

Patient journey mapping: emerging methods for understanding and improving patient experiences of health systems and services

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Patient journey mapping is an emerging field of research that uses various methods to map and report evidence relating to patient experiences and interactions with healthcare providers, services, and systems. This research often involves the development of visual, narrative, and descriptive maps or tables, which describe patient journeys and transitions into, through, and out of health services. This methods corner paper presents an overview of how patient journey mapping has been conducted within the health sector, providing cardiovascular examples. It introduces six key steps for conducting patient journey mapping and describes the opportunities and benefits of using patient journey mapping and future implications of using this approach.

Keywords Methods • Patient experiences • Patient journey mapping

Learning objectives

- Acquire an understanding of patient journey mapping and the methods and steps employed.
- Examine practical and clinical examples in which patient journey mapping has been adopted in cardiac care to explore the perspectives and experiences of patients, family members, and healthcare professionals.

Introduction

Quality and safety guidelines in healthcare services are increasingly encouraging and mandating engagement of patients, clients, and consumers in partnerships.¹ The aim of many of these partnerships is to consider how health services can be improved, in relation to accessibility, service delivery, discharge, and referral.^{2,3} Patient journey mapping is a research approach increasingly being adopted to explore these experiences in healthcare.³

Most recently, patient journey mapping has been defined 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.³

It is an emerging field with a clear patient-centred focus, as opposed to studies that track patient flow, demand, and movement. As a general principle, patient journey mapping projects will provide evidence of patient perspectives and highlight experiences through the patient and consumer lens.

Patient journey mapping can provide significant insights that enable responsive and context-specific strategies for improving patient healthcare experiences and outcomes to be designed and implemented.^{3–6} These improvements can occur at the individual patient, model of care, and/or health system level. As with other emerging methodologies, questions have been raised regarding exactly how patient journey mapping projects can best be designed, conducted, and reported.³

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In this methods paper, we provide an overview of patient journey mapping as an emergent field of research, including reasons that mapping patient journeys might be considered, methods that can be adopted, the principles that can guide patient journey mapping data collection and analysis, and considerations for reporting findings and recognizing the implications of findings. We summarize and draw on five cardiovascular patient journey mapping projects, as examples.

Why patient journey mapping?

One of the most appealing elements of the patient journey mapping field of research is its focus on illuminating the lived experiences of patients and/or their family members, and the health professionals caring for them, methodically and purposefully. Patient journey mapping has an ability to provide detailed information about patient experiences, gaps in health services, and barriers and facilitators for access to health services. This information can be used independently, or alongside information from larger data sets, to adapt and improve models of care relevant to the population that is being investigated.³

To date, the most frequent reason for adopting this approach is to inform health service redesign and improvement.^{3,7,8} Other reasons have included: (i) to develop a deeper understanding of a person's entire journey through health systems;³ (ii) to identify delays in diagnosis or treatment (often described as bottlenecks);⁹ (iii) to identify gaps in care and unmet needs; (iv) to evaluate continuity of care across health services and regions;¹⁰ (v) to understand and evaluate the comprehensiveness of care;¹¹ (vi) to understand how people are navigating health systems and services; and (vii) to compare patient experiences with practice guidelines and standards of care.

How is patient journey mapping conducted?

Patient journey mapping approaches frequently use six broad steps that help facilitate the preparation and execution of research projects. These are outlined in the *Central illustration*. We acknowledge that not all patient journey mapping approaches will follow the order outlined in the *Central illustration*, but all steps need to be considered at some point throughout each project to ensure that research is undertaken rigorously, appropriately, and in alignment with best practice research principles.

Five cardiovascular patient journey mapping research examples have been included in *Figure 1*,^{12–16} to provide specific context and illustrate these six steps. For each of these examples, the problem or gap in practice or research, consultation processes, research question or aim, type of mapping, methods, and reporting of findings have been extracted. Each of these steps is then discussed, using these cardiovascular examples.

Define the problem or gap in practice or research

Developing an understanding of a problem or gap in practice is essential for facilitating the design and development of quality research projects. In the examples outlined in *Figure 1*, it is evident that clinical variation or system gaps have been explored using patient journey mapping. In the first two examples, populations known to have health vulnerabilities were explored—in Example 1, this related to comorbid substance use and physical illness,¹³ and in Example 2, this related to geographical location.¹³ Broader systems and societal gaps were explored in Examples 4 and 5, respectively,^{15,16} and in Example 3, a new technologically driven solution for an existing model of care was tested for its ability to improve patient outcomes relating to hypertension.¹⁴

Consultation, engagement, and partnership

Ideally, consultation with healthcare providers and/or patients would occur when the problem or gap in practice or research is being defined. This is a key principle of co-designed research.¹⁷ Numerous existing frameworks for supporting patient involvement in research have been designed and were recently documented and explored in a systematic review by Greenhalgh et al.¹⁸ While none of the five example studies included this step in the initial phase of the project, it is increasingly being undertaken in patient partnership projects internationally (e.g. in renal care).¹⁷ If not in the project conceptualization phase, consultation may occur during the data collection or analysis phase, as demonstrated in Example 3, where a care pathway was co-created with participants.¹⁴ We refer readers to Greenhalgh's systematic review as a starting point for considering suitable frameworks for engaging participants in consultation, partnership, and co-design of patient journey mapping projects.¹⁸

Design the research question/project aim

Conducting patient journey mapping research requires a thoughtful and systematic approach to adequately capture the complexity of the healthcare experience. First, the research objectives and questions should be clearly defined. Aspects of the patient journey that will be explored need to be identified. Then, a robust approach must be developed, taking into account whether qualitative, quantitative, or mixed methods are more appropriate for the objectives of the study.

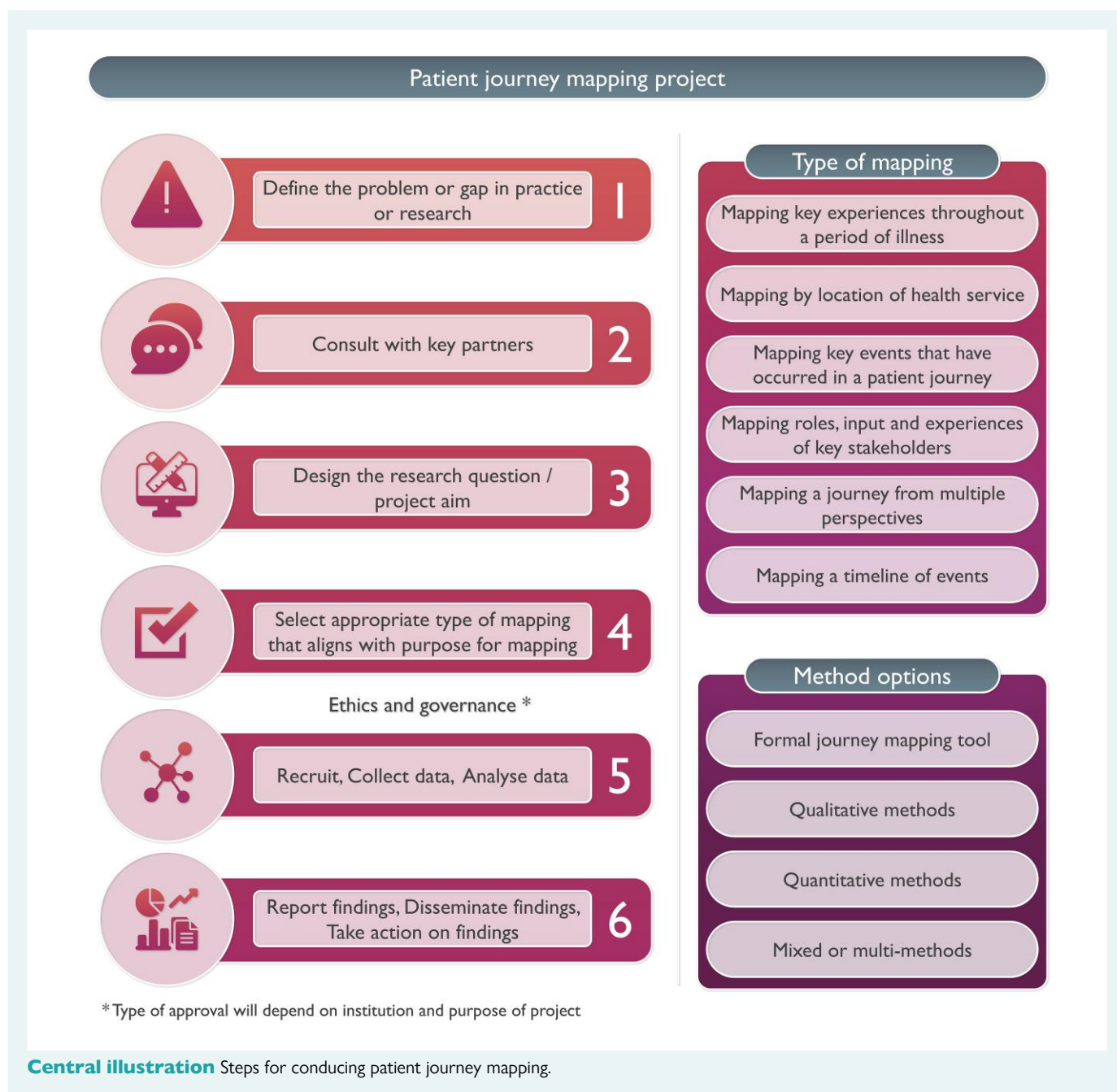
For example, in the cardiac examples in *Figure 1*, the broad aims included mapping existing pathways through health services where there were known problems^{12,13,15,16} and documenting the co-creation of a new care pathway using quantitative, qualitative, or mixed methods.¹⁴

In traditional studies, questions that might be addressed in the area of patient movement in health systems include data collected through the health systems databases, such as 'What is the length of stay for x population', or 'What is the door to balloon time in this hospital?' In contrast, patient mapping journey studies will approach asking questions about experiences that require data from patients and their family members, e.g. 'What is the impact on you of your length of stay?', 'What was your experience in being assessed and undergoing treatment for your chest pain?', 'What was your experience supporting this patient during their cardiac admission and discharge?'

Select appropriate type of mapping

The methods chosen for mapping need to align with the identified purpose for mapping and the aim or question that was designed in Step 3. A range of research methods have been used in patient journey mapping projects involving various qualitative, quantitative, and mixed methods techniques and tools.⁴ Some approaches use traditional forms of data collection, such as short-form and long-form patient interviews, focus groups, and direct patient observations.^{18,19} Other approaches use patient journey mapping tools, designed and used with specific cultural groups, such as First Nations peoples using artwork, paintings, sand trays, and photovoice.^{17,20} In the cardiovascular examples presented in *Figure 1*, both qualitative and quantitative methods have been used, with interviews, patient record reviews, and observational techniques adopted to map patient journeys.

In a recent scoping review investigating patient journey mapping across all health care settings and specialities, six types of patient journey mapping were identified.³ These included (i) mapping key experiences throughout a period of illness; (ii) mapping by location of health service; (iii) mapping by events that occurred throughout a period of illness; (iv) mapping roles, input, and experiences of key stakeholders throughout patient journeys; (v) mapping a journey from multiple perspectives; and (vi) mapping a timeline of events.³









Combinations or variations of these may be used in cardiovascular settings in the future, depending on the research question, and the reasons mapping is being undertaken.

Recruit, collect data, and analyse data

The majority of health-focused patient journey mapping projects published to date have recruited <50 participants.³ Projects with fewer participants tend to be qualitative in nature. In the cardiovascular examples provided in *Figure 1*, participant numbers range from 7¹⁴ to 260.¹⁵ The 3 studies with <20 participants were qualitative,^{12,14,16} and the 2 with 95 and 260 participants, respectively, were quantitative.^{13,15} As seen in these and wider patient journey mapping examples,³ participants may include patients, relatives, carers, healthcare professionals,

or other stakeholders, as required, to meet the study objectives. These different participant perspectives may be analysed within each participant group and/or across the wider cohort to provide insights into experiences, and the contextual factors that shape these experiences.

The approach chosen for data collection and analysis will vary and depends on the research question. What differentiates data analysis in patient journey mapping studies from other qualitative or quantitative studies is the focus on describing, defining, or exploring the journey from a patient's, rather than a health service, perspective. Dimensions that may, therefore, be highlighted in the analysis include timing of service access, duration of delays to service access, physical location of services relative to a patient's home, comparison of care received vs. benchmarked care, placing focus on the patient perspective.

	 1) Problem or gap in practice or research	 2) Consultation & key partners	 3) Question/Project aim	 4) Method for mapping	 5) Recruitment, data collection & analysis	 6) Reporting, dissemination & action taken*
Example 1 Bearnöt & Mitton, Mitton, 2020	Care for patients with opioid use disorder (OUD)-associated endocarditis is complex, fragmented & costly. Outcomes for people with these comorbidities are very poor and optimal care is not well understood.	Researcher driven. Consultation with key partners not reported.	To capture common trajectories and patterns of care for people with Opioid Use Disorder (OUD)-associated endocarditis.	Qualitative Secondary analysis of interview transcripts	Outpatient (n=5) and inpatient (n=5) participants Extraction of data relating to care experiences, dates, care settings & care plans. Locations & time plotted on individual graphs with colour blocking and labeling for detail.	Journal publication
Example 2 Cunnington, Plummer, McDiarmid & McComb, 2008	Geographic variations in permanent pace maker (PPM) implantation rates exist. Reasons for this are not clear, but could relate to local factors, including prior to referral may be important.	Researcher driven. Consultation with key partners not reported.	To investigate delays to permanent pacemaker PPM implantation and their causes.	Quantitative Prospective observational Patient record review	Patients (n=95) Patient records reviewed over 3 months to determine timings of symptom onset, hospital contact, documented pacing indication, referral and PPM insertion. Tables, graphs and text used to describe patient journeys and delays.	Journal publication
Example 3 Geerse, van Slobbe, Van Triet & Simonse, 2019	New technology can be embedded into new models of care that enable shared decision making and patient participation in their care through better access to data? How can this be designed for people at high risk for hypertension?	Researcher driven. Participants co-designed care pathways as part of the research design - this was in the data collection and analysis phase of the project.	To design a care pathway for monitoring the blood pressure of at-risk patients, in order to increase eHealth implementation in secondary preventative care	Qualitative Interviews with participants Visual mapping toolkit designed for project to co-create a Care Pathway with participants	Patients (n=3) and healthcare workers (n=4) Visual tool kit was used with participants to co-design a Care Pathway for managing data relating to blood pressure monitoring at home. Data were triangulated (interviews, maps and other documentation).	Journal publication Project enabled eHealth devices to be embedded into the service
Example 4 Leveau, Hammoudi, Berthelot, Belmin, Assayag & Cohen, 2017	There is a high system burden in France related to hospitalisation and re-hospitalisation of patients with heart failure. The reasons for this are not well understood.	Researcher driven. Consultation with key partners not reported.	To evaluate patients' journeys before and after hospitalisation for decompensated heart failure.	Quantitative Prospective observational	Cardiology patients (n=197) Geriatric patients (n=63) Case note audit and follow-up interviews with participants at 3months post admission Description of patients journeys and complementary figure with data relating to referrals presented.	Journal publication
Example 5 Naheed, Haldane, Jaraf, Chakma & Legido-Quigley, 2018	Public health measures being implemented in Bangladesh to reduce risk factors that lead to hypertension. Experiential evidence needed to complement data being collected in other related projects.	Researcher driven. Consultation with key partners not reported.	To explore patient pathways to care, as well as knowledge of, adherence to, and adherence to, hypertension care.	Qualitative Interviews	Patients (n=20) In-depth interviews Inductive, thematic analysis of data. Themes presented with figure that presents an overview of patient pathways	Journal publication

*Further dissemination of findings, and actions taken as a result of findings, were not investigated for this article

Figure 1 Examples of patient journey mapping projects.

The mapping of individual patient journeys may take place during data collection with the use of mapping templates (tables, diagrams, and figures) and/or later in the analysis phase with the use of inductive or deductive analysis, mapping tables, or frameworks. These have been characterized and visually represented in a recent scoping review.³ Representations of patient journeys can also be constructed through a secondary analysis of previously collected data. In these instances, qualitative data (i.e. interviews and focus group transcripts) have been re-analysed to understand whether a patient journey narrative can be extracted and reported. Undertaking these projects triggers a new research cycle involving the six steps outlined in the *Central illustration*. The difference in these instances is that the data are already collected for Step 5.

Report findings, disseminate findings, and take action on findings

A standardized, formal reporting guideline for patient journey mapping research does not currently exist. As argued in Davies *et al.*,³ a dedicated reporting guide for patient journey mapping would be ill-advised, given the diversity of approaches and methods that have been adopted in this field. Our recommendation is for projects to be reported in accordance with formal guidelines that best align with the research methods that have been adopted. For example, COREQ may be used for patient journey mapping where qualitative methods have been used.²⁰ STROBE may be used for patient journey mapping where quantitative methods have been used.²¹ Whichever methods have been adopted, reporting of projects should be transparent, rigorous, and

contain enough detail to the extent that the principles of transparency, trustworthiness, and reproducibility are upheld.³

Dissemination of research findings needs to include the research, healthcare, and broader communities. Dissemination methods may include academic publications, conference presentations, and communication with relevant stakeholders including healthcare professionals, policy-makers, and patient advocacy groups. Based on the findings and identified insights, stakeholders can collaboratively design and implement interventions, programmes, or improvements in healthcare delivery that overcome the identified challenges directly and address and improve the overall patient experience. This cyclical process can hopefully produce research that not only informs but also leads to tangible improvements in healthcare practice and policy.

Use of technology in patient journey mapping

Patient journey mapping is typically a hands-on process, relying on surveys, interviews, and observational research. The technology that supports this research has, to date, included word processing software, and data analysis packages, such as NVivo, SPSS, and Stata. With the advent of more sophisticated technological tools, such as electronic health records, data analytics programmes, and patient tracking systems, healthcare providers and researchers can potentially use this technology to complement and enhance patient journey mapping research.^{19,20,22} There are existing examples where technology has been harnessed in patient journey. Lee *et al.* used patient journey mapping to verify disease

treatment data from the perspective of the patient, and then the authors developed a mobile prototype that organizes and visualizes personal health information according to the patient-centred journey map. They used a visualization approach for analysing medical information in personal health management and examined the medical information representation of seven mobile health apps that were used by patients and individuals. The apps provide easy access to patient health information; they primarily import data from the hospital database, without the need for patients to create their own medical records and information.²³

In another example, Wauben *et al.*¹⁹ used radio frequency identification technology (a wireless system that is able to track a patient journey), as a component of their patient journey mapping project, to track surgical day care patients to increase patient flow, reduce wait times, and improve patient and staff satisfaction.

Future implications for patient journey mapping

Patient journey mapping has emerged as a valuable research methodology in healthcare, providing a comprehensive and patient-centric approach to understanding the entire spectrum of a patient's experience within the healthcare system. Future implications of this methodology are promising, particularly for transforming and redesigning healthcare delivery and improving patient outcomes. The impact may be most profound in the following key areas:

- **Personalized, patient-centred care:** The methodology allows healthcare providers to gain deep insights into individual patient experiences. This information can be leveraged to deliver personalized, patient-centric care, based on the needs, values, and preferences of each patient, and aligned with guideline recommendations, healthcare professionals can tailor interventions and treatment plans to optimize patient and clinical outcomes.
- **Enhanced communication, collaboration, and co-design:** Mapping patient interactions with health professionals and journeys within and across health services enables specific gaps in communication and collaboration to be highlighted and potentially informs responsive strategies for improvement. Ideally, these strategies would be co-designed with patients and health professionals, leading to improved care coordination and healthcare experience and outcomes.
- **Patient engagement and empowerment:** When patients are invited to share their health journey experiences, and see visual or written representations of their journeys, they may come to understand their own health situation more deeply. Potentially, this may lead to increased health literacy, renewed adherence to treatment plans, and/or self-management of chronic conditions such as cardiovascular disease. Given these benefits, we recommend that patients be provided with the findings of research and quality improvement projects with which they are involved, to close the loop, and to ensure that the findings are appropriately disseminated.

Conclusions

Patient journey mapping is an emerging field of research. Methods used in patient journey mapping projects have varied quite significantly; however, there are common research processes that can be followed to produce high-quality, insightful, and valuable research outputs. Insights gained from patient journey mapping can facilitate the identification of areas for enhancement within healthcare systems and inform the design of patient-centric solutions that prioritize the quality of care and patient outcomes, and patient satisfaction. Using patient journey mapping research can enable healthcare providers to forge stronger

patient-provider relationships and co-design improved health service quality, patient experiences, and outcomes.

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