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Integrated Patient Journey Mapping: A Sensemaking Approach for Health Information Systems Research

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Abstract

Health Information Systems (HIS) can help reimagine medical care pathways by using digital technologies to meet diverse patient needs. This is nevertheless a challenging prospect which is exacerbated by the conflicting interests of different stakeholders such as patient advocacy groups, allied health professionals, and policymakers. In this chapter, we present Integrated Patient Journey Mapping (IPJM) as an approach for sensemaking in HIS redesign processes and present a canvas for HIS researchers to constructively engage stakeholders in reimagining the status quo. We explain the scope and utility of IPJM, before outlining methodological considerations in the form of data collection and analysis. Recommended approaches for reporting results are then described including the use of storytelling techniques to weave together outputs from facilitated workshops and 'think-aloud' activities. The chapter concludes by presenting exemplars where journey mapping has inspired healthcare redesign in areas such as mental health services, head and neck cancer care, and post-partum care.

Keywords

Co-design, health care reform, mental health, patient experience, sensemaking

Background

The healthcare sector is a complex and evolving ecosystem with unbridled levels of change. The World Health Organization (2022) warned that current healthcare investment policies and practices in many member states are unsustainable, with a high cost to vulnerable groups including the socioeconomically disadvantaged and elderly. Crucially, inequity in accessing healthcare occurs both across nations and within nations, with some social groups being structurally disadvantaged (Bambra, 2022). To address this, the World Health Organization (2022) called for an urgent need to investigate

new medical care pathways which reduce health disparity and raise the quality of life across both developed and developing nations. Health Information Systems (HIS) play an essential role in realising this goal by transforming patient-clinician interactions across healthcare settings through digital technologies (McCarthy et al., 2022). For instance, connected health devices can help reimagine healthcare pathways, creating new touchpoints that enable the remote monitoring of patient wellbeing (Kvedar et al., 2014). However, this requires intensive design work to make sense of changing demands and prepare for the future of healthcare by analysing problem-solution couplings in the present.

In design work, all problems can be categorized, at a simplistic level, as either ‘tame’ or ‘wicked’ (cf. Rittel and Weber, 1973). Tame problems are well-structured which means that a linear problem-solving process is sufficient to produce a workable solution in an acceptable time frame, as the resulting solution can be objectively judged as either right or wrong (Conklin, 2006). On the other hand, wicked problems represent ill-structured scenarios involving many stakeholders who have incomplete and contradictory views on the problem, leading to cases where the resulting solution can never be judged strictly right or wrong (Conklin, 2006). Many problems that appear ‘tame’ at face value can be revealed as ‘wicked’ once they are tackled. For example, the construction of a bridge by experienced engineers may appear tame at first but can end up being wicked due to social complexity in the form of contradictory views from planners, environmentalists, public representatives, members of the public, and business owners in the surrounding area.

Likewise, design problems in the healthcare sector are often ‘wicked’ in nature due to the social complexity inherent in HIS research. In these cases, HIS design teams have no alternative but to move beyond a linear problem-solving process to deeply engage with multiple stakeholders to understand their diverse perspectives (McCarthy et al., 2023). This involves trade-offs and ‘satisficing’ (cf. Simon, 1996) to deliver HIS solutions that aim to satisfy the diverse needs of all involved. Stakeholders are tasked with working towards ‘the common good’, a notion sometimes elusive in real-life contexts. The importance of design tools in supporting these efforts cannot be underestimated as it provides an object or medium (either physical or digital) for stakeholder groups to explore, produce, and express one or more design ideas (Antunes et al., 2020).

In this chapter, we present Integrated Patient Journey Mapping (McCarthy et al., 2016, 2020) as a design tool and methodology for HIS research and sensemaking in ‘wicked’ healthcare contexts. We discuss Integrated Patient Journey Mapping as a ‘shared space’ for collaboration between individuals from diverse backgrounds (disciplines, organisations, cultures) who may have no prior experience of working together. Under such circumstances, we explain how Integrated Patient Journey Mapping can offer a valuable design tool for diverse stakeholders to give *“tangible form to concepts as a way of manifesting, developing and exploring them”* (Selin et al., 2015, p. 10). The processes described in this chapter allow design options to be visualized, handled, and critiqued by interested others. This might in turn prompt discussion on representations of design options that may be non-functional (e.g., a diagram of a HIS architecture), semi-functional (e.g., a mock-up of a HIS user interface), or functional (e.g., a coded component of the HIS).

Many scholars refer to this interactionist approach to design as a process of ‘sensemaking’ (Jenkin et al., 2019; Weick et al., 2005). Sensemaking is the search for meaning that stakeholders undertake whenever the current state of a phenomenon is perceived to deviate from its expected state (Zamani et al., 2021). This can essentially be thought of as *“a way station on the road to a consensually*

constructed, coordinated system of action" (Taylor et al., 2000 p. 275). Those partaking in the process interpret and reflect on phenomena to make individual and collective sense and in turn enact this sense back into the world to make it more orderly (Seidel et al., 2018; Weick et al., 2005). Individual and collective meanings are embodied in thoughts, formalized as language, and eventually as actions (Gioia and Chittipeddia 1991; Sandberg and Tsoukas, 2015). This results from being *"thrown into an ongoing, unknowable, unpredictable streaming of experience in search of answers to the question, 'what's the story?'"* (Weick et al., 2005, p. 410). While sensemaking is primarily concerned with reaching consensual understanding, the related process of sensegiving (Gioia and Chittipeddia, 1991) is concerned with influencing the understanding of others and communicating ideas. The aim is to persuade others about a preferred organisational reality which in turn provides a 'springboard for action' (Jenkin et al., 2019).

We present Integrated Patient Journey Mapping as an approach for sensemaking in complex HIS redesign processes, offering a canvas for HIS researchers to constructively engage stakeholders when reimagining the status quo. Discussions centre on how Integrated Patient Journey Mapping can support sensemaking and sensegiving by enabling stakeholders to continually redraft a new medical care pathway *"so that it becomes more comprehensive, incorporates more of the observed data and is more resilient in the face of criticism"* (Weick et al., 2005, p. 415). The value of storytelling for reporting outputs from Integrated Patient Journey Mapping is discussed. Storytelling can centre on the experiences of patients, clinicians, carers, and affected directly or indirectly by the healthcare system (McCarthy et al., 2016, 2020). This embraces the natural capability of humans to make sense of the world through composing stories. Storytelling must always involve both a teller and a listener (Hermans, 2004). The teller and listener may be two or more separate people (e.g., the patient and clinician) but may also be one person (e.g., the HIS researcher) who is trying to make sense of the world. When telling a story, the teller is at the same time listening to himself or herself, noticing, recording, and evaluating what is being said at a particular moment in time (Hermans, 2004).

The chapter sets out the value of Integrated Patient Journey Mapping for sensemaking when designing solutions to wicked problems in healthcare. We next elaborate on the purpose of Integrated Patient Journey Mapping as a method for sensemaking in HIS research.

Purpose

In his seminal work, *The Sciences of the Artificial*, Herbert Simon (1996, p. 130) suggests that *"everyone designs who devises courses of action aimed at changing existing situations into preferred ones"*. Design is therefore seen as being concerned *"not with the necessary but with the contingent – not with how things are but with how they might be"* (Simon, 1996, p. 130).

In the spirit of Simon (1996), the objectives of Integrated Patient Journey Mapping are to (i) model and represent existing medical care pathways, (ii) design new pathways that aim to solve organisational problems and (iii) analyse their differences, concentrating on the positive impacts of new pathways. Integrated Patient Journey Mapping's utility centres on helping stakeholders gain better approximations of the current reality (present continuity and change-based sensemaking) while also allowing them to explore different design options for future realities (prospective sensemaking) (Dawson and Skyes, 2019). This can enable a better understanding of the real world, ensuring alignment with existing systems through testing mental models against reality (Tan et al., 2020).

We next provide a brief overview of the template design to further outline the scope and utility of Integrated Patient Journey Mapping for sensemaking in HIS research. A base template of the Integrated Patient Journey Mapping tool is presented in Figure 1 below, with more complete descriptions of the design available in McCarthy et al. (2016; 2020). To summarise, the template consists of ‘swim lanes’ – aspects of the patient journey and changes over time – which will be populated by invited stakeholder groups. The template serves as a ‘boilerplate’ guide for stakeholders to explore key aspects of the medical care pathway and was designed for adaptation across different pathologies and medical contexts. It can be easily repurposed to save time and effort when producing multiple interpretations of the same setting.


	Patient Journey Map							
	Timeline	Week n	Week n+1	Week n+2	Week n+3	Week n+4	Week n+5	Week n+6
Name Age: Occupation: Family and marital status: Risk profile: Summary of journey:	Emotional Journey							
	Physical Journey							
	Device Touch Points							
	Encounters							

Figure 1. Base Template of the Integrated Patient Journey Map (McCarthy et al., 2016)

Healthcare information systems can broadly be conceptualised as the convergence of four elements: *people*, *processes*, *technology*, and *data* (cf. Twomey et al., 2020). In the healthcare sector, *people* can refer to doctors, clinicians, or other medical professionals involved in medical decision-making, as well as patients and carers. *Processes* then centre on medical engagements involving the people, including appointments and in-patient / out-patient visits, while *technology* refers to the HIS platforms and connected IT devices which are used in the processes, including the monitoring of patient wellbeing and diagnosis of medical conditions. Lastly, *data* relates to readings (e.g., vital signs) captured through the HIS during relevant healthcare encounters. The Integrated Patient Journey Map considers all four elements of IS which in the template (see Figure 1) are represented as the “Emotional Journey” of

patients (*people*), their “Physical Journey” through the healthcare system (*processes*), HIS “Device Touchpoints” (*technology*), and hospital / GP “Encounters” (*data*).

The base Integrated Patient Journey Mapping template provides a ‘blank canvas’ which is adapted to the HIS context under investigation. There are three key activities involved in completing the base template: *exploration*, *connection*, and *imagination*.

Exploration first involves the mapping of existing medical care pathways based on primary data (e.g., interviews with patients’ or doctors’ experiences) or secondary data (e.g., published reports, clinical guidelines and protocols). This centres on the status quo and allows the HIS researchers to capture first impressions of the patient’s journey which will later be refined through continuous engagement with different stakeholder groups. During exploration, stakeholders aim to map out the boundaries of the healthcare system and identify Relevant components such as different healthcare actors (*people*), appointments (*process*), medical devices (*technology*), and readings (*data*). Stakeholders aim to temporally break the medical care pathway into distinct parts which can then be summarised to provide a picture of the patient journey as a whole over a specified timeline.

The *connection* activity then aims to identify potential relationships between the emotional journey (people), physical journey (process), device touchpoints (technology), and encounters (data). Relationships can include actions and reactions, represented as a line arrow (→), or mutual effects on two or more things, represented as a double line arrow (↔). This could, for instance, represent a series of consecutive appointments and steps while a patient undergoes treatment. The patient may initially go for a consultation to diagnose their condition, followed by (→) a second appointment where they discuss options for medical intervention. Mutual effects may also occur where the patient may revert to another consultant to ask for a second opinion, or where they undergo two or more treatments at the same time (↔).

The final activity, *imagination*, aims to capture two crucial types of knowledge: context and emotion. Context aims to consider that multiple versions of the same journey may exist, and the same system can be looked at from different perspectives and points and view (McCarthy et al., 2023). This activity can also reveal new medical care pathways which may not currently exist but are essential to cater to the future needs of certain patient groups.

Personas (LeRouge et al., 2013; Maguire, 2001) can be created to represent different types of patients, fictional or real, who share similar backgrounds e.g., health conditions, medical histories, risk factors, or child-minding responsibilities. Emotional considerations then centre on patients’ subjective feelings about their experience of their journey through the healthcare system. A curved arrow (/) can be used to indicate the patients’ emotions over time which may pass from a peak of ‘elation’ to a trough of ‘despair’ at different points. For instance, a patient may experience despair when they initially are diagnosed with a condition but feel elation later when a treatment plan is created.

Our approach also aims to recognise inherent social complexity in understanding these different journeys, especially in the context of wicked problems. In such situations, different stakeholders are likely to arrive at different judgements of the pathway and create individual interpretations. In light of these challenges, some scholars (Barrow et al. 2000; Guba et al. 1989; livari 1988; Smithson et al. 1998; Symons 1991) are moved to argue that evaluations should instead adopt an ‘interactionist’ approach. This engages various stakeholders in collective dialogue to understand their interests and perspectives when making a judgement on the value of an artefact (McCarthy et al., 2023). In advance

of performing the evaluation, Avgerou (1995) advocates for extensive stakeholder participation in a dialectic process to identify how an artefact ought to be evaluated and the criteria against which it should be judged. Petter et al. (2010) also refer to this as a ‘soft’ approach to design in that it gives greater priority to human factors and the context under study. The next section outlines how to engage different stakeholders using a variety of data collection and data analysis techniques.

Data Management

To collect the data necessary for completing an integrated patient journey map, the HIS researcher must begin by identifying and reaching out to relevant stakeholders and scheduling dedicated times at which they will engage in discussion around the design of current and future medical care pathways. The identification of key stakeholders is a crucial stage in design (cf. McCarthy et al., 2020) to ensure that the process engages those who are directly or indirectly affected by the change. The exclusion of one or more of these groups can lead to the creation of incomplete or ‘biased’ maps where certain ‘voices’ are dominant, while others are absent. If certain stakeholder groups are unavailable, studies show that it is still possible to create personas (see Figure 2) which will represent the voices of those who may not be present in person (Conboy, 2021; McCarthy et al., 2020). Role-playing is one effective way of building empathy with absent stakeholders or otherwise marginalised groups who would otherwise be missing from the conversation (Damodaran, 2017).


 <p>‘Breda’ (Fictional persona)</p>	<p>Bio</p> <p><u>Age:</u> 38</p> <p><u>Occupation:</u> Pharmacist</p> <p><u>Status:</u> Married with one child.</p> <p><u>Personality:</u> Introvert who is prone to bouts of anxiety.</p>	<p>Medical History</p> <p><u>Risk profile:</u> Brenda is at high risk of hypertension during pregnancy. She has type II diabetes and it has been 10 years since her last pregnancy.</p> <p><u>Summary:</u> Brenda is diagnosed with severe gestational hypertension at week 24 and as a result, she is admitted to the hospital. However, as an inpatient, her BP reading quickly stabilises and her diagnosis is changed to white-coat hypertension. Therefore, she is discharged.</p>
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Figure 2. The persona of an Expectant Mother Suffering from White-coat Hypertension

The HIS researcher must also seek to involve those with the decision-making power to affect change. This helps ensure that the redesign efforts win support and gain legitimacy from the involvement of senior managers with the resources necessary to bring ‘ideas to life’. While senior involvement is important, it also requires an awareness of the potential for ‘groupthink’ (Janis, 1972) where the social pressure towards consensus, particularly in the presence of senior managers, can limit the ability to evaluate alternatives and make effective decisions. The aim should therefore be to balance diverse stakeholder voices to ensure none are squeezed out.

Once the relevant stakeholders have been recruited, the HIS researcher must then decide whether to engage in individual or collective forms of interaction during journey mapping.

Collective interactions can take place through scheduled workshops or focus groups where several stakeholders are invited into a shared room (physical or virtual) to discuss different parts of the medical care pathway from their perspectives. They are then invited to reflect on the contributions of their peers and add their points through deliberation. Facilitation is crucial to ensure that everyone is provided with ‘airtime’ to share their thoughts. The HIS researcher can moderate discussions and encourage stakeholders to expand on relevant points or direct attention to the next point. This can be supported through exercises such as ‘think-pair-share’ (see Figure 3) in which stakeholders collectively brainstorm, record their ideas on post-it notes, and visualise responses on the template. Post-it notes allow for the tactile manipulation of objects in the patient journey, allowing the stakeholder to add, move, and remove them as required. The HIS researcher can also record observations to capture points which may be implied in conversations but left unsaid, confirming understandings by vocalising these points for the stakeholders to clarify. The main advantage of collective interactions can offer a broader perspective on the theme studied by engaging a wider range of perspectives (Morgan, 1996).

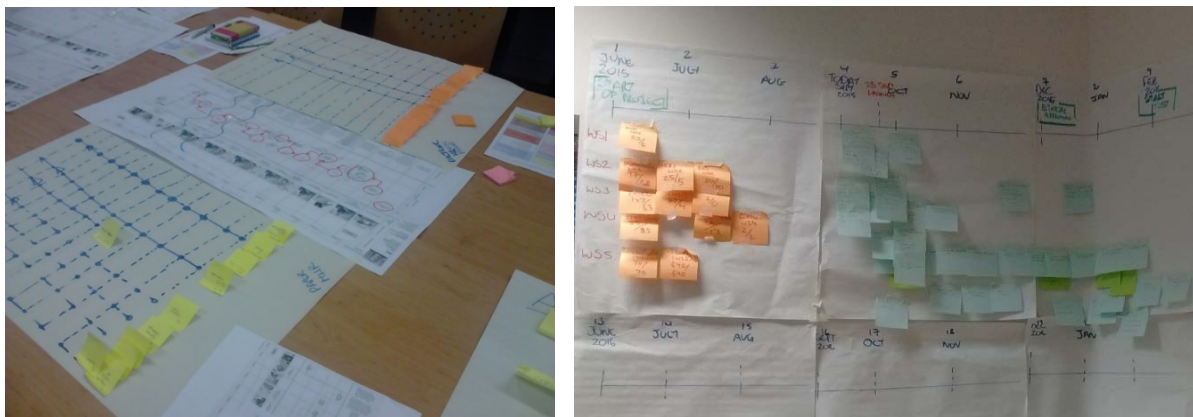


Figure 3. Outputs from a journey mapping exercise in a recent HIS project that aimed to analyse the experiences of pregnant women (McCarthy et al., 2016, 2020)

Individual interactions meanwhile centre on the conduct of one-on-one interviews with stakeholders. The main advantage of this approach is the opportunity to gain deeper insights into a topic through semi-structured questioning, and the convenience of scheduling separate meetings that suit individuals. Individual interactions are less susceptible to social influence, allowing stakeholders to speak openly, free from peer judgement (Morgan, 1996). However, a primary challenge is that multiple versions of the same IPJM will be created as stakeholders focus on their perceptions of the pathway in isolation from others. The task of the HIS researcher is therefore to aggregate individual insights into a more comprehensive map which can subsequently be reviewed by other stakeholders. This can be created through paper-based templates filled out in person, or virtual templates uploaded to collaboration platforms such as Miro (<https://miro.com/>) or Google Jamboard (<https://jamboard.google.com/>).

Data analysis requires stakeholders to engage in reflection, looking inward (into their own identities, thoughts, feelings and experiences) and outward (into their social positions, relationships, communities, and cultures). This form of analysis aims to invoke the self openly and transparently to “describe and systematically analyze personal experience” (Ellis et al. 2011, p. 273). Davies (2008 p.

184) writes that this reflexivity should be seen “[...] *not in terms of self-absorption, but rather [in terms of] interrelationships between researcher and other to inform and change social knowledge*”. Reflexivity is, therefore, more than a subjective phenomenon but is a ‘relational activity’ (Anderson 2006) that seeks to formulate and refine our understanding of ourselves and others. It interrogates the connections between the self and others, the personal and the social (Adams et al. 2014).

We next discuss the value of storytelling for reporting outputs from data gathering and analysis.

Reporting of Results

A key stage in Integrated Patient Journey Mapping is the reporting of outcomes that have been gathered during data collection and analysis. Reporting aims to graphically externalise domain knowledge by presenting stakeholders’ understanding of the medical care pathway and the shared meanings developed during the mapping exercises. The completed templates provide a visualisation of the patient journey including both the content and structural aspects of stakeholders’ thinking. A snapshot of one completed version of the Integrated Patient Journey Mapping tool is presented in Figure 4 below which represents the journey of ‘Fiona’, an expectant mother who is diagnosed with gestational hypertension at week 28 of her pregnancy. The visualisation shows when Fiona is hospitalised and the events which take place while she is an inpatient. The template provides a means for structuring the information gathered during stakeholder workshops.

The process of reporting supports sensemaking by organising and refining thinking. Stakeholders can identify *cues* in the wider healthcare environment, *frame* these within the context of a patient journey, and *bracket* them to create categories (Seidel et al., 2018; Weick, 2005). The HIS researcher must ensure that all perspectives are made explicit and that the maps adequately represent reality (cf. McCarthy et al., 2023). This may require periods of ‘sensebreaking’ to avoid the blind adoption of preliminary versions of completed maps which are often based on the assumptions of one group or on a normative vision of the process which does not apply in reality, as Harris et al. (2022a) found out in their investigation of the implementation of the Dundee ADHD clinical care pathway. At a certain point, the HIS researcher must seek to restore shared meanings through sensegiving to win buy-in for a preferred reality.

The use of different colours in the reporting process can provide a useful visual aid to separate elements of the patient journey map and set boundaries. For instance, elements related to the ‘physical journey’ could be formatted in green to show that they are all connected. However, it is important to carefully consider the use of colour as it can sometimes communicate unintended meanings such as when ‘red’ is used to signal danger. Excessive use of different colours may also detract attention from the key messages. When used sparingly, colour can add clarity by helping to create distinctions between elements of the map.

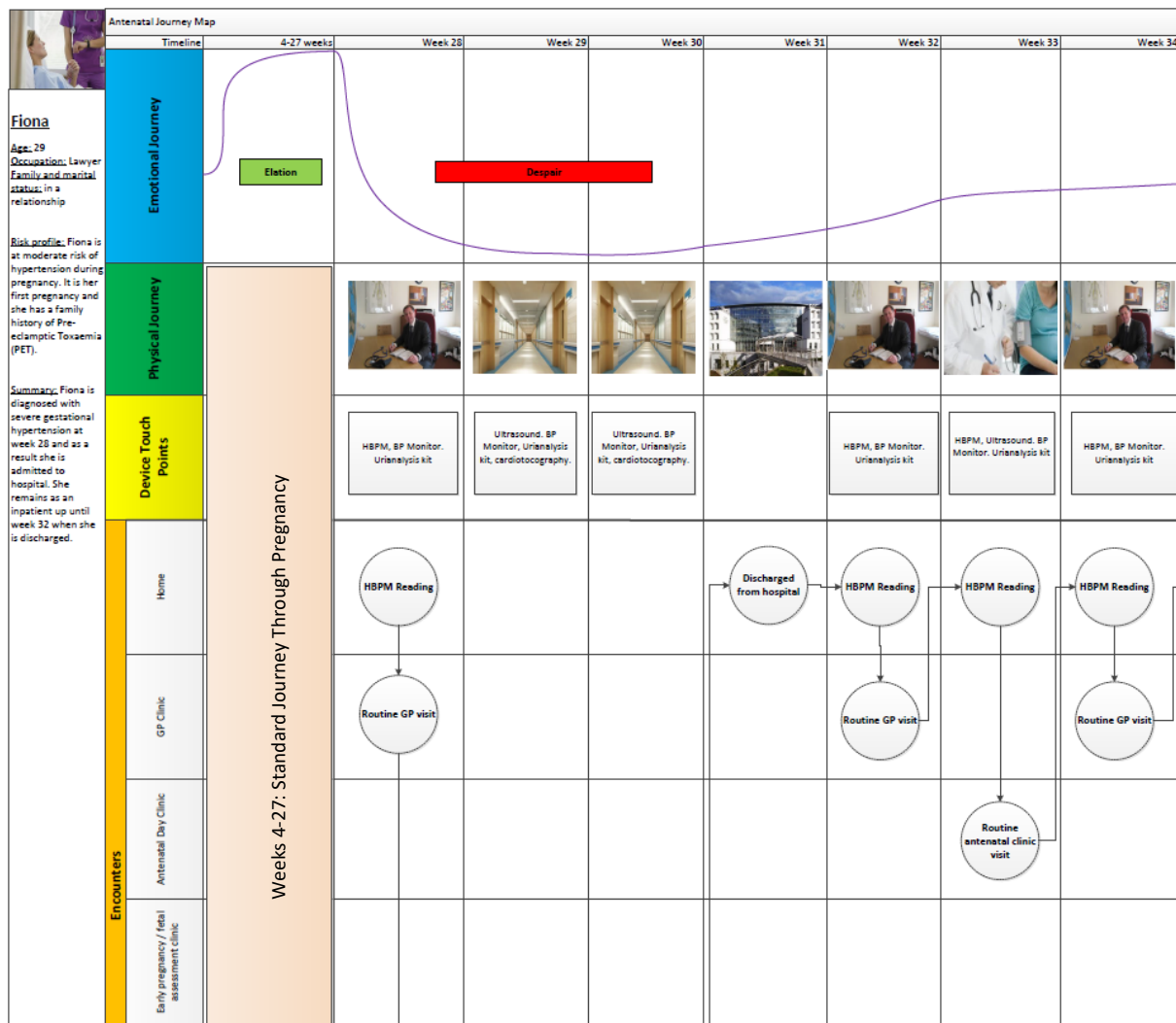


Figure 4. Snapshot of a Completed Integrated Patient Journey Map

Storytelling can also provide a useful approach for explaining the patient journey through collectively pooling sense into socially and incrementally constructed narratives (Ricoeur 1984). These stories can in turn ‘undergird decisions’ and give ‘warrant to action’ in the future (Julnes and Mark, 1998, p. 33). The HIS researcher can create narratives which aim to explain how central characters (e.g., patients, clinicians) progress across temporal events and the decisions they make. This may culminate in a peak event (Gabriel, 2000) such as when the patient is hospitalised to receive urgent care. Time may not only focus on the present (e.g., the time of the storytelling) but also the past (e.g., the prior situation of a character in the story) and the future (e.g., the near future use of an object by a character). Characters interact in the ‘story world’ through a process of questioning and answering, where each character draws on their distinct valuation system. This can stimulate discussions resulting in agreements and disagreements about the completed journey map.

Through ongoing storytelling efforts, the HIS researcher can also build empathy by helping stakeholders ‘see through the eyes’ of those affected by the proposed reforms e.g., patients and their families, clinicians, and carers. A story, therefore, is not coming from a singular self but is coming from a multi-voiced self which consists of different personas that the storyteller can hold concurrently. The voices function like interacting characters in the story and are involved in a process of questioning and

answering, agreeing and disagreeing, and cooperating and hindering (Hermans 2004). Some voices have more social power than others, with the result that some voices are neglected, suppressed, or just not heard (Hermans, 2004). This results in a complex, narratively structured self rather than the straightforward singular self. In this way, the listener is more than a passive participant in the storytelling and instead is actively engaged in imagining and designing the world, the characters, the prototype, and the setting. Storytelling serves to embellish and ‘humanify’ the process of journey mapping and designing HIS platforms. This complexity warrants the label of “wicked problem” attached to the development of successful, relevant HIS.

We next present exemplar case studies where integrated patient journey mapping has been applied in practice to map new medical care pathways while at the same time building empathy with the experiences of patients.

Exemplars

Child and Adolescent Mental Health Services

The first case study centres on the HIS context of Child and Adolescent Mental Health Services (CAMHS) and a doctoral research project being undertaken at University College Cork and Cork University Hospital, Ireland (Harris et al., 2022b). In this example, integrated patient journey mapping has been adopted to explore how connected health solutions can improve the delivery of mental health services to young populations by helping manage critical resources. The doctoral candidate has carried out semi-structured interviews with clinicians to fill in several integrated patient journey map templates. These journey maps aim to provide an understanding of how HIS can increase patient-facing time while decreasing administration workloads in CAMHS (Harris et al., 2022a&b). Maps have also been created to understand patients’ experiences of current services and the delays faced due to long waiting lists (oftentimes waiting up to a year to be assessed). Fictional patient personas have helped build empathy with these cases while also solving the practical problem of managing rising demands for CAMHS.

Based on this process, journey maps have revealed that current waiting lists are ineffective for triaging more serious cases as clinicians do not have visibility of the patients urgently needing care. Instead, access to CAMHS is provided strictly in the order that patients have requested services rather than based on the severity and urgency of the case. Journey maps have also revealed how connected health solutions can enable preventative measures against adverse outcomes such as self-harm and in extreme cases, suicide. By mapping touchpoints between connected health solutions and clinicians, it is possible to identify key moments in the patient’s journey where they may be at risk and require urgent referral. This aims to disrupt current medical care pathways where patients must ‘wait for their turn’ or request triage and assessments.

Integrated patient journey mapping created the visibility necessary for reimagining how cases can be triaged to prioritise the more urgent cases for appointment and treatment. Connected health solutions will later be developed to manage the limited resources available for CAHMS services and increase efficiency through reassessing waiting lists. By highlighting the key pain points that patients are experiencing with current services through journey mapping, it then becomes possible to explore opportunities for HIS to transform the patient journey and ensure that their changing needs are catered for proactively. This will ensure that going forward, clinicians are better able to proactively

monitor at-risk patients, including those who have been referred but are waiting for their first clinical service encounter.

Head and Neck Cancer Care

Integrated patient journey mapping was adopted by clinical researchers at Newcastle University, UK to investigate patient and family experiences of head and neck cancer (HNC) and end-of-life care. One in three HNC patients will die of the disease, many within a year of their diagnosis. Symptoms are highly complex causing major changes to basic functions. Despite this poor outlook, limited research has been undertaken to understand the needs of patients and their families in the last year of life. Journey mapping was used to investigate the care needs of HNC patients and families, developing core principles and a service outline to meet patients' diverse and evolving needs.

The clinical researchers explored how the integrated patient journey map could be used as part of their work to understand the medical care pathway across the last year of life. Discussions centred on how to visualise the patient journey by interviewing patients, carers, commissioners, managers and staff, using the integrated patient journey map to reimagine the care pathway. This exercise helped expose barriers and limitations to the provision of good palliative care as well as areas of good practice. Worked examples of the integrated journey map were provided, taken from the LEANBH project (Ambulatory Integrated Blood Pressure Monitoring in Maternity Services), (McCarthy et al., 2016, 2020), with the original files adapted for their work.

Based on meetings with a Public Patient Involvement (PPI) group for cancer, the clinical researchers learned how members were deeply concerned by HNC symptoms which they felt were extremely frightening. They also learned that access to specialist support may be inadequate and subject to variation. This helped to derive recommendations on the need for palliative services that are available early on, involve families, and coordinate with other services to support an enhanced physical and emotional journey for patients across different stages of end-of-life care.

Post-partum Follow-up Care

Journey mapping is being used by clinical researchers in Amsterdam UMC to explore new medical pathways for post-partum follow-up care among women who have experienced pregnancy complications e.g., hypertensive disorders of pregnancy or gestational diabetes. This patient group is more at risk of cardiovascular diseases than women who have experienced a normal pregnancy. The clinical research team has adopted integrated patient journey mapping to visualise current follow-up care practices and explore new pathways that can help mitigate the risk of cardiovascular diseases. Personas of women from different ethnic populations are being used also, as the perspectives of these patients have been overlooked in research until now. In particular, the integrated patient journey map has been adopted to investigate different patients' experiences when seeking follow-up care.

A qualitative approach is being adopted to collect patient and healthcare practitioners' viewpoints on patient experiences, requirements, and challenges when navigating current medical care pathways. The study has undertaken around thirty semi-structured interviews (each lasting 60 minutes) and three focus groups (each lasting 2 hours) to understand the needs of patients and healthcare practitioners and co-create new experiences through re-designing touchpoints between the patient

and healthcare system. The results will inform future pathways to provide optimal follow-up care which mitigates cardiovascular disease risk among women that have experienced pregnancy complications.

Concluding Comments

This chapter, and the examples it provides, demonstrate the power of Integrated Patient Journey Mapping in exploring the reality of existing medical care pathways in a systematic fashion and documenting the technology-enabled pathways which could augment or replace them. Once completed, the maps can become an effective and compelling communication display that is shared with a broad audience to convince decision- and policy-makers of the need and opportunity for implementing changes.

The strength of IPJM resides in its versatile nature, adaptable to both the domain of application and the intentions of the reforms. Thus, the template and instruments described in this paper can be amended and reshaped by the nature of the investigation and objectives of the HIS researchers, depending upon their specific projects. They will cope equally well with domains where rigorous protocols already exist, just as well as with others where tacit practices still dominate. Furthermore, IPJM will be effective in cases where medical care pathways are being optimised as well as those where radical reform is required. This flexibility will be very attractive to many HIS researchers facing the task of making decisive proposals towards improving the experience of patients and the effectiveness of healthcare systems.

There are, nevertheless, certain shortcomings in the IPJM model which HIS researchers should be aware of. Firstly, IPJM requires high levels of involvement from research participants to provide crucial input for the template sections and presentation of results. In the absence of this involvement, the value of IPJM may be constrained as HIS researchers have to rely on secondary data sources such as clinical protocols which may not always reflect day-to-day practices. There are also challenges in maintaining engagement from different participants as workload demands may impact clinicians' ability to contribute towards evolving versions of the IPJM over time. Consequently, the implementation of results may be hindered.

To overcome the first limitation, we suggest approaching 'gatekeepers' in the target environment to request that they sponsor the IPJM initiative and secure involvement from key stakeholders. In return, the HIS researcher can promise that new knowledge from IPJM will be disseminated to help enhance clinical practice going forward. We further recommend that HIS researchers try to organise meetings at a time that is convenient for participants and remain flexible to changes in availability to maintain involvement. Providing regular updates on the IPJM initiative can also ensure that commitment does not diminish over time.

The IPJM model has an important place among approaches available to HIS researchers currently. IPJM can provide HIS researchers with a holistic perspective of both the physical and emotional journeys of patients, as distinct from the workflow-centric view offered by business process modelling techniques. IPJM also offers a comprehensive template for visualising the interconnections between internal and external actors across care pathways, leading to deeper insights than tools such as flowcharts alone.

References

- Adams, T. E., Holman Jones, S., and Ellis, C. (2014). *Autoethnography: Understanding qualitative research*, New York, NY: Oxford University Press.
- Anderson, L. (2006). Analytic Autoethnography, *Journal of Contemporary Ethnography*, 35(4), 373-395.
- Antunes, P., Pino, J. A., Tate, M., & Barros, A. (2020). Eliciting process knowledge through process stories. *Information Systems Frontiers*, 22(5), 1179–1201.
- Avgerou, C. (1995). Evaluating Information Systems by Consultation and Negotiation, *International Journal of Information Management*, 15(6), 427-436.
- Bambra, C. (2022). Levelling up: Global examples of reducing health inequalities. *Scandinavian Journal of Public Health*, 50(7), 908-913.
- Barrow, P. D. M., & Mayhew, P. J. (2000). Investigating Principles of Stakeholder Evaluation in a Modern IS Development Approach, *Journal of Systems and Software*, 52 (2-3), 95-103.
- Conboy, K. (2021). Enabling Promethean Leaps: An Examination of Storytelling Techniques in Information Systems Development. *Communications of the Association for Information Systems*, 48, <https://doi.org/10.17705/1CAIS.04835>
- Conklin, J. (2006). Wicked Problems and Social Complexity, CogNexus Institute. Available at: <http://cognexus.org/wpf/wickedproblems.pdf>.
- Damodaran, A. (2017). Narrative and numbers: The value of stories in business. Columbia University Press. <https://doi.org/10.7312/damo18048>
- Davies, C. A. (2008). *Reflexive ethnography: A guide to researching selves and others*, Routledge.
- Dawson, P., & Sykes, C. (2019). Concepts of time and temporality in the storytelling and sensemaking literatures: A review and critique. *International Journal of Management Reviews*, 21(1), 97–114.
- Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography: an overview, *Historical Social Research/Historische Sozialforschung*, 36(4), 273-290.
- Gioia, D. A., & Chittipeddi, K. (1991). Sensemaking and Sensegiving in Strategic Change Initiation, *Strategic Management Journal*, 12(6), 433–448.
- Harris, R., Adam, F., & Murray, D. (2022b). Connected Health Avenues for Adolescent Mental Health – Modernizing ADHD Treatment Pathway, SIG DSA Pre-ICIS event, Copenhagen, Denmark, December 2022.
- Harris, R., Dempsey, E., Murray, D., Woodworth, S., O’Raghallaigh, P., & Adam, F. (2022a). Towards a blueprint for decision support in connected health: scenarios in maternal and child health. *Journal of Decision Systems*, 31(Sup1), 1-17.
- Hermans, H. J. (2004). Introduction: The dialogical self in a global and digital age, *Identity*, 4(4), 297-320.
- Iivari, J. (1988). Assessing IS Design Methodologies as Methods of IS Assessment, pp. 59-78, in N. Björn-Andersen and G. B. Davis (eds.), *Information Systems Assessment: Issues and Challenges*, North-Holland: Amsterdam, The Netherlands.

- Janis, I. L. (1972). Victims of groupthink: A psychological study of foreign-policy decisions and fiascoes. Houghton Mifflin.
- Jenkin, T. A., Chan, Y. E., & Sabherwal, R. (2019). Mutual understanding in information systems development: Changes within and across projects. *MIS Quarterly*, 43(2), 649-671.
- Julnes, G., & Mark, M. M. (1998). Evaluation as Sensemaking: Knowledge Construction in a Realist World, pp. 33-52, in G. Henry, G. W. Julnes and M. M. p.-. Mark (eds.), *Realist Evaluation: An Emerging Theory in Support of Practice*. Jossey Bass: San Francisco, CA., USA.
- Kvedar J., Coye M.J., & Everett W. (2014). Connected health: a review of technologies and strategies to improve patient care with telemedicine and telehealth. *Health Affairs*, 33(2), 194-199.
- LeRouge, C., Ma, J., Sneha, S., & Tolle, K. (2013). User profiles and personas in the design and development of consumer health technologies. *International Journal of Medical Informatics*, 82, e251–e268.
- Maguire, M. (2001). Methods to support human-centred design. *International Journal of Human-Computer Studies*, 55(4), 587–634.
- McCarthy, S., Fitzgerald, C., Sahm, L., Bradley, C., & Walsh, E. K. (2022). Patient-held health IT adoption across the primary-secondary care interface: a Normalisation Process Theory perspective. *Health Systems*, 11(1), 17-29.
- McCarthy, S., O'Raghallaigh, P., Woodworth, S., Lim, Y. L., Kenny, L. C., & Adam, F. (2016). An integrated patient journey mapping tool for embedding quality in healthcare service reform. *Journal of Decision Systems*, 25(sup1), 354-368.
- McCarthy, S., O'Raghallaigh, P., Woodworth, S., Lim, Y. Y., Kenny, L. C., & Adam, F. (2020). Embedding the pillars of quality in health information technology solutions using “Integrated patient journey mapping”(IPJM): Case study. *JMIR Human Factors*, 7(3), e17416.
- McCarthy, S., Rowan, W., Lynch, L., & Fitzgerald, C. (2020). Blended stakeholder participation for responsible Information Systems Research, *Communications of the Association for Information Systems*, 47, 124-149.
- McCarthy, S., O'Raghallaigh, P., Li, Y., & Adam, F. (2023). Control enactment in context: Understanding the interaction of controlee and controller perceptions in inter-organisational project teams. *Information Systems Journal* 33(5), 1029-1084.
- Morgan, D. L. (1996). Focus groups. *Annual Review of Sociology*, 22(1), 129-152.
- Petter, S., Khazanchi, D., & Murphy, J. D. (2010). A Design Science Based Evaluation Framework for Patterns, *ACM SIGMIS Database*, 41(3), 9-26.
- Ricoeur, P. (1984). *The Reality of the Historical Past*, Marquette University Press Milwaukee, WI., USA.
- Rittel, H. W. J., & Webber, M. M. (1973). Dilemmas in a General Theory of Planning, *Policy Sciences*, 4(2), 155-169.
- Sandberg, J., & Tsoukas, H. (2015). Making sense of the sensemaking perspective: Its constituents, limitations, and opportunities for further development. *Journal of Organizational Behavior*, 36(S1): S6-S32.

- Seidel, S., Chandra Kruse, L., Székely, N., Gau, M., & Stieger, D. (2018). Design principles for sensemaking support systems in environmental sustainability transformations. *European Journal of Information Systems*, 27(2): 221-247.
- Selin, C., Kimbell, L., Ramirez, R., & Bhatti, Y. (2015). Scenarios and design: Scoping the dialogue space, *Futures*, 74: 4-17.
- Simon, H. A. (1996). *The Sciences of the Artificial*, MIT Press Books: Cambridge, MA., USA.
- Smithson, S., & Hirschheim, R. (1998). Analysing Information Systems Evaluation: Another Look at an Old Problem, *European Journal of Information Systems*, 7(3):158-174.
- Symons, V. J. (1991). A Review of Information Systems Evaluation: Content, Context and Process, *European Journal of Information Systems*, 1(3): 205-212.
- Tan, B., Pan, S. L., Chen, W., & Huang, L. (2020). Organizational Sensemaking in ERP Implementation: The Influence of Sensemaking Structure. *MIS Quarterly*, 44(4): 1773-1809.
- Taylor, J. R., & Van Every, E. J. (2000). *The Emergent Organization: Communication as its Site and Surface*, Lawrence Erlbaum: Mahwah, NJ., USA.
- Twomey, M. B., Sammon, D., & Nagle, T. (2020). The tango of problem formulation: a patient's/researcher's reflection on an action design research journey. *Journal of Medical Internet Research*, 22(7): e16916.
- Weick, K. E., Sutcliffe, K. M., & Obstfeld, D. (2005). Organizing and the Process of Sensemaking, *Organization Science*, 16(4): 409–421.
- World Health Organization (2022). World Health Statistics 2022, available from: <https://www.who.int/publications/i/item/9789240051157>
- Zamani, E. D., Griva, A., Spanaki, K., O'Raghallaigh, P., & Sammon, D. (2021). Making sense of business analytics in project selection and prioritisation: insights from the start-up trenches. *Information Technology & People*. doi:10.1108/ITP-09-2020-0633