


Participatory codesign of patient involvement in a Learning Health System: How can data-driven care be patient-driven care?

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Abstract

Background: A Learning Health System (LHS) is a model of how routinely collected health data can be used to improve care, creating 'virtuous cycles' between data and improvement. This requires the active involvement of health service stakeholders, including patients themselves. However, to date, research has explored the acceptability of being 'data donors' rather than considering patients as active contributors. The study aimed to understand how patients should be actively involved in an LHS.

Design: Ten participatory codesign workshops were conducted with eight experienced public contributors using visual, collective and iterative methods. This led contributors to challenge and revise not only the idea of an LHS but also revise the study aims and outputs.

Results: The contributors proposed three exemplar roles for patients in patient-driven LHS, which aligned with the idea of three forms of transparency: informational, participatory and accountability. 'Epistemic injustice' was considered a useful concept to express the risks of an LHS that did not provide active roles to patients (testimonial injustice) and that neglected their experience through collecting data that did not reflect the complexity of their lives (hermeneutic injustice).

Discussion: Patient involvement in an LHS should be 'with and by' patients, not 'about or for'. This requires systems to actively work with and respond to patient feedback, as demonstrated within the study itself by the adaptive approach to responding to contributor questions, to work in partnership with patients to create a 'virtuous alliance' to achieve change.

Patient or Public Contribution: Public contributors were active partners throughout, and co-authored the paper.

KEYWORDS

codesign, coproduction, health data, patient involvement

1 | BACKGROUND

Greater efficiency in the collection and use of electronic health data is a goal for health systems worldwide. The increase in gathering of electronic health data, referring to digitally collected and stored information about services, treatments and clinical populations, has not, to date, been matched by an increase in exploitation of those data to improve services. Learning Health Systems (LHSs) offer a conceptual model of the collection and use of electronic health data. The LHS is a model of turning data into action, creating virtuous cycles that reduce the 'data to action latency', the gap between recognizing problems and implementing solutions in practice. The concept has gained international approval and interest, with burgeoning examples of LHSs in the United States, the United Kingdom and global south.¹⁻³

The LHS concept is notable for addressing not only informatics requirements but also for drawing attention to the 'sociotechnical' demands of such a system, specifically the need for the full engagement of all stakeholders, including patients themselves. A system that is 'trusted and valued by all stakeholders' was ranked as the number one requirement of a 'high-functioning' LHS.⁴

Research has begun exploring the perspective of patients themselves, as the 'primary donors' of health data within such systems, using deliberative methodologies to explore perceptions of trust and value in the secondary use of health data.^{5,6} This has demonstrated that perceived benefit to patients and the public is considered key to justifying access to health data, which suggests that an LHS framework could be a valuable and acceptable way of understanding health data use. However, there remains a gap in understanding the role of patients beyond being 'donors' of data. This is inconsistent with the literature on LHSs that explicitly describes patients as playing an active, not just passive role,⁷ and with international efforts to increase the direct involvement of patients in health research, with the goal of increasing the quality of care provided. To date, however, the more active role of patients in LHSs has been underexplored, with a 2017 study of LHS leaders noting an absence of discussion of the potential roles of patients in such systems.⁸ This is despite suggestions that the value of LHSs, which is integral to engagement with them, may be perceived differently by patient stakeholders,⁹ and that LHSs could offer innovative ways for patients to be more actively involved in their care and in research.¹⁰

The purpose of this study, therefore, was to explore, with public contributors, how this more active contributory role should be achieved. Participatory codesign with public contributors was used to develop this collaboratively. In this study, the contributors engaged critically not only with the topic but with the research itself, leading to changes in the framing of the research questions and with emergent rather than preconceived questions and perspectives explored. This paper reports what we as a group agreed to be the key messages and learning (these terms being more consistent with the contributor's own framing than referring to 'themes' from the data), rather than being a separate reflection by the research coauthors on

or about the contributor feedback. Traditional qualitative papers would present a more linear process of data being collected from patients and then analysed by researchers. While data were generated and analysed, this was a collective process in which the researcher's views were also data to be considered, and in which the contributors were analysis partners rather than this occurring independently.

This paper is therefore a collective account by both the contributors and the researchers. The way in which the researchers and contributors worked together provides an example of collaboration in action and of the need for patient feedback to correct assumptions and drive changes. This adaptation and responsiveness to feedback led contributors to comment 'We became a learning health system'. Consequently, this paper reports both our findings regarding how patients should be involved and reflects on how our process of achieving these findings demonstrates the need for this involvement.

Both the original research objectives and the revised research questions are presented, to demonstrate how the adaptations arose and their impact, and provide an empirical demonstration of how direct patient involvement can expose assumptions that may be made and lead to novel understanding.

1.1 | Aim

This study aimed to collaboratively, with public contributors, explore how patients should be involved in an LHS.

1.2 | Original research objectives

1. Explore with public contributors their perspectives on the LHS concept and the value of data-driven learning and improvement.
2. To consider how and where patients can be involved in the LHS 'data to action' cycle, and codesign prototype mechanisms of influence.
3. To collaboratively agree what impacts would be most important and how these would demonstrate 'signs of a patient-centred LHS'.

The collaborative process with the contributors changed these to research questions that could be asked together by us collectively as a group, as opposed to being objectives for research to be done about or to the contributors.

1.3 | Revised research questions

1. What does the term 'data' mean, what does it include or neglect and for whom and why is it collected?
2. How should patients be involved throughout the system to ensure that the data and the decisions made with the data are relevant and meaningful to them?

2 | METHODS

2.1 | Design

A participatory codesign methodology was adopted throughout a series of 10 collaborative workshops. Participatory codesign is an approach that focuses on close working and cocreation with 'end users'.¹¹ It has been successfully used to critique mental health technologies with public contributors¹² and to collectively generate ideas for improving care with public contributors.¹³ It aims to be both exploratory and generative, in line with accounts of participatory

mechanisms that can enable meaningful coproduction.¹⁴ Two key mechanisms are dialogue and iteration,¹⁵ with collaboration occurring in a shared conceptual space to generate, critique and revise understandings in iterative cycles. Participatory codesign in the study enabled (A) a shared focus on users of the LHS, particularly patients, and (B) a shared process of collective critique and ideation, to deconstruct existing ideas and generate novel solutions and (C) a shared knowledge between the researcher and contributors, through collective analysis and synthesis (Table 1).

The codesign methods involved a variety of visual and narrative materials to present ideas and to engage in 'real-time synthesis'

TABLE 1 Codesign methods used in the study

Codesign principle	Method used	Intended outcomes
<i>Emphasis on users and user experience</i> Establishes shared focus	Personas: Narratives describing archetypal users of a service. Qualitative studies of user experience of community wound care and stroke care were used to create two personas, representing populations of study in candidate LHS projects in the region. Stakeholder mapping: Creating a matrix of groups/ organizations who have interest in use of the data for improvement and/or power to influence the use of data for improvement.	Focuses on empathy with the end-user as a primary concern. Privileges experiential knowledge by emphasizing lived experience as crucial knowledge for design. Recognizes the multi-stakeholder nature of LHS and considers patients within this wider system.
<i>Collective critique and ideation</i> Enables a shared process	Design artefacts: Diagrammatic examples of summary LHS cycles presented to represent existing conceptualizations of data and improvement, for example, the 'data to action' cycle. These were combined with brief narrative examples of candidate studies (wound and stroke care) describing research intentions to develop or implement an LHS in each case (in the Wound case, establishing an electronic health record, and in the Stroke case, use of hospital discharge data to aid in the prevention of secondary strokes). Mind-mapping and dot prioritization: Paper-based free ideation around the study aim, and individual and group ranking of suggestions. Speculative modelling: 'Dark' and 'Utopia' modelling: Combining the idea of 'design provocations' to pose challenging questions and soft system modelling to qualitatively produce models of working, contributors were asked first to design a system that would exclude patients from involvement, and then to design an ideal system that would be the best example of patient involvement. Suggestions are compared to identify key points indicative of positive or negative ways of working.	Iterative cycles of problem identification and critique. Future ideation to generate potential ways of working and consider both novelty and feasibility. Generates guiding principles of both best and worst practice, to act as a measure of how the system should operate and consider risks that could prevent it from achieving its goals.
<i>Collective synthesis</i> Produces shared knowledge	Affinity mapping: Thematic analysis of discussions, presented visually using whiteboards and post-it notes, to organize and collate emerging understandings, capture and compare different points of view and agree on key findings. Tabletop modelling: Mapping activity with mini-figures chosen to represent key stakeholders, to focus on the specific processes of interaction required to realize a goal in practice. The figures cannot move to other parts of the system without a mechanism to enable this and cannot receive or be aware of information again without specific mechanisms included.	Collective and concurrent 'real-time synthesis'. Generation of prototype solutions grounded in understanding of the users and demonstrating how to achieve the ideal principles through explicitly modelling relationships, structures and information exchange.

Abbreviation: LHS, Learning Health System.

through active discussion in the workshops. Codesign techniques therefore avoid presenting contributors with a 'blank slate', from which it can be difficult to progress and which can also be misleading as they do not represent existing ideas or conceptions from research. Materials are described in Table 1. These were drawn from the literature on personas,^{16,17} visual mapping,¹⁸ speculative modelling^{19–21} and service innovation.²²

2.2 | Setting

The setting for the study was the Connected Health Cities programme in the north of England, UK.²³

2.3 | Sample

In the United Kingdom, the active engagement of patients in research processes is defined as 'patient and public involvement'. 'Public contributors' refers to patients, service users and carers who undertake collaborative roles in research activities, bringing expertise as the 'end users' of a service. The aim to assess opportunities for and prototype mechanisms of involvement necessitated the engagement of experienced contributors with expertise in a variety of formats of involvement. In the rest of the paper, we use the term 'patients' to refer to people using health care services or experiencing illness, including carers and service users, as the target group the study was concerned with. We refer to 'contributors' when we are discussing the views and contributions of the project contributors (and paper coauthors), often reporting their views about patients or reflecting on their own experiences as patients.

Originally, 11 contributors were engaged, via the researchers' (S. K.) existing health research networks. Three contributors (two females and one male) withdrew before the workshops commenced due to illness. The final group comprised of eight members, one male and seven females. One contributor was British Asian and one contributor was Black British; all others were White British. The researcher (S. K.) and the observer (L. B.) were both female and White British. All workshops were attended by all contributors and the researcher, with the exception of Workshop 3, which had seven attendees (one contributor absent), and Workshop 7, which had seven attendees (one contributor absent).

Contributors were recruited directly through receipt of an email invitation and project documentation including a 'person spec' that described the planned work and how they would be involved, and specifying the time commitment and reimbursement.

Contributors had experience of involvement in research ranging from 5 to 15 years across different clinical topics, including mental health, end-of-life care, stroke care, primary care and public health. Organizations they had worked with included the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care, the NIHR Research Design Service, several Royal colleges, multiple NIHR funding bodies, the National

Institute for Health and Care Excellence committees and NHS England. They also had experience of working with stakeholders beyond academic settings, including Clinical Commissioning Groups, NHS Trusts and NHS Healthwatch, third-sector local and national charities and in education and social care governance.

Contributors therefore drew on a range of experience both as users of health services and as contributors to research and health improvement. Two of the contributors had been involved specifically in work on health data as part of the Manchester Health E-research Centre. All contributors had been involved in applied health research comprising multiple methods, including trials research, qualitative research, evidence synthesis, formative evaluation and intervention design and contributing to health professional undergraduate education and training.

2.4 | Data collection

Ten sequential codesign workshops were held between November 2018 and October 2019. Workshops ran for 3 h each, with a total of 30 h of collaborative discussion. Further discussions by email and telephone were conducted to enable collaboration on producing study outputs, including discussing presentation of results and key findings. Five workshops^{1,3–6} were attended by a health researcher working in the CHC programme (L. B.) who acted as an observer and recorded written notes to support us to capture a record of discussions over time (attendance was pragmatically decided based on her availability rather than a decision not to observe certain workshops). Further documentary evidence included field notes produced by the lead author after each workshop and email discussions between contributors. Within the workshops themselves, feedback was captured live on post-it notes and whiteboards (Photo S1). These were photographed as a record. After each workshop, the lead researcher completed field notes and shared a written summary of the discussions, which contributors could add to or revise. Workshops were not audio-recorded, to focus more on active recording of feedback within the workshop, as interactive design tools can capture richer data compared to transcripts in codesign settings.²⁴

By engaging in codesign with public contributors with considerable experience of patient involvement practice, the workshops would draw on previous experience of barriers and facilitators to involvement to generate hypothetical mechanisms for optimal involvement in the LHS. A further goal was to agree on important impacts or attributes that would serve as indicators for a 'fully functioning patient-centred LHS' as an expansion on the original Friedman et al criteria.

The original intention for the workshop progression was to reflect on the exemplar cycles of 'data to action' with reference to the user personas, identify opportunities for involvement in this cycle and generate prototype mechanisms of involvement, and finally reflect on 'signs' that would indicate that such mechanisms were in action and adding value to the system from the patients' perspective.

The adaptations to the study in response to contributor feedback revised this process. As originally planned, the study began with discussion of the personas and then consideration of the exemplar cycles. However, this initial work (Workshops 1 and 2) exposed greater disagreement than expected between the academic conceptualization of the LHS and the contributors' perspectives. This was further explored in Workshops 3 and 4, with speculative modelling and mind-mapping used to elicit contributor ideas and contrast these with the existing models. In the persona discussion and modelling work, the contributors focused explicitly on the value (or lack of value) of data for patients and on the need for supporting roles, performed by patients, for patients. This was elaborated in Workshops 5 and 6 to describe these roles and their impacts in more detail. The remaining workshops focused on synthesizing the ideas into agreed learning outcomes, including deciding the core messages to be communicated in study outputs and reflecting on the findings in relation to concepts drawn from the academic literature.

The process throughout, however, was not linear and did not proceed in discrete stages, but was an ongoing and dynamic process of sharing and learning between the group members and the researcher. The contributors engaged in 'constructive dissent' throughout, both with the researcher and with other members of the group, which involved adapting viewpoints and returning to previous discussions with new perspectives. The different activities were also returned to at multiple points, for example, the personas were used as key reference points throughout the project, such as including the persona characters as example stakeholders in the tabletop modelling work.

2.5 | Analysis

Data generation and analysis are an integrated process in participatory methods.²⁵ Analysis was concurrent, collective and iterative, with ongoing discussion and reflection contributing to emerging findings.

2.5.1 | Concurrent

Rather than discrete stages of generation and analysis, analytical themes emerged within the workshops during the activities themselves. For example, working with the patient personas to think about experiences of health data collection became an analytical discussion about what would be considered to be health 'data'. Affinity mapping, a live visual synthesis occurring within the workshops, where the researcher (S. K.) summarized key points on whiteboards, served as a form of concurrent thematic analysis throughout (affinity mapping is used often in experience-based codesign studies²⁶). The discussions, supported by the affinity mapping and dot prioritization on whiteboards to thematically organize contributor and researcher comments, were akin to analytic conversations²⁷ between contributors and researchers to progress understanding and agree on issues of significance.

2.5.2 | Collective

The activities were all undertaken either as a whole group or as small groups, who then reported back to the whole. The concurrent process of both generating ideas and exploring them analytically was a collective activity, rather than the contributors producing reflections that were then separately analysed by the researchers. This report of the study is also a collective account, with the contributor coauthors having the final say on the content and presentation.

2.5.3 | Iterative

The discussions were ongoing through the series of workshops and involved revisiting earlier ideas or points of contention as discussions and understanding progressed. This ongoing reflection and analysis extended to actively reframing the questions that the researcher had originally asked.

The codesign was therefore enacted as a socially deliberative process of collaborative problem solving, comparing views and seeking consensus through ongoing dialogue, with the researcher constantly summarizing and sense-checking.²⁸ The final four workshops (Workshops 7–10) focused on synthesizing the discussions into core learning to be communicated in study outputs, returning to the stakeholder mapping activity to consider what messages would have wider relevance to the key groups (patients themselves, clinical professionals and health researchers). In these workshops, earlier completed materials (personas with written comments, mind maps, speculative models) were displayed on tables and walls to support the identification of key findings.

In Workshop 8, S. K. presented relevant concepts from the literature for consideration. The discussion focused on how much the concepts 'fit' the discussions (did they reflect something important that had emerged in the workshops?) and whether they added value (did they help in framing an important finding? Did it expand or deepen our own understanding? Did they help in communicating a finding to other stakeholders?).

To prepare this paper, all written feedback (observations, field notes, postworkshop summaries, email discussions) were entered into NVivo. Selective coding was performed by the lead author to gather illustrative evidence for the key findings as agreed within Workshops 7–10.

2.6 | Ethics

In the United Kingdom, public involvement activities do not require formal research ethics approval as the contributors are not participants in research but collaborators in a research project. However, the project was informed by standards of ethical practice in involvement.²⁹ This included ensuring clear communication of what was involved, transparency about reimbursement and costs, flexibility and sensitivity regarding contributor needs and adopting

an attitude of respect and partnership working. Evaluation of the processes (which is reported separately) indicated that contributors were satisfied that these principles had been adhered to. As a patient and public involvement activity, ethical approval and consent to participate were not required. All workshop participants, both researchers and contributors have given consent for publication.

2.7 | Comment on reporting

Early drafts of the outputs reviewed by the contributors revealed a common concern that the reporting reflected a 'tidy' or sanitized account of the process, which underplayed the importance of disagreements and debate and the impacts of contributor feedback on both the process and outputs of the study. It was agreed that these unanticipated changes should be better reflected, as this would more transparently demonstrate the need for open dialogue and ongoing iteration. For this reason, the adaptations to the original process in terms of the research questions and the workshop content have been described. This has also influenced the presentation of the study results. For example, S. K. would have approached the results section by presenting the results using the transparency framework, rather than presenting it as a later output of discussions. Instead, we have agreed to present the discussions in a broadly narrative form that juxtaposes the original and revised research questions, to communicate how the final agreed findings developed as a direct result of disagreement and challenge, and to demonstrate the impacts of direct patient involvement in provoking novel and unanticipated understanding.

3 | RESULTS

Section 3 is presented in order of the original objectives and the revised research questions. A summary of the changes that occurred in this adapted process, compared to what was originally anticipated or planned, is presented in Table 2.

Original objective 1: 'Explore with public contributors their perspectives on the LHS concept and data-driven learning'.

3.1 | Revised RQ1: 'What does the term "data" mean in health, what does it include or neglect, and for whom and why is it collected?'

Contributors immediately critiqued the concept of 'data' (Photo S2). This initially focused on terminological barriers to understanding, with the word 'data' itself potentially off-putting and confusing. Using the personas and the exemplars from the CHC project, the discussion expanded to explore what could be neglected by if data were only defined by professional interests. The conversation changed therefore from whether patients could understand data to whether the data would understand them, and adequately reflect their priorities and their experiences. Contributors emphasized the potential for what matters most to patients to be excluded if data were not opened up to reflect their needs and concerns (Table 3). This led contributors to question who the data was for, meaning that if it was intended to help patients (through using data to change services and make improvements to the care provided), then it should be decided by patients what data was collected and how it would be used.

TABLE 2 Schedule of workshops and how the process changed over time

Workshop no. and method used	Original intention	Revised process and results
Workshops 1 and 2: Personas and design artefacts (example LHS cycles), stakeholder mapping	Explore patient perspective on data-driven learning	Debate about what data is or is not and who has the power to decide this
Workshops 3–4: Speculative modelling, mind mapping and dot prioritization, affinity mapping	Identify opportunities for involvement in LHS cycles presented	More radically reimagine a 'patient-driven' LHS from beginning to end
Workshops 5–6: Tabletop modelling, affinity mapping	Identify 'Signs of' patient involvement in the LHS that could be communicated to patients	Identify principles of how patients were able or unable to work within the system, describing how the system would operate with patients rather than outputs being communicated to patients
Workshops 5–6: Tabletop modelling, affinity mapping	Prototype 'mechanisms of' involvement that could be added onto existing system processes	Description of involvement roles that patients could enact and were part of with the overall system
Workshops 7–10: Revisiting previous materials and activities to agree core findings to communicate and plan outputs	Agree core findings to present in academic papers and patient-facing outputs	Academic papers produced, but with explicit recognition of the changes made by contributors and need for ongoing dialogue Lay report includes illustrations to better represent contributor views

Abbreviation: LHS, Learning Health System.

TABLE 3 Patient data should be

Quality	Description
Dynamic	Health conditions and the circumstances in which patients managed them are changeable and data need to be collected that reflect change over time as a static snapshot could be misleading, and less than useful.
Holistic	Data should acknowledge the complexity of multiple 'worlds' that the patient is part of, rather than single systems or single perspectives (e.g., an individual may be a patient in one context, but a carer in another), to reflect the complexity of living with health and illness and avoid a reductionist focus on limited interaction with specific health services.
Affective	Data should be 'more than numbers' and include emotions, experiences and perceptions of the quality of care, not just type of quantity. The experience of health and illness mattered most to patients and data that excluded this experiential information would, by design, neglect patient realities and priorities.

The academic approach was described as being more quantitative and groups' ideas about data were more 'emotive'—they felt that their starting point was people and 'social' data whereas the academic LHS discussed collecting quantitative data. Contributors talked about missing 'messy data'. Observation notes Workshop 1

The group felt that the term data has connotations of 'numbers', being scientific, 'clinical'... They made a distinction between data that is gathered ABOUT patients and the data that is provided FROM patients. Observation notes Workshop 2

I didn't really have a perception of data before this, but now I'm thinking a lot more about where it comes from, and how complex it needs to be to be used in a positive way. Contributor email feedback after Workshop 2

As well as debating what conceptualizations of data would include or exclude, the contributors felt that splitting cycles into 'data' and 'action' was overly simplistic, as the actions that would be taken would depend entirely on what data was collected, or neglected, and who had the power to decide what data to include and prioritize for action. Contributors queried whether data resulting from 'actions' in the system would be communicated back to patients so that they could 'interpret' it, and again whether patients would have influence over deciding which outcomes were most important.

I am concerned that even if patients are able to feed in their views/experiences/suggestions, is the system equipped to deal with it, who will know about the required change? Contributor email feedback after Workshop 4

During these discussions, it became apparent that the original project design had hidden assumptions about contributors rather than deciding with them, specifically in the plan to identify opportunities within the framework of a data to action cycle, rather than to fundamentally question the concept and what it meant to patients.

The group described using the model as 'alien to us' it felt trapping; it felt forced'; other words used were 'uncomfortable' and 'restrictive'. Drew a similarity between using the LHS model to being a patient in a health care system and being 'corralled' into having to fit clinicians' views of care or pathways. Questioned who the model was aimed at—is it for the patient or is it to benefit health professionals/researchers? Commented: 'Somewhere within the use of a model, you lose the person'. Observation notes Workshop 1

This also applied to the original intended progression of discussions with the 'signs' of a patient-centred LHS being a final output for the third research question, whereas the contributors from the beginning focused on the value of the LHS as it would be experienced by patients, and considered this value—'what it means to patients'—to be fundamental and the primary question to be asked to explore the system. This led to revising and integrating the second and third research objectives into revised Research Question 2, to address issues of influence and decision-making about what data matter most and how patients could have an active role in ensuring this.

Original objective 2: 'To consider how and where patients can be involved in the LHS cycle, and codesign prototype mechanisms of influence' and Original objective 3: 'To collaboratively agree what impacts would be most important and how these would demonstrate signs of a patient-centred LHS' became.

3.2 | Revised RQ2: 'How should patients be involved throughout the LHS to ensure that health data and decisions made with health data are relevant and meaningful to them?'

3.2.1 | Part 1: Patient centred or patient driven?

The discussions began by rejecting the description of a 'patient-centred' LHS. This was based on the contributors drawing on their significant past experience of involvement. They reported that being 'in the centre' could in reality mean being marginalized and their

contributions being isolated, rather than given the opportunity to fully influence other processes and work alongside other stakeholders. Rather than fitting mechanisms of involvement into an existing model, contributors therefore wanted to more radically reimagine a system that would learn 'from and with' patients (rather than 'about and for'). Contributors preferred the phrase 'driving' the LHS, which suggested a more active role (noting that patients were passively 'put' in the centre by others) and also emphasized that the system should begin with patient priorities. There was also a preference amongst some of the contributors, though not all, to refer to 'the learning health environment', as this emphasized interaction with different stakeholders, networks and organizations, whereas the term system was felt to reflect a more closed loop.

Our focus is the patient not the system. The system is done to people not with them. Contributor email feedback after Workshop 3

Garbage in, Garbage out! If it doesn't start with patients then it won't matter to them at the end. Contributor note comment in Workshop 4

A patient-driven LHS would begin with patients, involve patients throughout and end with impacts relevant to patients (as measured by patients themselves). Dark and utopia modelling were used to consider how we could know if an LHS was 'patient driven' in this way. The principles collectively synthesized from these discussions focused on three attributes: Attitude, Access and Action (Table 4). Written comments on the Dark Model included 'Them and Us attitude/Hierarchy', 'Excluded from discussion, jargon', 'No action take after dialogue' and 'Don't listen, don't value'. Written comments on the Utopia Model included 'Patients first', 'Active listening and responding', '360 Communication on a regular basis', 'Everyone valued' and 'People understand 'their' data and know that happens to it'.

The principles were not intended to be independent. Action and Access overlap in terms of visibility of what is happening in the system (with both system inputs and outputs communicated clearly to patients) and recognizing that patients need access to the system to act within it. Neither access nor action would be achieved if

fundamentally there was not an open attitude of respecting patient contributions and expertise. Evidence of patient action and patient access would therefore be indicative that this attitude was genuinely held.

3.2.2 | Part 2: Achieving these principles—Modelling roles for patient contributors in the LHS

Tabletop modelling was used to explore how a patient-driven system would look and how it would meet patients' needs and expectations, by mapping out hypothetical people, places and roles on A3 paper. Contributors referred back to the personas to consider the patient users of the system and also to the stakeholder mapping to consider other groups, such as health professionals and commissioners, who would need to be involved or informed. The physical map created with minifigures therefore enabled us to reflect on who would be involved and how they should interact to help meet patient needs (Photo S3). The modelling work focused on the particular roles that patients would need to play to influence the system and address wider patient needs and expectations (Table 5).

Notably, contributors identified a variety of roles that would serve different functions but also account for different levels of expertise or interest for patients to perform. This included sensitivity to 'naive publics' who may not wish to become directly involved, but should still be able to understand how data were being used, and should still inform what data are collected, up to consideration of skilled roles with authority over what happens in the system.

The modelling exercise also demonstrated how contributors saw patients as working alongside other stakeholders. This could include supporting them—for example, the facilitator would work with clinical staff as well as with patients to help them understand and make use of data. The guardian role was recognized as needing people with skill and confidence to work alongside other decision-makers and willing to take on decision-making authority. Again, drawing on their experience of involvement, the contributors also emphasized the need for each role to be supported, with opportunities for training and development, and financial provision for more demanding roles. The contributors also recognized that the roles were ambitious, and

TABLE 4 Principles of a patient-driven LHS

Principle	Description
Attitude	Drawing on their extensive experience, the contributors argued that the primary feature would be a system that was open to learning from patients and with a genuine respect for patient experience and expertise. The foundation of a patient-driven LHS would be an attitude of partnership and recognition that the system would not be as valuable if patients were excluded. When asked to rank the suggestions, this was #1.
Access	This included accessibility in terms of understanding, with transparency around what data were collected and used. It also related to access to opportunities to influence this process, rather than the LHS being closed to patients or with barriers to how patients could become involved.
Action	This again had two meanings—first, it related to patients taking action, with active roles for patients to have impact on how the system worked. It also referred to 'action' in terms of demonstrating to patients that their suggestions were acted upon, and demonstrating that these actions were of value for patients themselves (e.g., by continuously improving care).

TABLE 5 Roles for patients within a patient-driven LHS

Role	Description
Patient data champion	The champion would help promote the work of the LHS to make patients and staff aware of how patients were involved and how the system was impacting patient care. Their front-line work would also involve gathering feedback from patients not directly involved, which would be passed to the facilitator to inform their conversations with other system stakeholders.
Patient data facilitator	The facilitator would serve a knowledge broker function, helping create materials that communicated the system (which would be distributed and used by Data Champions), helping translate patient feedback into suggestions for the system input and outputs and acting as a bridge between patient networks and communities and the other system stakeholders, such as managers, clinicians and commissioners, for example, supporting new patient contributors to become involved in particular projects.
Patient data guardian	The guardian would have an oversight and monitoring role, to provide a check on how data were collected and used. It was noted that this role needed to have power attributed to it to be effective, for example, playing a role in granting or withholding permission to access data in the system based on assessment of how well a project met patient needs and whether it had sufficient plans for communication of findings back to patient groups.

Abbreviation: LHS, Learning Health System.

discussed feasibility (e.g., suggesting that champions could be members of existing charity volunteer networks) and incentives (e.g., discussing how a facilitator role requiring funding would help achieve service goals for patient-centred working and could provide support to staff as well as to patients).

You need people with a passion doing the work but with a responsibility to report back to others. You need to support them on that journey. Contributor note comment in Workshop 6.

3.2.3 | Part 3: Drawing on academic concepts—Transparency and justice

In the later workshops, the researcher brought in concepts from the literature that she felt could contribute to the emergent understanding. This again was a process of collective critique and synthesis, with the (lead author) presenting the ideas, but the group as a whole then discussing whether they were valuable.

The first concept that was discussed was types of transparency. Aitken et al.,³⁰ in their work on the Scottish Health Informatics Programme, discussed the links between trust in a system and transparency of that system and drew on political science conceptualizations of three types of transparency: Informational, referring to transparency about what information is collected and used, participatory, referring to public participation directly in processes about them, and accountability, referring to mechanisms for the public to hold decision-makers accountable.

We discussed as a group how the three constructs overlapped with the roles that the contributors had conceptualized. The data champion would ensure informational transparency by making patients more aware of what information was being collected and why. The data facilitator would enact participatory transparency through working directly within the system to represent patient interests.

Finally, the data guardian would perform an accountability function of evaluating system actions and impacts.

The synchronicity between the three roles and the three types of transparency was an emergent finding (the modelling activity was open-ended and exploratory, and not directed around the constructs). Their correspondence supports the wider applicability of the findings beyond the present study, but more so demonstrates how contributors had operationalized into embodied roles these complex issues that have been recognized as conceptually relevant in the literature on health data.

The second concept introduced was that of epistemic injustice.³¹ This refers to exclusion of ways of knowing or exclusion of certain types of knowers who are treated as having less legitimacy. The latter describes testimonial injustice, where a person is excluded from contributing their knowledge because of who they are. This could be said to apply to the risk of excluding patients from an LHS on the basis that they lack the professional or technical understanding to contribute, when in fact the LHS proclaims to be 'for' patients and should therefore depend on their input. The risk of hermeneutic injustice meanwhile refers to the risk that patient ways of knowing—such as their affective, holistic and temporal understanding of their health and illness—would be excluded from the system if a limited conceptualization of 'health data' is used.

The concept of epistemic injustice has been applied previously to patient involvement in research, particularly to discuss testimonial injustice in how patients with lived experience of health services can be dismissed as they are not considered legitimate 'knowers' compared to professionals.³² Our discussions emphasized the particular risk of hermeneutic injustice, whereby the experiences of particular groups are excluded from understanding, regarding the use of health data. Data collected separately from patients (through secondary data use) would potentially be viewed as objective and risk misrepresenting the real 'messy' experiences of health and illness, thereby excluding information that mattered to patients themselves. The irony of using a complicated academic term, epistemic injustice, to express the risk of neglecting nonacademic understanding was not

lost on the group, but the term was approved because it emphasized the high stakes, with the risk of committing injustice if patients were not actively involved in the system both as legitimate knowers and with their way of understanding and conceptualizing health and illness experience being adequately reflected in health data collection.

It was agreed that a patient-driven system, underpinned by the principles of Attitude, Access and Action, would help prevent the risk of epistemic injustice in health data. The system would address testimonial injustice by recognizing patients as significant contributors of knowledge, as partners in the process of interpreting and applying that knowledge and as legitimate judges of the value of the system, including the power to revoke access to data. It would address hermeneutical injustice through ensuring that patient understanding of what data are—dynamic, holistic and affective—is not only recognized but also included as essential information, and with roles throughout the system that sense-check the meaning of data with the patients themselves.

4 | DISCUSSION

LHSs should seek to learn 'from and with' patients, not 'about or for'. This will require openness to partnership working and to debate, which should be driven by patients rather than being 'patient-centred' in a way that excludes them by decisions being made on their behalf. Establishing an LHS that is valued and trusted by patients will require demonstrating trustworthiness through transparent ways of working with patients and of negotiating value through exploring what matters most to patients and ensuring that this is represented in the data that are collected and used. This will require openness to challenge from patients and adaptation in response to their feedback, as demonstrated in this study itself.

The study provides novel insights regarding the potential for data-driven improvement that exclude patient perspectives to inflict epistemic injustice. Epistemic injustice had been discussed in relation to patient involvement in research and service improvement, particularly in the field of mental health or from the perspective of feminist-informed analysis, but we believe that this is the first time that the concept has been applied to understanding health data and data-driven service improvement and research. The concept of injustice may be usefully provocative in communicating the risks inherent to data-driven improvement, which, first, due to its technical nature and secondary analysis, can exclude patients from involvement within it and second, can exclude the reality of patient experiences if only attuned to population-level and quantitative measures.

The risk of testimonial injustice indicates the need for inclusivity and accessibility in enabling patient stakeholders to hold influence. This is consistent with the contributors' perception that an attitude of respect and recognition was the most important quality for such a system to have, and with the focus in the present study on roles that enact different forms of transparency as being more important than outward signs that patients were considered important. The signs of

a patient-driven LHS would be the collaborative processes that embody informational, participatory and accountability transparency, rather than discrete outputs that would provide reassurance that patients were considered.

Underpinning the virtuous cycle of learning from health data should therefore be a similar effort on building a "virtuous alliance"³³ that recognizes and draws on the wider expertise of patients and communities. Menear et al.⁹ have argued that crucial to the LHS approach is understanding how it creates value, including recognition that patients can have different conceptualizations of value that must be included. To achieve this, it may be useful to draw on studies that explicitly consider collaborative working, for example, work on Integrated Knowledge Translation³⁴ and on learning from communities.^{35,36} This approach could help in establishing a participatory data model of active involvement with health data, in contrast to the risk of a testimonial injustice black box of data use preventing the involvement of other partners.

The findings regarding testimonial injustice therefore deepen our understanding of the need for active roles for patients. The findings regarding hermeneutic injustice go further to emphasize that the system itself risks being irrelevant or ineffective in improving patient care if it neglects the experiences that matter most to those patients. This indicates a need for an expanded vocabulary of 'health data' that embraces experiential and affective elements. This is likely to require multidisciplinary input, to expand the big data of informatics with the rich data of narrative and experience.^{37,38} Ethnographic studies for example have shown that quantification of health data is a complex social process in its own right, with implications for which issues are made visible or obscured, and how quantitative data can support or restrict communication between patients and professionals.³⁹ Ethnographic study of how health professionals engage with a wider concept of data, by Montgomery et al.,⁴⁰ described how frontline staff will engage more with experiential and interactional feedback from patients, referring to this as 'wild data'. The present study indicates the need for patient understanding of and use of health data to be similarly explored.

There is now a considerable literature on patient experience data in health settings that should be considered. In the United Kingdom, there is a large body of patient experience data that are collected by the NHS, and the key challenge is effective use of such data.^{41,42} Adopting an LHS cycle approach may be a way of encouraging and measuring learning from such data sets, and adopting a patient-driven LHS would help ensure that patients are recognized as active agents in such a system rather than passive contributors of experiences.⁴³ It is notable that successful innovations have occurred outside of academia that have focused on patient experience as key sources of 'data' to drive improvement, for example, the Patient Experience Library (<https://www.patientlibrary.net/cgi-bin/library.cgi>), a database of patient experience as evidence for health improvement, and Care Opinion (<https://www.careopinion.org.uk/>), a digital repository of patient experience narratives used to encourage feedback on improvement. The potential for LHSs to learn from community- or patient-driven initiatives has been recognized, for

example, drawing on the Patients Like Me model.¹⁰ Future work on LHSs could therefore draw insight from such work.

Health data initiatives have been criticized for adopting a language of empowerment despite constraining patients to passive roles⁴⁴ and health data discussions have been criticized for focusing on 'calming controversies'.^{45,46} In health system change, conflict can be both inherent and also beneficial.⁴⁷ Although on a small, single-project scale, we have demonstrated how debate and constructive disagreement can lead to richer discussions that produce outputs that are credible and meaningful for both patients and researchers. The present study demonstrates the need to deliberately explore perceptions, engage with disagreements and negotiate differences in how fundamental concepts, such as 'health data', are understood.

Such a process is likely to be crucial in achieving the goal of a 'trusted and valued' LHS, recognizing that trust is relational and negotiated.⁴⁸ This will require professionals, including academics, who are involved in data-intensive research, to more mindfully consider how and why they are engaging with patients and the public, as aiming to 'persuade' the public of benefit can be in conflict with aims to work collaboratively with them.⁴⁹ The latter approach requires understanding that 'trust' cannot be established as a discrete and static quality of the system that can then be communicated to patients, but is instead a dynamic process that occurs with patients.

The process that we report in terms of the study data being collectively generated and collectively analysed is itself an example of the recommendations for LHSs more widely, in that we encourage researchers to involve patients as partners, and to examine data with them rather than drawing conclusions about them. It is notable, however, that such participatory work can pose challenges in reporting, as there is no discrete sequence of data being generated 'about' the contributors that is then separately analysed. We have attempted to provide a thorough description of the data (feedback and learning from both contributors and researchers) and analysis (as a collective process during and after the workshops) in the study in a way that does not undermine the collective ownership of the findings.

We suggest that more examination is needed of how to adequately report codesign outputs in health research in a transparent way, considering whether traditional qualitative criteria of trustworthiness in reporting are appropriate or not. For example, credibility in traditional qualitative studies is achieved by demonstrating that author interpretations are plausible based on participants' data. In this study, the contributors are themselves authors, and were involved in cycles of interpretation throughout. This constant interaction between data and analysis makes it difficult to specify in the style of an audit trail exactly where interpretations occurred. Dependability, referring to the stability of findings, also clashes with the participatory focus on ongoing dialogue that could lead to changes over time. In the field of Design, methods are evaluated based on the extent to which they enable participants to explore their own needs, and support collective meaning-making,^{24,50} which we argue was achieved here. In the PPI literature, authors have suggested that trustworthiness in the context of two-way learning is about

answering the question 'did the interaction lead to a change?'⁵¹ and transparently reporting changes in the researcher's thinking⁵² rather than about evidencing contributors' thoughts. We have attempted to do this here by contrasting the original and revised research questions and explicitly acknowledging within the text where disagreements or changes were encountered. The extent of the adaptations made in the workshops was surprising, however, for both the researchers and the contributors, and future participatory work should aim to expect the unexpected and consider how these changes can be better captured throughout and then reported.

4.1 | Limitations

Although the codesign work drew on actual examples of research being conducted in an emerging LHS, the work reported here is hypothetical, and there is a need to test and evaluate the suggestions in practice, to consider the feasibility of delivery and to determine impact. It is hoped that the specific roles and criteria for evaluation suggested here can support this further work. There is also a need to review the suggestions with other stakeholders, such as health professionals, commissioners and researchers using health data. This is necessary to consider how the suggestions would be received and implemented in the complex multi-stakeholder setting of an LHS, and would also enable contributors to work in a more integrated way with other stakeholders.

The paper should not be viewed as representing final views on the topic. The contributors emphasized that with further time and discussion, it is likely that views would have further adapted or that new issues would be uncovered. Although this may be seen as a limitation for reporting in this paper, we consider it a strength of the process itself and consistent with the ideas of ongoing learning that are fundamental to LHSs. This demonstrates the need for sustained involvement, with contributors as partners on a continuing journey of positive change, rather than as one-off contributors. Although our contributors had varied life experiences and offered a multiplicity of viewpoints, we acknowledge that the group was predominantly female and White British. We recommend that further research seek to maximize diversity, in terms of demographics, background and experiences, to ensure diverse perspectives in future collaborative work.

5 | CONCLUSION

The recognition of the risks of an inaccessible or exclusionary LHS should be considered alongside the corresponding potential for LHSs to herald new and innovative ways of working with patients. A truly participatory LHS could perform a civic data function that enables patients to marshal health data to support their aims, and embed collaborative and mutually beneficial ways of working between health care systems and communities. A patient-driven LHS that achieves the three forms of transparency could offer a model of

genuine patient empowerment, to realize the potential of health data in partnership with patients themselves. This study itself provides an example of how such active collaboration can lead to novel insights and how active involvement is necessary to correct assumptions made and focus on what is meaningful to patients themselves.

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CONFLICT OF INTERESTS

The authors declare that there are no conflicts of interest.

AUTHOR CONTRIBUTIONS

Sarah E. Knowles designed the study. All authors contributed to data collection and analysis. Sarah E. Knowles produced the first draft of the paper. All coauthors contributed to revisions and approved the final version.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

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