

Leadership Perspectives on Learning Health Systems: a qualitative study

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Abstract

Background: Integrated utilisation of digital health data has the power to transform healthcare to deliver more efficient and effective services, and the learning health system (LHS) is emerging as a model to achieve this. The LHS uses routine data from service delivery and patient care to generate knowledge to continuously improve healthcare. The aim of this project was to explore key features of a successful and sustainable LHS to inform implementation in an Academic Health Science Centre context.

Methods: We purposively identified and conducted semi-structured qualitative interviews with leaders, experienced in supporting or developing data driven innovations in healthcare. A thematic analysis using NVivo was undertaken.

Results: Analysis of 26 interviews revealed five themes thought to be integral in an effective, sustainable LHS: (1) Systematic approaches and iterative, continuous learning with implementation into healthcare contributing to new best-practice care; (2) Broad stakeholder, clinician and academic engagement, with collective vision, leadership, governance and a culture of trust, transparency and co-design; (3) Skilled workforce, capability and capacity building; (4) Resources with sustained investment over time and; (5) Data access, systems and processes being integral to a sustainable LHS.

Conclusions: This qualitative study provides insights into the elements of a sustainable LHS across a range of leaders in data-driven healthcare improvement. Fundamentally, an LHS requires continuous learning with implementation of new evidence back into frontline care to improve outcomes. Structure, governance, trust, culture, vision and leadership were all seen as important along with a skilled workforce and sustained investment. Processes and systems to optimise access to quality data were also seen as vital in an effective, sustainable LHS. These findings will inform a co-designed framework for implementing a sustainable LHS within the Australian healthcare and Academic Health Science Centre context. It is anticipated that application of these findings will assist to embed and accelerate the use of routine health data to continuously generate new knowledge and ongoing improvement in healthcare delivery and health outcomes.

Background

There is a growing interest in how best to use evidence and health data to inform decision making in healthcare delivery [1]. Systems are needed for ensuring that the most relevant and current information is used to guide decisions related to healthcare delivery [2, 3]. Improved health outcomes require informed decision making at all levels of healthcare, including decisions made by policy makers, hospital executives, clinicians and by patients themselves [4, 5]. Improving the ability to access, and understand, quickly visualise and compare high quality data related to patient care is known to enable improvements in health outcomes [4, 6]. However, only a minority (less than less than fifteen percent) of healthcare organisations worldwide are adept in data-driven processes to support informed decisions at point of care, as reported in a large study involving over 700 health care leaders [7]. The Learning Health System

(LHS) has been proposed as a framework for incorporating best practice and taking a systems approach [3, 8–10]. In a recent systematic review, it was found that a co-developed, sustainable LHS provides the necessary elements and environments to shape the healthcare systems of the future [11].

The Australian Health Research Alliance (AHRA) is a collaboration of ten Research Translation Centres, including three Regional Centres in Australia [12] accredited by the National Health and Medical Research Council. These Centres are modelled on international Centres including Academic Health Science Centres and Applied Research Centres in the UK [13]. AHRA, across these Centres covers over 90% of government-funded health and medical researchers in Australia, and over 80% of hospitals with significant primary care engagement. AHRA has developed three priority areas for Data-Driven Healthcare Improvement activity [12]. One is to create health data hubs within the Centres to stimulate partnerships across academic, clinician and other stakeholders. Monash Partners, an Australian Academic Health Science Centre in Melbourne Australia, led the development of the LHS framework through a systematic review [11], qualitative research and co-design workshop with the goal of developing a network of sustainable LHS in Australia.

Although definitions vary including those that identify an LHS as having operational precision medicine capabilities at point of care [8], here we took a broader definition, informed by broad expert stakeholder needs across community, healthcare professionals and managers, data and information technology experts, academics and policy makers. We defined the LHS as a system in which routine data, from service delivery and patient care, can lead to iterative cycles of knowledge generation and improvement in healthcare, as a result of daily practice [14, 15]. Despite the availability of big data from healthcare, little is known about how to create an effective, sustainable LHS that stimulate partnerships across different stakeholders, to utilise data iteratively for better healthcare and health outcomes. The aim of this project was to explore core elements of a sustainable LHS to inform development of a framework for LHS in Australia. We leveraged an expert Academic Health Science Centre committee, an expert National committee and our systematic literature review to inform this purposive, qualitative study with leaders who have experience of supporting or developing data innovations in healthcare nationally and internationally.

Methods

Design:

This was a qualitative study using semi-structured interviews. This study was approved by the Monash University Human Research Ethics Committee (Project ID: 19969).

Setting:

The Commonwealth of Australia has a population of 26 million and is highly urbanised with almost ninety-percent of people residing in cities of 100,000 people or more. Australians are covered by a tax-financed universal public health insurance scheme, which provides rebates against the cost of medical

fees. Private healthcare insurance is also available and the multi-payer health system is high quality but complex [16]. It is managed by different levels of Australian government (federal, state and territory, and local) and private providers to deliver (public and private) services through a range of funding and regulatory mechanisms [17]. Although complex, the Australian health system has relatively good outcomes and has been ranked as the second best health system (after the United Kingdom) by the Commonwealth Fund's International Health Policy survey [16, 18]. However, there is room for improvement, especially as the ageing population increases, and demand on the system is predicted to exceed capacity in the coming decades [17]. Already, waiting times for some elective procedures in public hospitals are considered too long, with up to 15% of patients waiting over twelve months in 2015-16 [17, 19]. Inefficiency, waste and provision of low value care are recognised in the Australian health system, and are estimated to account for approximately 30% of national health costs, through ineffective health interventions, administrative inefficiencies and inefficient pricing [20]. Quality and safety considerations are also recognised.

Procedures and data collection:

A purposive sample of leaders from a range of clinical and health informatics areas, who had experience of creating or developing data hubs, were invited to take part in a semi-structured interview. Leadership roles in managing data, as well as overseeing other leaders responsible for collection of clinical and health data were targeted. Purposive sampling also included those in a leadership role in healthcare delivery and/or health services research nationally or internationally.

The inclusion criteria for interviewees aligned with the above and included: 1) A nominated representative from each AHRA centre, 2) A nominated representative from each health service organisation of Monash Partners Academic Health Science Centre, and 3) international experts with published papers in LHS, or from leading organisations with known expertise in LHS or management of health related data. Nominated experts suggested by other interviewees were also considered for interview. Consumer representatives who were members of Centre data committees were also interviewed. Snowball sampling was used when a referral was suggested in a study interview. Contact details for potential participants were obtained from organisation's websites or through referral. The only exclusion criteria was non-English speakers.

Potential participants were invited to take part in the study by an introductory email or phone call and then followed-up by one of the authors (ACJ) to provide study information, answer questions and organise mutually agreeable interview times. Twenty-eight people were invited to take part in an interview. One potential candidate declined interview and another candidate cancelled and did not reschedule. Those who agreed to participate were sent a participant information form and provided verbal consent at time of interview.

Each interview commenced with the interviewer stating the purpose of the interview and a brief description of the LHS, ascertained from a recent systematic review [11]. The topic guide covered questions about what barriers and enablers were encountered when creating or sustaining LHS

environments (Fig. 1). Other questions explored what is important to ensure the sustainability of these environments, and sought insights into if they could create a LHS again, what might they do differently. This interview schedule was developed for this study (Fig. 1). The mean interview time was 55 minutes. After 26 interviews, no new themes were evident and recruitment was ceased.

All interviews were conducted by a single interviewer who is a health services researcher trained in semi-structured interviewing techniques. Twenty-four interviews were undertaken using teleconferencing software and two face to face between 2nd July and 11th October 2019. Interviews were audio recorded and professionally transcribed.

Analysis:

All interview transcripts were loaded into NVivo 12 (QSR International, Doncaster) for data management and coding. A thematic analysis was conducted using iterative and inductive processes [21]. To ensure familiarity with the dataset, transcripts were read multiple times. Coding involved identifying patterns of meaning and content that answered the research question. All codes were subsequently reviewed for connections and associations. Themes and subthemes were grouped, organized and checked to ensure they were reflective of the dataset. The analysis was finalised by ongoing discussions until consensus was reached between the first author and third author (AJ). Any discrepancies or varying perspectives were considered and resolved as the analysis was undertaken.

Rigor:

Records of key analytic and methodological decisions were made to ensure rigor throughout the analysis [22]. Regular consultation between the first author and third author, and meetings with the larger project team, fostered discussions about data interpretations enhancing trustworthiness. Presentations of the evolving analysis to peers and stakeholders enabled peer review to enhanced data validity [23]. A descriptor after each excerpt in the results refers to a unique participant identifier.

Results

The 26 expert participants interviewed were nominated lead representatives from: ARHA Research Translation Centres (n = 10), Monash Partners Academic Health Science Centre member organisation nominees (n = 8), the Australian Digital Health Cooperative Research Centre (n = 1), State Government (n = 1), National Australian Digital Health Agency (n = 1), Public Health Research Network (n = 1), National Stroke Registry (n = 1), a consumer advocate (n = 1) and international experts from the UK (n = 1) and Canada (n = 1).

Whilst clear themes were identified and little disagreement on the fundamentals emerged, there were nuances related to the role or experiences of participants. The key themes and subthemes identified for a sustainable LHS are described below and shown in Table 1.

Table 1
Themes and subthemes for a sustainable LHS.

Themes and subthemes:	
1	<p>Systematic frameworks, approaches and iterative, continuous learning with implementation of outcomes into healthcare</p> <ul style="list-style-type: none"> • Continuous learning
2	<p>Broad stakeholder, clinician and academic engagement, with collective vision and leadership</p> <ul style="list-style-type: none"> • Engaging diverse stakeholders from all levels and disciplines, including active health professional engagement • Governance, structure, culture • Vision and leadership
3	<p>Skilled workforce, capability and capacity building</p> <ul style="list-style-type: none"> • A data literate, skilled clinical and technical workforce is vital
4	<p>Resources and investment over time</p>
5	<p>Data access, systems and processes</p> <ul style="list-style-type: none"> • Data sharing, transparent processes and consent • Infrastructure, data storage, timely access and streamlined data linkage and processes

1. **Systematic frameworks, approaches and iterative, continuous learning with implementation of outcomes into healthcare**

Continuous learning

Establishing an iterative innovation cycle early in the implementation of a LHS was identified by interviewees as important. A cycle of innovation was needed to continuously drive better patient outcomes and improve services. Some participants reported that it was easy to make changes when initiating some type of quality improvement exercise, but the challenge was to make evidence based changes that were sustainable over time.

ID 01: 'You need that loop, you need that feedback so that the people who are entering the data could see the value of it and they start acting on it and they start making sure the data is of a high quality when it goes in.'

ID 02: 'This stuff takes time, it's not an instantaneous improvement you'll get, you do need to invest in time. And it's a bit like having to do a plan cycle; it is a continual improvement cycle. You are not going to get it right straight up.'

ID 03: 'You try and then you try again and then you try again and again and then you do it again and then you take a breath and then you do it again and again and again and again and again, and again and again and again and again. I've been doing this for 17 years now.'

Creating a vibrant learning culture that promoted continuous iterative learning through use of data and evidence within a LHS was noted by participants to be unsustainable without top down (e.g., CEO, leader, manager) and bottom up (e.g., clinician and consumer or patient) support. Support from all stakeholders was needed to ensure continuous learning and improvements, underpinned by data and measurement, as part of a 'business as usual' attitude. Further, a positive cultural environment was reported to foster ownership and a sense of responsibility for the quality and relevance of care and services provided.

ID 04: 'You attract more people and more organisations and so then you create a vibrant ecosystem where this kind of activity is going on all the time'.

ID 05: 'I think the other thing that's key to sustainability is if it's being used. So if it's being well utilised, not just by researchers, but by the health service as well, then people will see value in it. And that will help with the ongoing funding as well.'

Likewise, it was identified that a sustainable LHS is feasible only if the outputs fed back into the system to prioritise or escalate and implement changes in patient care if there were issues. As such, frameworks and systems need to be interconnected, iterative and cyclical.

ID 01: 'If you set something up and it just goes into a black hole and no one ever sees it you have problems. Not only are clinicians not interested in it, but the data you get will be rubbish. You need that loop, you need that feedback, so that the people who are entering the data can see the value of it and they start acting on it, and they start making sure the data is of a high quality when it goes in.'

Interviewees identified that a LHS must have a framework, systems and processes to survive when inevitable changes such as staff turnover and organisational restructures occurred. It was also noted that access to routinely stored data is often tied to knowledge held by individuals, in healthcare environments, rather than at a systems level. This limits sustainability of these systems with knowledge lost with staff movement. In a LHS, underlying frameworks, systems and processes should be documented and embedded. Adaptability, robustness and flexibility were also recognised as necessary to manage sustained growth into the future.

ID 06: 'I think so far a lot of these [LHS environments] have been done on goodwill and have worked best where people who have connected well get together and do some stuff. And we're now moving into a place, they're getting more substantial so it needs to be in more formal structures. I think where I've seen previously is you need to transition from the interested parties who can work well together to then actually the formalised structure that allows it sustainability of that, regardless of those particular individuals leaving that provide the sustainability.'

2) Broad stakeholder, clinician and academic engagement, with collective vision and leadership

Engaging diverse stakeholders from all levels and disciplines and governance

The importance of including diverse stakeholders in LHS environments, particularly at the governance level, was stated by multiple participants. Diverse stakeholders were needed to influence how structures were set up in the LHS. Participants recommended that governance committees should include stakeholders from clinical, community, research, human resources, finance, information technology, electronic medical record and data analytics teams. Involvement from analytics teams was considered important, as people from these teams could create meaningful (knowledge) from data, and use effective ways to improve data visibility. Further, participants considered involving consumers important in a LHS as they could make valued contribution to prioritising data, commenting on measures to be collected and analysed, and deciding time frames for data collection.

ID 07: 'So you need governance, you need process, you need engagement. You need to stare down the barrel of the self-interested groups and hold them to account through consumer, health service and health professional engagement. Then, you need to convince everyone that a system like this is the only way to go.'

Clinician engagement and ensured inclusion

Participants stated that clinician involvement was an important resource in a sustainable LHS, however their competing clinical workloads often made this challenging. Clinician input into all stages of a LHS from engaging in the vision, to setting clinical priorities, to bringing in expertise and evidence, to analysing data and implementing this back into practice improvement, was seen as important. A LHS was necessary to evaluate and optimise quality and accuracy of the data, use of data and to implement and drive improvements. Interviewees expressed that clinician buy-in would not be possible without protected time to contribute to the LHS as most clinicians were already operating at capacity. For example, without additional resources and data entry being an integrated and useful component of workflow, the quality of data entered was likely to be poor.

ID 02: 'Our priority is patient care, and I know data does drive improvement in care and service delivery, but you are continually battling with other priorities and it's the ability to show worth of the data.'

ID 05: 'Strong multidisciplinary approaches are really important. And then I think obviously a really important aspect of the team is having clinicians involved.'

ID 08: 'We showed you could get the clinicians in the hospital together, they look at the gaps in care, 'Ok, we missed out on people getting thrombolysis' or 'We're not meeting the indicator for patients with a care plan. What can we do about it?' And they get together and they look at their gaps in their quality of care.'

And then an external facilitator comes in and they do a workshop and they develop an action plan of how they can improve those processes. And by getting them all in together and getting buy-in that does actually improve care. And so we've found with the [data-driven project], it improves care by 14% over the time period.'

Vision and leadership

Participants stated that stakeholder engagement, collective vision and leadership were all important factors in a sustainable LHS. Developing a common vision informed by all stakeholders was essential for the coordination of multiple resources and for targeted approaches to achieve that vision. Some participants recommended that agreed priorities should be set and worked towards. To showcase the LHS approach, participants recommended starting with vision statements likely to result in prompt and positive change.

ID 07: 'You need a vision that everybody has. That needs to be co-designed, which means we need all the key stakeholders in the room.'

ID 06: 'There's got to be initially a really clear vision about what is it you want to achieve from it, and not just in the next two years but the next five to eight years.'

ID 05: 'If you can start with projects that are important to the health service and showcase what you can do with their data, that perhaps they're not currently able to do, that could be a good example to use to support the LHS.'

ID 04: 'There's nothing more powerful than demonstrating a positive outcome.'

While consensus on a collective vision was crucial, leadership actively committed to the vision was also identified as important. Leadership was necessary to ensure resources were available and directed towards supporting the vision, to foster the buy-in from multiple stakeholders. Strategic planning to embed appropriate processes and systems was also reported as essential for creating a sustainable LHS

ID 09: 'It's all about expert leadership.'

ID 08: 'Leadership is really important. If you've got really good leaders and they can get really good buy in....'

ID 10: 'The key enabler is leadership in my view – leadership that sets the direction, frames what you are trying to do and then brings people along. You will need some smart people, you will need some money to cover salaries and you will need some good technology.'

Leadership to cultivate trusting relationships between clinicians, other healthcare staff and managers was reported as important aspect of a LHS. A sustainable LHS need leaders to facilitate the agreement of measured outcomes, and to foster trust that these measures will be used for the agreed purposes and not for penalising individuals or the withdrawal of funding.

ID 03: 'Trust is the barrier, if you don't trust what data is being used appropriately. People get pretty tired, particularly in hospital settings, of data being used as a club, 'You're not hitting your four hour targets, bastards'

3) Skilled workforce, capability and capacity building in a sustainable LHS

A data literate, skilled clinical and technical workforce is vital

An important resource in a sustainable LHS identified by participants was data literate healthcare and technical staff. Data skills and knowledge identified as important for healthcare staff included familiarity with data collected, and understanding and interpreting data. To upskill healthcare staff they need access to education and training in these areas.

ID 02: 'I think we have a real skill shortage. How we address that, I am not sure. I think that the skill shortage is in the technical fields, and also in the clinicians that work on the ground. If we are moving towards more data-driven improvements and using data to help with workflows or patient flows, clinicians need to understand how to use the data. How do you drive improvements through the use of data?'

Further, participants suggested that a sustainable LHS needs people with highly developed data management and analysis skills embedded at various levels in a LHS. This ensures people with skills related to data management, linkage, analysis and the different 'languages' from related disciplines are available in a LHS.

ID 06: 'The informatics profession is an emerging profession and is going through its own process of specialisation. Where you previously would've had people putting data in and then you've had people getting data out, there's now a growing community. This includes data scientists, perhaps a visualisation expert, structural infrastructure expert, as well as those who design the architecture of the warehouse. There's growing specialisation. Historically, things were pretty simple. Whereas now that's probably about 10 different professions along that line.'

ID 11: 'There needs to be a core group of people who are well versed in several disciplines and that might mean handling of large data, informatics, computing, information technology people, machine learning and other similar related initiatives, data visualisation, the whole lot of infrastructure that comes with it; people infrastructure. And the trick will be to develop at least a core group who are constant and that's where the sustainability financial need will be critical.'

Collaboration between data specialists, clinical staff and academics was seen as beneficial in a LHS. University academics specialising in IT and statistical analyses were important resources that could

provide external expertise when required.

ID 05: 'Sometimes I will know what I want and I will be trying to say, 'Can we do this? Can we do this this way?'

ID 02: 'There needs to be really good relationships and partnership between the clinical and the data people. Because I think with that a symbiotic relationship, they're both dependent on each other. The clinical people are dependent on the data people to get it out and make sure it's the right thing and the data people were reliant on the business to actually run with it, know their own business, and understand how it can drive improvement.'

ID 11: 'Not one hub can do everything by itself; the one hub will have buy-in from related organisations industry, university organisations.'

4) Resources and sustainable funding

A key resource for creating a sustainable LHS was guaranteed funding. Interviewees identified that ongoing and protected funding for a number of years was key to the viability of a LHS. Costs were incurred as implementing a new LHS into a health system already running at capacity requires a coordinated and resourced approach. Additionally, costs were associated with obtaining, storing, analysing and using data.

ID 02: 'You need funding. It needs to be funded. And not a one-off funding but recognition that data changes and these types of hubs need some degree of maintenance as well, so there's the technical and obviously the workforce element to be able to pull the data out, and protect it.'

ID 06: 'And data doesn't come for free. It's expensive in terms of the setup of it and also the ongoing stories of that data in whatever form it is.'

ID 12: 'But right now, the situation is the funding for these things comes from multiple sources and sustainability is a major issue because people are usually unwilling to commit funding for more than a year, two years, two years and after that, they need to revisit things'

It is likely to take significant resources to establish a LHS and a number of years before benefits were seen. Interviewees expressed this type of long term investment is necessary.

ID 13: 'It takes a brave CEO, who tends to have an appointment term of about five years, to invest in something that may not bear fruit for a few years.'

ID 14: 'I want to create a structure that allows us to be a unit that has longevity and sustainability. So I'd really like to move towards three to five year plans where we can put data scientists in that aren't pre-committed to part of individual projects but can help build a resource to allow you to have a genuine hub.'

ID 15: 'Sustainability requires that this produces value which can be quantified that can then turn into profits or savings or increased values, which can go back into this spot. But it can't be left for the people in the periphery to find that money because the people in the periphery will always be short of money and will use this money to soak up their deficits wherever they happen to have them. Has to be allocated centrally, for that purpose.'

5) Data systems, processes, access and use

Data sharing, transparent processes and consent

Transparent governance, systems, structures, agreements and clarity of roles, responsibilities and activity within the LHS were all seen as vital for its continued success. Participants described the need for a clear LHS governance framework to assist with streamlining priority setting, ethics, data capturing, data access and consent processes. Transparent processes also aided the involvement of all stakeholders.

ID 05: 'We need to be more and more transparent around how to use people's personal data and having community education and transparency. That is, I think, very important.'

Participants perceived a key part of sustainable a LHS was transparent legislation that informed how patient data would be used within the system to create better healthcare. Timely access to data, information and reports was essential to a LHS. If layers of patient consent, agreements, permissions and sign offs resulted in major delays, then the LHS would not be sustainable.

ID 12: 'Make a learning health system function efficiently, within the workflow of an organisation, so all of the necessary approvals are done with the least amount of pain'

Infrastructure, data storage, timely access and streamlined data linkage and processes

Interviewees identified that there are available affordable, secure, accessible and integrated systems for data storage. It was stated that there are many options available in the current market and that emerging LHS environments would use existing infrastructure and technologies. Timely access to relevant data was reported as fundamental to sustainable LHSs. Access to data that is relevant to decisions made in real-time was seen as pivotal in a LHS.

ID 04: 'We want to move more towards identified, real time and live data that can be used to help patients, clinicians and researchers.'

Hospitals already generate mandated reports for the Government such as length of stay, waiting time in ED, and number of re-admissions. Participants identified that data linkage was important for producing information about quality, models of care, and health outcomes. Several participants mentioned a need to link health data to other relevant data. Health and healthcare does not exist in an isolated bubble. The social determinants of health are particularly relevant when evaluating value based care or health

outcomes when taking into consideration a wider social picture rather than a siloed health perspective. It was expressed that there is much that could be learnt through the linking of health data with that for housing, pensions, education, and crime and corrections data. However, current data linkage processes are often drawn out and convoluted and therefore unfavourable for current LHS environments in Australia. Participants suggested that streamlining federal and state based legislation would facilitate data linkage and more timely access to various data sources.

ID 01: 'So many things have been duplicated across Australia, every state is doing its own thing; it's so inefficient.'

A sustainable LHS efficiently produces practical, informative and up to date data. Some participants described how data from a LHS could be strategically used and the subsequent benefits.

ID 01: 'Now the beauty of it was that suddenly not only could you follow what was happening in real time in your department, but you could also interrogate and get all sorts of stats and there are all sorts of standard tables that they had, there were reports that would spit out. Using this reporting system, we could also refine the reports even more. You could also set up triggers, so - whether it was at triage or with the nurse inside with the doctor - when they put in certain words you could set it up so up come half a dozen questions as a result. So suddenly it just transformed the way that we were doing business.'

Participants described the importance of a culture and processes that make the integration of data, information and research, routine in healthcare delivery. For this approach to be sustainable in a LHS, organisational level support was seen as essential. Some participants emphasised the importance of embedding systems to automate data retrieval and reports which included benchmarking.

ID 02: 'It needs to be embedded in the business that information is valuable.'

this is about improving clinical care by getting organisations to understand the use of their data and the benefits of using their data, in many ways much more than it is about the academic use of the data.

ID 08: 'We want to be more internally-driven so that internal facilitation, the quality managers in the hospital look at these live reports and say, 'How can we improve that in our hospital rather than externally driven?'

Discussion

There is a need for transformation in healthcare to deliver better health outcomes. Digital health data has the potential to underpin this transformation towards more efficient and effective services. This project leveraged multidisciplinary leaders nationally and internationally to explore core elements of a sustainable LHS and inform development of a LHS framework for the Academic Health Science Centre context in Australia. Key themes were identified including the need for systematic approaches and iterative, continuous learning with implementation of outcomes into healthcare; broad stakeholder, clinician, academic and community engagement with collective vision, leadership, governance and trust;

skilled workforce, capability and capacity building; resources in human capital and investment, and; data access, systems, standards and processes.

A major theme identified was that a sustainable LHS requires systematic frameworks, approaches and iterative, continuous learning with implementation of outcomes into healthcare. Planning to embed processes into usual practice to capture and use data and learnings was key to success, consistent with literature on registry based LHS [4, 6]. Ad hoc LHS-like environments were acknowledged as common in healthcare, but participants agreed that these were unsustainable and waned, when key personnel moved on. These offered little for those at the frontline in terms of tangible healthcare improvement, yet frontline engagement was vital for success and sustainability. Transparent and iterative, cyclical improvement processes in the LHS to enable timely access, sharing and streamlined linkage of data, with mechanisms to feedback into frontline care, were recognised as important in ensuring the LHS approach was impactful and sustainable. These findings are commensurate with the emerging literature that describes systematic approaches and processes that are common in all LHS environments [2, 9, 11, 24–26].

Broad stakeholders including health professionals, managers, academics and community engagement was deemed important. Indeed partnering with all people who contribute to a healthy LHS including patients and the wider community, alongside all staff working in healthcare, was prioritised. The continuous learning within a LHS was dependent on diverse groups engaging and working together to innovate and solve complex healthcare problems around a shared vision. In this context, strong credible leadership, identification and commitment to a collective LHS vision was important. Transparent governance and clear structure was identified as a sub-theme. Collecting and storing data, without clear purpose or vision, was felt to contribute to lack of sustainability, because the worth of the data and interactive cyclical improvement benefits were not seen. This is worthy of consideration when a LHS is focused on data use only for research or health service management, rather than extension into improved clinical care. These views are in line with the vast literature on health care improvement and implementation science research [1, 27, 28], and also highlight the importance for improvement in complex health systems to assist clinicians and others to engage and lead change [1].

Skilled workforce, capability and capacity building in a sustainable LHS was another major theme. A data literate, skilled clinical and technical workforce, with access to education and training was reported as key to a LHS. Highly developed data management and analysis skills in staff embedded at various levels was also recognised. Collaboration between data specialists, clinical staff and academics was seen as beneficial and a strength of an LHS. University academics specialising in IT and statistical analyses were seen as important resources and can provide external expertise when required. These skills and resources in human capital underpin a sustainable LHS and also need to be iteratively enhanced and expanded over time. This is supported by a recent systematic review that identified health improvements arising within 23 LHS environments, and all had combined people with relevant workforce capacities and people with data analytic capabilities to make sense of the complex data arising from complex improvement cycles to address areas of unmet need, public interest and priorities [11].

Other resources and investment were also noted as essential in building a sustainable LHS. In addition to investing in workforce, there are costs associated with obtaining, storing, analysing and using data. It was reported that it takes significant resources and protected funding, sustained for a number of years to establish a LHS and often this investment is needed before benefits emerge. An essential component of a LHS is a collaborative platform that provides connectivity across silos, organizations, and professions. In the literature there is evidence that automated reports using the data from the entire LHS has led to the efficient identification of patients for standardised care, specialised care, follow-up or clinical trials [29–31]. Collection of information directly from patients before the clinical encounter has also been reported as beneficial due to time efficiencies [32], as well as creating PROMs (patient reported outcome measures) that are saved within the electronic medical record and can enable longitudinal tracking of individual patient outcomes and are used in aggregated research [4, 5, 32]. There are also examples of existing LHSs that invested infrastructure to enable patients to self-track their condition [4, 5], for example the electronic patient-reported outcome measurement system to identify distress and despair in cancer patients, which then lead to more referrals to psychological care [5].

Data access, systems and processes to producing useable, useful and quality data was identified as a theme and is generally reported in literature on the impact of LHS models [3, 8–11]. We found that appropriate infrastructure and transparent processes are reportedly needed to operationalise data access, linkage, analysis and applications. Participants clearly expressed that from the patient perspective, there is a responsibility to ensure their data can be compiled, accessed and analysed to benefit their own health and that of the broader community. This requires a culture of trust, transparency, partnership and co-design. For example, a Swedish system enables a patient to record symptoms, health status, and quality of life directly into their electronic medical record. Patients access their record at a clinic or at home. The LHS combines their data with other data (clinical examinations and laboratory results) in graphical displays of health status over time. The patient and clinician can view this together, or separately, and this helps patient and clinician partnership to optimize health. Data is also exported to the national registry, enabling research and ongoing learnings, contributing to improving population health. Evaluations have found that patients greatly value this system [4, 6].

Limitations

The semi-structured interviews were informed by a national steering committee in data-driven healthcare improvement and international systematic literature review. The nature of the questions may have influenced the breadth or responses provided. We aimed to inform development of LHS in the Australian context and hence interviews from Australian experts were preferred and results may not be generalisable. Overall, diverse stakeholders were interviewed and thematic saturation was reached, however additional stakeholders and stronger consumer and international participation may have influenced the outcomes.

Conclusion:

The themes identified in this qualitative study in data-driven healthcare improvement, provide insights into the core elements in a sustainable LHS. Fundamentally, an LHS requires continuous learning, generating evidence for implementation back into frontline care to improve outcomes. Structure, governance, trust, culture, vision and leadership were all seen as important, along with a skilled workforce and sustained investment. Processes and systems to optimise access to quality data were also seen as vital in an effective, sustainable LHS. These findings will inform a co-designed framework for implementation within the Australian Academic Health Science Centre context. Application of these findings, offers the potential to accelerate the use of health data to iteratively produce new knowledge to in-turn improve healthcare delivery and health outcomes.

Abbreviations

LHS Learning Health System

AHRA Australian Health Research Alliance

AHRTC Advanced Health and Research Translation Centres

CIRH Centre for Innovation in Regional Health

Declarations

- **Ethics approval and consent to participate:** This study was approved by the Monash University Human Research Ethics Committee (Project ID: 19969).
- **Consent for publication:** Not applicable as verbal consent obtained for interviews, and no identifiable information used in the publication.
- **Availability of data and materials:** The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.
- **Competing interests:** The authors declare that they have no competing interests.
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- **Authors' contributions:** HT, AJ, ACJ conceived the project. JE, SB and ACJ created the interview schedule. JE conducted all interviews. SB and ACJ analysed the data and analysis was finalised by ongoing discussions until consensus was reached between JE and ACJ. Manuscript was prepared by JE with significant contributions by SB, ACJ and HT. All authors reviewed, provided inputs and approved the manuscript.
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