Why data-driven care must be patient-driven care:

How to involve patients in learning from data to improve services

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What is this report about?

This report is a summary of our project exploring how patients should be involved in a **Learning Health System**. This is a system that uses health data collected by services, about patients and the care they receive, to identify where improvements are needed. The goal is to create cycles of feedback and learning to make care better for patients. We asked the question: **How should patients be involved in this?**

Who is this report for?

Our report can help with the following questions:

Patients, Carers, Service Users

• What is 'health data'? • How does the use of 'health data' impact on me? • Can it make things better for me? • What role could I have in making these improvements? • What questions should I ask about a system like this? • What would it look like for patients to be meaningfully involved in the collection and use of health data?

Health Professionals

• What kinds of data about their health matter most to patients? • How can we be sure the improvements we make are what patients want or need? • How can patients support the improvement process? • What are patients concerns about health data and improvement?

Policy Makers, Commissioners

• What are patients' attitudes toward using health data for service improvement – what are their expectations, assumptions, and concerns? • How can patients help make the goal of using data for improvement a reality? • What are the risks of excluding patients, for the system, for health services and for patients themselves?

Researchers

• What kinds of information should we count as data, to collect to drive improvements? • How can we make sure that patient knowledge is recognised and acted upon? • How can this process be transparent for patients? • What kind of learning health system should we be trying to create, and how do we support patients to be part of those systems?

We've included links to more information about Learning Health Systems on **Page 14.**

Our key messages:

Pages 03 - 04

Part 1:

We need to think very carefully about **what counts as ‘health data’ and what might be excluded.** Is the data helping us see what matters to patients themselves, or is it obscuring or over-simplifying their experiences and needs?

Pages 05 - 07

Part 2:

Involving patients directly is necessary to ensure we collect and analyse data that matters. It is a form of injustice to exclude patients from decisions made in the system.

Pages 08 -12

Part 3:

Patient involvement needs to happen throughout the system, with patients driving the decisions, not just seen as an add-on. Transparency is achieved at different levels, which will involve patients in different ways. Opening up the systems means being open to patients challenging our assumptions and being open to change.

This happened within our own project. We like to say that we became a Learning Health System – because the feedback from the patients in our group led to us changing how we worked together.

Part 1

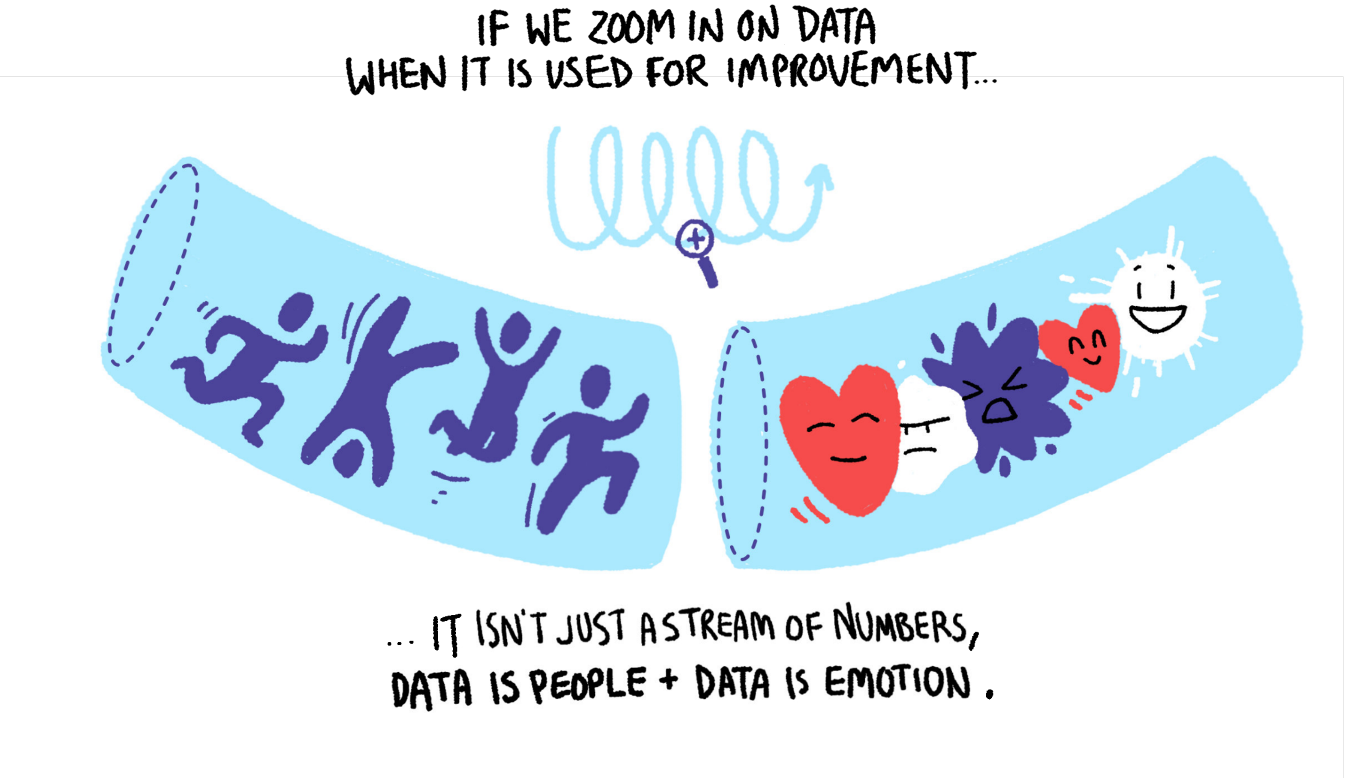
What counts as health data, and what might it exclude?

***Summary:** Health data is used to refer to information about patients collected about them, their illness, and the services they receive. Our group challenged whether the data typically collected and used would reflect the full, complex, dynamic lives of patients, or be a static picture about them that didn't tell the whole story. To make sure the data collected and used is meaningful, patients must have a say in what is included and analysed.*

'Health data' is a term used to describe information about patients' illnesses and care that is collected by their providers. This can be numbers about the patient (their age, weight, blood pressure) or information about what care has been received (such as medications prescribed, or information about what procedures have been done). It can also include data about health collected for research, such as symptom questionnaires completed in clinical studies.

The key challenge we identified was: who decides what is and isn't health data, and is and isn't worth collecting and analysing? What assumptions are being made in choices about what counts as health data and who gets to make those choices?

- Is data reducing complex experiences to 'just numbers'? How do we capture the 'messy data' – the emotions, experiences, changing needs and circumstances, that make up peoples' lives? Will these essential details be part of the analysis?



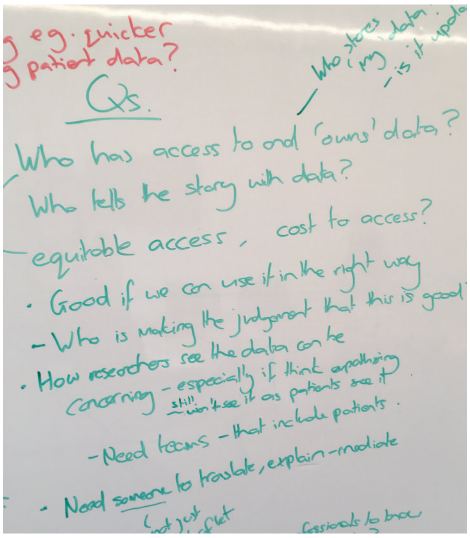
Part 1

What counts as health data, and what might it exclude?

- Who chooses what data to collect? Data can give the impression of ‘objectivity’ but someone must choose what data to include. Who has the power to do this? Who decides what data is important or not?

- Who is data for, and about? If we want to learn from data, we need to think about who has access to it and can understand it. The group questioned how patients and professionals on the front lines would be included in learning.

- Is data collection ongoing and living? It shouldn’t be a static picture, and there should be a way of checking in with patients to see if their data profile matches what they’re experiencing.



eg. quicker
patient data?

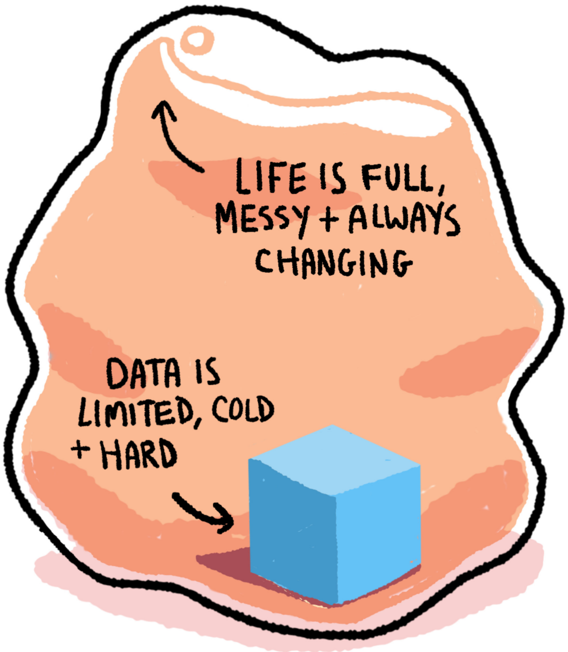
Qs.

Who stores data (my) : is it upda

Who has access to and ‘owns’ data?
Who tells the story with data?
— equitable access, cost to access?
· Good if we can use it in the right way
– Who is making the judgement that this is good
· How researchers see the data can be concerning – especially if think anything still won’t see it as patients see it.
– Need teams – that include patients.
· Need someone to translate, explain – mediate
(not just leaflet)
fessionals to know

The word ‘data’ itself was unpopular. Terms such as ‘health information’ may be better.

[The Understanding Patient Data website](#) for example explores different words and terms used to talk about data.



If patients aren’t involved in choosing what data is important in the system, it calls into question whether that system can really benefit them. How can a system deliver improvements for patients, if the information that goes into the system isn’t what matters to patients themselves?

This is just one of the reasons why we must involve patients as active partners in such systems.

Part 2

Why we must involve patients.

Summary: *Involving patients will mean better data and better improvements, and help realise aims for co-production of services with patients. Crucially, patient involvement is needed to avoid the risk of epistemic injustice in systems that use data. This means patients must be acknowledged as experts in their own right, who bring essential knowledge into the system.*

There has been work to date which has thought about whether patients have **trust in a system** that uses their data, but there has been less consideration of how patients can be active partners in such a system. **We identified three reasons this is essential:**

1. Better data

The whole point of a LHS is to use data to deliver change. This can't happen if the data isn't any good to begin with! We need patients involved to make sure the data reflects the actual experiences of health and illness and make sure data is accurate and valid. There is a well-known statistics warning called 'Garbage In, Garbage Out' (GIGO) - if the data going into the system isn't good enough, then it doesn't matter what is done with it, it won't produce anything useful.

2. Better improvements

A patient-driven LHS can make use of 'patient power' to deliver changes. It would also be better placed to identify what kind of meaningful improvements can be delivered, because patients can provide the context, the story behind the numbers, that helps to identify what kind of changes need to be made.

> "In a learning health system, the patient is an **active contributor** to, and supporter of, the learning process".
>
> *Institute of Medicine, Patients charting the course, 2011*

3. Better co-production

There is now a mandate in many systems to work with patients (eg. **In digital projects to produce shared records**). Involving patients throughout so that they can be partners can make sure data-driven change is also patient-driven change. Co-production is key to building and maintaining trust.

> "An LHS cannot simply be built by others for patients; it must be built **with and by** patients".
>
> *Rubin, Patient empowerment and the Learning Health System, 2017*

Part 2

Why we must involve patients.

The risk of injustice when working with data

Our group talked about the risks if systems don't involve patients. Flipping the points above, we can see that such a system would have poor data, would struggle to deliver meaningful improvements, and would fail at achieving co-production.
We identified the fundamental problem with such a system: that it would be unjust. Specifically, it would be a form of **'epistemic injustice'**.

Epistemic injustice means that certain types of knowledge or ways of knowing are excluded, putting people at a disadvantage because their knowledge isn't valued.

This leads to neglect of their needs because what matters to them isn't being recognised as important.

Epistemic: Relating to knowledge or knowing

Injustice: Neglecting the rights and values of another

In the case of a Learning Health System, injustice would occur if the emotional, experiential knowledge of patients is excluded and if patients themselves aren't given a seat at the table because their knowledge isn't considered valuable.

The irony was not lost on us that the term itself was difficult to understand! Nevertheless, the group felt it helped reflect the issues we had talked about and crystallised the key risk associated with data-driven health care - that service users are shut out of the system, and their needs and experiences aren't actually represented and responded to.

Part 2

Why we must involve patients.

'Injustice' is a strong word, but we hope it is deliberately provocative, to prompt all those working with such systems - clinicians, commissioners, data scientists, informaticians - to be mindful of these risks and proactive in addressing them, through supporting patients to understand and engage with health data. It is an injustice to exclude patients, and their ways of understanding and talking about the world, from learning.

While these challenges arguably apply to all kinds of patient involvement, the risk is even greater when we think about data. If we are not mindful of how inaccessible data can be, and how much 'just numbers' can leave out; then we risk perpetuating this injustice against the very people that the system is supposed to help.

This means that the drive towards more advanced and complicated uses of data in health care needs to be matched by a drive to make what is happening is clear to patients and enable them to have a say in what data is collected, and how it is used. It is not enough to say that this is "for" patient benefit. That judgment needs to be made by them, not about them.

How can we achieve this in practice?

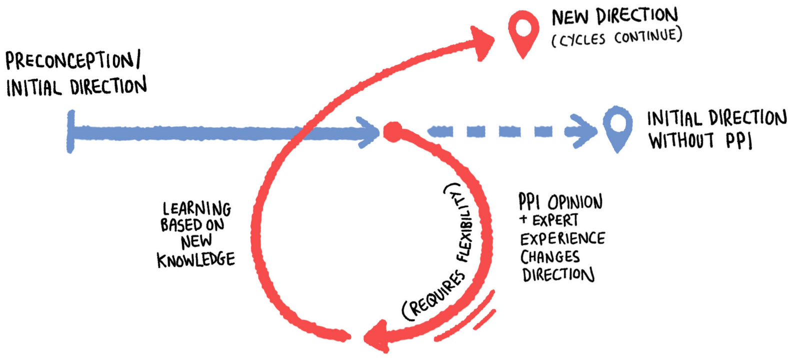
Part 3

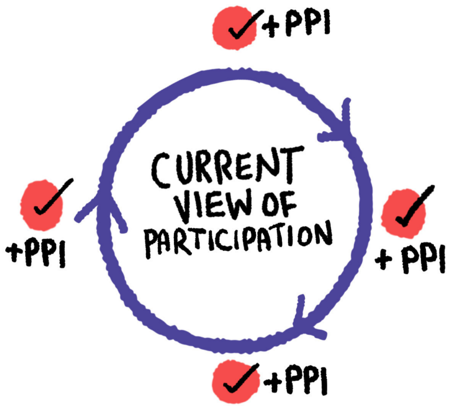
How to involve patients throughout.

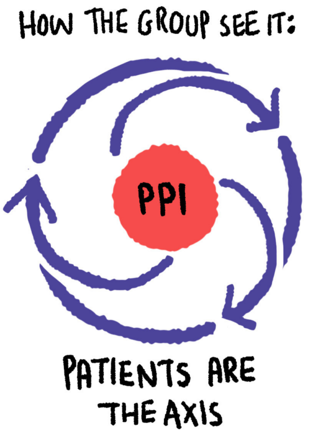
Summary: *We need to do things with patients - “With and by, not for and about”. Patients should be at the table, not on the menu. Our own project is an example of this in action, where public contributors challenged what the study was about, and their feedback led to changes in what we did and, as a result, what our learning was. A patient-driven LHS would achieve three kinds of transparency, through patients working alongside other stakeholders. We identified Access, Action, and Attitude as the key principles of how this would work.*

Over the course of the project, our group became a Learning Health System. This is because the public contributors gave feedback about what questions mattered to them, and the project changed to respond to them. This change and responsiveness is key to a Learning Health System being effective, and key to authentic work with patients.

This can be a challenging process! But the value of patient involvement in the project was to challenge assumptions and disrupt existing ideas. Specifically, the researcher (Sarah) had imagined the project would ask how patient and public involvement could be added into different stages of the improvement cycles. The contributors wanted to be much more radical, and reimagine how a patient-driven LHS would look. These challenging conversations, with the contributors themselves, were necessary to revise and improve the project. The way we, researcher and public contributors, learned together was an example of how a Learning Health System should learn with patients.







Part 3

How to involve patients throughout.

"Putting patients at the centre of services"

"Patients must be at the centre of everything we do"

"Joined-up services with patients at the centre"

"Put patients at the centre of your efforts"

"The digital revolution has patients at the centre"

"Healthcare for the future is about putting patients in the centre"

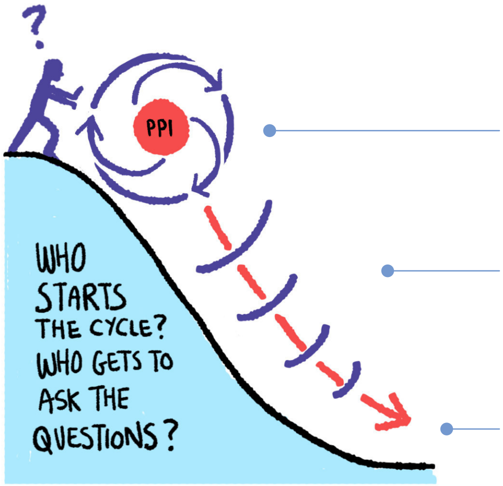
"Inviting leaders to put patients in the centre of decisions"

"Removing barriers by putting patients in the centre"

Very early in the project, the contributors expressed concern about the idea of a 'patient centred LHS". 'In the centre', in the group's experience, could too often mean being isolated from everything else, and things were done 'about', 'for' and 'around' patients but not actually with them. We decided that we wanted instead to propose a **patient-driven** LHS.

Part 3

How to involve patients throughout.



A patient-driven LHS would;

Start with patients - asking them what matters, making the system processes clear and justified, and with questions initiated by patients themselves.

Involve and be open to patients throughout, including them alongside other professionals and processes, rather than separating them out.

End with patients - the end results would be impacts that matter to patients, and would be actively communicated to them. Crucially, patients wanted to hear the good and the bad - they want to know what hasn't worked as well as what has.

We agreed that this system should achieve should three kinds of transparency:

Informational transparency

The information that is used to make decisions, in this case health data collected in services, is accessible and understandable to the people who those decisions are about.

Are patients not only informed about what data is being used, but able to have a say in whether the data about them is valid?

Are decisions about which data is being used and why communicated clearly to patients?

Participatory transparency

The people who those decisions are about have the opportunity to get involved directly in how decisions are made.

Have patients had the opportunity to influence what data is collected and analysed?

Have patient priorities driven decisions made to use data or to make improvements based on that data?

Accountability transparency

There is a mechanism for holding decision makers to account, and to seeing what has been done with the data.

Have patients been informed what happened to their data and what improvements were made?

Do patients have authority in the system to question what is done and demand changes?

Part 3

How to involve patients throughout.

Our patient-driven LHS would be achieved through working to three key principles:

Attitude

The most fundamental requirement is the right attitude to patient involvement – recognising the value of involving patients, and being committed to learning from and with patients. The group had seen enough tokenistic or tick-box involvement to know that without this attitude, meaningful partnership would simply not be possible. Delivering the other two (access and action) would demonstrate that this attitude was genuine.

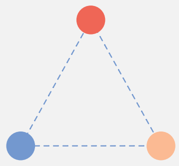
Access

Access means that the system would be accessible in terms of understanding, and accessible in terms of opportunities for patients to become involved. The LHS should avoid jargon and aim to use language that was understandable to patients, so that people outside the system could understand it.

The second part of Access was about people getting inside the system, if they wanted to, and making opportunities for patients to become meaningfully involved. This means creating spaces for patient input but also considering how to support different patients with different needs or wishes, meaning a variety of ways to be involved should be offered.

Action

Action meant that patients wanted to be active in how the system worked, acting themselves rather than being passive bystanders, and that actions should be visible and reported. This way patients can see the impact of their involvement, and be reassured that their input had real consequences and changed what happened.

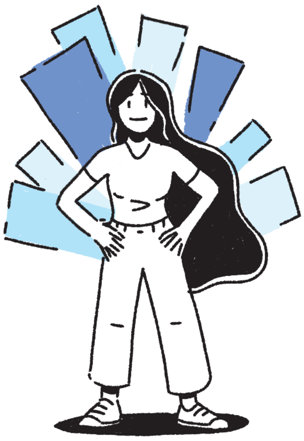


All three are interlinked. People need **access** to the system if they're going to take **action**. **Actions** need to be transparent, so that the learning is **accessible** to everyone. If both these things occur, then patients would be confident that the right **Attitude** was held. Similarly the reverse is true: they will only occur if the Attitude is right.

Part 3

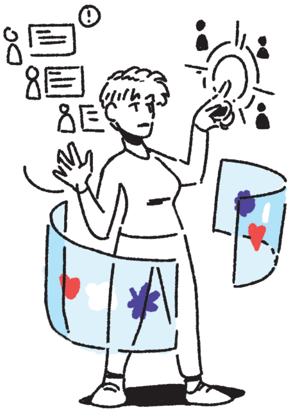
How to involve patients throughout.

Our group suggested three example roles for patients in the system which would help achieve the 3 kinds of transparency:



Data Champion

A volunteer on the front line who interacts with patients, carers and service users, to promote the work of the LHS and answer questions about how data is collected and used. They would also feedback the main queries and concerns of the service users, to make sure that the system is always aware of the needs of the 'data donors'. They would promote opportunities to become involved in specific pieces of work.

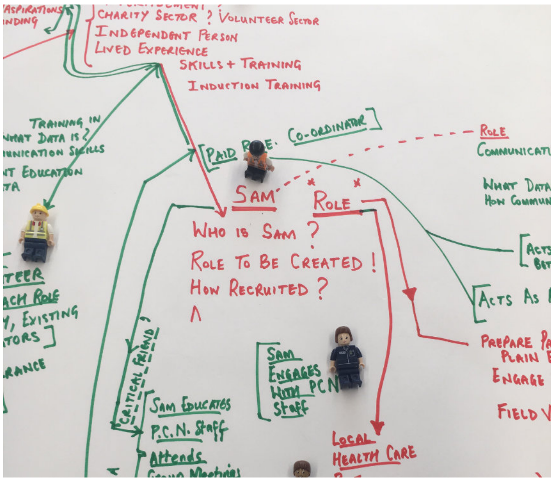


Data Facilitator

A more advanced, ideally funded role, for patients to work alongside professionals to help them make sense of the data and deliver improvements. They would support the Champions and ensure their feedback is acted upon.

Data Guardian

An oversight role, for example on a steering committee or review panel, with patients involved in monitoring how data is used, ensuring that decisions are made with patients and not for them, and importantly having the power to withdraw access to health data if it wasn't going to be used to really benefit patients.



The group recognised that different roles would be needed to address different needs. There is no single way of 'involving patients' that can accomplish this. This means that different patients, with different skills, interests, and levels of commitment, would be involved in different ways. There needs to be different opportunities available to them, both paid roles and volunteering positions, depending both on what they want to contribute, and what is needed. These 'patient roles' shouldn't be something isolated from the rest of the people and processes that are happening. Our group wanted to know how patients fit into that wider system, alongside other stakeholders, rather than being something separate.

Final Summary:

We have highlighted that there are many challenges to overcome to achieve a LHS that authentically involves patients as active partners.

We hope we have also demonstrated why this is necessary, for a LHS to achieve its goals of making improvements that matter to patients.

We have suggested ways this could be achieved, and principles to think about when planning for involvement in improvement.

Although there is a risk of exclusion of patients in data-driven learning, the flip side of this is the opportunity to build a truly participatory system that enables patients and professionals to work together to make services better and to improve lives.

Find out more:

We have described our work in more detail in two academic papers. Both are available open access. **This paper** summarises the work we did together to think about data and improvement, and to suggest how patients should be involved. **This paper goes into more detail** about how we worked together, and particularly tries to honestly capture how our productive tensions were crucial parts of the process!

Click the links below for more information:

Examples of patient-driven data for improvement

1. The Patient Experience Library - set up to answer the question, if we have clinical databases for research and care, why not patient experience databases? The goal is to help the NHS to "take patient experience evidence seriously".

2. Care Opinion - An online portal to share experiences of health care with the services themselves. Key to this process is that those services then respond to and act upon that feedback.

3. A report by Macmillan about how to collect and use data about cancer care in a way that includes patients throughout, encouraging transparency and considering how to make sure data collected is valuable to everyone involved.

More information about Learning Health Systems:

What are learning health systems?
A blog by Health Data Research UK

Why should the NHS be thinking about Learning Health Systems?
A blog by The Nuffield Trust

What is the vision for patients as partners in Learning Health Systems?
A report by the US Institute of Medicine

How is data being used for improvement in the NHS? A blog by NHS Digital

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