Public perceptions of NHS data use:
Rapid literature review

Patient
Experience
Library

Contents

Acknowledgements

1.   Introduction [1]

There is arguably a well-established legal and regulatory framework for sharing healthcare data, which can be summarised in headline terms as follows:

Since 25 May 2018, access to patient health records has been governed by the EU General Data Protection Regulation (GDPR), enacted by the Data Protection Act 2018.

The NHS Constitution states that patients have the right to privacy and confidentiality, the right to expect the NHS to keep patient confidential information safe and secure, and the right to be informed about how their information is used. Patients also have the right to request that their confidential information is not used beyond their own care and treatment.

In November 2014, Dame Fiona Caldicott was appointed as the first National Data Guardian (NDG) for health and care, to ensure patient trust in the use of their data and to review the balance between the protection and sharing of this data. The Health and Social Care (National Data Guardian) Act 2018 placed the role on a statutory footing.

On 25 May 2018, NHS Digital launched the national data opt-out programme, a tool that allows patients to choose to opt out of their data being shared outside of the NHS.

However, the framework is not foolproof – public confidence in the security of their healthcare data is likely to have been affected by a number of recent breaches:

The 2017 Wannacry ransomware attack affected 80 NHS Trusts, plus a further 603 primary care and other organisations, at an estimated cost of £92 million. None of the 80 NHS Trusts affected by WannaCry had applied an advised Microsoft patch update.

Dame Fiona Caldicott concluded in 2017 that data was improperly shared between the Royal Free NHS Trust and Google DeepMind, which had been given access to five years' worth of data from 1.6 million patients.

In 2018, Bupa was fined £175,000 after an employee was able to extract the personal information of 547,000 Bupa Global customers and offer it for sale on the dark web[2].

Public concern over data sharing came to the fore in 2016, when the government attempted to launch Care.data, a system to extract and link large amounts of data collected as part of NHS care. Following concerns over the opt-out system in place and over patient confidentiality, the scheme was first suspended, then closed.

This may be as much a public health matter as a technical matter: "*Public trust in the Health Service's ability and willingness to safeguard their privacy is a cornerstone of the NHS. If the public stop trusting that the information they share with their clinicians will remain private, then it may become*

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1   Information in this section (unless otherwise referenced) comes mainly from House of Commons Library Briefing Paper Number 07103, 28 April 2020. Patient health records: access, sharing and confidentiality.

2   Information Commissioner's Office: https://ico.org.uk/about-the-ico/news-and-events/news-and-blogs/2018/09/bupa-fined-175-000-for-systemic-data-protection-failures/

impossible to obtain the level of candour required for effective, safe treatment, posing risks to public health" [3].

Against this background, government is planning the launch of the General Practice Data for Planning and Research (GPDPR) programme. The programme, which will involve the daily collection of GP data to support health and care planning and research, has been deferred in the face of public concern. NHS Digital, which leads the programme, will use the additional time to speak with patients, doctors, health charities and others.

The Patient Experience Library was asked to conduct a rapid literature review to be presented to a group of charities: National Voices, Healthwatch England, the Richmond Group and the Patients' Association. They will use the results of the literature review as a basis for understanding public concerns about use of healthcare data, and to develop a set of patient-centred principles which will be recommended to NHS Digital.

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3   New Economics Foundation, 2010. Who sees what: Exploring public views on personal electronic health records.

2. Key messages

The planned launch of the General Practice Data for Planning and Research (GPDPR) programme has been deferred due to public concern. The concerns have arisen in spite of an arguably well-established legal and regulatory framework for sharing healthcare data, linking European regulation, UK law and the NHS Constitution.

To aid efforts to understand public attitudes to healthcare data sharing, we asked, "What are the barriers and enablers for patients and the public participating in sharing personal healthcare data?" From a wide-ranging search of patient experience and engagement literature, we identified the following barriers and enablers:

Barriers

PUBLIC UNDERSTANDING

In general, **public understanding is poor** – Ipsos Mori, for example, have made the point that: "*When it comes to patient awareness and understanding of health data in the UK, the public... often knew little about some key areas*" [4] Such findings are not new – in 2014, local Healthwatch, commenting on public reactions to the Care.data initiative, said: "*The debate showed that public awareness of the 'pros and cons' of the scheme is limited*" [5].

There is a **legal angle** on this: "*The law requires 'fair processing' – patients must be informed of the uses of their data but sometimes they are not*" [6].

Equally important is the **commercial angle**: "*One of the things that worries members of the public is what use their data might be put to that involves making a profit for somebody other than the health service*" [7].

Ethical considerations are also in play: "*... there was generally found to be low public awareness of current research practices and in particular, of current governance or ethics processes* " [8].

Finally, there are **technical issues:** "*The way that personally identifiable data could be translated into depersonalised and aggregate data was not understood... Some struggled to understand how aggregated datasets could give any useful learning about individuals*" [9].

4   Ipsos Mori, 2016. The One-Way Mirror: Public attitudes to commercial access to health data.

5   Healthwatch Essex 2014. Care.data: the debate. Summary report.

6   Citizens' Juries and Jefferson Centre, 2018. Use of Free-text Health Data. A report of a citizens' jury designed to explore when and how free-text data in patient records should be used.

7   House of Lords, 2017. Select Committee on Artificial Intelligence, Evidence session no. 14, Questions 128-142.

8   Aitken, M. et al., 2016. Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. BMC Medical Ethics.

9   Castell, S. et al, 2018. Future data-driven technologies and the implications for use of patient data. Dialogue with public, patients and healthcare professionals. Ipsos Mori.

PUBLIC ENGAGEMENT

To facilitate data sharing, there is a clear need for education and dialogue. However, past experience has revealed some barriers – for example, **poor planning**. At the time of Care.Data, one local Healthwatch reported that "*Unfortunately the pathfinder programme has been hampered by delays and lack of materials [which] have led to real difficulty for us locally as we have had to change engagement plans, cancel public meetings and contact groups and stakeholders to change information that we originally gave them*"[10].

Inappropriate language can also get in the way: "*The current language landscape around the use of patient data in care, treatment and research is difficult, complex and confusing....This acts as a significant barrier to having open discussions with the public about the use of data in ways that can build both understanding and trust*"[11].

Public engagement nowadays needs to take account of the influence of **misinformation**. For example, a study looking at why people chose to not use the NHS COVID-19 app found that "*Reasons included: – the (false) perception that the NHS COVID-19 app was run by a distrusted private company (Serco) rather than by the NHS* "[12].

It should perhaps go without saying that **public engagement should be inclusive**. Healthwatch England have made a useful point about public engagement and carers: "*Carers are often 'forgotten' because they are caring for someone and have also neglected the need to 'opt-out' if necessary*"[13].

CHOICE AND CONTROL

It may come as no surprise that "*Perceived autonomy, or individual control over how data is used, was found to be a key factor shaping public responses*"[14].

A key driver for concerns over choice and control is the question of **data privacy**. This has been recognised by the Department for Health and Social Care: "*The primary reason for not downloading the NHS COVID-19 app were concerns around privacy and not wanting to use the app*"[15].

Third parties' motives for wanting access to personal healthcare data is a further cause for concern. A Healthwatch survey on sharing of medical records found that "*The most common area of concern with respect to record sharing was access by third parties*"[16]. Commercial companies are a common focus of anxieties about third party use of personal healthcare data: "*The*

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10   Healthwatch Hampshire, 2015. care.data West Hampshire Pathfinder Engagement Report.

11   Good Business, 2017. Patient Data. Finding the best set of words to use.

12   Department for Health and Social Care, 2021. NHS COVID-19 app: early adopter evaluation report NHS Test and Trace programme.

13   Healthwatch England, 2015. Written evidence on Public Attitudes on Consent and Data Security for the National Data Guardian Review Team.

14   Aitken, M. et al., 2016. Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. BMC Medical Ethics.

15   Department for Health and Social Care, 2021. NHS COVID-19 app: early adopter evaluation report NHS Test and Trace programme.

16   Healthwatch Surrey, 2015. If I've told you once... People's views on record sharing between the health and social care professionals involved in their care in Surrey.

fear of data being misused by companies for their own gain was very apparent in all groups" [17].

Questions of **data security** can also affect people's perceptions of how much control they have over their own data: *"85% of people in one survey knew about the Wannacry hacking scandal and 53% said their confidence in the ability of the NHS to handle data was negatively affected*" [18].

Concerns over choice and control could perhaps be mitigated by **effective regulation**. But that might depend on the extent to which regulation is seen as keeping pace with technological developments: "*five public bodies were responsible for assessing the impact and safety of Babylon's products (CQC, MHRA, NHS Digital, NHS England, and Hammersmith and Fulham CCG), demonstrating the lack of clarity that currently exists in the oversight of technology products such as chatbots*" [19].

DEMOGRAPHIC DIFFERENCES

There may be some differences between **women and men** in attitudes towards data sharing: An Ipsos Mori study asked 2,000 people how important it was that the NHS treats a patient's medical records as confidential, and found that "*Women are more likely than men to say this is very important (89% vs 85%)*" [20].

There might also be some **age differences** in data sharing acceptance. However, conclusions regarding age or gender variations are not unanimous: "*Older people were generally more willing to have their records shared between the professionals involved in their care. In focus groups with over 65s there were comments from older people about the difficulty of remembering all the relevant details of their health history*" [21]. Conversely, "*16-24 year olds were significantly more likely than older age groups to be confident that their data would be handled securely*" [22].

A third factor that also appears to be influential is **social status**: "*ABC1s were more likely than C2DEs to view the use of health data as having a potential benefit to society, in the fields of research, disease prevention, planning of services, crime prevention and so on*". For C2DEs, "*Any linking resulting in the individual being targeted with specific messages prompts discomfort and resistance. The expectation is that blame and desired behaviour change will be implicit*" [23].

17   Hill, E. et al., 2013. "Let's get the best quality research we can": public awareness and acceptance of consent to use existing data in health research: a systematic review and qualitative study. BMC Medical Research Methodology

18   Understanding Patient Data, 2018. Public attitudes to patient data use. A summary of existing research.

19   All Party Parliamentary Group on Heart and Circulatory Diseases, 2019. Putting patients at the heart of artificial intelligence.

20   Ipsos Mori, 2018. Public views on data sharing. Report for NHS Digital.

21   Ipsos Mori, 2018. Public views on data sharing. Report for NHS Digital.

22   Department for Health and Social Care, 2021. NHS COVID-19 app: early adopter evaluation report NHS Test and Trace programme.

23   Wellcome Trust, 2013. Summary Report of Qualitative Research into Public Attitudes to Personal Data and Linking Personal Data.

Enablers

TRUST

A key enabler for patient and public attitudes towards data sharing is trustworthiness: "*The overwhelming factor in considering whether or not to share data… is whether or not people trust the organisation asking for it*" [24]. However, **trust is not distributed equally**. Ipsos Mori has found that "*Public sector healthcare providers are most trusted to use personal information*" in comparison to other organisations such as insurance companies and social media[25].

Trust is also not given unconditionally – there are caveats: "*If the parameters of medical and care record sharing are kept within the confines of the medical and care professions, and there are procedures in place to ensure security, confidentiality and accuracy, there is strong support*" [26].

Social and political context also matters: "*when discussing trust, many members of the public veered away from specific technologies and instead spoke about the social and political systems in which they are deployed*" [27].

PUBLIC BENEFIT

People are likely to support health data sharing if the reason for doing so offers clear public benefit: "*The vast majority of respondents reported that if their health information could help others (e.g. via research) they would be happy to share it*" [28].

The benefit **may not have to be specific**. People are willing to accept "potential" benefits, and to respond to broader ideas such as "altruism". "*Assurances that research would – or at least have the potential to – bring about public benefits were fundamental for ensuring public support or acceptance*" [29]. "*Participants [were] willing to share electronic health records (EHRs) for secondary purposes when there was a "common", "greater" or "public good", and when there was "social responsibility", "altruistic attitudes" and "giving something back"*" [30].

One study, however, takes a different view: "*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*" [31].

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24   Open Data Institute, 2018. Who do we trust with personal data?

25   Ipsos Mori, 2018. Public views on data sharing. Report for NHS Digital.

26   Healthwatch Surrey, 2015. If I've told you once… People's views on record sharing between the health and social care professionals involved in their care in Surrey.

27   Ada Lovelace Institute, 2020. No green lights, no red lines Public perspectives on COVID-19 technologies.

28   Healthwatch England, 2015. Written evidence on Public Attitudes on Consent and Data Security for the National Data Guardian Review Team.

29   Aitken, M. et al., 2016. Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. BMC Medical Ethics.

30   ADR UK, 2020. Trust, Security and Public Interest: Striking the Balance. A review of previous literature on public attitudes towards the sharing and linking of administrative data for research.

31   Curved Thinking, 2019. Understanding public expectations of the use of health and care data.

It may, however, be important to emphasise that the ultimate public benefit is **improved patient care**: *"Improved patient care has to be the main purpose for entering into data access partnerships in the eyes of Jurors...That should be the endgame"* [32].

The other side of the "optimism" coin is the **opportunity cost of not sharing healthcare data**: *"Jurors reflected on the cost of not using the data for access partnerships...They saw this, together with NHS organisations not being in tune with the fast-moving world of digital and technological innovation as serious challenges to success"* [33].

The "public benefit" case could also be important for commercial access to health data: *"Participants wanted companies accessing health data to demonstrate that they are making a contribution to public value and a real, long term benefit to health in the UK"* [34].

INFORMATION

Learning acquired from the Care.data scheme suggested that better quality information could have enabled public engagement and understanding. This includes **methods of communication**: *"There does need to be more effort to inform*

people of the programme in addition to the letter to each patient of the GP surgery" [35], as well as the **content of communications**: *"A more informative public awareness campaign — which better covers areas such as... ethics, data security and safeguards — would help to build trust"* [36].

Information on data sharing should be **part of a more general process**: *"patients and the public [should be] active partners in agreeing priorities for, and determining the acceptability of, data-driven technologies as part of an ongoing process"* [37].

Information also needs to be clear about **all sides of the data-sharing debate**: *"No use of technology is without risk... Public trust cannot be engendered if only benefits are highlighted"* [38], and there is a need to reassure patients and public that **risk is well managed**: *"Patients need to feel confident that their data is secure and in the hands of trusted actors"* [39].

RELATIONSHIPS

Various studies suggest that the **patient/professional relationship** may be an important enabler for healthcare data sharing.

One possibility is that *"the greater general level of trust in healthcare providers*

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32   Hopkins, H. et al. 2020. Foundations of fairness: views on uses of NHS patients' data and NHS operational data. A mixed methods public engagement programme with integrated Citizens' Juries. Hopkins Van Mil

33   Hopkins, H. et al. 2020. Foundations of fairness: views on uses of NHS patients' data and NHS operational data. A mixed methods public engagement programme with integrated Citizens' Juries. Hopkins Van Mil

34   Ipsos Mori, 2016. The One-Way Mirror: Public attitudes to commercial access to health data.

35   Healthwatch Hampshire, 2015. care.data West Hampshire Pathfinder Engagement Report.

36   Healthwatch Essex 2014. Care.data: the debate. Summary report.

37   The Academy of Medical Sciences, 2018. Our data-driven future in healthcare People and partnerships at the heart of health related technologies.

38   All Party Parliamentary Group on Heart and Circulatory Diseases, 2019. Putting patients at the heart of artificial intelligence.

39   All Party Parliamentary Group on Heart and Circulatory Diseases, 2019. Putting patients at the heart of artificial intelligence.

compared to other public bodies may be due to individuals' existing relationships with primary healthcare providers, which are in some cases built up over many years, suggesting that having a familiar relationship with an individual is important for securing trust" [40].

This might play into the **shared decision-making agenda**: *"The majority of people (77%) felt that it should be a combination of patient and professional who decide how records are shared. (Patient and doctor together, 42%, or patient, doctor and social care practitioner, 35%)"* [41].

Relationships at the organisational level may also be important: *"The NHS should engage key stakeholders on a regular basis to determine which datasets have the highest priority for them; what new datasets should be released as open data; and which open data collections are particularly easy or difficult to use"* [42].

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40   ADR UK, 2020. Trust, Security and Public Interest: Striking the Balance. A review of previous literature on public attitudes towards the sharing and linking of administrative data for research.

41   Healthwatch Surrey, 2015. If I've told you once… People's views on record sharing between the health and social care professionals involved in their care in Surrey.

42   Govlab, 2014. The open data era in health and social care.

3. Method

Review Question

Following discussion with stakeholders as listed above, the review team established a research question as follows: "What are the barriers and enablers for patients and the public participating in sharing personal healthcare data?"

Search strategy

SEARCH TERMS

The search was conducted using the following terms (listed alphabetically): apps, artificial intelligence, care.data, data/digital access, data/digital anonymisation, data/digital confidentiality, data/digital opt-out, data/digital privacy, data protection, data/digital regulation, data/digital safeguard, data/digital security, data sharing, disinformation, electronic health record, health information, hesitancy, misinformation, wannacry

EXCLUSIONS

Place: Evidence was taken only from UK sources. While some literature is available from non-UK countries, attitudes and opinions from patients and the public within the UK seemed most relevant to GPDPR as a UK government scheme.

Time period: No exclusions, as most of the relevant literature is recent (less than ten years old). The search was conducted up to and including the 2nd July 2021.

Sources: Evidence was not drawn from documents that are held behind journal paywalls, or other literature that would normally be for sale from booksellers. Our evidence was from open access sources (government, patient voice, charity, academic etc). It included "grey literature" from sources such as Healthwatch reports. Conventional academic literature reviews might exclude grey literature on the grounds that it is not peer-reviewed or formally catalogued. However, we see these documents as important sources of insight, grounded in lived experience, and built on trusted dialogue within communities and service user groups.

Relevance: Search results were filtered for relevance, with only documents that explored exclusively, or mainly, public perceptions of use of healthcare data included. For clarity, only information pertaining to public/patient perceptions of healthcare data sharing was extracted for the purposes of this review.

EVIDENCE BASE

Resource constraints prevented more extensive search across other databases. However, it was also an informed decision as the Patient Experience Library specialises in literature on patient experience and involvement and acts as the UK national evidence base for this kind of literature.

Search results

After de-duplication and relevance filtering, our search resulted in 107 documents, broken down as follows:

AGE

Year	No. of documents
2021	15
2020	16
2019	19
2018	18
2017	5
2016	12
2015	7
2014	8
2013	4
2012	0
2011	1
2010	3

SOURCE

Source	No. of documents
Government	18
Healthwatch	13
Other	76

Note: "Other" includes health charities, academic and research bodies, policy think tanks, etc.

Coding

The 107 documents returned were then read manually, and included/removed based on predetermined inclusion criteria (i.e. explores patient perceptions towards data sharing in a UK context, as previously described).

Relevant comments, findings and quotations from included documents were then extracted, and manually coded against the following themes:

- Choice and control
- Confidentiality/privacy
- Data security
- Influences on public attitudes
- Public understanding
- Regulation

Those were then categorised into the following headings as seen in this report:

- Barriers: Public understanding, public engagement, choice and control, demographic differences

- Enablers: Trust, public benefit, information, relationships

4. Barriers

Our research question was: "What are the barriers and enablers for patients and the public participating in sharing personal healthcare data?"

This section of our report looks at the barriers, which we have broken down to:
Public understanding
Public engagement
Choice and control
Demographic differences

Public understanding

Many studies have made the case for education and awareness-raising among the general public to address their anxieties about the use of healthcare data.

In general, **public understanding is poor** – Ipsos Mori, for example, have made the point that:

"*When it comes to patient awareness and understanding of health data in the UK, the public in the report often knew little about some key areas:*

Not aware of the current range of uses of health data, beyond in their own care

Underestimate the amount of data currently collected and used in healthcare

Do not understand why the NHS would need/want to allow commercial access to data, do not know how the commercial sector contributes to healthcare currently

Little understanding of the status quo when it comes to safeguards (some that participants want are already in place)

Confusion about the specifics of data and data science in general (e.g. the difference between anonymised versus identifiable data, or definition of aggregate data)." [43]

This is not new. As long ago as 2014, local Healthwatch were commenting on public reactions to the Care.data initiative, with statements such as: "*The debate showed that public awareness of the 'pros and cons' of the scheme is limited. This is of obvious concern, as the scheme relies on people having sufficient information to allow them to exercise their choice to opt out of sharing their data, or indeed to agree to the default opt-in position. Many people do not feel sufficiently informed to exercise this choice....*". The report went on to say that "*NHS England has much more work to do in terms of clarifying and explaining the complexities of care.data — both in principle and practice*" [44].

There is a **legal angle** on this: "*The law requires 'fair processing' – patients must be informed of the uses of their data but sometimes they are not. There is a lack of awareness about how patient data is used, or by whom, and that patients can opt out. People who might otherwise be willing to share information may be less willing to do so if they are unable to either give permission or be informed and able to opt out*" [45].

43   Ipsos Mori, 2016. The One-Way Mirror: Public attitudes to commercial access to health data.

44   Healthwatch Essex 2014. Care.data: the debate. Summary report.

45   Citizens' Juries and Jefferson Centre, 2018. Use of Free-text Health Data. A report of a citizens' jury designed to explore when and how free-text data in patient records should be used.

Equally important is the **commercial angle**. In 2017, Dame Fiona Caldicott said "*One of the things that worries members of the public is what use their data might be put to that involves making a profit for somebody other than the health service*" [46].

Caldicott went on to state "*We have quite a lot of education to do, not least with the professions that look after patients and with the public themselves, in explaining the benefits of this and giving reassurance that it is not going to be profit for companies they do not feel comfortable having access to their data, and making absolutely clear that this is safeguarded through anonymization and that it comes back into the national or public good*" [47].

Such conclusions have been echoed by the King's Fund and others: "*People generally have relatively little knowledge about how the NHS and commercial organisations use data for health research, which may be responsible for mistrust in some cases. Transparent public dialogue is needed about how data is currently used; what the opportunities are for the future; and how risks can be mitigated*" [48].

Ethical considerations of data sharing were also addressed via a paper which stated "*... there was generally found to be low public awareness of current research practices and in particular, of current governance or ethics processes. As such, in a* number of studies it was reported that public acceptance increased after participants were informed about existing safeguards and governance mechanisms*" [49].

Technical issues also come into play with regard to public understanding. For example, "*The way that personally identifiable data could be translated into depersonalised and aggregate data was not understood... Some struggled to understand how aggregated datasets could give any useful learning about individuals*" [50].

Public engagement

The studies above point to a need for better public education and dialogue. Clearly this depends on public engagement – but past experience has revealed some limitations with existing practice.

Some barriers arise from **poor planning**. At the time of Care.Data, one local Healthwatch reported that "*Unfortunately the pathfinder programme has been hampered by delays and lack of materials (such as the letter and leaflets) to use in the engagement of local groups. This has undermined the engagement's credibility and effectiveness thus far. These delays... have led to real difficulty for us locally as we have had to change engagement plans, cancel public meetings and contact groups and stakeholders to change information that we originally gave them*" [51].

46   House of Lords, 2017. Select Committee on Artificial Intelligence, Evidence session no. 14, Questions 128-142.

47   House of Lords, 2017. Select Committee on Artificial Intelligence, Evidence session no. 14, Questions 128-142.

48   Castle-Clarke, S., 2018. What will new technology mean for the NHS and its patients? Four big technological trends. The Health Foundation, the Institute for Fiscal Studies, The King's Fund and the Nuffield Trust.

49   Aitken, M. et al., 2016. Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. BMC Medical Ethics.

50   Castell, S. et al, 2018. Future data-driven technologies and the implications for use of patient data. Dialogue with public, patients and healthcare professionals. Ipsos Mori.

51   Healthwatch Hampshire, 2015. care.data West Hampshire Pathfinder Engagement Report.

Another found that "*A key theme raised at the outset was the question of public awareness of care.data and, specifically, the information leaflet and the video which were used by NHS England to inform the public... The leaflet sent out by NHS England was criticised for being sent out alongside junk mail*". It added that "*NHS England acknowledged that these issues had been raised frequently at public listening events, and that NHS England is aware it has not informed the public as much as it should have done*" [52].

Six years later, the Ada Lovelace Institute identified similar issues: "*As trials of the UK contact tracing app and muted success of other apps around the world have shown, failing to engage with the public can lead to vital gaps in understanding of what determines the successful roll-out of a data-driven health tool. To help address these gaps, deeper engagement with informed publics is needed*" [53].

Inappropriate language can also get in the way. One paper stated that "*The current language landscape around the use of patient data in care, treatment and research is difficult, complex and confusing. And current attempts to come up with alternatives have fallen short. This acts as a significant barrier to having open discussions with the public about*

the use of data in ways that can build both understanding and trust*" [54].

Another stated that "*Understanding is made more difficult by the complexity of the subject, and the unfamiliarity of the language. For example, participants struggled to understand the difference between anonymous and pseudonymous data*" [55].

One local Healthwatch, looking at efforts to collect data from GP records, found that "*Several groups felt that the introductory page was unwieldy, containing too much information which made it unappealing to read or difficult to digest. In terms of presentation, one person fed back that their first impression was that the form currently "does not look like one that you can trust"*" [56].

Any form of public engagement nowadays needs to take account of the influence of **misinformation**. A study looking at why people chose to not use the NHS COVID-19 app found that "*Reasons included: – the (false) perception that the NHS COVID-19 app was run by a distrusted private company (Serco) rather than by the NHS – lack of trust in government competence and public health response overall – concern about being monitored – phones' vulnerability to hacking could be increased when their Bluetooth was switched on*" [57].

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52   Healthwatch Essex 2014. Care.data: the debate. Summary report.

53   Ada Lovelace Institute, 2020. No green lights, no red lines Public perspectives on COVID-19 technologies.

54   Good Business, 2017. Patient Data. Finding the best set of words to use.

55   Britain Thinks, 2015. Secondary Uses of Healthcare Data Public Workshop Debrief.

56   Healthwatch Lambeth and NHS Lambeth Clinical Commissioning Group, 2016. Lambeth DataNet: Individual Patient Registration Profile Community Consultation.

57   Department for Health and Social Care, 2021. NHS COVID-19 app: early adopter evaluation report NHS Test and Trace programme.

Finally, it should perhaps go without saying that **public engagement should be inclusive**. There was very little in the literature about barriers and enablers for specific groups within society in respect of engagement on healthcare data – however, Healthwatch England have made a useful point about public engagement and carers: "*Carers are often 'forgotten' because they are caring for someone and have also neglected the need to 'opt-out' if necessary*" [58].

Choice and control

It may come as no surprise that "*Perceived autonomy, or individual control over how data is used, was found to be a key factor shaping public responses*". Indeed, "*Members of the public value having control over their own data. Participants explicitly referred to control over their own data in terms of individual or human rights. There was an evident link between levels of trust (in research organisations or data controllers) and desired level of individual control*" [59].

A key driver for concerns over choice and control is the question of **data privacy**. This has been recognised by the Department for Health and Social Care: "*The primary reason for not downloading the NHS COVID-19 app were concerns around privacy and not wanting to use the app*". Their report recognised that "*building trust in data privacy was the biggest hurdle in NHS COVID-19 app adoption*" [60].

Worries about privacy have been noted elsewhere: "*members of the public value opt-in consent and can perceive research without consent as an invasion of privacy*" [61]. Such concerns influenced reactions to the Care.data scheme: "*The chosen opt-out system was seen by some members of the public as unethical. The default system, which means that data will be extracted unless a patient explicitly rejects, caused much concern. The opt out system relies on everyone knowing about the scheme, being able to make an informed decision and being given the choice to opt-out if they so wish*" [62].

For some people, privacy concerns are directly related to their own health conditions. For example, "*When it comes to the use of social care services, mental health status and sexual health status, a low number of respondents reported being happy to share this information with health professionals and NHS services (39%, 38% and 34% respectively)*" [63]. Furthermore, "*Minors & vulnerable people have special*

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58   Healthwatch England, 2015. Written evidence on Public Attitudes on Consent and Data Security for the National Data Guardian Review Team.

59   Aitken, M. et al., 2016. Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. BMC Medical Ethics.

60   Department for Health and Social Care, 2021. NHS COVID-19 app: early adopter evaluation report NHS Test and Trace programme.

61   Hill, E. et al., 2013. "Let's get the best quality research we can": public awareness and acceptance of consent to use existing data in health research: a systematic review and qualitative study. BMC Medical Research Methodology

62   Healthwatch Essex 2014. Care.data: the debate. Summary report.

63   Healthwatch England, 2015. Written evidence on Public Attitudes on Consent and Data Security for the National Data Guardian Review Team.

considerations for permission and consent" [64], and "*Sharing sensitive data (mental health, sexual health, sexuality, religion) holds greater concern than for other types of data*" [65].

Third parties' motives for wanting access to data is another cause for concern. A Healthwatch survey on sharing of medical records found that "*The most common area of concern with respect to record sharing was access by third parties*" [66].

Commercial companies were a common focus of anxieties about third party use of data: "*The fear of data being misused by companies for their own gain was very apparent in all groups. Concerns were mainly around insurance companies obtaining health information which may affect their premiums or cover, or companies using the information for targeted advertising*" [67]. Insurance companies were also mentioned in a Healthwatch study: "*Fear that personal data will be shared with private companies (especially insurance companies)*" [68].

Concerns about profiteering is also a factor: "*Public trust is undermined when a data access partner is seen to profit excessively from realising the potential from NHS*

patients' and NHS operation data, and/ or the expected social value outcomes do not emerge from the agreement*" [69].

Alongside data privacy, questions of **data security** can affect people's perceptions of how much control they have over their own data: *"85% of people in one survey knew about the Wannacry hacking scandal and 53% said their confidence in the ability of the NHS to handle data was negatively affected*" [70].

Concerns about data security are as much about human error as about the strength of IT systems: "*... concerns related to the fallibility of IT systems to protect against breaches as well as to human error. Media reports of "laptops left on trains" or misplaced data were widely called upon to illustrate this latter point*" [71].

The point about "*media reports*" ties in with an observation that "*The media typically only analyse the process of using health data when something goes wrong, such as a data breach*" [72]. And a citizens' jury exercise found that "*Some jurors mentioned that news stories heard in the press about privacy and confidentiality breaches could act as a deterrent to wider public support for data access*" [73].

65   Understanding Patient Data, 2018. Public attitudes to patient data use. A summary of existing research.

66   Healthwatch Surrey, 2015. If I've told you once... People's views on record sharing between the health and social care professionals involved in their care in Surrey.

67   Hill, E. et al., 2013. "Let's get the best quality research we can": public awareness and acceptance of consent to use existing data in health research: a systematic review and qualitative study. BMC Medical Research Methodology

68   Healthwatch England, 2015. Written evidence on Public Attitudes on Consent and Data Security for the National Data Guardian Review Team.

69   Hopkins, H. et al. 2020. Foundations of fairness: views on uses of NHS patients' data and NHS operational data. A mixed methods public engagement programme with integrated Citizens' Juries. Hopkins Van Mil

70   Understanding Patient Data, 2018. Public attitudes to patient data use. A summary of existing research.

71   Aitken, M. et al., 2016. Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. BMC Medical Ethics.

72   Understanding Patient Data, 2021. Analysis of UK reporting on health data.

73   Hopkins, H. et al. 2020. Foundations of fairness: views on uses of NHS patients' data and NHS operational data. A mixed methods public engagement programme with integrated Citizens' Juries. Hopkins Van Mil

Concerns over choice and control could perhaps be mitigated by **effective regulation**. But that might depend on the extent to which regulation is seen as keeping pace with technological developments. One study notes that the "*need for [regulatory] clarity is becoming ever more pertinent with the speed of technological developments, and consumer healthcare apps using AI… Following complaints about Babylon's symptom checker the Care Quality Commission (CQC) referred them to the Medicine and Healthcare products Regulatory Agency (MHRA). However, five public bodies were responsible for assessing the impact and safety of Babylon's products (CQC, MHRA, NHS Digital, NHS England, and Hammersmith and Fulham CCG), demonstrating the lack of clarity that currently exists in the oversight of technology products such as chatbots.* The report states that "*This situation does not provide the general public the clarity that is required*" [74].

Demographic differences

We should not assume that all groups within society have the same attitudes towards sharing healthcare data. Evidence suggests that there may be some differences, as follows,

There may be some differences between **women and men** in attitudes towards data sharing. One study found that "*From the quantitative literature, males and those who were older seemed more likely to consent to a review of their medical records*". However, it adds the caveat that "*this was not confirmed in a meta analysis of 17 international studies*" [75].

An Ipsos Mori study asked 2,000 people how important it was that the NHS treats a patient's medical records as confidential, and found that "*Women are more likely than men to say this is very important (89% vs 85%)*" [76].

There might also be some **age differences** in data sharing acceptance, although conclusions are again not unanimous. The Ipsos Mori report cited above states that "*people aged 65 and over are less likely to say the NHS's treatment of patients medical records as confidential is important (95% vs 98% overall). Those aged 35-44 are the most likely of any age group to say it is very important (91% vs 87% overall)*". Furthermore, "*Older people were generally more willing to have their records shared between the professionals involved in their care. In focus groups with over 65s there were comments from older people about the difficulty of remembering all the relevant details of their health history*" [77].

Conversely, evaluation of early adopters of the NHS Covid-19 app found that "*16-24 year olds were significantly more likely than older age groups to be confident that their data would be handled securely*" [78]. It has also been stated that "*Younger people are much more familiar with the concept of big*

74   All Party Parliamentary Group on Heart and Circulatory Diseases, 2019. Putting patients at the heart of artificial intelligence.

75   Hill, E. et al., 2013. "Let's get the best quality research we can": public awareness and acceptance of consent to use existing data in health research: a systematic review and qualitative study. BMC Medical Research Methodology

76   Ipsos Mori, 2018. Public views on data sharing. Report for NHS Digital.

77   Ipsos Mori, 2018. Public views on data sharing. Report for NHS Digital.

78   Department for Health and Social Care, 2021. NHS COVID-19 app: early adopter evaluation report NHS Test and Trace programme.

data – and the technology that generates it – than older people. This means that they were much better able to imagine the benefits that secondary uses of healthcare data might bring" [79].

Yet another study asked respondents whether they would support their health data being accessed by commercial organisations if they are undertaking health research. It found that "*There was not a strong level of support across any of the age groups*", but then added that "*older age groups were much more resistant*" [80].

A third factor is **social status**. In this respect, one study found that "*ABC1s were more likely than C2DEs to view the use of health data as having a potential benefit to society, in the fields of research, disease prevention, planning of services, crime prevention and so on*". A further observation was of "*C2DEs feeling more powerless to deal with consequences, e.g. arguing their case if their identity were stolen*". According to this report, "*Any linking resulting in the individual being targeted with specific messages prompts discomfort and resistance. The expectation is that blame and desired behaviour change will be implicit... The lower socio-economic classes can feel particularly defensive*" [81].

79   Britain Thinks, 2015. Secondary Uses of Healthcare Data Public Workshop Debrief.

80   Castle-Clarke, S., 2018. What will new technology mean for the NHS and its patients? Four big technological trends. The Health Foundation, the Institute for Fiscal Studies, The King's Fund and the Nuffield Trust.

81   Wellcome Trust, 2013. Summary Report of Qualitative Research into Public Attitudes to Personal Data and Linking Personal Data.

5. Enablers

Our research question was: "What are the barriers and enablers for patients and the public participating in sharing personal healthcare data?"

This section of our report looks at the enablers, which we have broken down to:
Trust
Public benefit
Information
Relationships

Trust

A key enabler for patient and public attitudes towards data sharing is the perceived trustworthiness of different organisations and professionals. Research has found that "*The overwhelming factor in considering whether or not to share data... is whether or not people trust the organisation asking for it*" [82].

It appears that **trust is not distributed equally**. Ipsos Mori has found that "*Public sector healthcare providers are most trusted to use personal information*" in comparison to other organisations such as insurance companies and social media [83]. This ties in with other research, which found that "*The NHS is highly trusted compared to other organisations. Generally, GPs and the NHS are trusted the most, followed by academic researchers*" [84].

Trust is also not given unconditionally. A study by Healthwatch Surrey found a trusting attitude towards data sharing – but with caveats: "*If the parameters of medical and care record sharing are kept within the confines of the medical and care professions, and there are procedures in place to ensure security, confidentiality and accuracy, there is strong support from survey respondents for sharing all or part of their health and care record with all or some of the health and care professionals involved in their care*" [85].

Good regulation can help to engender trust, but **social and political context also matters**. One study noted that "*Public trust is essential for any technological system that is deployed widely and with significant impacts across society. For interventions like digital contact tracing or immunity certification... Transparency, accountability, independent oversight and appropriate data protection are key*". However, it also made the point that "*when discussing trust, many members of the public veered away from specific technologies and instead spoke about the social and political systems in which they are deployed*" [86].

One example might be that "*For some participants who came to the workshop with pre-existing concerns about privatisation, all other concerns were looked at through this lens*" [87].

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82   Open Data Institute, 2018. Who do we trust with personal data?

83   Ipsos Mori, 2018. Public views on data sharing. Report for NHS Digital.

84   Understanding Patient Data, 2018. Public attitudes to patient data use. A summary of existing research.

85   Healthwatch Surrey, 2015. If I've told you once... People's views on record sharing between the health and social care professionals involved in their care in Surrey.

86   Ada Lovelace Institute, 2020. No green lights, no red lines Public perspectives on COVID-19 technologies.

87   Britain Thinks, 2015. Secondary Uses of Healthcare Data Public Workshop Debrief.

Public benefit

Evidence indicates that people are likely to support health data sharing if the reason for doing so **offers clear public benefit**: *"The vast majority of respondents reported that if their health information could help others (e.g. via research) they would be happy to share it...A number of respondents see increasing data sharing as the only way for the NHS to achieve higher efficiency in the future (43%)"* [88]. This is confirmed by another report, which states that *"A commitment to public benefit is likely to increase support,* but which also warns that this *"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"* [89].

The public benefit **may not have to be specific**. People are willing to accept "potential benefits, and to respond to broader ideas such as "altruism". One study found that *"Assurances that research would – or at least have the potential to – bring about public benefits were fundamental for ensuring public support or acceptance"* [90]. Another states that there is *"widespread willingness to share patient data for research for the "common good". Participants [were] willing to share electronic health records (EHRs) for secondary purposes when there was*

a "common", "greater" or "public good", and when there was "social responsibility", "altruistic attitudes" and "giving something back" [91].

A public engagement exercise expands on this, again looking at potential, rather than proven benefits: *"important reasons given for voting "yes" from each jury were that the planned use [could] lead to improved treatments, services, and care delivery and eventually to better health outcomes and more lives saved... Could strengthen research and help identify health trends... lead to better diagnoses of conditions, more effective treatments, and improved health outcomes for patients... allow NHS to more efficiently target the use of resources for particular conditions or communities"* [92].

However one study disagrees: *"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"* [93].

It may, however, be important to emphasise that the ultimate public benefit is **improved patient care**. One study looked at *"reasons for optimism about accessing NHS patients' and NHS operational data".* It summarised these as *"Improved patient outcomes, Sharing knowledge and*

88   Healthwatch England, 2015. Written evidence on Public Attitudes on Consent and Data Security for the National Data Guardian Review Team.

89   Curved Thinking, 2019. Understanding public expectations of the use of health and care data.

90   Aitken, M. et al., 2016. Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. BMC Medical Ethics.

91   ADR UK, 2020. Trust, Security and Public Interest: Striking the Balance. A review of previous literature on public attitudes towards the sharing and linking of administrative data for research.

92   Connected Health Cities Citizens' Juries Report, 2017. A report of two citizens' juries designed to explore whether the planned and potential uses of health data by Connected Health Cities are acceptable to the public.

93   Curved Thinking, 2019. Understanding public expectations of the use of health and care data.

expertise, Efficiency savings and increased NHS revenue, Enhanced reputations for patient data partners*. It also made the point that *"Improved patient care has to be the main purpose for entering into data access partnerships in the eyes of Jurors…That should be the endgame"* [94].

The other side of the "optimism" coin is the **opportunity cost of not sharing healthcare data**. In this respect, *"Jurors reflected on the cost of not using the data for access partnerships. They thought about potential missed opportunities afforded by data access partnerships due to bureaucracy, inadequate or ineffective processes and complex organisational structures. They saw this, together with NHS organisations not being in tune with the fast-moving world of digital and technological innovation as serious challenges to success"* [95].

The "public benefit" case appears to **hold good for commercial access to health data** as well: *"Participants wanted companies accessing health data to demonstrate that they are making a contribution to public value and a real, long term benefit to health in the UK. They look to government and regulators to enforce it"*. This means, however, that *"we need a shared understanding of what that value actually is, and what kinds of public goods we want data analysis to create"* [96].

Information

Learning acquired from the Care.data scheme suggested that better quality information could have enabled public engagement and understanding. One suggestion was about **methods of communication**: *"There does need to be more effort to inform people of the programme in addition to the letter to each patient of the GP surgery. These should include posters and leaflets at GP surgeries and other public spaces, public meetings and an advertised phone line for further information"* [97].

A further suggestion was about the **content of communications**: *"A more informative public awareness campaign — which better covers areas such as the benefits of care.data, as well as the ethics, data security and safeguards — would help to build trust in the process and the wider healthcare system"* [98].

Information on data sharing should not be confined to the detail of specific government initiatives, but should be **part of a more general process**: *"data-driven technologies should include patients and the public as active partners. This means that patients and the public [should be] active partners in agreeing priorities for, and determining the acceptability of, data-driven technologies as part of an ongoing process"* [99].

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94   Hopkins, H. et al. 2020. Foundations of fairness: views on uses of NHS patients' data and NHS operational data. A mixed methods public engagement programme with integrated Citizens' Juries. Hopkins Van Mil

95   Hopkins, H. et al. 2020. Foundations of fairness: views on uses of NHS patients' data and NHS operational data. A mixed methods public engagement programme with integrated Citizens' Juries. Hopkins Van Mil

96   Ipsos Mori, 2016. The One-Way Mirror: Public attitudes to commercial access to health data.

97   Healthwatch Hampshire, 2015. care.data West Hampshire Pathfinder Engagement Report.

98   Healthwatch Essex 2014. Care.data: the debate. Summary report.

99   The Academy of Medical Sciences, 2018. Our data-driven future in healthcare People and partnerships at the heart of health related technologies.

Information also needs to be clear about **all sides of the data-sharing debate**: "*No use of technology is without risk, and honest discussions about the potential risks of the use of AI is necessary in order to ensure that progress on AI in healthcare is sustainable. Public trust cannot be engendered if only benefits are highlighted*" [100].

Alongside transparency about risk, however, there is a need to reassure patients and public that **risk is well managed**: "*Assurances of data security are important for public acceptability of research uses of data*" [101]. "*It is important that the public are made aware of the safeguards in place to ensure the security of data*" [102]. "*Patients need to feel confident that their data is secure and in the hands of trusted actors*" [103].

Relationships

Various studies suggest that **the patient/professional relationship** may be an important enabler for healthcare data sharing.

One possibility is that "*the greater general level of trust in healthcare providers compared to other public bodies may be due to individuals' existing relationships with primary healthcare providers, which*

are in some cases built up over many years, suggesting that having a familiar relationship with an individual is important for securing trust". This study added that "*trust in the NHS was expressed in terms of a perception that health professionals generally serve to help the public and are expected to abide by a moral code of conduct*" [104].

Another made the point that: "*Older generations are more likely to use digital health technologies if recommended to do so by their healthcare professional. This indicates that healthcare professionals can play an important role in establishing data-centric habits among older healthcare system users*" [105].

This could also play into the **shared decision-making** agenda: "*The majority of people (77%) felt that it should be a combination of patient and professional who decide how records are shared. (Patient and doctor together, 42%, or patient, doctor and social care practitioner, 35%)*" [106].

Relationships may also be important **at the organisational, as well as the individual level**: "*While the NHS' release of open health data will benefit both public and private-sector entities, those benefits can be enhanced if the beneficiary*

100   All Party Parliamentary Group on Heart and Circulatory Diseases, 2019. Putting patients at the heart of artificial intelligence.

101   Aitken, M. et al., 2016. Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. BMC Medical Ethics.

102   Healthwatch Essex 2014. Care.data: the debate. Summary report.

103   All Party Parliamentary Group on Heart and Circulatory Diseases, 2019. Putting patients at the heart of artificial intelligence.

104   ADR UK, 2020. Trust, Security and Public Interest: Striking the Balance. A review of previous literature on public attitudes towards the sharing and linking of administrative data for research.

105   Future Health Index, 2019. Transforming healthcare experiences. Exploring the impact of digital health technology on healthcare professionals and patients.

entities can help participate in shaping the government's open data programme. The NHS should engage key stakeholders on a regular basis to determine which datasets have the highest priority for them; what new datasets should be released as open data; and which open data collections are particularly easy or difficult to use" [107].

106 Healthwatch Surrey, 2015. If I've told you once... People's views on record sharing between the health and social care professionals involved in their care in Surrey.

107 Govlab, 2014. The open data era in health and social care.

www.patientlibrary.net