



DEVELOPING A DATA PACT

**The relationship between the public, their
data, and the health and care system**

September 2023

Acknowledgments

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Executive Summary

The relationship between patients and their data is deeply personal. Whilst we uncovered many different perspectives in this work, one thing was strikingly universal: data is of vital importance to patients. This covers their ability to access it, who it is seen by, when and how it used, and the other patients that benefit as a result.

It was also clear from this work that data is not just seen as something generated as a result of the care patients receive, it is an element of care itself. In turn the relationship between patients and their data should be seen as part of establishing patient partnerships and progress towards shared decision-making. These are two issues that are at the heart of the Patients Association's campaigning work.

As well as placing huge value on the importance of data, our participants were extremely positive about the potential for its different uses. Whilst they were supportive of the principle for their data to be used across all health and care uses, many expected something in return from the health and care system. Neither did their enthusiasm for their data to be used translate into confidence in the current system. In some cases, their own experiences and examples of data breaches in the health and care system had significantly reduced trust.

These concerns should not be seen as barriers to data use. On the contrary, our participants did not want them to limit that potential. Addressing them should be seen as enabling the potential of data use, with the health and care system fulfilling its part of the bargain, as the possibilities continue to expand. Some of these issues can begin to be addressed through a data pact. Others will need action outside of the scope of this work, as part of wider implementation of the [Data Saves Lives](#) strategy.

Against this backdrop, a data pact would be introduced into a climate of public mistrust. It should be developed with that in mind and acknowledged. Some participants believed that neither the health and care system nor patients themselves understand enough about data use – or have enough trust in it - for a pact to be developed at this point.

But if a pact is developed with honesty, the conversations we had indicated that a pact could be a useful first step in informing patients about how data is used in the health and care system. It can be a starting point in improving confidence if it contains the right commitments. To do this, it will need to acknowledge that the system is not perfect. Counter intuitive as it may seem, one part of building public confidence is acknowledging the reasons why that confidence may be absent as things stand.

To help build confidence the different uses of patient data will need to be explained simply but broadly. Any assurances it gives or commitments it makes will need to be meaningful, monitored, and enforced. Consequences and remedies will also need to be made clear. If a data pact recognises these and the other suggestions participants gave us, as part of longer-term efforts to make patients feel closer to and with more control

over the data they generate, the potential for data, and public support for its use in transformative initiatives will increase.

The term 'data pact' was initially chosen as a name for this document as reflected in the published commitment in the Data Saves Lives strategy. Participants felt like this name wasn't appropriate but did not conclude on an alternative naming convention. The final naming of the 'data pact' will be agreed at larger-scale public engagement. For the purposes of this report the document will still be referred to as the 'data pact'.

Introduction

The Patients Association embarked on this project, with the support of the Department of Health and Social Care (DHSC), because of the importance of data use in the health and social care system. Data plays a huge role in how the health and care system is designed and delivered.

That role will only become more significant. New possibilities will continue to develop as technology advances. There is enormous potential for data to improve the care that we all receive. For that to be realised patients will need to have confidence in how data about them is used. DHSC commissioned the Patients Association to explore what role a data pact could play in improving confidence and what approach should be taken.

The idea for a data pact emerged from the Government's *Data Saves Lives* strategy, which sets out plans to harness the potential of data. The pact was included as a commitment in the final version of the strategy following a period of public and stakeholder engagement on a draft in 2021.

Through these focus groups, we initially examined attitudes towards data sharing generally, as well for specific uses of data, before focussing on the implications and expectations of a data pact. The feedback and information presented in this report is based on the insights that participants gave us.

These were insights were gathered over the course of three focus groups which ran through May and June 2023. The Patients Association recruited a diverse group of participants according to age, gender, ethnicity and religion after seeking expressions of interest via an online survey.

Full details on the methodology used are included at the end of this report.

Aims and objectives

The data pact project delivered by the Patients Association and commissioned by the Department of Health and Social Care was launched to help shape the relationship between patients, their data, and the health and care system.

The research that underpins this report was designed to inform the development of a data pact. DHSC's aim in developing a data pact is to provide clarity to the public about what does and does not happen to health and social care data. Our research examined

what needs to be done to give the public confidence that the health and social care system is a trustworthy custodian of data. We set out to understand what concerns and expectations participants had about the use of data.

This report will inform the initial development of a data pact by DHSC and future larger-scale public engagement on this topic. We hope that our findings can also shape the thinking on the use of data across different programmes in the future.

Findings

Attitudes towards a data pact and data sharing

In our first session many participants were sceptical about the value of a pact. For some that opinion was unchanged throughout. For others, as our conversation continued across the three focus groups, there were numerous themes and areas that emerged where a pact or similar could provide a valuable starting point for beginning to improve patient trust and confidence.

We heard contrasting views amongst the cohort, some participants already understood the current system, whilst others remained unclear about how elements of it worked after reviewing the pre-reading sent in advance to participants. The system described in the information that participants received did not reflect the one that some of our group had experienced.

The majority of the group were extremely positive about the potential for data use. Some were happy for their data to be used in any circumstances by whoever needs it. The potential for data to improve their care and that which other patients receive was universally understood.

Patients sharing their data to help others and improve services was also presented as a responsibility. Despite participants having concerns, they recognised that putting obstacles in the way of data use could ultimately be damaging to themselves and their wider community.

'I don't agree with the term pact and I'm very worried about it. It is a unilateral concession by DHSC.'

'The patients I know are perfectly happy about how data are used currently if anonymised. Create a channel of information for patients about how the system works, including complaints, based on a Q and A. That way it would be clear how things operate for those that are concerned.'

'I don't feel we were given clear information about opt-in and opt-out.'

'I'm concerned about who will have access to my data and how it might be used.'

'I'm struggling to understand why anyone would opt out because to me the benefits of data sharing are so big?'

'Data sharing is so important for all of us. The potential for diagnostics could change the world.'

'We have a responsibility as patients to use our information to improve care for others.'

'I'm very pro data sharing, at all levels and with any organisation that needs to see it.'

'We have to share more data to improve the links between primary and secondary care. If we don't feed algorithms with more data, they can't improve care.'

'I am concerned that putting in place all these barriers around asking people to opt-in and out are going to prevent us from using data to help people. We will slow progress down.'

'After reading the information I felt comfortable with how data could be shared. It's particularly important for carers.'

Many participants had similar attitudes towards their data being used in the health and care system across all of the different potential uses we discussed. However, there were also some contributions that applied to specific uses. In the following section, we explore the discussion the group had on the different specific uses of data.

- **Direct care:** using patient data to improve the care that individual care patients themselves receive.
- **Planning and service improvement:** using patient data to improve how services are planned, delivered, and improved.
- **Population health:** using patient data to improve the quality of health of the wider population or specific groups of people.
- **Research and innovation:** using patient data to develop new drugs and treatments.

Attitudes towards the different uses of data

Direct care

The focus group participants were universally positive about data sharing for direct care and understood how the system works. They recognised the improvements it makes to their care, how safely it is delivered, and that it can avoid patients having to repeat themselves.

They firmly believed that responsibility for sharing this information should be placed on the NHS because of the medical understanding needed to explain and utilise it. It can also be difficult and traumatic for patients to repeatedly remember and explain information to different clinicians.

Participants wanted to know who had seen and used their data, as well as what outcomes it had led to, as part of a feedback loop. They felt that data sharing should happen but only as clinically necessary to provide care.

'I'm very clear about how my data is used for my direct care.'

'It's dangerous not to share because it may result in being given the wrong treatment. It shouldn't require consent.'

'I had a heart operation a few weeks ago. Without data about me it wouldn't have been able to take place.'

'I'm all for it. It can join up care and is absolutely essential.'

'I don't want to have to remember and repeat complicated medical info about myself to different consultants. It can be upsetting and traumatic.'

'The responsibilities about data should be with healthcare professionals because they have the knowledge about a patient's morbidities, and implications for new treatments.'

'Because the appointments are so short it's hard to get everything across yourself if one consultant has said to ask the next consultant something about a different condition. You can't always do this and ask the questions you had yourself.'

'It's a pain to keep on having to repeat information.'

'I'd feel happier with a feedback loop. I would like to be able to see who could see and had used what.'

'Some aspects of personal care are very sensitive to the individual and may need some protective exclusions.'

'My dentist doesn't need to know everything my hospital consultant knows.'

Planning and service improvement

During the discussion on data use for planning and service improvement, the need to use simple terminology in any data pact was made clear. Participants felt that most members of the public will not be aware of the role of organisations such as the Care Quality Commission and NHS England. This will require explanation in advance of describing their role.

Some participants felt that more information on the practical steps organisations take and how they use data here should be made clear. Overall, the group was once again very supportive of data being used to plan and improve services, particularly as it can improve care for patients who are disadvantaged. They placed value on patients been told how their data has been used here and felt this could help increase public support.

'We need to explain to people how this works. Most don't have the vaguest idea, or what the organisations mentioned in the pre-reading are.'

'As it stands, the pre-reading just tells me nothing except that if the CQC is worried, it does something.'

'It's hard to see how anyone would object to this in principle if they understood it.'

'I have no objection to my anonymised data being shared. If this method is explained to people, it will be a really good way of moving forward and I think there would be support.'

'I am comfortable with my data being used for this. People want to know how other patients benefit. It can reduce costs, inequalities, and duplication, and I'm good for that.'

Population health

The group cited several examples they had seen of data use to improve population health and were again positive of the principle. Given the way data was used for population health during the pandemic, they felt there is likely to be significant public interest in similar future uses.

The group felt that a lot of engagement on data use for population health would be needed at local level, using the principles of co-production to look at the details. The risk of the commercialisation of data was flagged during the conversation on population health, which needs to be addressed to ensure public confidence in data use for this purpose.

'I can think of 3 or 4 examples where I live. Data from GPs surgeries is used to target patients who are at higher risk of different types of conditions.'

'There will be a lot of public interest in data after covid. We came together to address the biggest problem of our lives. People will be very interested in how data can be used to improve our population health as a result. Use of data just needs to be safe, confidential, and it has to be clear who uses it, and to what end.'

'It's very important to take co-production into the community here. During covid we used that to address vaccine hesitancy, but now it's being used on health inequalities, and to inform things like mobile clinics.'

'Keep information, short, sweet and easy. With some concerns, people will be supportive of their data being used, but a lot of engagement on how that looks needs to be done at a local level.'

'Commercialisation of data is possible through phrases like population health, such as emails from online pharmacists and gyms. Companies impersonated surgeries during the pandemic after getting hold of our data from the NHS somehow. Support for data use for population health could decline if things like that continue.'

Research and Innovation

One of the significant distinctions during the discussion on research and innovation was the need to differentiate between studies that people have chosen to become part of, and where patient data is used without their consent being sought.

Significant public interest is likely to lie in the breakthroughs that emerge as a result of data use for research and innovation, when these come from trusted sources. This is also an important part of tackling misinformation. Examples of important research

projects were given that could help persuade the public of the value of and trust in data use for research and innovation if they are publicised.

When research has improved care or treatments for specific groups of patients, it is important that they receive targeted communications so they can see the benefits. We also heard the view that relying too heavily on patient understanding and consent in research and innovation can be damaging to patients in the long term.

'One the examples in the pre-reading talked about people being recruited to studies, another example talked about data being used without people being asked. I think the big question is what will happen to data and how will it be used where people don't come back to you on it. That's a very important distinction.'

'The Moorfields example is an important one to follow. I have been involved with something similar. Having patients on a supervisory committee is an important way forward. Patients having input at every stage is needed as you can't think over everything in advance.'

'If we could show people are doing research on things that may affect particular groups of people, we should publicise this and say 'this will affect people like you'. This is particularly important in big data trawls, with millions of people involved, where it isn't practical to ask them all.'

'The Born in Bradford project involves 35,000 children. The purpose is to target kids with early stage autism. It will end up being nationwide. This is a great example of data use.'

'One of the things we need to do is broadcast the many successes we've had. The UK Biobank has been a huge success.'

'Patients tend to be focused on their own interests and protection. I don't think the public would want to be made aware once generic permission has been granted, but publicising breakthroughs would be well received, when presented by knowledgeable clinicians.'

'I think there is too much emphasis on patients and their understanding and permissions. GPs are failing to take part in enough trials. If the NHS doesn't give them support, the UK loses out as drugs are developed abroad, which costs us more in the long run.'

'When I worked in Data and Analytics there were so many things we could have done with data to improve patient care, but we were hampered by data protection regulations.'

In the next section of this report we explore the general attitudes participants displayed towards data. Most have direct implications for a data pact and what it should cover. Others would require action outside the scope of this project to be delivered. All of them point how patient trust and confidence can be improved in the short and long term.

Considerations when developing and publishing the data pact

Contextual factors

Data, the NHS, and the private sector

The relationship between the NHS and the private sector and its implications for data use came up in several conversations the group had. Participants felt that there is a particular lack of clarity here. Whilst in many cases the sharing of data here may be a perfectly legitimate part of care, where the line between this and commercial use of information sits needs to be explained.

Others felt that across the board, the NHS exists in a commercial environment, and the implications needs to be explained to patients. We also heard of an example of where the NHS and private sector had failed to communicate and share data where appropriate, despite the opportunity for a private referral being presented by the NHS.

'A lot of services within the NHS have always been delivered by private companies. That needs to be more upfront. What is and isn't it legitimate for them to do with data? I think people are worried that if they are suffering from a condition, someone might come along and try to sell them something.'

'GP surgeries get people from pharmaceutical companies to review people who are prescribed their medication. They stand to make more money, but at the same time the NHS has already decided the medicine is appropriate.'

'I had a surgery with a private provider. The subsequent information was not shared with my GP and I had to chase them several times. My surgery couldn't see the data and felt it was none of their business as I decided to take a private option, even though it was offered by the NHS. I had to call the ward to speak to the surgeon who did the operation. It was all my responsibility.'

'Medicine reviews can be done by pharmacists. People will be worried they will try and sell them something. I don't think that's true but people need to be told. They need to know that if they take a medicine, it's a commercial product, and it's proper for people to look at the impact of the medications they produce.'

'These issues apply across the board – because the NHS exists in a commercial environment – and we need to be clear with people about what that means.'

'I'm thinking of sight and hearing. Opticians will approach people on the basis of referrals from the NHS, legitimately, because they have been asked to do a procedure.'

'If we outsource certain duties in the NHS, there will always be people trying to sell you things.'

'I'm happy with the idea that my patient data could be used by commercial companies, if I was given the opportunity to consent.'

The importance of consent

Despite the positive attitudes, the support participants displayed towards data sharing did not come without expectations from the health and care system. The most crucial of these was the importance of patient consent as a key part of trust. Some felt that this should apply across all uses of data.

Participants understood that individual consent is not sought in some use cases, and instead implied consent is relied upon, for example data sharing for their direct care operates on a model of implied consent, to provide the most effective and efficient level of care.

For the majority this was about setting out clearly how consent works for the different types of types of data use and ensuring it is sought as appropriate on a case-by-case basis. The intention behind this was not to make the use of data more complex, but providing reasonable information to patients.

Participants saw value in a system of rolling consent, with patients being informed when their data has been used for the uses they have agreed to, for what purposes, and who has used the data. Fundamentally, the group felt that their data belongs to them, rather than to the health and care system. The ability to access information themselves was important to the group.

When consent is sought from patients early on in their care, it can be an important part of securing their support for their data to be used in the health and care system. Conversely, seeking consent without giving that clarity, or doing so accompanied with a veiled threat, was seen as counterproductive.

'Health data are the most private thing about us. It would be terrible if we didn't know or consent when it was shared.'

'It is paramount to have individual consent.'

'We need more detail on who can access our data and under what circumstances.'

'I don't feel patients and carers have ever been offered the option to opt in or opt out.'

'How often will the authorities ask us for consent on data sharing? Who should we reach out to if we change our mind? Making things clearer might change people's point of view.'

'If I can check the information myself, I can check whether it is being used and shared.'

'It's important to record what info is available and how it's used.'

'It boils down to who can share your health history. It needs to be set out clearly who can and can't see your data.'

'I think we can update patients about this regularly. We get regular text messages from GPs and hospitals. Perhaps we could do reminder notifications for patients about consent.'

'It's not so much about rolling consent for me, it's about rolling reminders. Every few years you should get a reminder that these are the sort of data that can be used, specifying purposes, with what you can do if you want to opt-in or out.'

'The advantage of continually updated NHS records is that these notes and reminders can be put in place. People change as well as technology, and this should be reflected.'

'People still regard their data as theirs rather than it belonging to the NHS.'

'A pact won't mean anything if I can't influence what happens to the data about me.'

'It suggests a commitment between me and my GP but it means nothing if I don't know what data it covers and how up to date it is.'

'Spending a couple of moments with a patient early on can make a massive difference to the care they get if they are told about the benefit of giving consent. Sometimes patients get a tick box saying 'are you happy to share this information' with no narrative about how or why. When you take a moment to explain that to them, almost all of them say that they are happy to do it.'

'A few years ago there was a form about data we were told to take to our GP quickly. It didn't mention any detail at all, it was just about being data being used. If you didn't put the form and give consent it was implied your data could be sold on.'

The quality of data

Participants felt that for the potential of data use to be realised, the data itself needs to be of better quality. They described several instances where the quality of data recorded was poor, and in turn the impact of being shared was lacking. Several participants questioned the quality of things like Summary Care Records (SCRs) and queried why they have still experience difficulties in accessing and getting information shared between clinicians if they are in place.

Clinicians can also struggle to understand what data means and to assess its implications when data quality is poor. Potential benefits are lost and it can fall on patients to fill in the gaps. Participants saw huge potential for data sharing to join primary and secondary care, but this is often not realised.

Whilst in part they felt this is due to the quality of data, it is also about the infrastructure that facilitates how data is shared. All of this contributes to a climate of distrust, as well as to additional costs and poorer outcomes for patients.

'The number one priority for me is the quality of SCR. This is not updated by clinicians often so is not always accurate or written in consistent language. How do patients check this? Why is there often no information from secondary care?'

'SCRs are not consistent and people don't know what they contain.'

'If the SCR has been about for a while, why is it that carers are still having the burden of frequently explaining details of their loved one to every health and care professional they come across?'

'Lack of understanding by professionals about data sharing increases mistrust.'

'If GPs took more notice of their own data, would this stop them duplicating contact with patients when they already have info from secondary care relating to the patient's condition?'

'There is also an enormous cost implication if patient data are not available to secondary care clinicians. Patients will spend longer in A&E while doctors have to take new tests with no baseline reference concerning their usual health.'

'The most interesting part about Data Saves Lives was about the data architecture right. This should be at the top. If we get that right, a pact would have more value, but so much time is wasted because it isn't in place currently.'

'Some people have to go to 5 different hospitals. Without data being shared it would rely on the patient to keep track.'

'There is a total failure of inputting between primary and secondary care and it must be addressed. Patients shouldn't have to run around and make sense of or obtain sketchy forms from hard pressed consultants to pass on to GPs who don't have enough context to make sense of the data.'

'We can't just focus on GP practices. Other people rely much more on other parts of the NHS than their GP.'

'I agree that researchers and drug companies should have access to data but this NHS is very poor at recording it.'

Scope, development and content of the pact

The name of a data pact

Our group discussed the potential name for any agreement. All participants felt that the term data pact was inappropriate. Most of the opposition to this name centred on the idea that a pact is developed between two sides, but participants felt they were being told what to expect. They are also recognised the challenges in establishing such an agreement, given the difference in size and scale between individual patients and the NHS as a whole.

Despite consensus that the term data pact was inappropriate, there was none on an alternative. Whilst several alternatives were suggested, broadly speaking there were two sets of views. On the one hand, some participants felt that agreement or partnership set a more collaborative tone, but this gave rise to what to the question of what role patients have and will play in establishing the rules and expectations it contains.

On the other hand, some participants felt that commitment was a more appropriate name as this was the health and care system setting out to patients what they should expect and how data are used. Yet for some participants, this felt an overly cold description. One participant felt no name should be given because neither the NHS nor patients yet understand enough about how data are used.

Because of the rejection by participants of the term data pact, and lack of consensus on alternative naming, this issue will need to be explored further in the next stages of public engagement, once a draft is available.

'It suggests a commitment between me and my GP but it means nothing if I don't know what data it covers and how up to date it is.'

'It implies an agreement but patients aren't agreeing to anything. They are simply being told by the NHS what the NHS will do with their data.'

'It doesn't sound like a partnership to me if I am one individual with no power, versus a huge organisation with all of it on the other.'

'The fundamental thing is that it must be consensual between two sides. That's incredibly difficult to do, as we're just individual patients within the whole machinery of the NHS. It's hard for people to feel an equal part of an agreement.'

'Sometimes staff just pay lip service to charters. Partnership seems more fitting given the scale of a potential partnerships between patients and the NHS.'

'Partnership is the only suggested name that implies a two-way channel of communication, but it raises questions that patient might ask like 'what partnership'?

'Speaking to other patients about this, they all said data commitment. It's one sided.'

'There isn't enough knowledge on either side. To rush now to an agreement or pact implies that we know a lot more about how data are being used than we do. My name would be 'not yet'?

The value of patient focused examples

The examples in the pre-reading set out the benefits to patients from data sharing were praised by the group. They felt that these could be an important part of explaining the current system and publicising the benefits of data sharing to patients as part of a data pact.

'Many people are suspicious about data sharing. More examples are needed of data sharing and the benefits it brings.'

'More patient focused examples like those in the pre-reading would be really helpful. In my area work has been done on the effect of vaccination and its take up among different ethnic groups. They now going around and talking to them. That is really powerful.'

Covering social care

The group had several concerns about social data being covered under the scope of a data pact. Some felt that all – or parts of it - should be excluded entirely. They felt that the NHS and social care measure and record according to different standards. Aside from these different standards, the NHS and social care also measure different things.

Participants felt that the NHS traditionally records information according to a medical model, whilst social care system measures a social one. Concerns were raised that inappropriate or inaccurate assessments of patients could be made because of these differences. Practical issues, such as how information could be shared easily across the two systems, were also raised.

'Social care is so different that I don't think most of it can be in the same agreement.'

'I have reservations about sharing with social care. I think social care and the NHS work on different standards. Thinking of dementia there is the medical model and the social model, and they aren't integrated at the moment.'

'People could be rejected from care homes because their data are misinterpreted. There is a massive gap between NHS data and social care data.'

'Data has to be seen and used honestly. If it isn't compatible, we need to be honest and transparent about that.'

'In social care settings at the moment the problem with getting data into the systems is the different programs used. It's hard to use data from GPs and turn it into something useful. The interpretation of the social care data isn't there yet.'

A legislative underpinning

As the group's conversation on the principle and nature of a data pact evolved, it became clear that there are things that it can and should do in a first step towards improve patient trust and confidence.

At the core of this was the need to set out the relationship between the current system, any commitments that are made in a data pact, and existing legislation. For patients to have faith in any pledges or guarantees, the pact will need to clearly reiterate how use of patient data is underpinned by legislation. Our participants felt this would give assurances that commitments are serious and long standing.

Although the group acknowledged that UK GDPR was not universally understood, it was most frequently cited as the best piece of legislation. In some cases, participants assumed data use in the health and social care system was already covered by GDPR. The Data Protection Act was also suggested.

'There be should legally enforceable ways of dealing with data issues, based on data protection law. A 'pact' implies something informal which is not the case with data issues. It's legally necessary to define it.'

'Why invent something new. Can't we use the Data Protection Act?.'

'GDPR is still my thing. There was a story recently about the NHS sharing data with Facebook without consent. How can we have trust when these things are happening already?'

'Sometimes it's hard to differentiate between the law and the government, but the law gives up a sense of hope. Governments can change their mind. It's harder to do that with the law.'

'I think we have to link this to GDPR. I don't think we have the time for new legislation when there are so many other challenges. I see no reason not to link this to existing protection.'

'I'm not sure there is any need for this further work on data sharing as I believe it's already covered by GDPR.'

Acknowledging an imperfect system

Another theme that emerged from the focus groups was that in setting out how the system of data use is supposed to work, it is also important to acknowledge that the system is imperfect and that sometimes things go wrong. Participants acknowledged that this will happen regardless of any rules that are place.

The group felt that setting out that the benefits of data sharing for patients could help outweigh the risks of potential breaches in the minds of the public. Part of setting out the risks is also acknowledging that in the wrong hands, patients can still potentially be identified even where their data is anonymised. This was all seen as part of being honest, transparent, and accountable in order to be trustworthy

'You have to earn trust by what you're doing and be honest about breaches.'

'Accidents with data will always happen. Laws don't prevent people from breaking them.'

'Being honest about the risks of breaches and showing the potential good can help outweigh concerns.'

'We need to be really transparent in any agreement that things can go wrong regardless of any rules. Being honest that these mistakes can happen, but setting out that in spite of that risk, data sharing continues to promote the greater good.'

'No data can be totally anonymised. Someone seeking to use it wrongly could identify you, and we need to accept and be open about that.'

Enforcement and monitoring, consequences and remedies

Alongside the need for a legislative underpinning, participants repeatedly expressed the importance of clarity on the consequences for any breaches. This should apply to remedies for the individual, action taken by or against the organisation responsible for following any breaches, and what will be done to prevent them happening again. For rights and promises to have value, they need to be monitored and overseen.

'I want a commitment that says what the mechanisms we can hold people against are.'

'The NHS constitution was launched with big fanfare a few years ago. It tells you about all the rights you have, but there are no remedies if these are breached. If people have rights, they need a remedy too.'

'Any commitment is only as good as its enforcement. We've had no real information on how enforcement is going to be improved and I think that's a fundamental point.'

'Who monitors the pact?'

'If we set out rights and commitments, consequences need to be clear.'

'There's need to be a mechanism to challenge any uses or sharing of information in a pact.'

'The other thing is where patients can go when they are not happy about how their data is handled. Somewhere they can make an inquiry or put a stop. If I'm not happy with how my data is being used, how quickly can I stop or escalate this.'

Approach to ongoing communication

Investing in communication

Most participants were keen for government and the NHS to invest time into explaining how data is used to patients, particularly as many will be starting from a position of little to no knowledge. This was part of giving confidence, but it was felt that previous attempts to explain the system had fallen flat.

Without that confidence, the group felt that patients may withdraw their consent due to fear of inappropriate uses. However it should be noted again that consent is not required for direct care purposes, and implied consent is the main legal basis for appropriate professionals to access people's confidential information. The public have the choices, to limit the use of data about them for secondary use purposes (e.g. research and planning) via the National Data Opt-Out.

This concern was particularly acute for certain communities. The group felt that the system needed to be explained in simple language, but recognised the challenges in communicating a complicated message in this way. They also understood that a data pact itself could not cover everything.

The information available on the NHS App was praised by several participants and it seen as a starting point for hosting a pact by many, though concerns were raised about digital poverty. Online and traditional media can both help inform patients, as can information available in services themselves.

A pact would also need to be accessible to all to ensure that everyone is included. The information in it will need to feel relevant to individual patients. Participants cited Integrated Care Boards (ICBs) and Primary Care Networks (PCN) as being structures within the health and care system that could help inform patients.

'The last attempt to do this – the NHS National Programme for IT – was cobbled together and counterproductive. If you want to communicate a complicated message, you need to spend

time doing that in different ways, using different methods, and different languages. GP surgeries, websites, local radio – take it seriously.'

'I'm worried about people who are going to be anxious about their data being misused. If they drop out, it undermines the point of the exercise.'

'We need to remember about ICBs. They have Engagement Officers. They should take responsibility for disseminating this information.'

'Primary Care Networks can also be a great method to spread the message on data use.'

'From my experience In the South Asian community, there is a lot of mistrust and misinformation that goes around via WhatsApp about how your data are used. It needs to be really clear, easy to understand, and written in lay terms.'

'Community and faith groups are a really important way of countering misinformation.'

'I just want to make the point again about reaching out to people from marginalised groups. Those from low socio-economic backgrounds, people of colour, immigrants, travellers, homelessness people. Those who are not captured automatically.'

'We also need to communicate not only broadly, but more importantly specifically with people with specific backgrounds and conditions.'

'The NHS App already prefaces use with info about agreeing to data being used. The pact could be put there.'

'Don't forget digital poverty. The NHS App may be our first solution, but it's not the be all and end all.'

'A few lines on the GP practice website pointing people to an expert within surgeries could help. There will always be people who won't be reach but we must try.'

'How flexible and personalised will the data pact be? Some people have sensory and cognitive impairments. How can we make it relevant and applicable to everyone?'

'The information needs to be made relevant to individuals in order to grab their attention.'

The evolution of data use

Participants recognised not only the potential for data use, but also that this will evolve over time. They felt that a data pact should come with an accompanying commitment that it will be reviewed over time as things change. The group felt that patients should have a say in the issues around how data is used in future as possibilities change, including through, for example, a citizen's jury.

'Data will change how we use the NHS and our lives. We need to make the importance of this clear. It can't be emphasised enough how big this is.'

'It isn't just about future engagement on the product, it's about a commitment to revise it as the way data are used when things change. Things like AI come along which wouldn't have

been relevant 5 years ago but are now. An agreement can't be set in stone. It needs an explicit provision for being rethought and rediscussed at fairly regular intervals.'

'There needs to be constant monitoring because the way data is used is always changing. Large data sets didn't really exist 5-10 years ago.'

'There needs to be wider public engagement about this through a citizen's jury.'

Conclusions

The findings of our research point to a clear path for the relationship between patients, their data, and the health and social care system both in the short and long term. It is clear that transparency, honesty, a flow of information to and from the patient, and ensuring that the system works as described will be at the heart of this.

There is scepticism around these issues as things stand. This does not mean that patients are against the use of their data. On the contrary, the patients involved in our research understood the potential for the use of their data, and wanted that to be realised.

A data pact will not be a panacea, but for some patients, particularly those with little or no knowledge, it can be a first step. Explaining the benefits of data sharing and reaching as many people as possible can reduce the levels of mistrust and scepticism that currently exist. Patient focused examples and simple language should be at the heart of this.

In explaining the system, the data pact should do so honestly. The system of data use as described is not always the one that exists for a patient in reality. A data pact should be clear that the use of patient data is a journey that we are only at the beginning of and we do not yet know where it will go. In the meantime, mistakes will be made. Not acknowledging this will be counterproductive. It will also need to be clear to patients that as the potential for data use changes over time, so will the commitments that the system makes to patients.

To improve trust and confidence the commitments a data pact makes will need to be long-term to be meaningful to patients. It will need to set out how the existing system is backed by existing legislation, particularly GDPR. It should also be clear about the consequences for any misuse of data for organisations involved and the steps taken to prevent them in future. The remedies available to patients and where they can go if they are concerned about the use of their data should be set out. To do all of this a data pact will need to be monitored and overseen.

The relationship between patient data and the private sector came up in several of our discussions on the different data uses. This will need to be covered in the pact if patients are to understand what they can expect here. The concerns about a data pact covering social care should also be acknowledged. Whilst our discussion on a potential name was inconclusive, it was clear that an alternative to data pact is needed.

Our research also uncovered several longer term issues that will need to be addressed to give patients confidence in the use of their data. Central to this was improving the quality of data collected within the health and care system and the ways in which it is shared.

Recommendations

The recommendations we make on the back of our research cover both those with implications for the development of a data pact, but also important areas of focus for improving the relationship between patients, their data, and the health and care system in the longer term.

Contextual factors

Bringing patients closer to their data: Seeking consent early and providing reminders, feedback and clear information to patients about their data were all shown to be key parts of building trust and confidence with patients. Failure to make patients feel closer to their care and build that into the fabric of the health and care system will limit the potential of what data can do. Suggestions to reference data on referrals to new services, more informed conversation between patients and clinicians, amendments to patient records and notes, rolling consent, and referencing letter patients receive were all made. These all come with different implications and more ideas would emerge if this question was examined in more detail. We believe that work is needed.

The relationship between the NHS, the private sector, and data: The data pact should outline the impact of the NHS' relationship with the private sector for data use. This should include where data sharing between the NHS and organisations that are partly or wholly commercial is a legitimate part of care, as well as what patients should expect if they are referred to a private provider through the NHS.

Improving the quality and use of Summary Care Records: Many participants felt that the potential of SCRs is not being properly utilised. The quality of data contained in them can be poor and it can fall on patients to fill the gaps. Some participants were unaware of their existence, other relayed difficulties in getting them shared. Further work is needed to understand why the quality of SCRs and how widely they are used varies. This should be done with a view to better harnessing the ability of SCRs to improve care.

The need to improve connectivity between primary and secondary care: We heard many examples of difficulties patients had in receiving joined up care between primary and secondary services. Whilst part of SCRs are part of this, we need a deeper understanding of how data can be used this connectivity for patients.

Scope, development and content of the pact

Naming a data pact: Data Pact was deemed as an inappropriate name in our research. Whilst several alternatives were suggested agreement or partnership and commitment received most support, for different reasons. We recommend that these options are tested further in the next stage of public engagement.

Testing the use of language: The exact use of the language the pact contains should be tested during future engagement with a willingness to simplify it based on the feedback received. If a lack of health literacy prevents patients from understanding the way data is used, benefits will be lost. Given the different views and level of understanding on opt-outs and the system of consent identified in our research, these areas should also be explicitly covered.

Remedies available to patients and the consequences for organisations: The existing mechanisms available to patients if they believe data has been misused should be clearly explained, including where they can go to make a complaint, as well as how inappropriate uses can be challenged. The consequences (under existing laws and regulations) for any organisations responsible for any misuses and any steps that are taken to prevent them happening again should be clearly set out.

Directly addressing the questions patients have: A data pact should directly address the questions that patients have about data. We recommend that the next stage of public engagement seeks to identify these and answers them in the final version of the data pact.

An acknowledgment that the system is imperfect and will continue to evolve: In setting out the potential for data use in the health and care system, a data pact should acknowledge that mistakes and breaches can and do happen, as well as any risks of patients being identified. A data pact should also recognise the ways data are and can be used will change, with an accompanying pledge for it to be reviewed regularly. Patients should be part of that conversation.

Linking the data pact to existing legislation: How the use of NHS data links to existing legislation, such as UK GDPR regulations and the Data Protection Act, should be clearly explained. Legal protections will be needed to give patients confidence that any commitments a data pact makes are being taken seriously.

Clarity on monitoring and enforcement: A data pact should set out how the use of patient data is monitored and how the principles that underpin it are enforced.

Including patient focused examples in a data pact: Showing the benefits that data sharing can have for other patients will be an important part of ensuring public support for its use. Patient focused examples should be used to do this in a data pact.

The inclusion of adult social care in a data pact: Many participants were sceptical about the inclusion of social care with a data pact. If DHSC decides include social care

within the scope of the pact, it should acknowledge where the gaps between social care and NHS data lie, their implications for data sharing, and how they will be addressed.

Approach to ongoing communications and engagement

Further engagement with the public on the data pact is needed: We welcome DHSC's intention to conduct further public engagement on the introduction of a data pact. We recommend that an initial draft is developed on the basis of this research and shared with future cohorts for review, amendment and confirmation. We recognise the challenge in balancing the need to keep a data pact short and simple enough to be accessible, but also substantive enough to be insightful. We recommend that this balance is refined over the next stage of public engagement.

Sharing the data pact on the NHS App: The final version of the data pact should be publicised on the NHS App, given the potential the platform has to reach large numbers of patients.

Ensuring the data pact reaches as many people as possible: Those who are digitally excluded, as well as those from marginalised or disadvantaged groups, should also understand the information contained in a data pact. This will mean making it available in formats such as easy read and different languages. It should also be promoted through existing structures in the health and care system, such as PCNs and ICBs, and accessible through services themselves.

Appendices

Methodology

The Patients Association recruited for this project via an expression of interest form publicised in the weekly email newsletter. 115 expressions of interest were received and following vetting phone calls, 12 participants were recruited to participate in 3 online focus groups, held on Zoom, across May and June 2023. These focus groups covered different topics related to the subject our research covered.

Due to health issues one participant was due to contribute via written submissions and follow-up conversations for the first two groups, before joining in person at the final group. In the end they were unable to take part in the project. One participant was unable to join the second and third group due to a change in personal circumstances, and another was unable to participate in the third group. Two other participants contributed to one of the sessions via written submissions and follow up conversations. All participants were given the opportunity to comment on a draft of this report prior to publication.

Our participants experienced a range of health issues. These included musculoskeletal problems, pain and fatigue, mental, behavioural, and neurodevelopmental conditions, sight problems, asthma and diabetes, as well as blood and heart problems. Many were

active patient representatives in their communities and three had caring responsibilities. Demographic information on our sample is provided below.

Gender	
Male	5
Female	6

Age	
25 - 49	4
50 - 64	1
65 - 79	5
80+	1

Ethnicity	
White British	4
White British / Polish Jewish	1
White other	3
Black African	1
Asian / British Asian - Bangladeshi	1
Asian / British Asian – Indian	1

Religion	
Christian	3
Muslim	3
Jewish	1
No religion	4

Over the course of the three focus groups we ran, we covered a number of topics related to a data pact and the relationship between patients, their data, and the health and care system. These included:

- Expectations of a data pact: Including what the term pact means, whether a pact would be helpful and can build trust, responsibilities for patients, and how it should be communicated.
- The content and commitments of a data pact: the material it should cover, the commitments it could make, and how the public should be informed and engaged.
- Different uses of patient data: direct care, planning and service improvement, population health, and research and innovation were all discussed. We explored specific commitments for each of these uses, as well as those that apply across the board. Attitudes towards patient data being used for each of these uses, the

level of public interest in each of them, and how to improve understanding were also discussed. Social care was also included in these conversations.

The findings of our research are presented in this report thematically based on discussion across the three focus groups. The text of our recruitment survey is included below.

Your chance to help shape the future of patient health and care data

Thank you for your interest in working with the Patients Association.

We are about to embark on an exciting new project with the Department of Health and Social Care that will help shape how patient data is used in future.

The use of NHS data was a crucial part of the fight against Covid-19. Looking ahead, how the health and social care system uses patient data will be a key part of the future challenges we face. At the same time, the public need to have confidence in how their data is used to improve the care that they and others receive.

This is your chance to shape the agreement with that is made with the public on how patient data is used. Over the next few months the Patients Association will be holding 3 focus groups with the same participants to have a detailed conversation on this topic.

We will be examining issues such as the challenges and concerns people have over data use, the different ways data could be used, and how all of this impacts the data pact that will be in place with the public.

Full details will be shared with all focus group participants. All the information participants share with us will be anonymous. Every participant will receive a voucher worth £80 for participating in each focus group, as well as £60 per session to cover carers costs if relevant.

We hope you will join us in our work on this vital topic.

If you'd like to register your interest for this project, please complete the form below.

Your name
<input type="text"/>

Your email address
<input type="text"/>

Please complete the below questions on your potential availability for the 3 focus groups and tick as many as apply. We will confirm all details at a later date.

Your availability for the focus group 1

Thursday 27 th April AM
Thursday 27 th April PM
Friday 28 th April AM
Friday 28 th April PM
Tuesday 2 nd May AM
Tuesday 2 nd May PM

Your availability for the focus group 2
Wednesday 17 th May AM
Wednesday 17 th May PM
Thursday 18 th May AM
Thursday 18 th May PM
Friday 19 th May AM
Friday 19 th May PM

Your availability for the focus group 3
Monday 5 th June AM
Monday 5 th June PM
Tuesday 6 th June AM
Tuesday 6 th June PM
Wednesday 7 th June AM
Wednesday 7 th June PM

Age
Under 18
18-24
25-49
50-64
65-79
over 80
Not known
Prefer not to answer

Sexual Orientation
Heterosexual
Gay
Lesbian
Bisexual
Asexual

Pansexual
Prefer not to say
Not known
Other Sexual orientation not listed (please specify)

Carer
Yes
No
Prefer not to say
Not sure

Gender
Male
Female
Non-Binary/Third Gender
Not-known
Prefer not to say
Prefer to self-describe (please specify)

Same at birth?
Yes
No
Not known
Prefer not to say

Ethnicity
White English/Welsh/Scottish/Northern Irish/British
White Irish
White Other
Mixed/multiple - White and Black Caribbean
Mixed/multiple - White and Black African
Mixed/multiple - White and Asian
Asian/British Asian - Indian
Asian/British Asian - Pakistani
Asian/British Asian - Bangladeshi
Asian/British Asian - Chinese
Black African
Black Caribbean
Black British
Any other ethnic group or background,
Prefer not to say

Don't know

Geography
East Midlands
East of England
London
North East
North West
South East
South West
West Midlands
Yorkshire and Humberside
Wales
Northern Ireland
Scotland
Outside the UK

Religion
Buddhist
Christian
Hindu
Jewish
Muslim
Sikh
No religion
Prefer not to say
Other religion

Disability
Learning disability e.g. dyslexia and dyspraxia
Autism
Both
Neither
Any other disabilities:
Yes (no specificity)
No
Yes, physical impairment e.g. mobility difficulties
Yes, sensory impairment e.g. hearing or sight
Yes, mental health conditions e.g. depression or obsessive-compulsive disorders

Yes, genetic and progressive conditions e.g. motor neurone disease or muscular dystrophy
Yes, conditions characterised by a number of cumulative effects e.g. pain or fatigue
Yes, hidden impairments e.g. asthma or diabetes
Yes, history of impairment e.g. no longer disabled but met the definition in the past.