Understanding public expectations of the use of health and care data

July 2019

Foreword

Understanding Patient Data is delighted to welcome this timely report, which provides detailed insights into what is known about people's expectations and attitudes to the use of health and care data. It offers a unique contribution to our knowledge and understanding, that will be critical in ensuring that OneLondon and other Local Health and Care Record Exemplars (LHCRE) build meaningful engagement and involvement of their communities into their plans right at the outset.

From our perspective, one of the most powerful insights from this report is the profound impact that clarity and transparency can have on people's views and expectations. Transparency can mean different things to different people but boils down to "do what you say and say what you do". It is a cornerstone of building a trustworthy system that people can scrutinise and get clear, meaningful, consistent answers to questions and concerns they may have.

While the local health and care record is undoubtedly complex to implement in practice, there should be no barrier to providing straightforward and comprehensive answers about why, by whom and how patient data is collected, managed, protected and used. Ideally this would be informed by meaningful engagement with patients and publics as those with rights and interests over the data. The push for transparency can also shed light on tricky issues that decision-makers need to be publicly accountable for, such as the balance between local and national-level benefits and what role commercial organisations can or should play in using data to improve care and services.

The report cites that previous engagement and research has tended to focus on perceived benefits and risks of data access and use, but has yet to explore how publics might balance these within the constraints of how health systems and research operates in practice. Exploration of such trade-offs would be a hugely useful next step in deepening our understanding of how public institutions build trust and confidence with their local populations.

It is striking that little attention has been paid to date on people's views of data use for service planning, given that this is a major area of potential for improving the efficiency, effectiveness and operational functioning of health and care services. There may be ethically difficult trade-offs to make here, between the rights and interests of individuals, communities and the health service, so it is

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important for OneLondon to further explore what people – patients, publics and health professionals – consider is reasonable in these contexts.
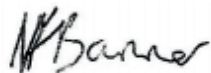
The report also surfaces significant gaps in our understanding of people's views, most notably around the perspectives of minority and marginalised groups. Given the diversity of London's population, this is concerning as it suggests there are significant communities or groups whose attitudes and expectations about data use are invisible to decision-makers. Some groups may have good reason to feel distrustful of the health and social care system and be inherently concerned that data about them could be used to target or discriminate against them. It will be imperative for OneLondon to think carefully about how to reach and work with these seldom-listened to groups if it is to create a LHCR system that serves all Londoners fairly and equitably.

The findings also reveal a healthy degree of scepticism among publics about whether the proclaimed benefits of better data use are actually realised in practice. It is incumbent upon those managing and using data to describe a clear trajectory from the collection of data to delivery of benefits. Without this, the public will have every reason to question whether the case for using data beyond individual care really stacks up.

Understanding Patient Data

Foreword

While research purposes are not the central focus of the OneLondon LHCRE programme, they will be vital to explore as part of the patient and public engagement work. Improvements in care often do depend on research, whether into demographic differences in diseases, drug safety monitoring or learning about the biological risk factors for different conditions. Research is critical to the development of learning health systems; we should not shy away from engaging with patients and publics about this if we are to create more responsive services that better meet the needs of patients and the health and care workforce.

This report makes for essential reading for all those involved in the development of the LHCRE programme, both at local and national level, and for other programmes and organisations that manage and use patient information. Many people talk about the importance of public trust as essential for underpinning exciting new innovations in data integration and use. Trust can only be earned, and that starts with understanding what people think, want and expect. This report shows us the steps that need to be taken to put the rhetoric on trust into practice and make trustworthy care record systems a reality.

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Understanding Patient Data

OneLondon response

Response from OneLondon Local Health and Care Record Exemplar

Local health and care systems across London are working together - as part of the OneLondon programme - to improve how health and care services are delivered and experienced. In part, this is about making health and care information more consistent, more joined-up and more available to the clinicians, patients and families who need it.

As one of the country's first Local Health and Care Record Exemplars (LHCREs) - designated by NHS England - OneLondon is helping to meet Londoners' expectations of a 21st Century health and care system.

There are significant benefits to be realised from joining up health and care information, for example, better integration of care, reduced risk of errors and better planning of services to ensure Londoners' needs are met.

Whilst the benefits of joining up information may be obvious to many, we cannot assume that the case has been made more broadly across our population. It is therefore vital that we engage with Londoners to understand exactly what people's expectations are; and to build trust, support and confidence amongst the public (and health and care professionals) about the use of health and care information for direct care delivery and for a range of other uses.

This independent research, authored by CurvedThinking and developed in collaboration with Understanding Patient Data, provides detailed insight into what is currently known about people's expectations and attitudes to the use of health and care data. In doing so, it also identifies the gaps in evidence and our understanding. The result is a unique contribution to a growing body of research which will not only inform OneLondon's wide-reaching engagement process, but can support the development of the LHCRE programme nationally.

The importance of building and maintaining public trust and confidence with regards to data use should not be underestimated. There are multiple factors that have confused debate around information sharing in the past. These range from genuine uncertainty from

data controllers, e.g. GPs; to broader implicit public assumption as to what is already happening. The scope for misunderstanding and cynicism is high, and therefore the need for clarity and transparency is crucial.

If we are to deliver the benefits of data sharing for Londoners, we must address this risk by avoiding past mistakes. We must not repeat the assumptions that bureaucratic conviction or political endorsement are alone sufficient. Both are necessary, but the most important factor will be to engender much wider understanding, support and confidence amongst the public and health and care professionals. To create and sustain legitimacy and trustworthiness, we must understand and respond to Londoners' expectations around data sharing for multiple purposes, and ensure we operate in line with these expectations.

As an example, one of the most notable findings detailed in the report is the strong expectation of Londoners that their information should be available to clinicians at the point of care to support their individual care. OneLondon is therefore expediating this work, with implementation over the course of 2019/20. This is great news for both citizens and health and care professionals, and will bring significant benefits.

For example, an elderly woman living in south London who presents at a north London A&E can be treated safely and efficiently after access to her patient record identifies her current medication and multiple long-term conditions. A GP treating a young teenager who has recently moved from Hammersmith to Hackney can see that he's previously been affected by mental health challenges, and can provide the best care without the patient having to re-tell his story.

Whilst Londoners' expectations around using data to support their individual care are clear, what's less understood - as evidenced in the report - is their expectations in relation to other uses of health information; for example, service planning or proactive care. OneLondon has an opportunity as part of its remit, to help develop the technical infrastructure required to support these secondary uses. However, we must fulfil this remit in line with Londoners' expectations. As such, we need to find out more.

OneLondon response

Previous public engagement has tended to focus on surfacing concerns or perceived benefits around information and data sharing. It hasn't focussed on what Londoners really expect of their health and care system, and what trade-offs people find agreeable in practice between benefits and concerns. To build trust and gain a clearer understanding, we need to engage Londoners in a meaningful conversation to surface these expectations and explore trade-offs.

This autumn, OneLondon's engagement programme will mobilise a different type of conversation with citizens and professionals: one that is open, honest and frank, one that doesn't shy away from the issues and complexities, but which embraces and respects them.

Working with the NHS and local government across London as well as the Greater London Authority (GLA), and the three Academic Health Science Networks, this programme will have significant reach across London.

As recommended by this report, we will have a focus on engaging with seldom-heard as well as vulnerable groups: these are the people who arguably have the most to gain from the OneLondon initiative, but whose voices historically have been too rarely heard.

With visible leadership from clinicians, regional NHS executives and the GLA, we will - for the first time - establish empirical evidence of the expectations of Londoners in this space, working with Londoners to shape 'the rules of the game' and to ensure that we proceed in a way which builds trustworthiness and confidence.

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Introduction

This work was commissioned to inform the development of the OneLondon Local Health and Care Record Exemplar. A central commitment is to involve Londoners in an authentic and purposeful process of engagement and deliberation to help design and develop an approach to the sharing of patient health and care information. The objective of OneLondon's engagement is to ensure that the Local Health and Care Record Exemplar operates in a way that is in line with the public's expectations of the appropriate functions of a health and care system.

To that end, this report collates and synthesises existing knowledge about public expectations and attitudes towards the sharing of patient health information. Our aim is to clarify:

- those things that can be said with some confidence about the public's expectations and attitudes towards the sharing of patient health information; and

- those areas where conclusions are much less certain in regard to the public's expectations and attitudes, and which should be a focus for OneLondon's next phases of public engagement and deliberation.

Our review highlights areas of significant consistency emerging from our review and stakeholder interviews in relation to public expectations and attitudes:

- The public has an expectation that patient health information will be shared for the purposes of individual direct care, with that information available to the full range of NHS clinicians; and research to date shows a degree of surprise amongst the public that this expectation is not routinely met. The literature consistently indicates that the public has an expectation that this will be executed in a way which is secure and proportionate.

- The evidence is consistently underdeveloped or equivocal in several other areas, and more specific work needs to be undertaken to explore the public's expectations about the use of patient health information by the NHS for the purposes of system planning and research. Deliberative exercises have shown that the public is more comfortable with secondary data sharing for research where it results in clear public benefit, but the evidence for system planning, and indeed what public benefit might be perceived as constituting in this context, has been far less investigated. Particularly for system planning, more specific exploration is needed of the underpinning values that inform expectations and the potential trade-offs that people would see as tolerable between increasing or restricting the sharing of patient health information, and the increases or decreases in public benefit (for example through effectiveness, efficiency or new knowledge creation) that are anticipated as a result of such sharing.

Summary

Setting the scene

Background

OneLondon aims to 'create an information sharing environment that helps our health and care services continually improve the treatments we use, ensures that care is tailored to the needs of each individual, and can empower people to look after themselves better and make informed choices about their own health and care'.

It will bring together existing patient information sources and sharing initiatives to create a unified health and care record for use in direct individual care; proactive care; system planning and, ultimately, research. Access by patients for their own self care is also expected.

This report summarises existing knowledge on public and professional attitudes around health information sharing and identifies gaps in our understanding.

Living in a world of data

We are all increasingly involved in the sharing of our personal data, much of it highly personal, and do not always have a choice over whether or not to share. The public's view is conflicted; many people say they are concerned about the security of their personal information, but behaviour does not necessarily match concern.

The public does not have a uniform view of the issues. Around a quarter of people seem to be unconcerned about the collection and use of personal information about them; another quarter are unwilling to provide it even for service enhancements; the remaining 50% of the population will make trade-offs on a case by case basis.

Citizens' relationship with the NHS can be seen as underpinned by the principles of reciprocity (a transactional exchange), solidarity (provision of care based on need) and altruism (generosity to others). All these play a role in attitudes towards the sharing of individual health and care information and the expectation and concerns that go along with it.

This report

This report highlights where the evidence presents a quite consistent picture on public attitudes and expectations around the sharing of patient health and care information for different purposes, and where it is less clear-cut. It discusses a few areas where the evidence suggests a difference between London and other areas of the UK, concluding with themes we feel could most usefully be explored with Londoners in the forthcoming dialogue.

The evidence used for the report is drawn from:

- a rapid literature review, including both formally published documents and relevant 'grey literature' and media reports, related to public and professional attitudes towards the sharing and use of patient health and care information.

- 27 interviews conducted with a cross section of key stakeholders across the five London Sustainability and Transformation Partnership (STP) areas. These individuals were identified as having experience of previous and existing information sharing initiatives with the objective of making best use of learning to date.

Summary

Care of the individual

Direct individual care

Most people expect their medical records to be available to the full range of NHS clinicians providing direct individual care. They know there are health records kept about them, and that this has been the case for years. Few people have any in-principle objection to this; on the contrary it is commonly seen as important and welcome

There is surprise that different health professionals in different places within the NHS are not already able to access health records for the purposes of individual care; the public widely assumes that it already happens. There is some evidence that heavier users of health services may be particularly supportive of health data sharing, due to their personal experiences.

Perceived personal benefits from health information sharing particularly relate to **avoiding the need for repetition** of their story to different healthcare professionals; better understanding of their **individual circumstances**; faster access **to key information in emergencies**; more **up to date records** for all those providing care; and **avoidance of repeat tests**.

Discrimination between different users of individual health records seems based on a combination of how close the user is perceived to be to the direct delivery of care, and the sensitivity of the information. **Few have problems with sharing amongst their NHS clinicians**, including ambulance staff, but have more caution around access by people outside clinical roles.

The public seem to have little understanding of the relationship between the NHS and Social Care services, meaning sharing with social workers is viewed with more caution. Some evidence suggests that higher awareness may be able to shift opinions, but **the understanding of the role of social care in health data sharing initiatives is poorly represented in the literature.**

Concerns and expectations

'The NHS' as a whole, is awarded high trust ratings to look after and use individuals' information well, despite people having little knowledge of how it is done. Nonetheless, reassurance on data protection is viewed as essential.

When asked, a variety of concerns are expressed by the public including hacking; data loss; inappropriate or malicious sharing; information 'being used against you'. Reassurance on the protection of the patient health information held in the shared record will be crucial to building trust in OneLondon.

Types of data most likely to be cited as sensitive, and therefore where the most caution should be exercised in terms of access, include those related to sexual health; mental health and history of substance misuse.

There are expectations that individuals should **know exactly what information will be made available** to users of shared data systems, and have the opportunity to **exercise some control over which items should be shared**, and with whom.

There is relatively little published evidence currently on **the actual views of those identified by others as most in need of protection**, vulnerable users of mental health services for example, as opposed to those speculating or speaking on their behalf.

In addition to the types of information to be shared, there are also concerns about **the quality of information in records**, and the implications of inaccuracies or out of date information being acted upon by those accessing them.

When offered the option, people seem to show **a high level of demand for, and expectation of, control over their individual health record**; what information is seen; how much of it; by whom; and in what circumstances. There is little exploration in the literature of details of how such control might feasibly be offered; nor how it might relate to the national Opt-Out; nor how people might trade-off perceived benefits of record sharing if the only technologically possible option for 'control' was a simple binary choice – 'in' or 'out'.

Summary

Care of the individual

Concerns and expectations (continued)

The wider the range of professionals who have access to a patient's data, the greater **the expectation that individuals should also have access to their own health records**, including to see what has been shared; to have some degree of control to add to, challenge or amend the content; and to express preferences for example over organ donation. Professionals generally welcome the principle, but have some concerns about the practical implications

Patient attitudes towards accessing their records specifically to support **self management of conditions is poorly represented in the literature**, but there are indications that it can work well for both patients and health and care professionals. Concern is occasionally expressed in published literature that some patients may feel under pressure to take on responsibility for managing their condition.

Proactive care

Proactive care is routinely discussed in the professional sphere but makes few appearances in literature concerning public attitudes. Some evidence points to **a generally positive stance towards identifying people for screening**; less for outreach to offer health advice. GPs are most often seen as the most appropriate people to make contact if 'unexpected' information is to be delivered.

More and better examples of proactive care are needed to tangibly express to the public what it might mean, and what potential benefits may be, and to test in more depth their attitudes and expectations in different situations.

Summary

Secondary uses in general

There is **much less evidence available on attitudes towards the secondary use of patient data for system planning** than for its use in research. Overall the public has little spontaneous understanding of potential secondary uses of health and care data, and struggles to distinguish between direct and secondary uses.

Where it is discussed in the literature, support for secondary uses of shared health data is shown to be **higher when the information is de-personalised**.

The public quite readily accept the need for data sharing **within the NHS**, but has little understanding of the role of bodies outside the NHS and is more suspicious of their involvement in secondary uses of data. This applies to local and central government; universities; the voluntary sector; and, especially, commercial organisations.

Views can become rather more positive with greater knowledge and deliberation. **A commitment to public benefit is likely to increase support**, and is key to increasing support for the use of shared health information for research, but has been little considered in engagement in relation to system planning.

Being clear about **specific secondary uses**, and providing examples that are tangible and meaningful to the wider public, is likely to gain more support than presenting it in a more abstract or generic way.

The **importance of clarity in the intended use of patient data was a consistent theme of the stakeholder interviews** amongst both professional staff and patient representatives, and identified as a possible weakness in the presentation of the Local Health and Care Record Exemplars to date. **Clarity about <u>intended</u> use, and transparency around <u>actual</u> use of patient data were reasonable expectations** that should be built into the OneLondon engagement process from the earliest possible stage. This was felt important for the record overall, but especially for secondary uses of patient data.

Systems planning

The secondary use of patient data for systems planning, has been less explored in research to date and usually only in quite abstract terms referring, for example, to 'service provision'. Tangible, meaningful examples

of what effective planning by the health and care system might be, and the role that aggregated patient information plays in delivering it, will be needed if public attitudes and expectations towards the sharing of data for this purpose are to be understood. Currently this is a gap in existing published information and therefore an important area for further exploration and engagement.

Amongst stakeholders, those expressing most doubt about the ambitions of OneLondon overall were particularly likely to **focus questions and criticism on what they perceived as the current lack of clarity about how patient data overtly collected for the purpose of improving direct individual care might also be used for secondary purposes** that people would find less acceptable.

However, the majority of stakeholders interviewed were far from being completely negative about the secondary use of patient data for system planning; **many could see significant potential benefits leading to genuine improvement in overall healthcare provision.**

Research

A large proportion of the available evidence on public attitudes to health information sharing relates to the use of patient data in research.

Interest amongst the public in health research overall is high, as is belief in its importance. But **awareness and understanding of the ways research makes use of health data**, and the complexity and multi stakeholder nature of much health research, are much **lower**.

There is good evidence for **public support overall for sharing patient data for the purposes of medical research**. Public benefit may be a **necessary** condition in the public's mind for secondary uses of patient health information in research. Commercial involvement results in consistently lower levels of expressed support, perhaps because the assumption may be that public benefit is secondary or absent.

Lower levels of support for sharing patient data for the purposes of research may also be **associated with degrees of scepticism as to whether the supposed public benefits will in fact be realised**.

Summary

Is London different?

There is relatively little published information on whether, or how, London may be different from other areas of the country in terms of attitudes toward patient health information sharing.

However, there is some evidence that people in London are more worried about the use of personally identifiable data overall; more sceptical about the NHS in this arena; and a little less trusting of their GPs. There is also some evidence of higher levels of awareness and experience of previous data sharing initiatives.

The most recent NHS Digital reports show London as having a higher rate of opt-out overall compared to the average for the rest of the country.

Notably absent from the published survey data is analysis by ethnic minority status, a clear gap given London's highly diverse population. Other issues where London's differences might influence attitudes in relation to health information sharing, although published evidence is lacking, include the diversity of languages; high rates of internal movement and population turn-over; and the role of the Mayor and the Greater London Authority (GLA) in London's Health and Care system.

A number of engagement exercises conducted in parts of London have been reported, which contribute useful localised insights particularly in relation to detailed expectations of a local online digital care record for individual care; specific issues related to joining health and social care records; and patient views of the use of technology in primary care.

The research also incorporates the views of London based stakeholders. Patients' and healthcare professionals' attitudes towards the introduction of shared health (and care) records in their current form are reported as generally positive, although to date no real evaluations of impact have been carried out.

Greater clarity over the additionalities that OneLondon is intended to bring will be important to allay some concerns expressed about how OneLondon would sit alongside, without duplicating or destabilising, these quite recently introduced local initiatives.

Summary

Themes and implications for engagement

Previous engagement exercises with public and patients have tended to explore and focus on questions and concerns around data sharing, without setting it in the context of expectations about how their health and care system should work overall. From published evidence we know that:

"People will express concerns if questioned about 'concerns' but will readily trade these 'concerns' for health or other benefits, even altruistic ones. 'Real World' choices can be very different (and constrained) from those offered in opinion surveys where costs and trade-offs may not appear…it is important to dig deeper into the trade-offs that the public is willing to make, under what circumstances and with what conditions".[1]

To date there does not seem to have been much engagement with the public around either the practical operational feasibility of addressing expectations and issues raised through engagement exercises, nor the potential reduction in benefits that may be implicit in attempts to address participants' concerns.

A more nuanced and practically useful exploration of the trade-offs people balance when considering issues related to information sharing during the OneLondon engagement process would be a distinctive addition to the evidence base.

1. Support for the **sharing of health records between clinicians**, for the purposes of direct care, and indeed the assumption that it is already happening, is well established in published literature. Our interviews confirm that the experience on the ground in London is that where this is happening, provided there is prior engagement with public and patients, and in as much as patients perceive there to have been a change, the response is positive. However, there remain questions about how to meet operationally public expectations around data protection; access beyond clinicians; potential to restrict access to 'sensitive' information; and personal access to medical records.

2. Although there is far less published evidence available currently, the integration of social care records seems to raise more questions. The potential benefits are not as immediately obvious; there appears to be more caution about records being viewed by 'local government' staff (in part because their role in provision of care is not understood); concerns about data protection and accuracy seem to be exacerbated.

3. Introducing the idea of sharing of information beyond the NHS also increases the pressure for, and expectations of, patient access to their own records about which some professional stakeholders interviewed have operational concerns.

4. The attitudes of some specific groups are not well understood. Whilst professionals and advocates offer opinions there is a lack of direct testimony from, for example, the most vulnerable people or those with complex, multiple conditions, many of whom may have the most to gain from improved health and care information sharing, but who may also have different attitudes towards data sharing. These groups are often those most likely to have both NHS and social care interactions, which reinforces the importance of fully addressing the concerns and expectations around the creation of integrated health and care records.

5. There is frequent mention in the literature, and in interviews, about particular concerns related to **'sensitive information'** - mental health, sexual health and substance abuse history being the most mentioned - but also the very varied and indeed unpredictable nature of what might be sensitive for any given individual. It is not clear, in an 'all or nothing' situation where complete records are available to a wide range of authorised users, what effect this would have on attitudes to sharing, nor how expectations about the potential to restrict use to sensitive information by patients themselves might be traded-off against a reduction in other perceived benefits of a shared record.

6. Evidence from the stakeholder interviews, as well as from some published evidence shows that the potential benefits of **proactive care** are well understood by professionals in both health and social care. However, it is much less clearly understood by most members of the public. There is a clear need for good 'stories' that illustrate the potential value of proactive care in a tangible and meaningful way. There are also some expectations and concerns about how individually identifiable data will be used appropriately so as not to disadvantage or penalise individual patients – those who might be identified as needing and receiving high-cost care for example.

Summary

Themes and implications for engagement

7. Beyond direct care there are clear expectations, expressed by both public and professionals, about **clarity** and **transparency** in the sharing of patient data for **secondary uses**. There is some published evidence about how these expectations might be met, and trade-offs that might be acceptable, for the sharing of data for research - for example if de-personalisation of data can be guaranteed and public benefit can be demonstrated. The desire for a degree of hands-on control of their own records is a possible way to address these issues, but may be impractical – caution is needed in this area so as not to raise expectations if they cannot be fulfilled. Sharing of patient data for the purposes of research is currently beyond the OneLondon funding remit although the potential that the data could be used in this way will inevitably have some impact on attitudes to the shared health and care record overall and can be expected to be raised by participants in any engagement programme.

8. There is much less evidence around the secondary use of data for **systems planning**. In order to better understand public attitudes and expectations in this area there is a clear need for narrative examples that are meaningful and relevant for patients and public. The few examples explored in the published literature in previous engagement exercises tend to emphasise 'positive' results of using shared data in this way – the provision of new clinics and services for instance. Attempts in surveys to understand attitudes towards use of data to facilitate more 'efficient' delivery of services have generally resulted in far lower levels of support. However, evidence from stakeholder interviews suggests that the secondary use of data for system planning, particularly if it is shared with other more central authorities, will be an area of concern for some and should be considered in the development of the engagement programme.

9. The broadly positive stance towards sharing data for research in return for public benefit (as long as there are sufficient safeguards built in) is a good example of the Altruism principle, and the evidence is good for the potential of deliberative engagement processes to increase support for the idea of 'helping others'. System planning's benefits have not been explored nor spelled out clearly in public engagement exercises to date but are arguably more related to the principle of Solidarity as described in the recent work for Genomics England. Examples of tangible relevance to the public will need to be developed if this is to be explored in the OneLondon engagement process.

10. Londoner's apparently more sceptical view of the health and care system and data protection issues merits further investigation, particularly if it proves to be associated with aspects of the diversity of its population. Engagement should anticipate the raising of issues of particular importance to different groups, and different understandings of how reciprocity, solidarity and altruism operate – this might for example point to more specifically targeted examples and communications.

Chapter 1 Setting the scene

OneLondon

OneLondon, as a first wave site in the Local Health and Care Record Exemplar (LHCRE) initiative, aims to 'create an information sharing environment that helps our health and care services continually improve the treatments we use, ensures that care is tailored to the needs of each individual, and can empower people to look after themselves better and make informed choices about their own health and care'.[2]

Achieving this involves bringing together a wide range of existing patient information sources and data sharing initiatives to create one health and care record that will be accessible to all those providing direct care to individuals in the NHS and social care system across London. Additional uses for the record are also contemplated including supporting the provision of 'proactive' care through, for example, targeting those with particular conditions for preventative treatments; planning and administration of the health and care system in London; and for health research. The intention is also that patients should be able to access their own records so as to support increased self-care.

The NHS has seen moves towards shared, multi purpose electronic health records of this nature for some time, but LHCREs aim in particular to deliver comprehensive common records at an unprecedented scale (in OneLondon's case covering nine million citizens). It also aims to improve the quality, utility and accessibility of the data available for planning and research, much of which involves methods and technologies that have only become possible relatively recently.

If follows that such a large initiative which involves collating and sharing such sensitive personal information must proceed on the basis of a high level of public trust and acceptability. This report is designed to feed in to the early development of OneLondon's engagement with the people of London by summarising existing knowledge on public and professional attitudes around health information sharing issues, and identifying where there are gaps in our understanding.

OneLondon does not, of course, exist in a vacuum, and there are a number of contextual points that should be borne in mind.

Living in a world of data

We are all increasingly involved in the sharing of our personal data. The world of universal internet coverage, high speed connectivity and portable devices has brought with it services, goods and interactions that the majority of us use and value, as well as sometimes fear and resent. Most, if not all, rely on the sharing of information, much of it highly personal and sensitive, and we do not always have a choice as to whether to share or not – filing a tax return or applying for Universal Credit must be done online; buying goods from a web based retailer will only happen if we share bank details; interacting with our friends and family through social media requires us to share our locations and electronic address books.

The public's view of all this is conflicted. Many say they are concerned about the privacy and security of their personal information – the Direct Marketing Association (DMA)[3] reports the proportion of people saying they are concerned about online privacy at 75% in 2018, although this has fallen from 84% in 2012 as more younger people who grew up in the connected world become adults – only 58% of 18-24 year olds say they are concerned. A Healthwatch survey from 2018[4] reports 53% of respondents as being more aware of data protection issues than three years ago. However, behaviour does not necessarily match concern – a Sciencewise report[5] on data sharing concluded that:

As Singleton and others (2007) highlight, "people will express concerns if questioned about 'concerns' but will readily trade these 'concerns' for health or other benefits, even altruistic ones. 'Real World' choices can be very different (and constrained) from those offered in opinion surveys where costs and trade-offs may not appear.

The apparent unconcern with data privacy displayed by many in their day-to-day lives stands in stark contrast with their stated preferences. This suggests that government and companies should be careful not to take the public's seeming willingness to part with their personal data for granted or as a sign of consent, but neither should opposition be taken at face value or as applicable to all circumstances. Rather, it is important to dig deeper into the trade-offs that the public is willing to make, under what circumstances and with what conditions."

Chapter 1 Setting the scene

No unified view about data sharing, but patterns exist

It is also important to note that the public does not have a uniform view about data sharing issues. Everyone, of course, has their own particular stances and behaviours, but a number of 'tribes' or clusters of people have been identified. The DMA[6] for example identifies a number of overall types amongst the general public:

- **Data Pragmatists:** those who will make trade-offs on a case by case basis as to whether the service or enhancement of service offered is worth the information requested – 50% of the population in 2018

- **Data Fundamentalists:** those who are unwilling to provide personal information even in return for service enhancement – 25%

- **Data Unconcerned:** those who are unconcerned about the collection and use of personal information about them – 25%

Whilst the Joined Up Yorkshire and Humber[7] engagement programme with the public around its health and care data sharing initiative described five fictitious personas that summarise the different clusters of beliefs that people have about how their health and care information is used and Wellcome[8] put forward seven 'mindsets' in relation to commercial use of shared healthcare data, including two specifically related to the particular perspective of patients with long term conditions who have actually taken part in research – one favourable to any data sharing that might help improve treatment for themselves or other people, the second quite resistant as a result of their continued and 'intrusive' exposure to demands for information and permissions to use it.

OneLondon is for all the people of London and needs their trust and understanding. The recognition that a wide range of different views and perspectives exist amongst them will be key to successfully achieving meaningful engagement with the very diverse London population.

A social contract?

All citizens have a relationship with the NHS to a greater or lesser degree, many having strong and well informed opinions. Whilst all these are of course unique to them, work for Genomics England[9] this year has put forward a useful model to help make sense of the different dimensions of the 'social contract' between people and the NHS:

Public views of key behaviours in the social contract now

Public don't understand how research ecosystem works / feeds clinical care

Reciprocity
- Turn up to appointments, don't waste resources, appreciate value of care
- Collect taxes; manage and deliver service efficiently
- Provide best, evidence-based care; patient data used for clinical care only

Altruism
- Choose to benefit others e.g. blood donation, participate in health research (if explained)
- Provide services that are free at point of delivery and not based on citizenship e.g. emergency care
- Provide highest quality diagnoses and treatment

Solidarity
- Accept progressive taxation and comply with healthy lifestyle advice to reduce public health burden
- Triage across whole system to allocate resource based on need and to balance books
- Treat all equally and with respect

Commercial interests aren't spontaneously seen as part of the system

From: A public dialogue on genomic medicine: time for a new social contract. Ipsos MORI for Genomics England 2019

Chapter 1 Setting the scene

Derived from an engagement exercise considering, amongst other things, people's attitudes towards the use of their data for genomic research, the report is clear that:

Each principle is important to participants. They framed discussions of healthcare in sometimes contradictory ways, emphasising transactions on some occasions (the principle of reciprocity) and generosity on others (the principle of altruism), and the provision of care based on need, rather than citizenship (the principle of solidarity), overall these three themes were always present, and participants felt they were necessary features of the social contract.

In relation to OneLondon it is useful to consider how these principles might relate to its patient data sharing goals, and the nature of the evidence available:

	OneLondon goals	**Available evidence for patient attitudes**
Reciprocity	Unified records for direct patient care: your assent to sharing within the health and care system intended to bring you better care	Good evidence of support in principle and ability to recognise as potentially beneficial; weaker in relation to detailed expectations and in particular the appeal of specific benefits, particularly beyond the most basic requirements; less evidence to test public expectation about the contribution made by individuals
Altruism	Information for research: gifting your data will help improve treatment for others	Good in relation to common motive to 'help others', and conditions to maintain trust in use; less evidence to on how best to encourage and support altruistic behaviour
Solidarity	Information for system planning: your information will enable our collective budget to be allocated optimally in relation to need	Generally weak – rarely a topic for debate, little evidence of specific concerns or expectations

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Chapter 1 **Setting the scene**

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This report

This report was produced by the CurvedThinking partnership for OneLondon. It is based as far as possible on the most recent and relevant information sources available. It highlights where the evidence presents a quite consistent picture on public attitudes and expectations around the sharing of patient health information for different purposes, and where it is less clear-cut. We then discuss a few areas where the evidence suggests a difference between London and other areas of the UK, before concluding with the themes we feel could most usefully be explored with Londoners in the forthcoming dialogue to fill existing gaps in knowledge and understanding.

The evidence used for this report is drawn from:

- a rapid literature review, including both formally published documents and relevant 'grey literature' and media reports, related to public and professional attitudes towards the sharing and use of patient health and care information. The emphasis has been on:

  - the most recently published material;

  - survey evidence, particularly that supported by details of samples and statistical significance;

  - reporting of public engagement events directly addressing data sharing initiatives;

  - material discussing different aspects of data sharing, particularly that dealing with OneLondon's remit

  - material related specifically to London

- The sources used directly in the report are noted in the text with full references and urls (where possible) listed at the end.

- 27 interviews conducted with a cross section of key stakeholders across the five London Sustainability and Transformation Partnership (STP) areas, including:

  - Clinicians and others (primary; secondary and CCGs) with a role in existing patient data sharing initiatives

  - Representatives of local authority Social Services

  - Patient representatives

  - A small number of interviews with relevant national organisations with a particular interest in patient information sharing

- These stakeholders were identified as having experience of similar record sharing initiatives or as having publicly expressed views on the issues surrounding health and care information sharing. The objective was to include as wide a range as possible of different perspectives, whilst at the same time making best use of existing experience, particularly in London, to avoid duplication of effort and identify current gaps in knowledge.

Chapter 2 Care of the individual

This chapter looks at the uses of shared health and care records for the care of individual patients. It focuses mainly on direct care, using information in real or close-to real time situations, those with which patients are familiar – visiting the GP, hospital treatment, attendance by paramedics, visits by social workers etc. It also considers 'proactive care', circumstances where information is used to anticipate and meet needs in advance or for prevention, for example screening, or identification of people at higher risk of particular conditions so as to offer treatment or advice. The issue of patient access to their own shared records is also covered.

Direct individual care

Expectation that personal health information will be shared amongst clinicians

Most people expect their medical records to be available to the full range of NHS clinicians providing direct care. They know there are health records kept about them, and that this has been the case for years. 'Data sharing' may not be the most appropriate term in this context, at least from the public perspective.

Widespread support

Few people have any in-principle objection to this; on the contrary it is commonly seen as important and welcome, and scores very highly when tested against other possible uses of patient health information. Although numbers vary depending on the questions asked, findings from surveys uniformly point in the same direction as shown by the examples below:

94% agree	'I would allow my healthcare record to be shared within the NHS if I needed medical treatment'[10]
90% agree	'If there were a national electronic health records system would you want your records to be part of it for the purposes of your own care'[11]
77% agree	'All GPs and hospitals nationally should be able to access your record for reasons relating to your direct care'[12]

A systematic review of 65 studies of public and professional attitudes towards confidentiality of healthcare data conducted for the General Medical Council (GMC) in 2015 concluded that:

Professionals and members of the public widely agree that it is appropriate (and important) for information to be shared between members of a patient's care team.[13]

Surprise that it is not already the case

Evidence from conversations with the public reveals surprise that different health professionals in different places within the NHS are not already able to access health records for the purposes of individual care, widely assuming that it already happens – for example public engagement with a range of people in Yorkshire and Humber led to the conclusion that:

…many people were surprised that their health and care records are not already shared across the NHS.[14]

And in a 2014 survey 67% thought that record sharing between GPs and hospitals for the purposes of direct care was already happening[15].

Heavier users of services may be more likely to support sharing

A 2015 report for the GMC concluded that:

Some studies indicate that patients with more experience of healthcare may be more accepting of data sharing than those who do not make much use of health services.

In the stakeholder interviews patient representatives specifically mentioned that the more multi-faceted an individual's relationship with the NHS, for example patients with multiple complex conditions, the greater the potential benefit from effective sharing of health information. Professionals in both the health and social care arenas made the same point.

Chapter 2 Care of the individual

Anticipated benefits for patients

The expectations of the public about benefits for themselves from the sharing of their health records are relatively straightforward, and relate to the expectations that this is, or should be, happening already. There is a little survey data - Healthwatch[16] for example recorded 73% agreement that 'my healthcare treatment relies on the ability of healthcare providers to access my patient data quickly' – one of few surveys which include questions related to specific rather than general benefits.

More evidence comes from the various engagement exercises carried out with the public and different types of service users. **The most commonly mentioned is avoiding the need for repetition.** A report for Surrey Healthwatch (2015) reported that:

58% agree with:

'Have you or any members of your family had any experience where you have had to repeat your story to different health and care professionals?'[17]

And quoted experiences:

"When I have had hospital appointments I wonder why I am asked questions I feel they should know. It's a total waste of time. I feel time at hospital appointments is precious. If all the information is on the screen surely it aids speedier treatment."

"I was referred from GP to hospital and had to repeat everything to the consultant, radiologist, phlebotomist, nurses and oncology staff. When you are really worried about something, it is difficult to remember if you have told everyone all they need to know and whether you are repeating yourself."

From the professional perspective, in a 2018 report evaluating the benefits of the East London Patient Record 80% of primary and secondary clinician respondents felt that patients were 'pleased' that the system made it possible for the clinician to access all their information, wherever it had originated in the system [17].

From the stakeholder interviews, the need for repetition was felt to be a particularly sensitive issue with key vulnerable groups, particularly:

- Those with mental health issues

- Those experiencing domestic abuse

- Those caring for people with dementia

Engagement work around a proposed online digital care record by Islington CCG[18] focussed on people with long term conditions, and concluded with a number of clear expectations as to what they would like to see:

…people want services that are joined up, and work together as one team, with the patient being the key team member… people don't want to have to tell their story more than once, and want different care providers to understand what is happening in the person's care – professionals being prepared, services being able to communicate with each other.

Whilst the Southwark citizens jury[19] identified:

Not having to retell their stories, saving time, having more accurate and responsive services, and the ability to take timely and appropriate action, supporting a multidisciplinary approach and ensuring the service will have a total picture of the person. One theme kept cropping up about the strength of record sharing as a tool to create a person centred approach.

Other anticipated benefits consistently mentioned during the stakeholder interviews included:

- Immediate/quicker access by health professionals to key patient information in 'emergency' situations, A&E and ambulance services being the most cited

- The most up-to-date information being available to all in the healthcare team across primary, secondary and, potentially, social care

- A full and up-to-date list of medications in one place, reducing the burden on the patient/carer to 'remember'

- Avoidance of repeat tests
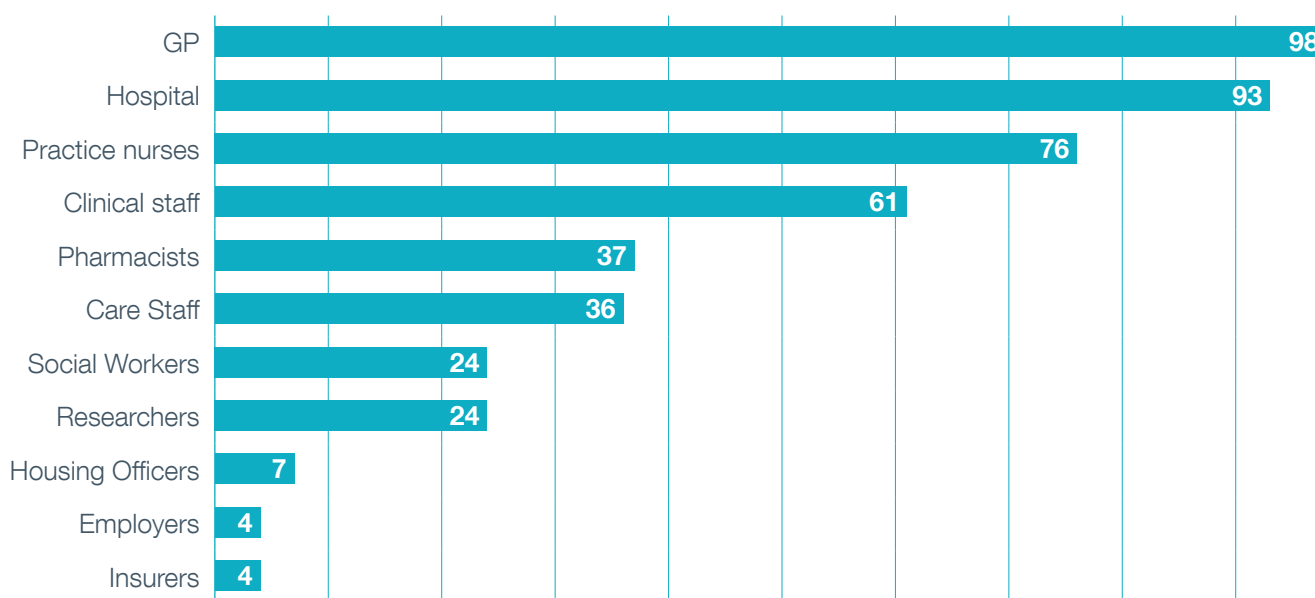
Chapter 2 Care of the individual

Access to information

Discrimination between different users of individual health records seems largely based on a combination of how close the user is felt to be to the direct delivery of care to the individual, and how sensitive the information is felt to be – although knowledge of who does have access at present is low, with only 30% of respondents to a Healthwatch survey[20] agreeing that 'I am aware of who has access to my personally identifiable data that is stored by the NHS'.

Engagement in Yorkshire and Humber[21] ranked professional access as follows:

% who believe different professionals should be able to access their health and care records

Professional	%
GP	98
Hospital	93
Practice nurses	76
Clinical staff	61
Pharmacists	37
Care Staff	36
Social Workers	24
Researchers	24
Housing Officers	7
Employers	4
Insurers	4

Few people have problems with doctors, nurses and other involved clinicians viewing the entire record, although with limits – the Healthwatch survey[22] showed 78% agreement that 'I trust my GP to know how best to use my patient data', but also 66% agreement that 'there are aspects of my patient data I would rather my GP did not share with anyone else'.

A separate Healthwatch survey[23] showed a very similar pattern to acceptability of professional access to the records except that **Paramedic/Ambulance staff** were included in the list. **71%** of people answered that they would be happy for this group to view their full records, behind only GPs (96%), hospital doctors (93%) and other practice care staff (75%)

There is considerably more caution in relation to people without clinical training accessing individual records, for example GP receptionists (even though they already have access to traditional records). A comment recorded during the Joined Up Yorkshire and Humber engagement process[24] is typical:

"At our doctors, our receptionist can ask you questions so they can find out what's wrong with you – well, I am not sure about that – it's dangerous because they are only receptionists, they are not medically trained at all."

Whilst a Citizens Jury process used by the Office for the National Data Guardian[25] exploring when it is reasonable for patients to expect patient data to be shared noted greater reservations amongst jury members following their deliberations about access to personal information by hospital administrators for example as part of internal NHS invoicing.

Chapter 2 Care of the individual

Social care

National policy is seeking to bring health and care services into much closer alignment, clearly reflected in OneLondon's remit to develop a unified individual record embracing information from both NHS and Social Care sources. Although there is less published evidence on the issue of record integration, what is available tends to suggest that that the relationship between the NHS and Local Government in providing care is not well understood by the public as a whole (two thirds think the NHS pays for social care for example)[26], and access to shared records by care workers tends to be viewed with some caution.

The Joined Up Yorkshire and Humber engagement report tested people's understanding:

In the workshops people were asked to draw a map of who has access to their health and care records. The results show a wide variation in how extensive people believe data sharing to be. Some participants' maps contained just their GP, hospital doctors, and midwives. Others contained wider groups providing direct care, such as pharmacist, dentists and opticians. Others also included government bodies, such as the Department for Work and Pensions, the DVLA, the police, and the ambulance service, or commercial organisations such as private hospitals, and private therapists. Very few included social care or public health professionals.

The Southwark event, involving Adult Social Care users concluded that:

'A wide range of organisations were seen as appropriate to share [joined health and social care] records with, such as the ambulance service, statutory health services, charities that support people, homecare providers, council commissioned services, and groups such as falls clinics, hearing clinic, mental health teams, but only registered and supervised staff groups with relevant tasks.'

As users of care services themselves, the Southwark jury was particularly aware of the use by Local Authority social services of external care providers (who were expected to be part of the sharing initiative under consideration), specifically recommending that:

Care agencies must take steps to provide assurance to the Council that care workers are trained to write good quality and accurate notes and work within GDPR guidance.

There is evidence however to suggest that providing more explanation of the background and purpose of wider sharing for individual care may be able to create higher levels of acceptance. Survey work for the Great North Care Record[27] generated overall 75% agreement with the statement: 'If I needed support from adult social services, I would allow my healthcare record to be shared with my local social services', and the National Data Guardian[28] work on reasonable expectations saw its Jury almost unanimous in seeing it as reasonable for an individual's social worker to access their records whilst planning for their post treatment homecare package.

During the stakeholder interviews, social care staff raised the issue of the amount of time spent trying to find out even quite basic health information necessary to provide appropriate care to often vulnerable clients. They also felt that since the introduction of GDPR this had become even more difficult (and time consuming), reflecting that healthcare professionals had become very cautious about sharing information even with social care staff. Whilst they believed that there needed to be clear safeguards built in to protect inappropriate sharing of sensitive information, they were of the view that access to quite limited amounts of information, on medication for example, would make a very significant difference to the quality of care they would be able to give, and the efficiency with which they would be able to work.

Chapter 2 Care of the individual

Concerns and expectations

Data protection – reasonable trust in the NHS

As discussed in Chapter 1, citizens are concerned about the security of their data generally, even though they often end up sharing information because they have little choice or are willing to trade off the risks against perceived benefits. However, convincing reassurance that their data is held securely is undoubtedly important in building overall levels of trust, particularly amongst the 50% or so Data Pragmatists identified by the DMA.[29]

The NHS as a whole is awarded relatively high trust ratings to look after and use individuals' information well, outstripping other public bodies and private organisations:

77% confident	How confident or not are you currently in the ability of the NHS to protect your patient data?	Healthwatch survey[30]
70% confident	How confident or not are you that the patient data the NHS holds on you is stored securely?	Corsham institute survey[31]

This is despite the fact that the public has very little idea how their health data – particularly electronic information – is stored. The Corsham Institute[32] survey reported that less than half were aware of any given storage method (local servers, the Cloud etc.), and 88% felt it important for the NHS to make publicly available information on 'how and where my patient data is stored'.

Unsurprisingly concerns remain:

66% concerned	Thinking about your NHS patient information, please indicate how concerned you are about cyber attacks	NHS England[33]
63% concerned	Data being shared unlawfully or accidentally with organisations outside of the NHS and care system	NHS England[33]

These results are likely to reflect awareness of data protection issues which have affected the NHS, and have impacted on confidence. 85% of respondents to Healthwatch[34] survey had heard of the Wannacry hacking incident, and 26% the accidental sharing of sensitive data from a sexual health clinic, and in both cases more than half of those aware of the incident reported that their confidence in the NHS's ability to protect their data had diminished as a result.

Overall, security concerns relating to personal data held by companies and organisations generally, not simply by the NHS are raised in relation to:

- Data being 'hacked' or stolen

- Data being lost accidentally

- Data being inappropriately shared

- Data being 'sold'

- Data finding its way, in one way or another, into the hands of an individual or organisation who then 'use it against you' (in the context of medical information, insurance companies are often cited here)

- Data from one source being combined with data from another in a way that is to your disadvantage (although the sharing of NHS data with the Home Office for the purposes of tracing people suspected of immigration crime secured 72% support[35])

In the stakeholder interviews, the need for OneLondon to communicate 'Gold standard' levels of security to build trust and confidence was frequently mentioned. This included the perceived importance of 'proactive' auditing to pick up 'unusual' patterns of access which was felt to be important to build confidence amongst both healthcare professionals and public, as well as complete clarity around agreed rationales for access to data.

Also mentioned was the idea that 'transparency' should extend to the extent of a willingness to be open about where mistakes or lapses had occurred, and a clearly signposted route for any individual to seek further information or explanation should they feel that the security of their data had been breached.

Chapter 2 Care of the individual

Sharing of sensitive information

Health information is naturally regarded as highly sensitive, as are key personal details such as dates of birth and credit histories. As discussed in Chapter 1, many people are generally concerned about the security of their information (at least three quarters according to the DMA[36]) and are more so with regard to those issues they see as potentially damaging or compromising to themselves. In an Open Data Institute[37] survey only one in five people were willing to share their medical history or credit history with an organisation they already knew, compared to half who were prepared to share their address or date of birth.

The Great North engagement[38] process identified specific health issues regarded as even more in need of protection:

'Citizens… expected an even higher level of care for data sharing about potentially sensitive or stigmatizing issues like mental health, reproductive health and sexuality.'

In the stakeholder interviews substance misuse was also mentioned in this context.

Other engagement processes also include discussion amongst participants of the importance of being clear about exactly what information is expected to be made available to users of shared data systems, as well raising the possibility that individuals might be able to decide differently which items could be shared and which not – work by Joined Up Yorkshire and Humber[39] for example identified as a key challenge for its data sharing initiative that:

'People differ in how much of their information they want to be able to share for their direct care, particularly with social care and third sector professionals. But who decides which information is current and relevant? How can people be reassured that non-clinical staff understand what they access? Will access be time limited to the duration of their referral?'

In stakeholder interviews some clinicians also referenced the unexpected and unpredictable nature of patient sensitivities. One mentioned, for example a patient who had not wanted the fact that she had previously had an operation to treat hemorrhoids included in information sent to her local hospital where she was to be treated, but also worked.

We should note that there is relatively little published evidence currently on the views of those identified by others as most in need of protection, vulnerable users of mental health services for example, as opposed to those speculating or speaking on their behalf. One mental health service user interviewed for this report was relatively relaxed about records being shared within healthcare; more concerned about the information being viewed by social care where he was not convinced that the 'ethos of confidentiality' existed to quite the same degree; and very concerned that the information might be shared with other government departments or organisations such as the police. He viewed patient access to records as a key component of building trust in the sharing process, including the possibility of seeing when, and by whom, a record had been accessed.

Chapter 2 Care of the individual

Quality of information

In addition to the **types** of information to be shared, there are also concerns about the quality of information in records, and the implications of inaccuracies of out of date information being acted upon by those accessing them.

The Southwark engagement process[40] identified a number of issues, particularly whether information in the proposed shared record:

- is accurate

- is legible (participants noted the continued prevalence of handwritten notes particularly in the care system)

- can be understood correctly by different users, particularly those with less training such as day-to-day carers

- is up to date (echoed by an engagement process in Enfield[41] where participants questioned how long new updates would take to appear)

- contains information that is no longer relevant but which might influence treatment

- contains information, particularly comments or observations, with which they might disagree (and if so how this could be challenged and corrected)

The report concluded that:

People were most concerned about the accuracy of their records and their ability to challenge successfully where they felt the information was wrong. They felt that with sharing there was a greater risk of misinformation being held by a wider group of people, this in turn raised concerns about how this might be acted on by a wider pool of staff. There was concern about people seeing their whole record where this may no longer be relevant and how this might prejudice care and health providers.

From the point of view of professionals the joining together of large amounts of data raises some similar issues, for example the risk of being swamped with information that is hard to interpret or requires a considerable amount of work before being shared with patients (for example mention of third parties – mentioned particularly by social care workers during the stakeholder interviews).

Patient control

The Great North Care Record[42] initiative puts forward the possibility for patients to opt out of specific sharing situations as they arise. Its public engagement initiative presented respondents with video explanations of its proposals, and went on to ask a specific question about preferences which delivered a quite emphatic answer:

'When sharing healthcare records, people can have control over their privacy preferences (e.g. being able to pick and choose who sees our healthcare record, why they can see it, which parts of the healthcare record they can see etc.). This could be done using a mobile phone application, a website, a paper application form, or a helpline. After seeing the previous video and reading the above, how important or unimportant would it be for you personally to have the ability to set and change your privacy preferences for sharing your healthcare record?'

Very Important	57
Important	29
Don't Know	4
Unimportant	8
Very Unimportant	2
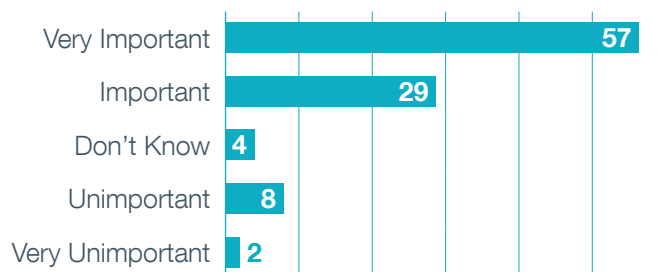
Base: 824 adults in the North East

We have presented this finding in some detail since it suggests a high level of demand for, and expectation of, patient control over individual health records. Although it is from only one source, the very high level of importance attached by the 800+ respondents is striking, and reinforced by testimony from the public engagement events organised by Great North CR, which concluded that:

Citizens wanted to be reassured that they would have a choice about sharing information about them and they could control what information is seen, how much of it, by whom and in what circumstances. They expected to be given control over their decisions about information sharing and did not think that health care professionals should make decisions on behalf of patients or citizens.

Chapter 2 Care of the individual

The issue of patient control was also reported from the Joined up Yorkshire and Humber engagement:

How can individuals maintain control over their records? Will they be able to track who has accessed their record?[43]

This should sound a cautionary note when considering the practical feasibility of delivering in reality what people may feel they have been offered – engagement processes do not seem to address the operational implications of these sorts of expectations and what effect this might have on willingness to share information should they not be achievable. Nor do they look at the relationship between local arrangements for a specific shared record and the national opt-out process.

The question of patients exercising control over the use of records naturally leads on to whether they themselves will be able to access the same records.

Patient access to their own records

Evidence from engagement events suggests that the wider the range of professionals who have access to patient data, including for the provision of social care for example, the greater the expectation that individuals should also have access to their own health records, to see what has been shared; to have some degree of control to add to, challenge or amend the content; and to express preferences for example over organ donation or the use of their information beyond direct care.

Overall, individual access to health records is very positively viewed by patients and public. The Southwark Citizens' Jury project[44] was particularly keen on the ability of service users to be able to check the saliency and accuracy of their records, citing experiences of out of date or incorrect information and the current difficulty securing corrections.

In stakeholder interviews, the potential for patients to see who had accessed their records, and for what purpose, was frequently mentioned as a way of increasing levels of confidence about the appropriate sharing of data.

The GMC review of literature on data sharing up to 2015[45] reported that:

A consistent piece of feedback from patients seems to be that those who want electronic self-access to their records should be allowed this, but that nobody should be forced to use these systems: choice was the most important factor for patients.

This raises the question of increasing expectations for patients to access their own health information to support self-care, which is envisaged by OneLondon. The quote above suggests there may be some reservations about this, if people suspect they are having responsibilities pushed on to them. The literature reviewed is not extensive on patient perceptions of self management of their own conditions. However an effectiveness report on its own patient controlled electronic health record app, used by a number of NHS organisations as well as globally, by Patient Knows Best[46] cites a number of case studies of positive outcomes arising from active information sharing and condition management involving clinicians and patients all working together, facilitated by the use of technology and information sharing.

There is also evidence that both 'basic' (such as emails) and quite sophisticated functionality (health goal setting and tracking) might be expected from sharing systems which are designed to involve patients actively. The engagement process by Islington CCG[47] in 2017 asked participants – mostly with three year plus long term conditions – to consider what its planned 'online digital care record' should contain, concluded that:

A care record which shows a patient's and service user's regular interactions with health and care services and their overall journey, as well as goals to support them to self manage, is supported by the Islington local population we spoke to.

Chapter 2 Care of the individual

Islington residents would like to see these elements incorporated into their record:

- Able to book appointments for GP and other services

- To show upcoming appointments for all services

- Ordering repeat prescriptions

- To show any medicines they take

- To show current test results

- Links to other help services (young people gave the example of BEAT and sexual health services)

  - A development of this would be a search function for local services using GPS location tracker i.e. walk-in-centre, young people sexual health services

- Condition specific information such as blood sugars for diabetes (and a way to input and personally monitor this information)

- A one page profile which would give an overview of the person's key information

- A space for health / wellbeing goals and how they have been achieved

- Be able to message their GP and potentially other health and social care professionals (but only if it is assured they will message back and there is a set number of hours to respond)

The variety of elements identified is shown left, and is an example of the sorts of uses patients aspire to when asked what a shared record should contain and how they themselves might use it.

It is important to note that participants were not asked to consider the feasibility and pros and cons of their recommendations in this case – this being typical of most of the available evidence that touches on system design and content.

From the professional perspective, although there was considerable support expressed in the stakeholder interviews for the principle of patient access, some concerns were also raised:

- Safeguarding issues, at both an individual level and to protect third parties who may be referenced in the records

- Time/workload issues dealing with patients needing clarification or reassurance about information included in the records, especially 'new information' e.g. from a very recent test result in primary or secondary care which had not yet been discussed with the patient

- The possibility that in order to make the language used in the records accessible to patients, the content would become less informative/valuable for healthcare professionals

Chapter 2 Care of the individual

Proactive care

'Proactive care' is considered here under 'Direct Care'. The difference with the sort of individual care discussed above is that proactive care is essentially preventative and/or initiated by the healthcare system rather than by the patient. It embraces, for example, screening programmes and outreach to people identified as being at increased risk of developing a particular condition.

Weak evidence on attitudes towards proactive care

Proactive care is actively discussed in the professional sphere, for example in relation to risk stratification and outreach, but makes few appearances in literature concerning public attitudes to the use of patient data in this way. A little evidence from engagement exercises points to a generally positive stance towards using information to identify people for screening; somewhat less for outreach to offer health advice, as shown for example in Yorkshire and Humber[48]:

73% agree	To contact people at risk to invite them for screening
60% agree	To contact people at risk to give them health advice

Base: 1031 respondents during widespread engagement programme

The same exercise also looked at the consequences of analysis of health information leading to identification of those at higher risk of a condition, prompting a range of views including possible stimulation of anxiety, and implications for insurance and employment. Most participants were clear that ideally GPs (or at least staff from their own practice) should be the providers of 'unexpected' news such as this, and there was also a view that people should be able to opt in or out of such interventions.

In the stakeholder interviews, the potential for early identification of patients at increased risk was cited by professionals as a real potential benefit. Some concerns are expressed however, by both professionals and patient representatives. Joined up health and care records bring together a wide range of information, not limited to clinical data – for example, the costs of treatment and drugs prescribed, or social and domestic circumstances. Some stakeholders talked about the potential implications for both healthcare providers and patients of being able to identify, for example, 'the most expensive three patients in the practice'.

If the potential benefits, concerns and expectations associated with the use of patient data to provide proactive care are to be explored further during the OneLondon engagement process there will be a need to develop a wider range of examples which more tangibly express the concept from a public perspective.

Chapter 2 Care of the individual

Themes and implications

- Support for the sharing of health records between clinicians, for the purposes of direct care, and indeed the assumption that it is already happening, is well established in published literature. Our interviews confirm that the experience on the ground in London is that where this is happening, provided there is prior engagement with public and patients, and in as much as patients perceive there to have been a change, the response is positive. However, there remain questions about how to meet operationally public expectations around data protection; access beyond clinicians; potential to restrict access to 'sensitive' information; and personal access to medical records.

- Although there is far less published information currently the integration of social care records seems to raise more questions. The potential benefits are not as immediately obvious; there appears to be more caution about records being viewed by 'local government' staff (in part because their role in provision of care is not understood); concerns about data protection and accuracy seem to be exacerbated.

- Introducing the idea of sharing of information beyond the NHS also increases the pressure for, and expectations of, patient access to their own records about which some professional stakeholders interviewed have operational concerns.

- The attitudes of some specific groups are not well understood. Whilst professionals and advocates offer opinions there is a lack of direct testimony from, for example, the most vulnerable people or those with complex, multiple conditions, many of whom may have the most to gain from improved health and care information sharing, but who may also have different attitudes towards data sharing. These groups are often those most likely to have both NHS and social care interactions, which reinforces the importance of fully addressing the concerns and expectations around the creation of integrated health and care records.

- There is frequent mention in the literature, and in interviews, about particular concerns related to 'sensitive information' - mental health, sexual health and substance abuse history being the most mentioned - but also the very varied and indeed unpredictable nature of what might be sensitive for any given individual. It is not clear, in an 'all or nothing' situation where complete records are available to a wide range of authorised users, what effect this would have on attitudes to sharing, nor how expectations about the potential to restrict use to sensitive information by patients themselves might be traded-off against a reduction in other perceived benefits to a shared record.

- Evidence from the stakeholder interviews, as well as from some published evidence shows that the potential benefits of proactive care are well understood by professionals in both health and social care. However, it is much less clearly understood by most members of the public. There is a clear need for good 'stories' that illustrate the potential value of proactive care in a tangible and meaningful way. There are also some expectations and concerns about how individually identifiable data will be used appropriately so as not to disadvantage or penalise individual patients – those who might be identified as needing and receiving high-cost care for example.

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Secondary uses overall

Little known about system planning, more about research

Beyond the use of shared patient data to provide a 'ubiquitous view'[49] of individual patient circumstances and history to those charged with providing direct health and social care, the ambition for OneLondon is **that the sharing and use of health data should extend to include system planning and research.** The LHCRE initiative talks of using information:

'To support local health and care planning and management as well as to better understand the health and care needs of their population.'[50]

The literature covers 'secondary use'[51] in its own right to only a limited extent; there is certainly far less evidence on public attitudes here than for the use of patient health information for direct care. Within 'secondary use' as a whole, there is less evidence on attitudes towards the use of patient data for system planning than for its use in research.

A British Medical Association (BMA) engagement initiative[52] exploring levels of consent to sharing health information for secondary uses reported in 2015 that:

There is little spontaneous understanding of how and why healthcare data might be used… and many struggled to spontaneously identify any secondary uses of healthcare data… Participants often struggled to differentiate between secondary uses of data and the use of data for direct care.

The report attributes this in particular, to the inherent complexity of the subject, and the unfamiliar language used around it. Detailed qualitative exploration of how people understand different terms in relation to health information sharing by Understanding Patient Data[53] in 2018 reported that:

'Secondary uses' was seen as remote and uninformative – hard to understand what it means. Experts felt being clearer about the benefits of the use would help people 'get it' which led to [the recommended term] "improving health, care and services"

Although the alternative term 'research, planning and development' was also seen as useful.

We feel it is important to keep in mind that there are overlaps between these terms, in particular that system planning makes use of significant amounts of research work, particularly in relation to population level issues, epidemiology, evaluation of service delivery performance etc.

Support is higher if information is 'de-personalised'

In many, but not all, circumstances, secondary uses involve 'de-personalised' data, where records are shared only once data has been de-identified at source, and there is no intention of re-contacting individuals. A study from 2013[54] conducted in West London amongst a representative sample of patients and public at GP surgeries and hospitals reported 80% support for the use of electronic health records for planning and policy.

However, three quarters of those who supported the use of data for those purposes (so 60% of the sample overall), agreed only on the basis that data would have all identifying details removed before sharing. The remaining 20% were not happy to have their patient data shared for this purpose even if de-identified.

However, the BMA report suggests the reassurance intended to be offered by the de-personalisation of shared data may be limited by people's lack of engagement with the issues:

It was difficult for many participants to understand why different types of data would be needed in different situations… identifiable data is understood in a very literal way as name, address and date of birth – as a result it was very hard for participants to understand why this would ever be needed.

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Secondary use within the NHS is more acceptable

The BMA research[55] asserts that the public quite readily accept the need for data sharing **within the NHS**, but importantly point out that this seems based on a:

Simplistic view of the NHS as a 'walled garden', clearly separate from other organisations and institutions… even sharing with other governmental or educational institutions 'outside of the NHS' tends to increase concern.[56]

We have already identified this issue in relation to individual direct care, where although Local Authority social care is closely aligned with health services, it tends to be seen as separate from the NHS itself.

In reality, of course, the **majority of 'secondary' uses of patient data will entail the involvement in some way of companies and organisations beyond the NHS. The evidence suggests that this is not at all well understood by the public**, and, as identified in the BMA report above, reactions to the idea that patient information will be shared beyond the 'walled garden' of the NHS tend to be regarded with some suspicion.

In fact, in this context, some evidence suggests that the public is more confident about sharing personal data with some 'private sector' organisations – banks and building societies for example – than it is in sharing it with national government and local authorities, as shown by an Open Data Institute survey[57]:

Which, if any, of the following would you trust with data about you?	% say yes
NHS and Healthcare providers	**64%**
Banks, building societies and credit card companies	**57%**
Local government	**41%**
Central government	**37%**

Base: 2023 UK representative

Specifically relating to private companies a 2019 report by Genomics England[58] described how:

Because the healthcare system isn't sufficiently understood by its users (the dialogue participants), there was initial consternation among some about private companies being involved in healthcare.

Among some this was based on a belief that private sector interests should not be allowed to have any involvement in public institutions like the NHS, as 'private' was associated with a decline in service standards.

Although it went on to say:

Once explained that the NHS has for many years partnered with commercial companies to ensure the NHS can provide services, and equipment (e.g. electrocardiogram) that meet the needs of its users, the importance of public-private sector partnerships was acknowledged. But, there remained an unease among many about companies profiteering from people's vulnerability and poor health, as they perceived it.

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Attitudes to secondary use can change with more information

An engagement exercise carried out by Manchester University[59] in 2016 looked at the extent to which participants felt different organisations should be allowed access to patient information for different purposes. It used a before and after methodology to test participant attitudes at the start of the deliberations and then again once they were over, having been involved in detailed discussions, provision of information, expert testimony and questioning etc.

Whilst the number of people involved was relatively small, distinct patterns in attitudes were visible. The acceptability of different users and uses was largely consistent with evidence from other sources:

- Highest support for NHS based research; university research into NHS issues; and NHS service funding decisions.

- Lower levels of support for local authority planning; contracted out analysis for the NHS; and private pharmaceutical drugs research.

- Very low support for use by insurance companies for setting insurance premiums.

What is striking in this case is the change in attitudes reported during the course of the process, shown in the table below:

Who should be allowed to access and extract data from the records created?	Pre Jury	Post Jury	Change
NHS clinicians and administrators doing approved research into whether doctors are prescribing medicines appropriately	29	33	+4
NHS clinicians and administrators who decide which health services should (and should not) be funded	17	30	+13
University staff doing approved research into whether doctors are prescribing medicines appropriately	23	28	+5
Staff employed by a pharmaceutical company investigating whether they should begin research into a new drug for a genetic disease for which there is currently no treatment	12	24	+12
Staff employed by local authorities planning the future need for residential care homes	10	18	+8
Staff employed by a private company being paid by a hospital NHS trust to compare the number of people dying after surgery with other hospitals	6	18	+12
Staff employed by an insurance company aiming to set health insurance premiums accurately	2	7	+5

Base: 34 participants in Citizens Jury

Support for the uses with the highest initial support (two different approaches to use of data to investigate how doctors are prescribing) does not increase by that much, unsurprising given most people thought this was acceptable in the first place.

More striking is the significant increase in the support for use of data for administrative and planning purposes; for sub-contracted analysis; and for drugs research.

Whilst not reaching the levels of support for the NHS based work, carried out by NHS staff, the potential of an

informed and active debate to move views positively in the direction of shared information uses beyond individual care, and by staff and organisations outside the NHS, is evident. In fact, the method of engagement was selected specifically because it 'enables citizens to learn about, and deliberate on' the issue.

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Some evidence that commitment to use for 'public benefit' increases support

The Manchester Research above concluded that 'public benefit was a necessary justification for access'; it was one aspect of the evidence presented to the participants for debate that resulted in the shift in views.

Wellcome[60] also reports that any secondary use of patient health information must pass a clear public benefit test in order to be acceptable to the public.

Systems planning

Systems planning less well covered in the literature

There is a considerable amount of what might constitute public benefit in the context of medical research in published literature. However, the concept of public benefit in relation to **systems planning, has been less explored in research to date**, and usually only in quite abstract terms referring for example to 'service provision'.

Direct comparison between the evidence is difficult due to the many different terms used, but in some material people seem supportive of the sharing of information to, for example:

- 'plan the best services' (88% agree)[61]

- 'allow the NHS to understand what services patients in your area require' (scoring 7/10).[62]

- 'allow the NHS to understand more about peoples' needs and improve the services and treatments it provides' (77% agree)[63]

On the other hand:

- only 60% agree that it should be used to 'plan which areas might need extra services'[12]

- only 51% agree that 'increasing patient data sharing is the only way for the NHS to increase efficiency in the future'[64]

And the 2015 BMA report concluded that:

Where benefits are unfamiliar or it was difficult to see how they would arise from sharing healthcare data, the public were much less willing to accept them, for example commissioning [and] service design.[65]

Specific uses may be more motivating than bundles

The West London study[66] referenced above, as well as highlighting the importance of using de-identified data, also concluded that the clearer and more specific the intended use of the data was made, the higher the levels of support for the creation of the electronic health record. So:

- 80% supported for its use in planning and policy (especially if it was de-identified)

- 90% support for its use in 'personal health care provision'

- 81% for health research

- But only 62% for 'the development of a national EHR system… that would simultaneously support health care, planning and policy, and research'

Base: 2857 representative GP/hospital service users in London

The importance of the language used to describe the underlying rationale of the shared health and care record is clear here. Using 'catch-all' descriptions that bundle too many things in together may be counter-productive in terms of building trust and levels of support.

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Making systems planning tangible

Survey questions aimed at deciphering public attitudes towards health information sharing rarely move beyond quite general statements about services and planning.

Whilst there is little existing published research, a few engagement exercises have instead explored the issue through the use of patient stories in an attempt to make the abstract and poorly understood concept of system planning more tangible. The example below comes from the Yorkshire and Humber[67] engagement exercises: this was one of six different examples covering different aspects of data sharing, and deals explicitly with data used to plan services. Participants were asked to 'vote' as to which were a good use of information and for which people would be happy for the NHS to use my information this way – in practice there was relatively little discrimination between the different cases, all being rated quite highly.

Nevertheless, it is clear that the participants readily understood what it was the cases meant, and responded to them positively. This approach may have merit as a way of bringing the subject to life – but should perhaps be balanced with material raising the possibility that implicit in system planning is the idea that not every individual can be expected to benefit equally, or even at all, from proposed changes.

Mohammed's story

Mohammed is 42 years old and has recently been diagnosed with diabetes. During a review of people's health records, the NHS found that there were a lot of people with diabetes in Mohammed's area. They set up a local diabetes group to support people with diabetes. It provides information about diabetes, advice about exercise and healthy eating, blood tests and medical treatments.

"I probably wouldn't go to the diabetes group if it were in the hospital but because it's local I go every week"

The NHS used information from the healthcare records of everybody in the region to find out where new healthcare services are needed.

The importance of clarity

The importance of clarity in the intended use of patient data was **a consistent theme of the stakeholder interviews** amongst both professional staff and patient representatives.

This was true for the shared health and care record overall, but especially when considering potential secondary uses of data – both system planning and research.

In fact, **the two related concepts of 'clarity' and 'transparency' were spontaneously cited as necessary underpinning values for building trust in the OneLondon shared health and care record by the majority of stakeholders interviewed.**

Those expressing most doubt and/or suspicion about the ambitions and intentions of OneLondon and LHCREs overall were particularly likely to **focus questions and criticism on what they perceived as the current lack of clarity about how patient data overtly collected for the purpose of improving direct individual care might also be used for secondary purposes** that the public might find less acceptable. Some suggested that if such potential uses were only to become subsequently clear to people, perhaps by being drawn to public attention in the media, or through social media, trust in OneLondon overall might be undermined. Care.data was cited by some as an example of how this might occur.

Two particular 'types' of secondary data use were consistently referred to in this context; use by **commercial organisations** for the purposes of research; and use by **central government or NHS England for system planning purposes which might prioritise national rather than local issues**.

In the context of service provision, for example, most questions used in surveys, or examples given in engagement exercises, tend to imply, albeit often very subtly, an 'increased' level of service which the respondents might, not unreasonably, interpret as being of personal benefit to themselves.

The few examples that do not, that refer for example to 'efficiency'[68] or which ask about use to 'plan which areas might get extra services'[69] (implying that other areas may not), attract lower levels of support from the public.

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One stakeholder interviewed pointed out that, particularly in the context of a stretched NHS budget, aggregated data that could be used to, for example, identify where a new diabetes clinic could be set up could also be used to determine service provision in a way that could lead to reduced service provision from a specific hospital or in a particular area.

It is important to note that the majority of those interviewed were far from being completely negative about the secondary use of patient data for system planning; many could see significant potential benefits leading to genuine improvement in overall healthcare provision. However, there was a widespread feeling that **clarity about <u>intended</u> use, and transparency around <u>actual</u> use of patient data were reasonable expectations** that should be built into the OneLondon engagement process from the earliest possible stage.

For professional stakeholders, who generally understood how the data could potentially be used, but were often not clear about the specific intentions under the OneLondon programme, there was an expressed desire for greater communication between the programme team and those delivering services in the five STPs, particularly in primary care.

Evidence from patient and public engagement supports this view, with for example the Great North Care Record[70] adopting Transparency as one of its guiding principles as a result of its public engagement process:

Citizens expected to be informed about how data about them is or may be used, and by whom.

For engagement with patients and publics the challenge is greater since expressing the potential secondary use of shared patient data in system planning in a way that makes it tangible, but also allows real world exploration of potential trade-offs and red lines, is complicated and has not really been attempted in previous engagement exercises.

Planning and administration of the health and care system can arguably be seen as the solidarity principle in action. Solidarity means the collective acting on behalf of its members and the NHS is founded on provision paid for by all at the point of need. Setting the sharing of information in the context of making sure the NHS and care system is organised well to meet the needs of all does not seem to have featured in surveys and engagements. More focus on emphasising solidarity based uses, made specific, and using language that makes it tangible to the public, may well have merit.

Chapter 3 **Beyond direct care: improving health, care and services**

Research

Medical research is supported – but within limits

A large proportion of the available evidence on public attitudes to health information sharing relates to the use of patient data in research. We focus in this section on the material most relevant to OneLondon specifically, including the extent to which the public sees it as a legitimate and useful use of their health information, and their stance towards the fact that it typically involves sharing data with organisations outside the NHS.

High interest in research, but lower understanding

There are many different types of health research, and different reasons for doing it. **Interest amongst the public in health research overall, and belief in its importance, is high**, demonstrated consistently in published research.

For example:

- Wellcome[71] reports 77% of respondents indicating interest overall (22% 'highly interested')

- And 42% as having 'actively sought out information about health research in the last year'

- The Health Research Authority[72] reports 96% belief in the importance of health research (83% 'very important')

But, **awareness and understanding of the ways research makes use of health data**, and the complexity and multi stakeholder nature of much health research are much lower.[73] Wellcome in 2016 reports that:

- Twice as many people know 'just a little' or 'nothing' (66%) about such uses by the NHS, as 'know a fair amount' or 'a great deal' (33%)

- Fewer than one in five know 'a fair' or 'great deal' about the involvement of commercial or academic organisations (16% and 18% respectively)

'How much, if anything, would you say you know about how the following organisations use health data for… research into diseases and treatments?'	The NHS	Commercial organisations, e.g. drug or medical equipment companies	Academic researchers
A great deal	12%	5%	5%
A fair amount	21%	11%	13%
Just a little	29%	25%	25%
Heard of, know nothing about	21%	27%	25%
Never heard of	16%	31%	31%
Don't know	1%	1%	1%

Base: 1524 UK representative

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Nonetheless, widespread support for sharing of data for research

Despite low levels of understanding, there is good evidence for public support overall for sharing patient data for the purposes of medical research. Questions and expressed levels of support vary considerably as shown in the table below, but in all but one case two thirds or more of the public agree with the use of shared data for research:

% Giving favourable response	Question / topic	Source and date
81%	To research the best way of treating diseases	
74%	To research what puts people at risk of diseases	Joined Up Yorkshire & Humber 2018
71%	To understand the genetics of diseases	Base: 1031 from widespread engagement
58%	General research for the public good	
81% - (67% if de-personalised, 14% if identifiable)	Support using electronic health records for health research	Luchenski et al 2013 Base: 1524 representative patients
77%	Willing to allow your de-personalised medical records to be used in a medical research study	Wellcome 2016
75%	Willing to allow de-personalised information from your genes to be used in a medical research study	Base: 1524 UK representative
68.7%, 77%, 81.4%, 83%	Support for sharing patient data with researchers shown in earlier studies (systematic review of studies UK and Ireland)	Stockdale et al 2018 Various representative bases
73%	I am happy for the NHS to use my patient data to improve the healthcare treatment of others	Healthwatch 2018
67%	I would be happy for a research team to use my patient data if it were anonymised	Base: 2072 UK representative
53%	My identifiable healthcare record being on a secure database which can be accessed by independently approved university researchers.	Great North Care Record 2018 Base: 824 North East representative

Overall support is also evident from qualitative and engagement evidence, with one systematic review of 25 studies concluding:

'The included studies point to a clear trend that there was generally widespread – albeit conditional – support for uses of data in health research. This is typically expressed in relation to a view that health research… is "in the public interest" or is expected to bring about benefits "for the greater good".'[74]

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The same study also noted the different conditions which shape the acceptability of patient data use for research purposes in the public's mind:

Conditions for support:

- such research must have public benefits

- assurances of individual's confidentiality

- perceived autonomy, or individual control over how data is used

- addressing concerns over the potential of data to be misused or abused

As noted above[75], public benefit can be seen as a necessary condition in the public's mind for secondary uses of patient information. This has been considered in the literature particularly in relation to research uses, tapping positively into the 'altruism' dimension of the NHS social contract discussed in Chapter 1, but more negatively when combined with, or subservient to, private benefit and profit making.

Involvement of non-NHS bodies, particularly commercial, lowers support

Where questions are unspecific about who is conducting the research, or where the NHS is specifically mentioned, support in surveys tends to be relatively high. On the other hand, where it is clearly referenced, commercial involvement results in consistently lower levels of expressed support, perhaps because the assumption may be that public benefit is secondary or absent:

% Giving favourable response	Question / topic	Source and date
53%	Support your health data being accessed by commercial organisations if they are undertaking health research	Wellcome 2015 Base: 1524 UK representative
16%	Commercial research	Joined Up Yorkshire & Humber 2018 Base: 1031 from widespread engagement

Evidence from engagement processes, as well as some stakeholder interviews suggests the resistance to the involvement of 'for profit' companies is also closely associated with belief in the NHS non profit ethos, and associated fears about privatisation:

- 'For those who are most concerned about privatisation everything related to the NHS is viewed through this lens

- For these people, any hint of private sector involvement significantly raises concern about the sharing of data within the NHS because of questions about where it will end up and what it will be used for'[76]

And:

'Participants in the workshops did not know that commercial companies already play a part in delivering healthcare and biomedical research. They also did not spontaneously mention academics and charities as part of the health system. They did not draw a meaningful distinction between private companies' research and retail aims.

Some were shocked to hear that private companies were engaged at all with healthcare. The motivations of commercial companies in delivering health services were questioned in deliberation and the private sector in general was mistrusted. Many approached the discussion of data sharing with some caution, as a result.'[77]

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There is some scepticism about whether benefits will emerge

Lower levels of support for sharing patient data for the purposes of research may also be associated with degrees of scepticism as to whether the supposed public benefits will in fact be achieved. A survey for NHS England[78] which couched questions in terms of beneficial outcomes, recorded relatively low support:

% Giving favourable response	Question / topic
53%	Allowing different NHS organisations to share patient information and data allows them to research new treatments, speed up diagnosis and improve patient care
27%	Allowing the NHS to share patient information and data with other organisations, such as local authorities, university and hospital researchers, and pharmaceutical companies improves patient care

Base: 1014 UK representative

An engagement exercise in Scotland to consider public expectations as to who should benefit from sharing patient data for research reported that:

'Workshop participants were unwilling to narrowly define or constrain public benefits and preferred to keep this definition open recognising the very many forms public benefits could take. They were more concerned with the likelihood that benefits would be realised – that research would make a difference… a theme consistent across all workshops. The discussions highlighted the need for action in response to research findings, suggesting that ensuring impact itself was an important component of achieving public benefit.'[79]

And research conducted for Genomics England observed that:

'There was healthy scepticism about how well any data sharing system can work in the NHS given that it is not known for high tech data management.'

Research sometimes overlaps with direct care – for good and ill

Wellcome in 2015[80] reported **that a quarter of respondents or a member of their family had taken part in a medical research project**, unsurprisingly more likely amongst those with serious long term conditions. Those who had done so were more likely to know more about research and be more interested in it.

Further engagement work by Wellcome in 2016 pointed out that people:

'… with severe, non-severe and rare long term conditions in the deliberative research had often witnessed the benefits and risks of sharing health data, through having greater contact with health services…'

'Two distinct mindsets emerge from discussions with patients and cohort members: 'Monitor Me', and 'Fed Up'… a tension exists for these participants, between the pragmatic challenges of having their very sensitive and potentially highly identifiable health data shared… and the life-saving benefits that either they or others may receive…'

'For 'Monitor Me's'… their experience of taking part in health research or their understanding of how necessary health research is for medical advances makes them more comfortable with the activity…'

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'Fed Ups… can feel over-monitored and frustrated at what some see as constant demands for them to share very personal and sensitive information… which can radically colour their views of health data sharing more generally.'

This suggests the importance of taking people's lived experiences over the course of a lifetime into account when considering the range of attitudes likely to exist towards data sharing generally and research in particular, which could be explored in more depth in future engagement work.

In some specific cases research and treatment go hand in hand – genomics in particular requires the use of an individual patient's data in comparison with others to both decide on possible treatments, and to build the underlying data sets upon which the technique is founded. Recent research by Genomics England[81] concluded that:

'Realising the potential of genomics in the longer term will require a critical mass of UK citizens supporting it to the extent that they are willing to participate…'

And that, after discussion and deliberation:

'Almost all were relaxed about their health and genomic data being used in health research.'

This support is, however, conditional on:

- consent being obtained first;

- the use of de-identified data only and red lines being respected;

- robust risk assessment and safeguards being implemented and maintained by policy makers, researchers and clinicians;

- and genomics seen to be having a real clinical impact

This is a good example of the areas where the public sees there being trade-offs between sharing their patient health information and the potential for both personal and public benefit. Where there is currently less evidence is how expectations such as those outlined above can be met operationally in ways which are feasible and cost effective.

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Themes and implications

- Beyond direct care there are clear expectations, expressed by both public and professionals, about clarity and transparency in the sharing of patient data for secondary uses. There is some published evidence about how these expectations might be met, and trade-offs that might be acceptable, for the sharing of data for research - for example if de-personalisation of data can be guaranteed and public benefit can be demonstrated. The desire for a degree of hands-on control of their own records is a possible way to address these issues, but may be impractical – caution is needed in this area so as not to raise expectations if they cannot be fulfilled. Sharing of patient data for the purposes of research is currently beyond the OneLondon remit although the potential that the data could be used in this way will inevitably have some impact on attitudes to the shared health care record overall and can be expected to be raised by participants in any engagement programme.

- There is much less evidence around the secondary use of data for systems planning. In order to better understand public attitudes and expectations in this area there is a clear need for narrative examples that are meaningful and relevant for patients and public. The few examples explored in the published literature in previous engagement exercises tend to emphasise 'positive' results of using shared data in this way – the provision of new clinics and services for instance. Attempts in surveys to understand attitudes towards use of data to facilitate more 'efficient' delivery of services have generally resulted in far lower levels of support. However, evidence from stakeholder interviews suggests that the secondary use of data for system planning, particularly if it is shared with other more central authorities, will be an area of concern for some and should be considered in the development of the engagement programme.

- The broadly positive stance towards sharing data for research in return for public benefit (as long as there are sufficient safeguards built in) is a good example of the Altruism principle, and the evidence is good for the potential of deliberative engagement processes to increase support for the idea of 'helping others'. System planning's benefits have not been explored or spelled out clearly in public engagement exercises to date but are arguably more related to the principle of Solidarity as described in the recent work for Genomics England. Examples of tangible relevance to the public will need to be developed if this is to be explored in the OneLondon engagement process.

Chapter 4 Is London different?

The evidence about attitudes to health data sharing comes from many different sources, including national level surveys and deliberations, and engagement work associated with specific initiatives in particular places. In this section we discuss the relatively limited amount of London specific information available, and point out some particular features of London which might have a bearing on people's attitudes but for which evidence is lacking.

Londoners may be more wary

Some national level surveys allow London to be compared with other areas, although sample sizes mean that observed differences frequently do not reach norms of statistical significance. There is, however, evidence that **people in London are somewhat warier about patient health information sharing**. The Healthwatch survey from 2018[82] referred to previously is one of a small number looking at health information sharing issues which includes analysis by region. Although not apparent in all questions, responses by Londoners compared to the national picture are less positive in relation to a number of issues to a statistically significant level:

National vs London specific responses		National	London
How do you feel about how your personally identifiable data is used, compared to three years ago?	% more concerned	**57%**	**65%**
How confident or not are you currently in the ability of the NHS to protect your patient data?	% confident	**77%**	**68%**
To what extent, if at all, do you trust [the NHS] to use your personally identifiable data appropriately?	% rating 8/10 or more	**44%**	**36%**
I am confident that, as a patient, my data privacy rights are protected by the NHS	% agree	**75%**	**70%**
I trust my GP to know how best to use my patient data	% agree	**78%**	**71%**
There are aspects of my patient data I would rather my GP did not share with anyone else	% agree	**66%**	**70%**

Base: 2072 UK representative

The pattern here is clear. Carried out with more than 2,000 respondents, and stratified to be representative of the UK population, Londoners appear to be more worried about the use of personally identifiable data overall; more sceptical about the NHS in this arena; and a little less trusting of their GPs. A different (but equally representative) survey of 2,000+ for the Open Data Institute[83] gives some corroboration – nationally 64% said they would trust the NHS 'with data about you', but only 58% of Londoners.

London as a whole has a higher opt-out rate

NHS Digital has been tracking the rate of opt-outs since the national data opt-out was introduced in May 2018[84]. The most recent figures, to the end of March 2019, shown in the table below, indicate a significantly higher opt-out rate for secondary uses of data in London, 3.15% of registered patients, compared to the national figure of 2.63%, which seems consistent with the higher degree of scepticism reported above.

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Percentage of registered patients exercising Opt Out by end March 2019

Area / CCG	% Opted Out	Median	
UK excluding London	2.63	2.32	
London as a whole	3.15	2.83	
NHS Camden CCG	9.32	NHS City & Hackney CCG	2.81
NHS Central London CCG	8.07	NHS Merton CCG	2.74
NHS Lewisham CCG	5.16	NHS Richmond CCG	2.68
NHS Haringey CCG	4.81	NHS Sutton CCG	2.59
NHS Islington CCG	4.46	NHS Enfield CCG	2.41
NHS Bromley CCG	4.22	NHS Bexley CCG	2.27
NHS Basildon and Brentwood CCG	4.15	NHS Waltham Forest CCG	2.16
NHS Wandsworth CCG	4.05	NHS Havering CCG	1.98
NHS Greenwich CCG	3.70	NHS Dartford, Gravesham and Swanley CCG	1.94
NHS Lambeth CCG	3.61	NHS Hillingdon CCG	1.92
NHS Ealing CCG	3.46	NHS West London CCG	1.90
NHS Kingston CCG	3.36	NHS Hammersmith and Fulham CCG	1.82
NHS Tower Hamlets CCG	3.20	NHS Harrow CCG	1.59
NHS Newham CCG	3.05	NHS Barking and Dagenham CCG	1.52
NHS Croydon CCG	2.97	NHS Redbridge CCG	1.40
NHS Barnet CCG	2.86	NHS Brent CCG	1.26
NHS Southwark CCG	2.85		

Source: NHS Digital (2019)[85]

These figures also show a wide variation in opt-out rates. London has two of the top five CCGs for opt-outs in the country, Camden and Central London, but just two in the bottom 20, Hounslow and Brent. The overall pattern across London is consistent with the national picture, with a relatively large number of CCGs with low opt-out rates (median in London 2.83, nationally 2.32), and a small number with much higher rates.

Chapter 4 Is London different?

Londoners may have more experience of data sharing initiatives

From one source only, but the Healthwatch survey also reported a significantly higher proportion of Londoners – 30% – as saying 'I have seen or heard of a project where the NHS is already using patient data to improve healthcare', compared to the 24% national figure. Since the Healthwatch research was carried out, more data sharing initiatives have been launched across London.

Little evidence reflecting the diversity of London's population

Notably absent from most of the published national survey data is analysis by ethnic minority status. London's population is, of course, highly diverse, with 40% of residents identifying with either the Asian, Black, Mixed or Other ethnic group – by some distance the highest figure in the UK; the lowest proportion of White British (45%); and the highest proportion of White Other (15%)[86].

One survey from 2013[87] carried out in west London to assess attitudes towards the possible introduction of a national electronic health record reported that:

Black British respondents…show significantly less support than respondents from other groups…Our study resonates with previous research showing that ethnic background affects attitudes towards health information sharing: people from BME (Black and Minority Ethnic) communities or people who do not identify themselves as White British have been shown to be less inclined to allow their data to be used for public health and medical research.

This suggests that there may well be different patterns of attitudes towards data sharing in London compared to other areas, and extrapolation from national surveys or other regions of the UK should be treated with caution. It also points to the importance of reflecting the diversity of the London population in the OneLondon engagement process.

Other issues where London's differences might influence attitudes in relation to health information sharing, although published evidence is lacking, include language diversity; high rates of internal movement and population turn-over; and the role of the Mayor and the GLA in London's NHS.

Some insights from local engagement, but a need for more

A number of engagement exercises conducted in parts of London have been reported, which contribute useful localised insights sourced from Londoners. These include:

- Detailed expectations of a local online digital care record for individual care from an engagement exercise conducted by Islington CCG with local residents and youth groups[88], which reported broad support for 'a care record which shows patients' and service users' regular interactions with health and care services and their overall journey, as well as goals to support them to self manage'. The results specify expectations for a high level of patient access and functionality; a highly accessible system; and strict data protection measures.

- Specific issues related to sharing health and social care records from Southwark Borough Council[89], which unusually focussed on the perspectives of social care users. This reported support for sharing between the NHS and Adult Social Care, but noted a range of specific concerns and expectations derived from participants' own experiences particularly focussed on the accuracy and legibility of records; whether the information is up-to-date; restrictions on access; the need for an audit trail of access and amendments; and concerns about the implications of information sharing for care providers beyond the local authority.

- Patient views on the use of technology in Primary Care carried out by Healthwatch Enfield[90] with 1000+ residents. Although not focussed specifically on data sharing, this report provides insights into patients' experiences of using new technologies in a Primary Care context, which they broadly welcome. These include, for example, online access to GP services, and notes both positives but also concerns and frustrations about the realities of their use in practice such as difficulties in registration and unfriendly user interfaces. It also highlights patient expectations of greater functionality and a wider variety of services.

Chapter 4 Is London different?

Insights from stakeholder interviews

Patient data sharing initiatives for the purposes of direct care exist across London – each slightly different from the other; a number have been launched quite recently.

Patient attitudes towards the introduction of shared health and care records in their current forms were reported by both professional and patient representative interviewees to be positive, although to date no real evaluations of impact have been carried out.

It was also widely felt that the experience of working with the new records and, in particular, the efficiency and time-saving benefits that had resulted from their introduction, had done much to dispel the understandable concerns and caution that healthcare professionals, particularly in Primary Care, had expressed prior to their introduction.

Although positive aspects to the introduction of a London-wide shared health and care record could be appreciated, there were also **some concerns expressed about how OneLondon would sit alongside such recently introduced local initiatives** - sometimes described as still 'bedding-in'.

There were a few examples given of patients experiencing, and being disappointed by, situations where healthcare professionals have apparently been unaware of the new system, or reluctant to use it for some reason.

The main issues raised by stakeholders were:

- A need for clear communication with both public and professionals about the benefits of a London-wide record, over and above the benefits of the existing local sharing initiatives

- A concern that the Information Governance Framework(s) needed to support OneLondon's data sharing ambitions might prove to be overwhelmingly complex

- A worry that the introduction of another data sharing initiative might create considerable confusion amongst both patients and professional staff and derail the progress made so far at a local level

- A concern that differences in the approach to, for example, coding, between areas, would make consistency very difficult to achieve and extracting 'meaning' from the data complicated

- A feeling that the NHS in London, and Primary Care in particular, is currently under intense pressure and the investment of time and money necessary to underpin and facilitate OneLondon's successful introduction simply does not exist currently

The eco-system surrounding the OneLondon programme is a particularly complicated one, emphasising the need for high levels of engagement with both public and professionals from the outset.

Themes and implications

Londoners' apparently more sceptical view of the health and care system and data protection issues merits further investigation, particularly if it proves to be associated with aspects of the diversity of its population. Engagement should anticipate the raising of issues of particular importance to different groups, and different understandings of how reciprocity, solidarity and altruism operate – this might for example point to more specifically targeted examples and communications.

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