data relating to study characteristics. Textual data on why patient journey mapping was used were synthesized narratively using a descriptive qualitative content analysis approach (Peters et al., 2020). Data that were synthesized included the justifications that were provided for adopting patient journey mapping approaches and summaries of the types of approaches used to map patient journeys.

The process for synthesizing and categorizing data relating to the reasons for mapping being undertaken, using an inductive approach was collaborative and iterative. The scoping review team met on three occasions in blended online/in-person workshops to examine each of the justifications from the 81 included articles to discuss initial thoughts, to code extracted statements and to consider similarities that would lead to distinct categories. Figure 1 provides an example of one such statement.

The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) (combined) checklist and Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were used to examine the reporting of the majority of included, primary research articles (Tong et al., 2007; von Elm et al., 2008). In the absence of specific reporting guidelines for patient journey mapping projects, this exercise was conducted to explore any significant gaps in the reporting of these projects and to provide preliminary recommendations for fundamental details that should be reported in future projects of this nature. Review data are presented in tables, figures and narrative summaries of findings relevant to the review aims and questions.

3 | RESULTS

A search of nine databases yielded 21,356 articles. After removing duplicates, 9956 articles remained and were uploaded to Covidence for title and abstract screening. After excluding irrelevant articles, 671 full-text articles were retrieved and screened by two independent reviewers—a process that resulted in 76 articles that met the eligibility criteria. An additional 44 articles were identified through screening citations of the included studies. Five of these fulfilled the

eligibility criteria. In total, 81 articles met the eligibility criteria for this review. Figure 2 details the selection process and reasons for exclusion.

Of particular interest is the surge in patient journey mapping projects. As demonstrated in figure 3, the number of patient journey mapping publications has accelerated since 2015, with approximately three quarters of included articles published since then.

3.1 | Characteristics of included articles

There was significant variation in the types of articles that were included in this review, as reflected in Table 1. The majority of included articles were primary research articles ($n = 70$; 86.4%), and just over half ($n = 44$; 54.3%) used a qualitative approach to patient journey mapping. Close to one third used mixed or multi-methods approaches ($n = 23$; 28.4%) and the remainder were quantitative in nature ($n = 14$; 17.3%). More than half of the included studies were undertaken in European countries ($n = 42$; 51.8%).

A broad array of illnesses, disease processes and injuries have been mapped. For the purposes of this review, these have been grouped by treatment specialities. The largest treatment speciality where patient journey mapping project were undertaken was oncology, with just over one fifth of articles ($n = 18$; 22.2%) focusing on people diagnosed with cancer. Two thirds ($n = 54$; 66.7%) of the journey mapping studies were conducted in tertiary care facilities and approximately half ($n = 39$; 48.1%) were conducted retrospectively.

3.2 | Why were patient journey mapping studies undertaken?

The justifications and reasons for patient journey mapping methodologies being adopted in the included studies were analysed inductively. Through a process of reviewing the content of these justifications as a team of reviewers, it became apparent that there were eight distinct reasons for using a patient journey mapping approach. These are detailed in Figure 4, with expanded information provided in Appendix S2, Worksheet “Justifications for using PJM”.

For some included articles, the justifications may have fit more than one of these categories. Each article was placed into one category that was determined to be the ‘best-fit’ column for

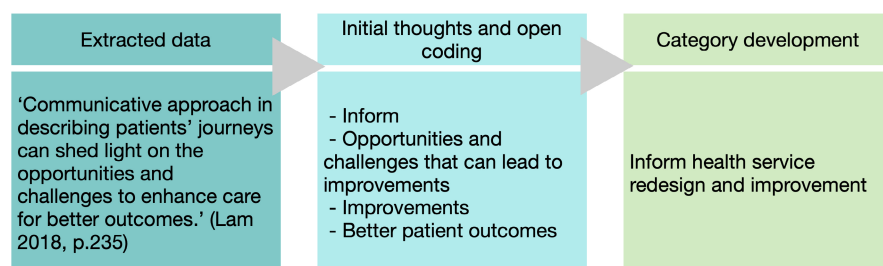


FIGURE 1 Data synthesis process—reasons for undertaking a patient journey mapping project.

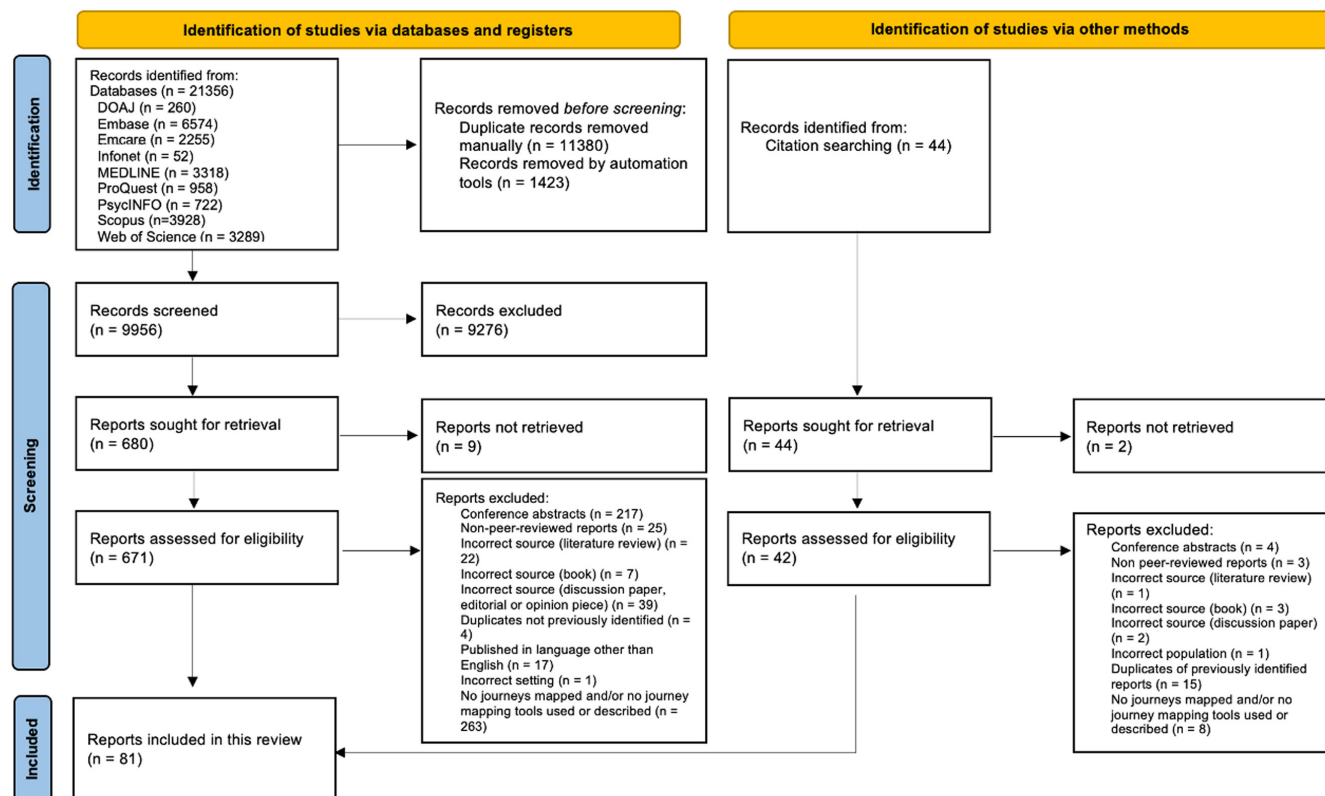


FIGURE 2 PRISMA flow chart.

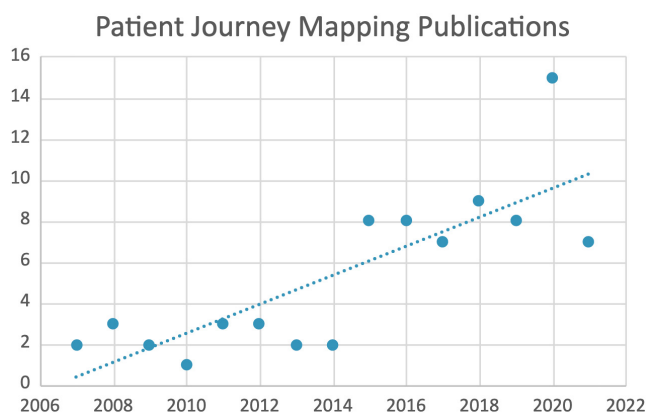


FIGURE 3 Timeline of patient journey mapping publications, 2007–2021*.

the purposes of presenting these data. There was one included study (1.2%) where a clear justification was not reported (Bowers et al., 2016).

3.2.1 | Inform health service redesign/improvement

One of the earliest and most prevalent reasons for adopting a patient journey mapping methodology in the included articles was to inform the redesign and improvement of health service delivery. One third ($n = 26$; 33%) of all included papers justified the adoption

of a patient journey mapping process or methodology to advocate for the improvement of health service delivery.

"Bringing together findings of patient experience, pathway, and profiles would help all the stakeholders involved to develop better practices for the healthcare process" (Cherif et al., 2020, p. 2).

A variety of approaches were adopted to address this purpose, with most papers arguing that services require the insights from people with lived-experience of both the illness and local health services to adapt and optimize care to meet the needs of patients.

Studies included those which described single sites, as well as healthcare provided through multiple agencies.

"The effective delivery of treatment represents an iterative relationship between client and treatment programme... With services commonly provided by a number of different agencies with varying treatment approaches, the organization of provision including choice of services, allocation of funding and gate-keeping criteria can further influence pathways into services, quality of treatment and completion. Building an understanding of how these factors interact is important to improving the effectiveness of provision" (Gilbert et al., 2015, p.445).

3.2.2 | Develop a deeper understanding of a person's entire journey through the health system(s)

The second most prevalent reason provided for adopting a patient journey mapping approach was to develop a deeper understanding of individuals' and families' experiences of their journeys through

TABLE 1 Description of characteristics of included articles

| Study/article characteristics | n / 81 (%) | Study/article characteristics | n / 81 (%) |
|--|------------|---|------------|
| Type of evidence source | | Sample size (Total number of patients for whom journey mapped = 53,235) | |
| Primary research article | 70 (86.4) | <10 | 16 (19.7) |
| Methodology paper | 10 (12.3) | 10–30 | 23 (28.4) |
| Thesis | 1 (1.2) | 31–50 | 6 (7.4) |
| Methodology used | | 51–70 | 3 (3.7) |
| Qualitative | 44 (54.3) | 71–100 | 5 (6.2) |
| Mixed or multi-methods | 23 (28.4) | >100 | 16 (19.6) |
| Quantitative | 14 (17.3) | Region where the studies were conducted | |
| Method of data collection | | Europe | 42 (51.8) |
| Multiple methods | 40 (49.1) | North America | 13 (16) |
| Interviews | 25 (30.6) | Oceania | 13 (16) |
| Survey and/or questionnaires | 6 (7.4) | Africa | 2 (2.5) |
| Clinical record audit | 4 (4.9) | Asia | 5 (6.2) |
| Focus groups | 2 (2.5) | Middle East | 1 (1.2) |
| Personal video stories on YouTube | 1 (1.2) | Multiple regions | 2 (2.4) |
| Oral stories | 1 (1.1) | Unknown | 3 (3.7) |
| Not applicable (not primary research paper) | 2 (2.5) | Patient Journey Mapping tool or methodology described | |
| Types of illness, disease process or injury being mapped (grouped by treatment specialities) | | Yes | 45 (55.6) |
| Oncology | 18 (22.2) | No | 36 (44.4) |
| Mental health | 7 (8.6) | Presentation of data | |
| Cardiovascular | 6 (7.4) | Multiple methods | 46 (56.8) |
| Musculoskeletal | 6 (7.4) | Written description (only) | 28 (34.5) |
| Respiratory | 5 (6.2) | Flow chart | 16 (19.7) |
| Surgical procedure | 4 (4.9) | Diagram | 16 (19.7) |
| Dermatology | 3 (3.7) | Image | 9 (11) |
| Neurologic | 3 (3.7) | Graph | 9 (11) |
| Gastrointestinal | 2 (2.5) | Timeline | 7 (8.6) |
| Infectious disease | 2 (2.5) | Figure | 3 (3.7) |
| Renal | 2 (2.5) | NA | 3 (3.7) |
| Other | 12 (14.8) | Journey mapping timing | |
| Not specified | 11 (13.6) | Retrospective | 39 (48.1) |
| Type of health service | | Prospective | 35 (43.2) |
| Tertiary | 54 (66.7) | Not applicable (not primary research paper) | 6 (7.4) |
| Secondary | 7 (8.6) | Not specified | 1 (1.2) |
| Primary | 6 (7.4) | Reporting tool documented | |
| Multiple | 3 (3.7) | No | 75 (92.6) |
| Not specified | 6 (7.4) | Yes | 6 (7.4) |
| Not applicable (not primary research paper) | 5 (6.2) | | |

health systems (n = 14; 17%). A range of methodological approaches were used to gain a deeper understanding of people's journey through the health system from diagnosis to completion of treatment, with all using qualitative approaches.

“Providing ... patients with patient-centered care that is effective, safe, and supportive throughout their journey requires knowledge of patients' progressive experiences and evolving perspectives” (Lamprell & Braithwaite, 2018, p. 1564).

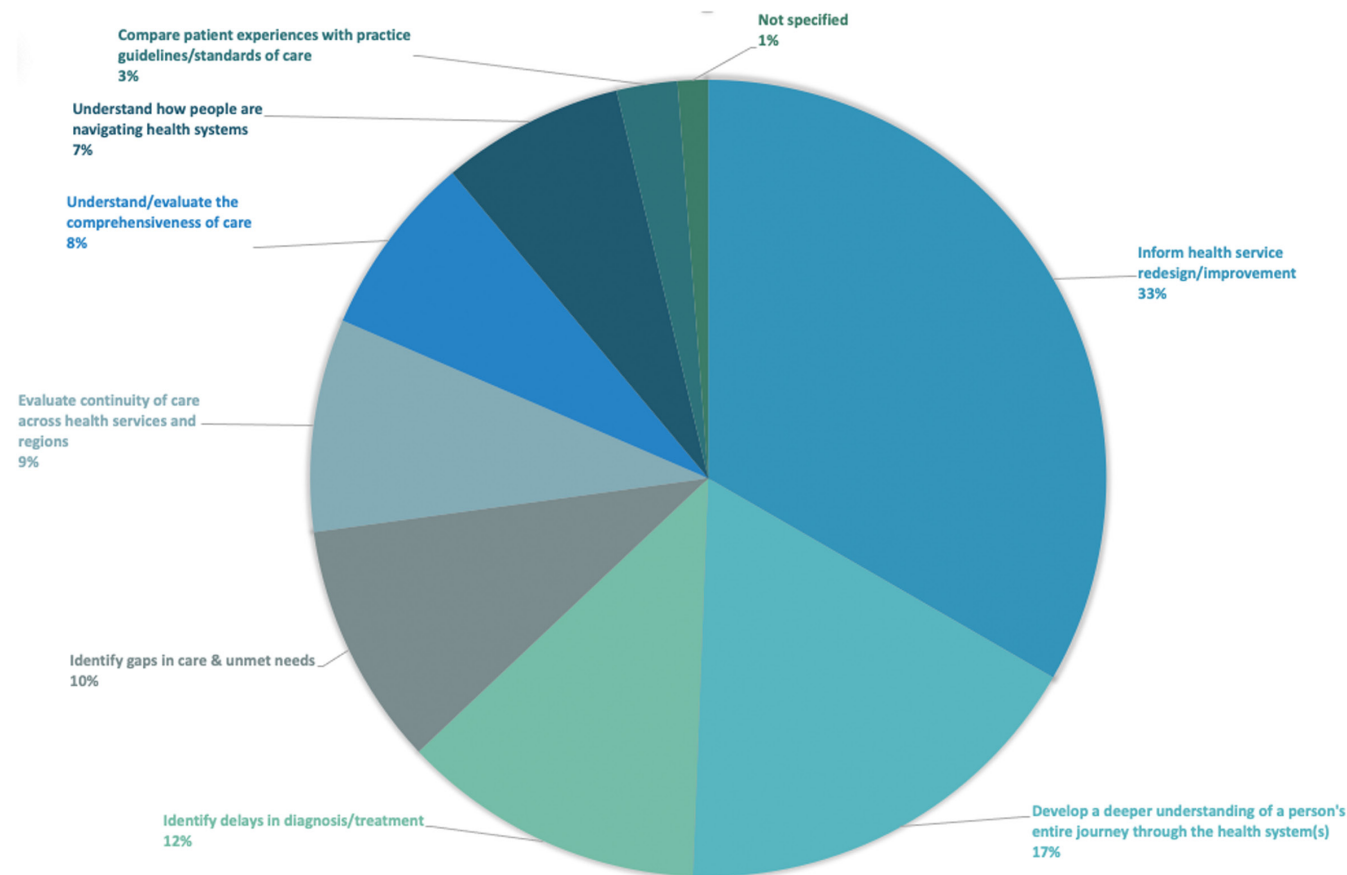


FIGURE 4 Justifications provided for undertaking a patient journey mapping research project.

3.2.3 | Identify delays in diagnosis/treatment

Just over 10% of articles sought to better understand patients' experiences of their health journeys ($n = 10$; 12.3%). Articles in this category used either quantitative or multi-methods approaches to identify specific delays when people were seeking diagnosis or treatment.

"To identify the points of delay in referral and presentation and determine the factors associated with delay" (Gichuhi et al., 2017, p. 2).

3.2.4 | Identify gaps in care and unmet needs

Close to 10% of studies sought to identify specific gaps in care that could then be addressed ($n = 8$; 9.9%).

"By focusing on multiple perspectives and illustrating a journey along multiple timelines representing different aspects of a journey, this approach can allow for identification of gaps in healthcare processes that could be mitigated" (Kushniruk et al., 2020, p. 406).

Transition into and between health services was recognized as important moments in patient journeys in articles included in this category. The results of this type of research were viewed as important for improving the provision of services through better understanding and then better meeting people's needs.

"A patient-centred approach focussing on the patient's experience and 'life journey' would provide a deeper understanding of patient and family needs during transition. Furthermore, it will provide a deeper understanding of the factors that affect the patient's and the family's quality of life. This rich information can then be used in future interventions to improve transition for patients and families..." (Sezgin et al., 2020, p. 346).

3.2.5 | Evaluate continuity of care across health services and regions

Continuity of care within and across healthcare services has long been considered a vital component of patient safety and patient-centred care. This was recognized in the seven papers (8.6%) that adopted a patient journey method to directly evaluate actual and perceived continuity of care.

"There is a need to address healthcare system issues and patient journey mapping may prove to be an essential tool for decreasing fragmented care for patients across healthcare systems" (Borycki et al., 2020, p. 526).

The settings in which these studies were undertaken included primary, secondary and tertiary health care settings and a variety

of approaches were adopted to identify enablers and barriers to accessing appropriate and timely care.

3.2.6 | Understand and evaluate the comprehensiveness of care

Six articles (7.4%) adopted and advocated for patient journey mapping approaches to evaluate the comprehensiveness of care, often with patients who had complex needs. For example, Barton et al. (2019) state:

"We sought to examine the applicability of multi-method case tracking to understand client journeys in primary healthcare (PHC). Use of multiple methods achieves a more thorough picture of the client journey that includes service data, client perspectives and health logs. The results are potentially very valuable, as there is generally a lack of evidence about the experiences of people receiving multidisciplinary PHD services over time" (p. 2).

All studies in this category included qualitative data, with half adopting a multi-methods approach to capture quantitative data.

3.2.7 | Understand how people are navigating through health systems

Three of the six articles in this category mapped the journeys of patients considered to come from vulnerable populations: transgender individuals (Roller et al., 2015), patients with opioid-use disorders (Bearnot & Mitton, 2020), and people who experience psychosis (Lawrence et al., 2021).

In these studies, it was recognized that health risks existed, that optimal navigation of health services may be impacted as a result of stigma, and that patient journey mapping offered a way to capture information from this population to facilitate better engagement and enhance healthcare experiences (Bearnot & Mitton, 2020; Roller et al., 2015).

"Journey mapping is a novel, patient centred approach to capturing the care experiences and trajectories of a patient population experiencing significant stigma, who engage with the healthcare system in unexpected and fragmented ways" (Bearnot & Mitton, 2020, p. 726).

3.2.8 | Compare patient experiences with practice guidelines and standards of care

Two papers (2.5%) adopted a patient journey mapping methodology to compare the experiences of patients with practice guidelines and standards of care (Alkandari et al., 2019; Oliver et al., 2008). Alkandari et al. compared the pharmacological treatment prescribed to patients with peripheral neuropathy with treatment guidelines from the UK (2019). Oliver (2008) used a patient journey mapping approach to compare patients' experience with Standards of Care

developed by the Arthritis and Musculoskeletal Alliance and the British Society for Rheumatology. Both studies used a qualitative approach, interviewing participants to understand their experiences of healthcare service provision, and both studies presented flow charts to represent the patient journey (Alkandari et al., 2019; Oliver et al., 2008).

3.3 | Mapping tools and processes

As seen in Table 1, numerous methodological approaches were identified through this review. In the majority of studies, methods for journey mapping were novel but familiar: research techniques from traditional qualitative and quantitative methods, for example, semi-structured interviews, case note audits and observational techniques were adapted to map patient experiences. The majority of studies mapped patient journeys from the patients' own perspectives through collecting data about experiences via interviews. Nearly a third ($n = 25$; 30.8%) incorporated perspectives from healthcare workers, carers or relatives. Despite the range of methods adopted in the included articles, there were some commonalities to mapping approaches that are represented in Figure 5. These are not exact replicas of the maps generated in the included articles, but collectively representative of the form, structure and emphasis used to map patient journeys.

Two visual approaches not represented in Figure 5 include the maps generated by patients in Salamonsen et al.'s (2016) study, and in Rix et al.'s study (2014). In the former (2016), patients took quite different approaches to visually mapping their journeys—one with a linear approach and the other using a mind-map. In the latter (Rix et al., 2014), the journey of Aboriginal people from rural Australia who rely on haemodialysis is depicted in cultural imagery, with each element of the painting signifying a different and important element of the journey.

3.4 | Reporting of patient journey mapping in published literature

As patient journey mapping is a novel, evolving and expanding field of research, this review sought to evaluate the quality of reporting of patient journey mapping studies. In undertaking this evaluation, data were extracted from each article to provide insights into the quality, gaps and opportunities for improvement.

No formal reporting guidelines are recommended in the methodology papers that were included in this review ($n = 7$; 9%), and no specific recommendations or guidance regarding what should be reported are documented in those articles (Ben-Tovim et al., 2008; Borycki et al., 2020; McCarthy et al., 2020; Simonse et al., 2019; Sudbury-Riley et al., 2020; Trebble et al., 2010). Of the two articles (2.5%) that were study protocols, one provide a reference to the COREQ reporting guidelines that were to be used in reporting the study (Rushton et al., 2018).

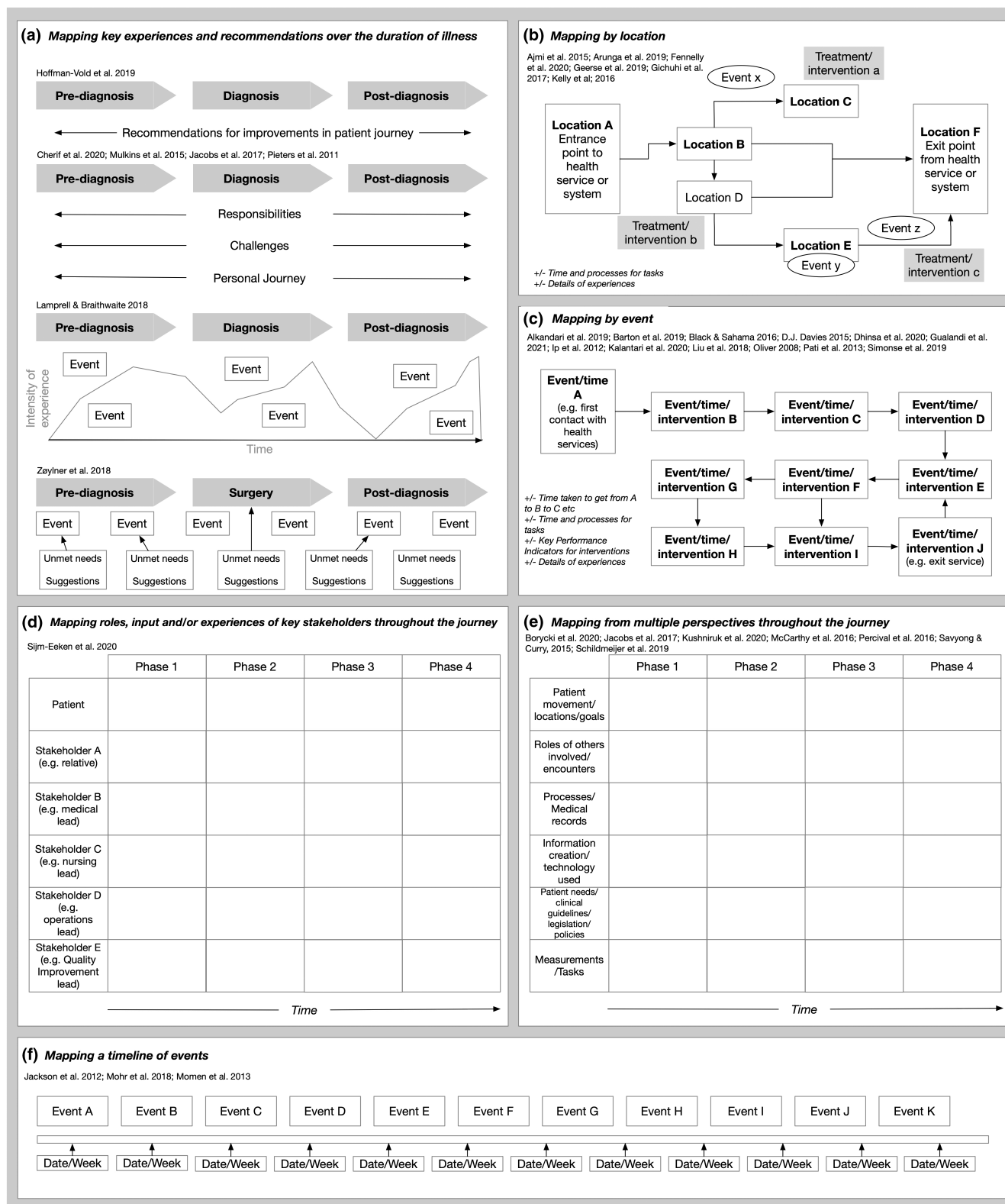


FIGURE 5 Approaches to mapping patient journeys.

Six of the studies included in this review ($n = 6/72$; 8.3%) used or identified specific reporting guidelines, including the Standards for Reporting Qualitative Research (Rushton et al., 2020), the COREQ

guidelines (Fennelly et al., 2020; Gualandi et al., 2019; Rushton et al., 2020) and the STROBE guidelines (de Vries et al., 2021; Tan et al., 2017). The remaining studies did not indicate any adherence

with reporting guidelines. To equitably evaluate studies, the majority were evaluated by reviewers of this project using either COREQ or STROBE guidelines.

In Table 2, the adherence of studies to best-practice reporting of research practices is presented, with COREQ for qualitative studies (Tong et al., 2007), STROBE (von Elm et al., 2008) for quantitative studies and a combination of COREQ and STROBE for multi- or mixed-method studies. (Appendix S2, Worksheets "Quant reporting STROBE, Qual reporting COREQ and MM reporting COREQ+STROBE") Case studies (Kushniruk et al., 2020; Martin et al., 2011; Meyer, 2019) and the one included thesis (Swanger, 1984) were omitted from this analysis, as the COREQ and STROBE guidelines are not generally appropriate for these types of research.

As identified in Table 2, gaps in the adherence to both the COREQ and STROBE reporting guidelines were found for qualitative, quantitative and multi- or mixed-method patient journey mapping studies. Quantitative studies demonstrated a higher level of adherence to reporting guidelines, whilst mixed- and multi-methods studies demonstrated lower levels of adherence to reporting recommendations.

In the qualitative studies, significant reporting omissions were observed in Domain 1 (Research Team and Reflexivity) regarding the personal characteristics of the research team including who conducted the interviews or focus groups, their credentials, occupation, gender and experience. Additionally, the relationship between the researcher and participant cohort was usually poorly reported or absent. Data extraction from the qualitative studies indicated variation in reporting rigour across all three COREQ domains, —*Research Team and Reflexivity, Study Design and Analysis and Findings*. Qualitative studies demonstrated higher levels of reporting in Domain 2 (Study Design), particularly the reporting of participant selection, although the reporting of how data was collected was varied and unclear. In Domain 3 (Analysis and Findings), higher levels of adherence to the reporting section are noted, but there were inconsistencies and omissions in reporting of how data were analysed. Most of the qualitative studies included participant quotations and demonstrated consistency with the data and findings and clarified the major themes.

Quantitative studies demonstrated higher levels of adherence to the STROBE reporting guidelines. The major gaps in adherence to these recommendations for quantitative research were found in the methods section, particularly when explaining missing data and loss to follow up. There was also a gap within the results section with many of the quantitative studies not clearly reporting the number of participants with missing data.

Many gaps were found in the reporting of qualitative data in the mixed- and multi-methods studies. Significant gaps were evident in the reporting of the research team and reflexivity (Domain 1), participant selection and data collection (Domain 2) and data analysis and reporting of the findings (Domain 3). The mixed- and multi-methods studies demonstrated higher levels of adherence to the reporting of the quantitative components. The major identified gaps included explaining how missing data was addressed (Methods section),

explaining the number of participants with missing data, and generalisability of results (Discussion section).

3.5 | Engagement and inclusion

Involvement and engagement with patients, families and health-care providers beyond the roles of recruited participants was reported in 17 of the included articles (20.99%). The extent to which these members were involved included co-design and evaluation of studies (Davies, 2015; Dollard et al., 2018; Fennelly et al., 2020; Liu et al., 2018; Liu et al., 2021; Outlaw et al., 2018; Richardson et al., 2007; Rushton et al., 2018; Sijm-Eeken et al., 2020); co-producing journey maps (Geerse et al., 2019); reviewing and validating study results (Jackson et al., 2012); developing, testing or providing suggestions and recommendations for journey mapping tools (Kelly et al., 2016, 2017; Wauben et al., 2015) and; facilitating participant recruitment (Oliver et al., 2008). These engaged personnel were acknowledged in all of these articles either within the body of the text or in a dedicated acknowledgements paragraph. For some, this was by name, initials or position title and for others these details were not reported. In ten of these articles, engaged personnel were involved in the reporting of the study, and in three, shared authorship (Kushniruk et al., 2020; Oliver et al., 2008; Rushton et al., 2020). Member checking was reported in eight of the 36 qualitative studies (22.2%), and none of the 16 mixed methods studies (refer to Appendix S1, worksheets "Qual reporting COREQ" and "MM reporting COREQ + STROBE").

4 | DISCUSSION

This scoping review sought to identify how and why patient journey mapping research is being undertaken and the ways in which this research is being reported in peer-reviewed literature. A total of 81 articles were included in the review, including ten methods articles, 70 primary research articles and one thesis. A recent acceleration of patient journey mapping publications was identified, with three quarters of included articles published from 2015 onwards. A broad array of methods were recommended, adopted and adapted for mapping patient journeys in health systems, including qualitative, quantitative and mixed methods approaches. There were also a variety of reasons patient journey mapping projects were undertaken. Justifications for patient journey mapping research were grouped into eight categories, and include: (1) to inform health service redesign and improvement; (2) to develop a deeper understanding of a person's entire journey through the health system(s); (3) to identify delays in diagnosis and treatment; (4) to identify gaps in care and unmet needs; (5) to evaluate continuity of care across health services and regions; (6) to understand and evaluate the comprehensiveness of care; (7) to understand how people navigate through health systems and; (8) to compare patient experiences with practice guidelines and standards of care.

TABLE 2 Adherence with COREQ and STROBE reporting guidelines

| COREQ | Adherence qualitative studies | Adherence multi-methods studies | STROBE | Adherence quantitative studies | Adherence multi-methods studies |
|--|-------------------------------|---------------------------------|--|--------------------------------|---------------------------------|
| Domain 1: Research team and reflexivity | | | Title and abstract | | |
| Personal characteristics | | | Indicate the study's design | 12/12; 100.0% | 16/16; 100% |
| Interviewer/facilitator | 17/35; 48.6% | 5/16; 31.1% | Informative and balanced summary | 12/12; 100.0% | 14/16; 87.5% |
| Credentials | 13/35; 37.1% | 2/16; 12.5% | Introduction | | |
| Occupation | 9/35; 25.7% | 2/16; 12.5% | Background/rationale | 12/12; 100.0% | 16/16; 100% |
| Gender | 6/35; 17.1% | 1/16; 6.3% | Objectives | 12/12; 100.0% | 16/16; 100% |
| Experience and training | 10/35; 28.6% | 1/16; 6.3% | Methods | | |
| Relationships with participants | | | Study design | 12/12; 100.0% | 16/16; 100% |
| Relationship established | 11/35; 31.4% | 2/16; 12.5% | Setting | 12/12; 100.0% | 16/16; 100% |
| Participant knowledge of the interviewer | 6/35; 17.1% | 1/16; 6.3% | Participants ^a | 12/12; 100.0% | 12/14; 85.7% |
| Interviewer characteristics | 5/35; 14.3% | 1/16; 6.3% | Variables | 9/9; 100.0% | 8/15; 53.3% |
| Domain 2: Study design | | | Data sources | 12/12; 100.0% | 9/16; 56.3% |
| Theoretical framework | | | Bias | 4/12; 33.3% | 4/16; 25.0% |
| Methodological orientation and theory | 27/36; 75.0% | 4/16; 25.0% | Study size | 9/12; 75.0% | 7/16; 43.8% |
| Participant selection | | | Quantitative variables | 11/12; 91.7% | 8/16; 50.0% |
| Sampling | 31/36; 75.0% | 9/16; 56.3% | Statistical methods ^a | | |
| Method or approach | 30/36; 83.3% | 11/16; 68.8% | Describe all statistical methods | 10/12; 83.3% | 7/15; 46.7% |
| Sample size | 32/36; 88.9% | 10/16; 62.5% | Describe methods to examine subgroups | 6/7; 85.7% | 5/12; 41.7% |
| Non-participation | 12/36; 33.3% | 1/16; 6.3% | Explain how missing data addressed | 1/7; 14.3% | 3/16; 18.8% |
| Setting | | | Loss to follow up | 0/1; 0.0% | 1/3; 33.3% |
| Setting of data collection | 33/36; 91.7% | 13/16; 81.3% | Results | | |
| Presence of non-participants | 11/36; 30.6% | 0/16; 0.0% | Participants ^a | | |
| Description of sample | 26/36; 72.2% | 10/16; 62.5% | Numbers at each stage | 11/12; 91.7% | 7/16; 43.8% |
| Data collection | | | Reasons for non-participation | 4/6; 66.7% | 3/15; 20% |
| Interview guide | 26/35; 74.3% | 5/16; 31.3% | Descriptive data ^a | | |
| Repeat interviews | 5/35; 14.3% | 2/16; 12.5% | Participant characteristics | 8/12; 66.7% | 7/16; 43.8% |
| Audio/visual recording | 30/36; 83.3% | 4/16; 25.0% | Number of participants with missing data | 2/10; 20% | 2/16; 12.5% |
| Field notes | 11/34; 32.4% | 2/16; 12.5% | Outcome data ^a | 11/12; 91.7% | 13/14; 92.9% |
| Duration | 21/35; 60.0% | 2/16; 12.5% | Discussion | | |
| Data saturation | 7/36; 19.4% | 2/16; 12.5% | Key results | 12/12; 100% | 16/16; 100.0% |
| Transcripts returned | 6/35; 17.1% | 0/16; 0.0% | Limitations | 10/12; 83.3% | 11/16; 68.8% |

(Continues)

TABLE 2 (Continued)

| COREQ | Adherence qualitative studies | Adherence multi-methods studies | STROBE | Adherence quantitative studies | Adherence multi-methods studies |
|---------------------------------|-------------------------------|---------------------------------|-------------------|--------------------------------|---------------------------------|
| Domain 3: Analysis and findings | | | Interpretation | 11/12; 91.7% | 14/16; 87.5% |
| Data analysis | | | Generalisability | 4/12; 33.3% | 5/16; 31.3% |
| Number of data coders | 20/36; 55.6% | 3/16; 18.8% | Other information | | |
| Description of coding tree | 11/36; 30.6% | 1/16; 6.3% | Funding | 8/12; 66.7% | 13/16; 81.3% |
| Derivation of themes | 29/36; 80.6% | 6/16; 37.5% | | | |
| Software | 18/36; 50.0% | 3/16; 18.8% | Colour Code | | |
| Participant checking | 8/36; 22.2% | 0/16; 0.0% | 75.0%–100% | | |
| Reporting | | | 50.0%–74.9% | | |
| Quotations presented | 27/34; 79.4% | 5/16; 31.3% | 25.0%–49.9% | | |
| Data and findings consistent | 30/36; 83.3% | 6/16; 37.5% | 0.0%–24.9% | | |
| Clarity of major themes | 31/36; 86.1% | 5/16; 31.3% | | | |
| Clarity of minor themes | 15/34; 44.1% | 0/16; 0.0% | | | |

^aNot all items included—refer to Appendices S1 and S2.

Varied use of reporting guidance was seen within the included studies, with very few studies citing or using established reporting guidelines. In a number of articles, diagrammatic figures were used to provide a visual map of patients' journeys, and in others, written descriptions were relied on to document experiences of patients as they traversed health services and systems.

This review used two established reporting guidelines to evaluate quality of reporting, namely COREQ for qualitative studies and STROBE for quantitative observational studies (Tong et al., 2007; von Elm et al., 2008). In the absence of an appropriate reporting guideline for mixed-methods studies, both the COREQ and STROBE guidelines were also used to evaluate the reporting of the mixed method studies. The results of this evaluation suggest that the quality of reporting is problematic in this emerging field of research, with several gaps existing across all domains of established reporting guidelines.

The accurate and detailed reporting of research methods and results is critical if the research being described is to be trusted and useful (Altman & Moher, 2014; Wager & Kleinert, 2010). Two key principles of reporting research include the requirement for authors "to describe their methods clearly and unambiguously so that their findings can be confirmed by others", and that "researchers should follow applicable reporting guidelines...publications should provide sufficient detail to permit experiments to be repeated by other researchers" (Altman & Moher, 2014, p. 7).

With regards to the former principle, the reporting in the qualitative and mixed methods studies could have been more clearly articulated, particularly with the descriptions of the personal characteristics of the research team and the methods for data collection and data analysis. In relation to the second principle,

reporting guidelines that suit this emerging field of research may not appear to be obvious, however, there are guidelines that may be suitable for use and could have been considered by researchers. In the comparisons undertaken in this review between included articles and established reporting guidelines, COREQ and STROBE were used as they are reputable, recognizable and comprise domains for reporting research elements that largely match the research designs that were used in the included patient journey mapping projects.

Inadequate reporting of research projects to participants, the academic and the general public is not an issue that is limited to patient journey mapping, but rather a concern across the research landscape (Taylor, 2019). Principles of best practice in the conduct of research, such as transparency, reproducibility and trustworthiness, have been built into a plethora of reporting guidelines to facilitate best practice in reporting of research projects (Tong et al., 2007; von Elm et al., 2008; Wager & Kleinert, 2010). It is perhaps a reflection of the novelty of this research that articles included in this review did not all adhere to reporting guides and principles that align with selected methods. A general lack of awareness or education about the value of reporting guidelines and how to select an appropriate guideline for the research being undertaken may also be a contributing factor.

Despite concerns with the reporting of the included articles, many advantages of patient journey mapping approaches were demonstrated. Patient journey mapping afforded researchers and other stakeholders with opportunities to understand health navigation experiences from multiple vantage points, using observable and non-observable data provided by patients, relatives and health professionals (Cherif et al., 2020). Mapping also provided an avenue

for privileging the voice of people who come from populations who are, or are at risk of, marginalization or stigmatization or who had medical or psychiatric conditions that are stigmatized (Bearnot & Mitton, 2020; Lawrence et al., 2021; Roller et al., 2015). Research with and about communities who experience social exclusion or stigma is critically important in health settings to reduce marginalization and stigma, to increase engagement with health services and to design appropriate pathways to healthcare that are respectful, acceptable, evidence-based and effective (Millum et al., 2019). Patient journey mapping, when co-designed, co-led or undertaken in consultation with end-users appears to be an avenue of research that can lead to targeted action and health service reform that matches the needs of service users.

4.1 | Recommendations for future reporting of patient journey mapping research

Fundamentally, reporting guidelines provide a framework for adequately detailing the methods and results of research (Altman & Moher, 2014). Given the range of research methods used in this field of research, reporting guidelines specific to patient journey mapping may not be appropriate. However, the inconsistent, and often inadequate, reporting of journey mapping research needs to be improved, with authors adhering to principles of accurate, appropriate and comprehensive reporting (Altman & Moher, 2014). Our recommendation

for meeting reporting requirements is for authors to select an established guideline that most closely aligns with the research methods they are using. In this review, COREQ and STROBE were used as a benchmark, but other guidelines may be more appropriate for some studies. For example, the CREATE guidelines for assessing the quality of health research from an Indigenous perspective may be most appropriate when mapping journeys of people who are Aboriginal and/or Torres Strait Islander (Harfield et al., 2020). Other reporting guidelines can be found on the EQUATOR Networks' online repository of health research reporting guidelines (www.equator-network.org).

In addition to resources that can be located via the EQUATOR Network, some specific considerations for reporting patient journey mapping that have been identified through the process of reviewing articles included in this review can be categorized into the 'who, why, what, when, where and how' of the project as outlined in Table 3.

4.2 | Limitations and strengths

Limitations of this review largely relate to the scope of the search. This was limited to peer-reviewed articles, resulting in the absence of patient journey mapping projects that were conducted by organizations as part of quality improvement processes and that were not published on an academic platform. Articles published in languages other than English were also not captured. The terminology used

TABLE 3 Prompt questions to consider when reporting patient journey mapping research

| Domain | Prompt questions |
|--------|---|
| Who | <ul style="list-style-type: none"> Who is undertaking the research? Who has been consulted or involved in designing the project? Who are the target population? Who are the participants? Whose voice(s) will be privileged in the reporting of the project? Who is involved in the analysis and interpretation of the results? Who is funding the project? (if funders involved, influence and involvement to be acknowledged) |
| Why | <ul style="list-style-type: none"> Why is patient journey mapping being undertaken? Why is the selected population being targeted? |
| What | <ul style="list-style-type: none"> What methods are being used to recruit participants? What methods are being used to map patient journeys? What timeframe is being captured? What are the results of the project? What inferences or conclusions can be drawn from these results? What reporting guidelines will inform the reporting of the project? |
| When | <ul style="list-style-type: none"> When is the patient journey being mapped? |
| Where | <ul style="list-style-type: none"> Where is the patient journey mapping occurring? |
| How | <ul style="list-style-type: none"> How have end-users and/or stakeholders been consulted in or engaged with the design, conduct and reporting of the project? How does this mapping address the research question or clinical problem that has been identified? How are results being interpreted? How are results being confirmed with participants? How do the results compare with other data relating to the targeted patient population? How will the results of the project be translated into practice (if appropriate)? |

to determine inclusion criteria may also have led to the omission of research that is effectively patient journey mapping that goes by another name.

Strengths of the review include the rigorous and transparent approach taken to select relevant articles, and the reporting of the review, conducted in accordance with the PRISMA-ScR guidelines (Tricco et al., 2018). Strengths also lie in the collaboration of a multi-disciplinary team of reviewers, comprising clinician researchers who have experience with designing and implementing patient journey mapping projects, academics with expertise in primary and secondary methodology and an academic librarian. The multiple perspectives, expertise and experience of reviewers has contributed to a detailed overview of the current landscape of patient journey mapping and the development of recommendations for future reporting of these projects.

5 | CONCLUSION

Health service reform is a continuous process, and one that has rapidly evolved with advances in health technology, patient tracking capabilities, diversity of services and evidence-based practice research. Patient experiences of health services are increasingly recognized as vital in the process of system improvement and need to be considered in the evolution of health service delivery. Mapping patients' journeys as they traverse health services and systems is a research approach for capturing patient experiences that is growing in popularity. These projects are providing clarity on the personal experiences of patients and their family members as they move through complex health systems at times when they are experiencing acute or chronic illnesses. As journeys are being mapped, barriers, enablers and gaps in service delivery are being identified and reported from a patient-centred perspective. Whilst this is an exciting time for the person-centred care movement, there are significant gaps and flaws in the reporting of many of these projects that hinder transparency and replicability. There are no current reporting guidelines specific to patient journey mapping, and due to the various methodological approaches, a one-size-fits-all guideline for this type of research may not be feasible. Recommendations for future journey mapping projects have been discussed to improve reporting and guide future research.

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All listed authors have made a substantial contribution to this review and have been involved in drafting, revising and critically reviewing this manuscript. All authors give final approval of the version to be published and agree to be accountable for all aspects of the work.

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There are no conflicts of interest to declare.

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No patient or public contribution due to nature of manuscript. This is a review paper, and all contributing individuals are listed as authors.

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