

Acknowledgements

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Executive summary

Executive summary

1. Robust qualitative dialogue

Background and objectives

The Academy of Medical Sciences has convened a **Steering Group** to develop principles for the use of future data-driven technologies in healthcare. The group will provide guidance on **how patient data should, or should not, be used to support new data-driven technologies**, to aid regulators and data controllers as well as users and developers.

This report gives findings from a **programme of dialogue** which was commissioned to enable these principles to be informed by **members of the public, patients and healthcare professionals**. The dialogue elicited views on how new future data-driven technologies in healthcare should interact responsibly and usefully with patients, and the data collected about them, in the course of health care.

The objectives of the dialogue were to gather **awareness, expectations, aspirations and concerns** around any future technologies which would require **patient data** to be **accessed, analysed, or linked with innovative types of data and/or analysis**, in order to augment clinical diagnosis and management.

Key areas of focus included **data acquisition, analysis and delivery**.

The central dialogue question posed to participants was: what does success look like in the development and use of these future data-driven technologies in the NHS?

Method and sample

Fifty three participants including both general public and patients came to day-long Saturday events in Sheffield, London and Cardiff. A proportion of each group was reconvened to an evening session in the same location the following week, when healthcare professionals joined the groups. A total of 15 healthcare professionals attended the evening sessions. The sessions were facilitated by a team from Ipsos MORI.

Wide ranging and nuanced discussion used a range of stimulus materials

- Workshops began with **general discussion of healthcare**, perceptions of how patient data is currently gathered, analysed and used in delivery of information.
- **New technology concepts**, including Machine Learning¹ and Artificial Intelligence², Data Science³, and the Internet of Things, were introduced, and spontaneous views were gathered.
- The major part of the workshops was dedicated to discussion of **eight case studies** representing the different ways data could be gathered, analysed and applied by using modern technologies in healthcare.
- The second, reconvened workshop returned to the eight case studies and asked **where the boundaries lay** in different potential uses of patient data in the context of these applications.

¹ Machine Learning is an application of artificial intelligence (AI) that provides systems with the ability to automatically learn and improve from experience without being explicitly programmed. Machine learning focuses on the development of computer programs that can access data and use it learn for themselves.

² The theory and development of computer systems able to perform tasks normally requiring human intelligence, such as visual perception and speech recognition. In particular, AI differs from machine learning as it implies the creation of agents which can create and achieve goals, by mobilising a range of ways to learn and improve from experience, including using machine learning itself.

³ Data science is a multidisciplinary blend of data inference, algorithm development, and technology in order to solve analytically complex problems. It relies on the use of large datasets which can only be interrogated by computers and demands computers with considerable processing and storage power.

Brief descriptions of each case study used in the workshops;

1. Machine Learning and Artificial Intelligence used to create a 3D automated antenatal scan for pregnant women, for quicker and more accurate scans.
2. A Machine Learning programme used to analyse an electronic patient record to identify undiagnosed kidney disease, whilst the patient is in hospital for a different, unrelated medical reason.
3. A finger sensor used to record a patient's tremor, to measure the risk of Parkinson's, during their stay in hospital, even if the patient is in hospital for other reasons.
4. A camera used in a patient's own home, fitted underneath their bed, to take photographs of their feet to monitor the risk of heart failure, post-operation.
5. An insulin implant which constantly collects readings, and administers insulin automatically. The implant is linked to a smartphone app which feeds back to clinicians, and alerts both the user and clinicians when the readings suggest the patient is becoming ill.
6. Natural language processing used (on written notes, or on other materials) during or after a consultation to spot and diagnose psychosis, and to flag when someone with a mental health condition is at risk.
7. A Machine Learning programme putting patients into different cancer treatment groups based on their genetic data.
8. NHS trust sharing results from electronic patient records, which illustrate drug efficacy differences for different groups of patients, with commercial companies.

The key findings from the study are as follows.

2. Expectations of patient data and new technologies in healthcare

- 2.1 There is **optimism about new technology in healthcare**. Participants felt new technologies in general could **increase efficiency**, improve **success rates** of diagnoses, and save **administrative and diagnostic time** meaning clinicians could spend **more time on patient care**.
- 2.2 This is despite **low awareness**: of the types of data-driven technology discussed; how data is currently used; and how the NHS is organised, in particular its commercial partnerships.
- 2.3 **New technologies should support the NHS ethos**:
 - Public and patients particularly felt that benefits of these new technologies should be distributed **equitably** to NHS users.
 - All participants wish to **preserve the clinician-patient relationship**, characterised by human interaction, and involving an individual and their health professional building a shared narrative of health, illness and treatment.
 - Beyond the potential impacts and risks to individual patients, participants **rejected any ideas which they felt might lead to a longer-term erosion of choice or delivery in healthcare**.
- 2.4 There are nuanced views on **what kinds of data should be shared, and with whom**, in the contexts of new technologies.

Previous projects have explored public attitudes to data sharing with commercial companies, and identified **public support** for this data sharing; but only where they perceive it to be **beneficial to individuals and the wider society**, and only where the **companies carrying out the work can be trusted to deliver these social benefits**.

Participants in this study expressed very **similar sentiments**.

If they see both individual and social benefits, they:

- Support sharing **personally identifiable data with commercial companies for individual care**
- Support sharing **depersonalised data with commercial companies for broader social benefits**

When it comes to **sharing personally identifiable data with commercial companies for broader social, but not individual, benefits**, they find it harder to come to a conclusion.

Participants in general did not express concern over **patient data being linked to other datasets (e.g. shopping data, travel, financial)** so long as the benefits were in place. However, they expressed some caveats around linking genomic information with these other kinds of datasets. There was concern that the rich information derived might create new knowledge about hidden patterns in our society, which would inevitably have big consequences for the way we think about healthcare.

In line with other studies, data sharing was not seen as acceptable for purely **commercial** purposes; such as for **marketing** purposes, or to provide information to **insurers**. Commercial companies are often not **trusted** (especially **pharma, big tech** companies, **marketing** and **insurance**).

Participants assumed that the **NHS 'owned' patient data and would retain control of this data when engaging in commercial partnerships**. The NHS was seen as ultimately responsible for the outcomes of these partnerships and was **trusted to protect the public interest**.

Understanding of **current safeguards around data sharing** was limited and many of the provisions participants wanted to see are already covered under data protection legislation.

- 2.5 Of the three participant groups, the **public** knew least about new technologies, and about healthcare. The **patient** group were the most open minded about the potential benefits of data sharing. The **healthcare professionals** were the most positive about data-driven technologies.

3. Response to new types of data gathering, analysis and delivery

Participants expressed the following views:-

- 3.1 Universal support for data-driven technologies which are based on scans and imaging automation for diagnosis.** Data collected and used in this way for direct clinical care was accepted by all participants; these new technologies were enthusiastically welcomed especially by healthcare professionals. There was support for outcomes from machine learning being used to support shared decision making.
- 3.2 Incidental findings from new technologies should be treated no differently from incidental findings discovered by other means.** Any incidental findings revealing risk of future disease should be treated with caution. Participants felt it could be useful for a machine to pick up new findings relating to patients in hospital. However, if they reveal risk of future illness, the clinician's judgement as to how to feed this back to the patient should be paramount.
- 3.3 New technologies which perform continuous observation were seen as acceptable in hospital, but are more contested in everyday life; especially when they contain live images or video.** Any kind of observation in hospital was felt to be acceptable, whether through future data-driven technology or not. Outside hospital, participants wanted to know when the data was being collected, to have a sense of control over the provision of the data, especially where it contained identifiable images of the person.

If data is depersonalised this could still lead to a 'surveillance society'; there was a question over how we use technology to look at the whole of society and achieve preventative medicine, without putting everyone under surveillance all the time.

- 3.4 Desire to preserve the valued clinician-patient relationship. Technologies should support clinical judgement and not overrule it.** Participants overwhelmingly wanted humans to deliver results, to maintain the clinician-patient relationship.

Public and patients wanted the clinician to have final say on whether to accept the results of machine learning algorithms - even in some cases where these are more likely to be accurate than a human. HCPs had a more nuanced view but also wanted to empower clinicians wherever possible.

- 3.5 Linking non-NHS data with patient data is potentially beneficial, in particular, data from wearables could give patients a sense of autonomy and responsibility over their own health.** Linking data from wearables with health data could potentially empower both doctors and patients to preserve health and combat disease.

However, collecting data from wearables might exclude those who do not want to or cannot wear or operate the devices. This might lead to a lack of correct data about some social groups; or a two-tier health system relating to data.

There are concerns over the technologies used in future to observe individuals' behaviour and lifestyles and linked to health data. Participants do not want this data to be used to determine access to future treatment.

They also wanted to preserve their autonomy to make **choices about their own health and lifestyles** without this being noted or judged by healthcare professionals (for example making choices which the individual patient is happy with, but which go against prevailing official advice for good health).

- 3.6 Very little awareness of, and belief in, the potential of natural language processing to structure data for analysis.** Disbelief among patients and public (and some healthcare professionals) that machines could ever diagnose complex mental illnesses. This was partly because participant struggled to understand the idea of, and potential of, **natural language processing**.

Because of this, there was a feeling that data-driven technology in this context should only be accepted if used as a guide for clinicians. For some, even if this technology could accurately identify mental illness, it should not be used to do so.

- 3.7 Support for analysing big datasets to stratify patients into groups.** In the context of clinical trials this is welcomed and it is assumed data would be depersonalised. The majority see this as potentially very beneficial.

There were questions around how this should be used in the context of all the new learnings about patients which might be possible in the emerging discipline of genomics. Some concerns that developing genetic stratification could lead to undesirable social outcomes, such as a 'eugenics' society where insurance or access to care is limited by your genes.

4. Raising public awareness on data and new technologies

This project suggests that **greater education may be necessary to have informed debates on the uses of new technologies in healthcare:-**

- 4.1 Gaps in patient and public awareness.** Participants lacked knowledge about data, statistics and did not know how machine learning worked. This meant that participants rejected ideas which involved **conclusions about behaviour being drawn from combined datasets**, such as shopping and health data. This was because they did not understand how such conclusions are arrived at, hence they tended to think the conclusions would be invalid and inaccurate.
- 4.2 Machine capabilities are judged by the standard of human capacities.** Participants underlined **that machines should not replace human clinicians**. This stemmed partly from a concern that human intelligence encompasses intuition, which was felt to be necessary to diagnose, treat and provide care. Participants (including healthcare professionals) did not really believe that machine learning would be able to account for the inferences made by humans using their intuition. So, they did not want to empower machines to make recommendations in areas which depended on human behaviours and human variables, as they felt human intuition would be critical.
- 4.3 NHS bears a weight of expectations when it comes to taking responsibility for patient data.** It was notable in this dialogue that public and patient participants were relatively uninterested in safeguards and governance,

despite probing and prompts from facilitators. We judge in analysis that this is because they have **implicitly devolved this responsibility** to the NHS, which they trust unequivocally to protect their data. However, designing new data-driven technology demands specialised skillsets; there may be a need to raise public awareness of this, in order to have a wider discussion on **how we can equip the NHS with the skills necessary** to negotiate with technology companies around the design of new technology.

5. Conclusions: criteria for new technologies working with patient data

Patients, public and HCPs wished the Academy to take their views on board when considering the three aspects of focus for the study.

- **Data gathering:** Wearables and continuous observation devices have great potential but be careful about how images of people, especially faces, are stored and shared. Be aware of the ‘context collapse’ (i.e. that people will feel uneasy about being observed in places they consider to be private); and the impact of this on consent.
- **Data analysis:** Linking data from wearables, other datasets and data collected outside the healthcare system with patient data is potentially beneficial. Universal support for machine learning analysis of scans or other data, though natural language processing may need some more explanation of how it works and the benefits. Push forward with stratification of patients into groups where this can help deliver personalised medicine. However, be wary of any long-term impacts on society of developing stratified genetic datasets as these could be used in many ways and there may be negative unintended consequences for society as a whole.
- **Data delivery:** Do not erode the choice of patients or the relationship between patients and human NHS staff. Do not allow technology efficiencies to lead to cuts to clinician-led services. Human interactions are valued more than faster and cheaper processes. Explain how diagnoses inform delivery of healthcare especially when machines are empowered to diagnose.

Overall, any new use of data needs to have a **proven social benefit to make it worth sharing patient data with commercial companies** (especially personally identifiable data).

The NHS should be **in charge of patient data and administer it for public benefit**. Make sure the NHS has the skills to protect the public interest – the public are not thinking too deeply about safeguards and assume the NHS can handle it. Is the NHS equipped to negotiate in our best interests?

1. Introduction

1. Introduction

1.1. Background: the need for dialogue

In 2017, Ipsos MORI was commissioned by the Academy of Medical Sciences (the Academy)⁴ to undertake a dialogue project which sought the views of the public, patients, and healthcare professionals (HCPs) on the **future use of data-driven technologies in healthcare and the implications for use of patient data**.

Many new devices and services rely on new applications of novel technologies, with the potential to change many facets of healthcare. In particular, future data-driven technologies (which rely on collecting and processing patient data) have the potential to change conversations between HCPs and patients, and even affect the wider social contract around healthcare. At the same time, the amount of data collected in many areas of life is growing exponentially, with similarly growing interest in how datasets can be linked and exploited for both public and commercial benefit.

As these technologies are developed and rolled out, and data capture and analysis becomes more sophisticated, there is a need for the NHS, regulators and other stakeholders to consider the implications of the ways patient data, and other personal data, is used.

The AMS is keen to uncover how technologies should interact responsibly and usefully with patients and the data collected about them in the course of their health care. It is developing principles for the use of future data-driven technologies in healthcare, and has convened a **policy Steering Group** to investigate the issues and develop a report.

This **programme of dialogue was commissioned** to enable these principles to be informed by public, patient and HCP views on the implications for patient data use which arise from the development of new technologies. The **Steering Group** has played a valuable role in the design and implementation of this dialogue process.

A number of studies⁵ in recent years have investigated public, patient and HCP's attitudes to data sharing for health research and for clinical care purposes. Studies overall have revealed that the public often support data sharing for public benefit, but defining what this is can be difficult. Participants in dialogue also tend to be very wary of the role of commercial companies in the healthcare system. In particular, members of the public tend to oppose health data being shared for marketing or insurance purposes, even when it has been de-identified.

New devices and services, however, may require **data to be used and shared in new ways**, for new purposes, which may uncover new practical or ethical decisions to be made; hence the need for dialogue specifically on these points.

1.2. Objectives and terms of reference for the dialogue

The overall objectives of the public dialogue were:

- To establish **awareness, expectations, aspirations and concerns** around the deployment of future emergent data-driven technology in the NHS.
 - In particular, where future data-driven technology, in its development or operation, requires **personally identifiable or depersonalised patient data to be used, shared, or linked with other datasets**.

The functions of future data-driven technologies were defined in the following ways by the Steering Group:

- **Data acquisition:** technologies that gather data in new ways, such as from wearable or imaging devices, via the Internet of Things, via continuous data collection, or through gathering spoken or written materials.
- **Data analysis:** technologies that analyse data in new ways, particularly those applied to different types of patient data, or to patient data that has been linked with other data collected outside of health care, and that

⁴ The Academy is the independent body in the UK representing the diversity of medical science. The Academy's Fellows are central to its work: the excellence of their science, their contribution to medicine and society and the range of their achievements are reflected in the Academy's work.

⁵ Studies are cited throughout this report where relevant

may employ novel methods and algorithms for its analysis. These methods include Machine Learning and natural language processing of unstructured text.

- **Data delivery:** ways in which information based on the data collected is relayed back to HCPs and patients. The information can help provide knowledge which helps HCPs and patients take decisions and make judgements. This might include feedback processes where patients are able to see their own data, or feedback which goes only to clinicians.

Devices often involve new technologies operating in network with one another to solve a number of different problems. This is a fast moving and quickly evolving sector.

The **terms of reference** for this dialogue were:

- To focus on the types of **challenges unique to the deployment of future data-driven technologies in the NHS**, as distinct from general ethical or practical concerns about technology, data, or clinical practice.
- To encompass future data-driven technology which can be used by **individuals** at home and linked to patient NHS data; through to technology used by clinicians or hospital administrators in a **care setting**, and to technology enabling public health or administrative decisions to be made on a **population-wide level**.
- To explore the use of data in **new ways which have not yet been undertaken** by clinical or research practice; this could include situations where a HCP would communicate diagnoses or other outputs created by the future data-driven technology, and situations where the technology might convey such information directly to patients without a HCP present or involved.
- To explore how data was used **from the point of generation through to the way it was analysed and used in decision making**; what did participants think acceptable, desirable or more concerning, in the use of data at these different stages. The Steering Group hypothesised that opinions might differ according to a range of factors including:
 - **Awareness** of data collected (does lack of awareness lead to perception of **unease** or **discomfort**?)
 - The **context** in which the data is collected (was it patient data collected in the context of delivering NHS care or is data collected in another setting and then linked to patient data)
 - The **timeframe** of use of data (for individual care or other immediate benefit, for long term research use)
 - The context of **use** of patient data – is the healthcare professional present, how are any conclusions communicated
 - **Who** is using it: third party user and who is it being shared with and in what form?
 - **Who** benefits?

1.3. Project design

The dialogue design

Materials development and stakeholder involvement: In developing the dialogue approach and stimulus Ipsos MORI consulted with stakeholders including clinicians, data academics, commercial developers, pharma, think tanks and organisations representing patient voices in a stakeholder development workshop. Members of the stakeholder group are listed in the Appendix. Some members of the Academy's Steering Group also attended the development workshop, and the attendees contributed their thoughts as to the issues they thought should be raised with the public.

The main part of the study consisted of **three face-to-face dialogue workshops** in London (11 public, 7 patients), Sheffield (12 public, 10 patients) and Cardiff (7 public, 6 patients) in February 2018. Workshops in the three locations were reconvened; all public and patient participants came to a day-long session on Saturday (Event 1) then some

returned on a week night for a reconvened evening session (Event 2). A proportion of participants from each session returned for the reconvened discussion.⁶

The workshops covered England and Wales to give coverage of a spread of locations, but did not include Scotland or Northern Ireland, where there are some differences in legislation around data.

The dialogue workshops were attended by members of the public and patients⁷, who were then joined by GPs and other healthcare professionals at the reconvened evening sessions. This was to enable all participants to join the debate, and for patients and the public to have discussions separately, and then together.

We wanted to include the voices of those with specific and recent experiences of engaging with health services, so we invited some people on this basis. However, facilitators reminded participants at the start of each session, that all members of the public are to some extent 'patients', whether we live with health conditions or not, and reassured participants that each person would speak from the perspective of their own lives as an individual rather than feeling they had to act as representative of any group.

Participants were recruited by quota to reflect the spread of ages, gender, ethnicity, life stages and sociodemographic segments of London, Sheffield and Cardiff respectively. Additionally, in Sheffield and Cardiff, a proportion of participants were recruited from rural areas. Participants voluntarily joined the process; and they were incentivised with a thank-you gift of money for giving up their time and to cover their expenses.

HCPs were mostly recruited using Ipsos MORI's panel of GPs and consultants and were incentivised with a thank you gift of money. The panel members were recruited via an online screener, ensuring a mix of gender and number of years of professional experience. Other HCPs, such as pharmacists, community nurses, hospital consultants and additional GPs were recruited using leads provided by the Academy of Medical Sciences.

What was covered at the sessions?

The central dialogue question posed to participants was: what does success look like in the development and use of these future data-driven technologies in the NHS?

The Saturday workshops:

- **Introduced concepts;** explaining the NHS today, the nature of patient data, the ways it can be aggregated and analysed including depersonalisation.
- **Described future data-driven technology,** giving a broad introduction to Machine Learning, Data Science, Artificial Intelligence, cloud computing, and the Internet of Things/wearable devices. Participants then discussed their aspirations and concerns about uses of future data driven technologies.
- Explored a series of **case studies;** these were designed to give concrete examples of the types of future data-driven technology and data uses which might be possible now and in future and to test the different factors highlighted above by the SG. The discussion was focused on the principles illustrated rather than simply gathering response to the case study itself.

In the following weekday workshop, patients and public were joined by Healthcare professionals. The workshops ran as follows:

- **Introductions in separate groups;** patients and participants recapped on the previous session, while the healthcare professionals group described their work and also discussed their views on what healthcare will look like in the future.

⁶ Facilitators noted participants who were the most involved with and engaged in the discussions, and ensured that across each location a spread of different types of views was represented and the reflective gender, age and ethnicity balance was preserved. We then invited back around two-thirds of participants in each group.

⁷ Patients recruited with a range of different conditions including both mental health and physical conditions

- Then the groups were mixed so that HCPs sat with each group of participants, such that across the dialogue different groups had exposure to those working in different specialisms, including GPs, nurses, clinical nurses, hospital consultants and others.
- The **case studies were reviewed again**, but this time facilitators pushed the examples to a more ‘**extreme**’ extent, changing the variables to cover different contexts, timeframes and types of use of the data, in order to establish participants’ ‘red lines’ and the trade-offs they saw in the deployment of technology in this way.

The **types of technologies** we discussed included the following. Participants were given short presentations and written materials on each concept.

- **Machine Learning** is an application of artificial intelligence (AI) that provides systems the ability to automatically learn and improve from experience without being explicitly programmed. Machine Learning focuses on the development of computer programs that can access data and use it learn for themselves.
- **Artificial Intelligence:** the theory and development of computer systems able to perform tasks normally requiring human intelligence, such as visual perception and speech recognition. In particular, AI differs from machine learning as it implies the creation of agents which can create and achieve goals, by mobilising a range of ways to learn and improve from experience, including using machine learning itself. AI uses many different disciplines and resources from neuroscience to philosophy.
- **Data Science** is a multidisciplinary blend of data inference, algorithm development, and technology in order to solve analytically complex problems. It relies on the use of large datasets which can only be interrogated by computers and demands computers with considerable processing and storage power.

1.4. How to read this report

Interpretation of findings

Data was analysed using a **thematic qualitative analysis process**. The core facilitation team met for analysis sessions to derive hermeneutic themes, the transcripts were then read and sifted in the light of these themes. For this project, no specific analysis software package was used, but themes were reviewed using Excel and paper-based clustering of ideas as well as the detailed transcripts of each session along with the flip chart and post it note exercises created by participant.

Qualitative research is designed to be illustrative, detailed and exploratory. It provides insight into perceptions, feelings and behaviours rather than conclusions from a robust, quantifiably valid sample. These findings are not statistically representative of the wider audience.

For reporting on dialogue we use the conventions of qualitative social science reporting:

- We indicate via "a few" or "a limited number" to reflect views which were mentioned infrequently and "many" or "most" when views are more frequently expressed. Any proportions used in our reporting should be considered indicative, rather than exact.
- However, we also indicate strength of feeling even when views are expressed by a minority, as this may also give useful insight into the range of feelings which exist within different groups of people.
- We are reporting perceptions rather than facts; in the case of this project there are various misconceptions our participants expressed about questions of fact, for example lack of understanding of legislation around data protection, and little awareness of data science in general. We have indicated where we are reporting perceptions of participants and where we are offering analysis of the implications of these perceptions.
- Where views apply only to a subset of participants, e.g. participants in London, we highlight this in the text.

Structure of chapters

An initial introduction sets out what each chapter contains, with key messages from that chapter. We then describe the findings and implications in detail illustrated by verbatim quotations from participants. In brackets there is a reference to where the quote is taken from: by location and event.

Stylistic conventions

We have used the convention of describing the word data in the singular rather than plural, plus the terminology around patient data recommended by Understanding Patient Data⁸ (e.g. 'data or information about you' rather than 'health information'; talking about individual care rather than clinical care; and describing data as either personally identifiable or depersonalised).

⁸ <https://understandingpatientdata.org.uk/what-are-best-words-use-when-talking-about-data>

2. Expectations of patient data and new technologies in healthcare

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This chapter explores expectations of future healthcare from the participants. We describe the range of public and patient starting points, looking at participants' spontaneous expectations of healthcare and how new technology could help, as well as what they know (and don't know) about patient data.

2.1. Optimism about new technology in healthcare

There is optimism about new technology in healthcare, and support for use of new tech to augment and support clinicians, both for direct patient care, and for wider efficiencies in the NHS/healthcare system overall.

All participants hope that future data-driven technology will preserve and enhance the current NHS levels of care. There were concerns raised about NHS cuts and 'pressure on the system'. In particular, the background of the impact of cuts on waiting times for a GP appointment and ambulances in Wales and Sheffield were mentioned.

"...the state of the NHS waiting lists! Someone in my family has been waiting for a year and a half for an operation. It's not great. Waiting 4 hours for an ambulance."

Cardiff, event 1

There was little awareness before the sessions of the types of technologies we were describing (beyond the idea of wearable devices, which most had heard of, though only in the context of fitness monitors). However, thinking about technology in general, and bearing in mind the new ideas we introduced, patients, public and HCPs were positive throughout about the potential for technology to improve the NHS.

Participants suggested that the new technologies could offer improvements, including the following:-

- **Improved efficiencies and time saving.** Technology could support and help healthcare providers in the system. For instance, administrative technologies could improve GP appointment waiting times. HCPs are particularly keen for support as they say much administrative work involving data is routine and duplicated and could easily be automated.

"Currently, you have to wait 4 weeks for a GP appointment. You get a 10-minute slot, then you're in and out. Hopefully, with new technology, it will cut out the need to see a GP for things that can be dealt with in a different way."

Sheffield, event 2.

- **Avoiding errors in individual care by sharing data within the NHS.** Participants were at first very positive as they anticipated that future data-driven technology would improve the sharing of patient data within the system and it would lead to improvements in individual care. Patients, especially those with several long-term conditions, had first-hand experience of the drawbacks arising from lack of data sharing between different healthcare services, especially between GPs and consultants. Participants hoped that, for example, contra-indicated medication could be flagged up automatically, or incidental findings could be revealed, by more thorough analysis of data about them. They did not expect that new technologies would be essential to enable this to happen, but an upgrading of systems to take advantage of current technologies for sharing data and for communicating directly between individuals.

"Having a fluctuating long-term condition, I would like a closer relationship with my consultant, rather than having to go through so many different layers. If I'm discharged back to my GP, I then have to wait until my condition is bad enough to go back through the process, and have to join a waiting list where I might not get to see the same consultant at the end of it. Technology can be a step in the right direction in terms of enabling more direct communication."

London, event 2.

HCPs agreed, hoping that consultants and long-term care providers could have better access to individual care and medication records so joined-up care can be seamlessly provided, clinical care decisions can be based on more patient data, and human error can be minimised.

- **Increasing accuracy of procedures and success rates of diagnoses**, for example by automating scans or finding correlations in large data sets which humans cannot find.

“It could be that a doctor is more likely to make a wrong diagnosis than a machine.”

London, event 2.

- Ideally, this would save time for the **clinician-patient relationship**, so that patients and clinicians can connect with each other more easily and spend more quality time in discussion. GPs could be made more accessible e.g. via email and out of hours.
- Participants felt new technologies using health data could also help **individuals take responsibility for their own care**. This would be especially true if live data (e.g. from wearables) could be accessed by patients, and linked to patient data. HCPs see future data-driven technologies providing patients with more information, so they can manage their conditions proactively and feel self-confident.

All aspire to a more **preventative NHS**, and so they looked to future data-driven technologies to prevent ill health and provide cures.

2.2. But lack of awareness about what new technologies involve and their data requirements

There was a general **lack of awareness and understanding** of new and emerging technologies amongst almost all participants including some HCPs.

Public and patients had little prior knowledge or understanding. The **Internet of Things** was understood in terms of the phones, watches and connected home tools with which participants were familiar, but most had never considered medical applications.

A small minority had encountered **Machine Learning** technology in their place of work. **Artificial Intelligence (AI)** was the least understood, with some participants finding it difficult to see how this technology could be applied to healthcare.

Also, the **terminology** of future data-driven technology created some confusion; some areas, such as **natural language processing**, were not known at all, and there were some misinterpretations of terms in the materials we showed (e.g. ‘analysis of free text’ was interpreted as analysis of people’s text messages).

Despite this, all participants generally welcomed the use of future data-driven technology in healthcare with the general feeling that this was already happening.

There was also **low awareness amongst the public participants of how patient data is currently stored and used**. Many understand that their record contains their doctors’ notes, but do not appreciate all the different kinds of data that a health record about them would include, or how this information has to be shared in a care context. They were surprised to hear about the amount of data the NHS has about them; and had not thought at all about the potential for other datasets, such as data from wearables or loyalty cards, being linked to data for their own or others’ benefit.

“You don’t think about it. You go to the doctor and say, ‘I’ve got this problem.’ They fix it, you don’t think about it being shared.”

Cardiff, event 1.

In terms of the way that these new technologies might come in to the NHS, there is some awareness amongst the public and patients that **commercial interests are already working together with the NHS** (this was introduced during the slides at the beginning of the workshop) but public and patients were surprised at the extent to which this occurs.

The examples used in the workshop of commercial companies running **patient transport services** and **handling scans** were areas patients and public were unaware of, and some surprise was expressed. There was more awareness of community **pharmacies** and contracted services within NHS premises e.g. **cleaning**.

Therefore, there might be a need to explain **why new services require commercial partnerships**, as this is by no means obvious to public and patient participants.

2.3. New technologies should support the NHS ethos

This ethos was felt to be **an equitable distribution of care and resources**, built on the foundation of the relationship between care provider and patient.

Technologies which involved patients themselves using technology were felt to have potential, but **alternatives** would need to be available for groups who cannot use or access these. Also, participants, especially HCPs, felt it is important to have a **consistent roll-out** to ensure the same experience for each patient rather than a 'postcode lottery'. Choice was seen as an important principle; HCPs do not want a 'one size fits all' approach and feel patients should always be able to **choose to have access to a healthcare professional**.

Beyond the potential impacts and risks to individual patients, participants rejected any ideas, whether to be applied in individual care or in research, which they felt might lead to a **longer-term erosion of choice or delivery in healthcare**.

Specifically, they did not want additional data provided through technology to be used to **stratify groups which might eventually be used to determine access to treatment**; whether this was collected from individual wearables, individual data collected in clinical settings (e.g. genetic information), or from mapping non-health data with health data. This was seen as vital for **personally identifiable patient data**, as it may disadvantage individuals directly. But it is also important to consider when thinking about **depersonalised data**, because results from aggregate data could still theoretically be used to deny care to whole classes of patients.

"This data has value...I don't want my patient record out there, someone knowing I'm ill and getting marketing for coffins or a funeral plan. Or if I get something that's expensive to treat, will I be denied the treatment?"

Sheffield, event 1.

While this is something of a 'slippery slope' argument, and none of the specific examples we gave suggested this, it was nevertheless an important point that the public, in particular, wanted to make. Participants were expressing their **concerns about the future of technology and the NHS**, and describing the principles of **equity and choice** they wanted the NHS to express in its services.

Overall, future data-driven technology that provides more information on managing health and current conditions is welcomed, but technology that is perceived to take control or choice away is not.

"We've noticed you've been drinking more alcohol in the last month.' It's not being told what to do. If someone said, 'You've had far too many takeaways this month.' It might just remind you. I don't mind being kept on the straight and narrow."

Cardiff, event 1.

The clinician-patient relationship was brought up frequently during the sessions. Public and patients understand medicine to be about the clinician and patient creating an individual's narrative of their own care, not just a mechanistic search for, and cure of, symptoms.

There is a concern that **future data-driven technology could erode this relationship**. Public and patients were very worried about lack of contact with healthcare professionals e.g. a video call instead of human contact.

In particular, the role of the healthcare professional plays a vital role for vulnerable groups especially the elderly and those with mental health problems with empathy being a very important element in the consultation process. Patients in rural areas and older patients value their relationship with their GP, and sometimes this can be a lifelong relationship.

"A machine might analyse data and say someone has a better life expectancy, but it takes away that therapeutic part of being able to sit and talk to someone about how you're feeling. How do we measure that? There isn't a one-off tool that suits everyone. Being able to talk through different options, which you can't do with a machine."

HCP, Sheffield, event 2.

2.4. Nuanced views on what kinds of data should be shared, and with whom; in new technology contexts.

Ipsos MORI's 2016 study for the Wellcome Trust⁹ looked at data being used **for research purposes** only, and did not discuss the specific use cases of new technologies in direct care. The current study covered how people felt about data sharing for individual care and/or for administrative purposes, as well as in research. We also restricted discussion to the particular contexts of new technologies, with an aim to pull out what is specific to the new technology context in views of acceptability of data sharing.

Findings from Wellcome Trust study

In this study, we analysed the views of public, patients and healthcare professionals and developed a model of 'four key tests' which are tacitly applied when the question of access to healthcare data by commercial organisations is considered.

The four tests of acceptability are:

- **Why?** (Does the proposed sharing lead to a clear benefit both to individuals and to wider society?)
- **Who?** (Can the organisations doing this be trusted to have public interests at heart?) Participants in the Wellcome study did not object to profit making in principle but this should be second to public interests. There was also a hierarchy of trust in organisations, with analytics and research companies working with the NHS seen as more trustworthy than pharmaceutical companies, and insurance companies not trusted at all.
- **What?** (Is the data individual level, depersonalised, and how aggregated is it?) Participants in the Wellcome study were somewhat concerned about the risks of being identified from individual data and whether individuals might come to harm, but if the risk of harm was low, they were not so concerned about data usage. A minority were opposed to data sharing on principle, on privacy grounds.
- **How?** (Does the safeguarding, access and storage protocol reassure me that the data will be safe?)

Crucially, the tests are applied in this order, so giving information (for example) on the safeguarding process (**how**), will not work to reassure, if a proposed project has already failed the tests on **why** and **who**.

Participants in the current study appeared to approach the issue of acceptability of different kinds of data sharing using the same prioritisation as identified in the 'four tests' model.

Participants in the current study expressed the following views:-

When new technologies are introduced, personally identifiable data can be shared to benefit individual care, and depersonalised data can be shared for individual or broader social benefits.

Participants asked about the potential benefit of the technologies first (the '**why**'). If their data was to be used, (whether personally identifiable or depersonalised data), the reason for its use and the benefits derived from it need to outweigh any perceived infringement of privacy.

"I liked the visual analysis [in Event 1] where we had the risks and benefits of these scenarios, and we felt the benefits outweighed the risks. I think technology has really benefited the majority. We just need to try and be efficient with the technology, for the benefit of the patients."

Sheffield, event 2.

Participants accepted that **personally identifiable patient data would need to be shared** if they were to get the benefits of improvements to individual care. In cases where the sharing would *not* lead to direct individual benefit, **public and patients wanted depersonalised data to be used.**

⁹ <https://wellcome.ac.uk/sites/default/files/public-attitudes-to-commercial-access-to-health-data-wellcome-mar16.pdf>

Though many of the new technology applications might be run by commercial companies, there was no real concern expressed over **linkage of patient data to other types of data, or sharing this data with commercial companies, in principle - as long as it is for these purposes.**

Participants understood that currently, commercial partnerships exist within the NHS to deliver services, and that these companies might need to use patient data. However, sharing of data **solely for commercial purposes** was not supported; patient data was seen as belonging to the NHS, and to be used for social good only.

As also seen in the Wellcome Trust study, these social goods could include drug development by pharmaceutical companies, as they are seen to provide public health benefits as well as profits for the company.

To prevent profiteering, patient data should only be used for **defined purposes, and in clear timeframes**, and not be **reanalysed** or **onwardly shared** by any third party.

Marketing campaigns or insurance policies which are developed based on access to either personally identifiable or depersonalised data were seen as unacceptable.

“All the factors come in and they’ll say this type of person has predisposition to this type of sickness...if this data goes to companies outside the NHS, these companies may use marketing tactics into influence your choice, make you buy this thing, do that thing.”

Cardiff, event 2.

“Passing information to that company, is it going to benefit me? So, telling a community pharmacist that a lot of people have diabetes in the area will be beneficial, because they’ll stock the necessary drugs. Do you think, if insurance companies got that information, they’d reduce the premiums? I don’t think they would. There’d be more profits for them.”

Sheffield, event 1.

Participants did not think only about themselves – they wanted to ensure that information derived from new data-driven technologies would not be used to set insurance premiums which **disadvantage whole groups of people** (especially if this is based on the ill health of that group).

“Is there potential for that information to be... linked to a third company, like insurance companies, to the detriment of ethnic groups? It could be a problem with mortgages too, because certain ethnic groups may have a prevalence of certain health problems.”

London, event 1.

There were also specific concerns expressed about the social impacts of new technologies which **linked genomic data with other patient data or non-health datasets** (financial, transport, shopping, etc.), even if this data was depersonalised and aggregated. These are discussed further in Chapter 3.

Participants found it hard to assess the potential social benefit against the risk to individuals if personally identifiable patient data is shared with commercial companies

Some participants struggled with the idea that some new technologies **might need personally identifiable patient data in order to create wider social benefits, and yet these technologies might not benefit the individual sharing their data.** We discuss this further at Chapter 3.7, when we describe responses to case studies using depersonalised and personally identifiable genomic data, and in Chapter 4 on communication, where we suggest that lack of understanding of the concepts prevented people coming to an informed view. This suggests a need for greater public literacy around statistics and the ways datasets can be used, to help people better conceptualise the benefits and risks of data sharing.

This emerged when discussing a case study describing an NHS Trust sharing results from depersonalised electronic patient records (which illustrate drug efficacy differences for different groups of patients), with commercial companies, for research purposes and wider public health benefits, rather than to inform individual care.

The case study enabled participants to discuss the extent to which they are happy for patient data to be collected and shared and to what level (de-personalised, anonymised or aggregated) if there is no direct benefit to themselves. In this discussion, public and patients did not have a clear sense of **how best to value patient data in the NHS in general** – and there was no consensus on how best to assess the benefits and risks.

The NHS should retain control of data. The ‘trustworthiness’ of organisations developing the technology was important, but the NHS is ultimately responsible for the care delivered.

Overall, participants believed the **NHS ‘owned’ health data**, especially data gathered during monitoring in hospital or the aggregate datasets which came from combining patient records.

Participants assumed that **in all commercial partnerships the NHS would retain ‘control’ of its data and would be ultimately responsible for the outcomes of these partnerships.**

Hence, issues of trust in the **different organisations who might gain access to the data** were important, but there was a belief that the **NHS would be responsible for protecting the public interest and ensuring no harms came to individuals.**

This may be why there was widespread acceptance of data sharing within these groups; they felt the NHS would calculate the risks on the public’s behalf.

“There needs to be accountability. Presumably you set up data sharing contracts. There needs to be damage limitation in case something goes wrong.”

Sheffield, event 1.

Participants did feel that whatever the regulations, **unscrupulous companies and industries** are likely to try and bend or break the rules, but felt the NHS will still safeguard our data.

Pharmaceutical companies were discussed with some suspicion. In line with previous studies, participants were concerned about whether patient data would be used in the best interests of patients, or in the interest of greatest profits. However, the fact there would be a societal benefit as well as potential profit meant that most participants felt ultimately that the companies were trustworthy enough.

“I’d worry about sharing the data with the companies. Couldn’t they use that to monopolise the market? If one drug is shown to be more effective, might they push the price of that drug up?”

Sheffield, event 1.

Large multinational companies were not particularly trusted simply because the scale and scope of having access to NHS data might prove too tempting. It was felt that the NHS would need to reassure the public that their interests were being protected.

“Say it’s somebody like Virgin...they have commercial interests already. Would your personal information find itself in Virgin’s commercial operations? With the size of the contract, there’s a big disincentive to misuse that information, not even taking into account the law, but it still needs to be looked at as a potential problem. People are going to have to be reassured.”

London, event 1.

When it came to **big tech/social media companies**, especially Google and Facebook, participants felt they had already voluntarily shared a great amount of personal data with these companies and had a rather fatalistic view of what could happen to that data, assuming it was already widely shared. However, they felt it would be important to ensure that health datasets were only linked in to other data if there was a clear benefit.

*“Public: There are positives and negatives. If the data goes to the NHS then it’s fine, but if it’s going to third parties then I’d want to know what they are using it for.
Healthcare professional: My NHS trust has already sold anonymised data to Google’s Deep Mind, which can tell us whether the area is at high risk of a certain illness. It’s already happening.”*

London, event 2.

There were very few specific reflections on **particular cases of concern around data sharing** with these kinds of companies. We heard only one mention of data-related “misadventures”, which might have been a reference to the DeepMind/Royal Free case of 2017¹⁰. Other groups did not recall this case despite some prompting from facilitators.

¹⁰ <https://ico.org.uk/about-the-ico/news-and-events/news-and-blogs/2017/07/royal-free-google-deepmind-trial-failed-to-comply-with-data-protection-law/>

“There have been misadventures of hospital trusts talking closely to commercial companies. It’s a fraught territory.”

Sheffield, event 1.

Similarly, we heard no mentions of the earlier 2014 reversal of the care.data project or any other discussion of public lack of trust in data sharing projects in general. However we did hear one or two mentions of the NHS cyberattack in spring 2017. While participants did not discuss specific ways their data might be ‘hacked’, lost or stolen (and indeed that cyberattack did not involve data theft); there was a general sense that the overall security of any network-based computer system was not a given.

Recent allegations that Cambridge Analytica harvested data from 50 million Facebook users to personalise political advertising¹¹ may herald a new change in public consciousness as to the potential uses of both individual level and aggregated data. Had we conducted the fieldwork after this story broke, rather than before, we may have heard different views and concerns.

Legal and other safeguards on data sharing are welcomed (though participants had low awareness of what these already involve)

The greatest concern expressed by public and patients was in relation to **hacking and data loss**. HCPs emphasised that in their view electronic patient records are better protected than paper data, but were still concerned about security and questioned how the NHS could enforce companies to adhere to the spirit as well as the letter of the regulations.

There is an awareness that the NHS currently does not sell data, but the legal nuances of the role of the data processor, (e.g. what would happen if commercial companies have access to data, versus data transferred to the company for later use), were not, spontaneously, well understood.

During the dialogue, participants said that they assumed new future data-driven technologies would **comply with existing legal and ethical frameworks** for use of patient data and research. Though public and patients knew little about what these actually involved, participants had clear criteria over how they would like their personal data to be stored and used. Much of what they requested is covered under the new GDPR legislation from May 2018.

- Personal healthcare data should be kept secure (ideally in a UK datacentre) with a large fine to prevent data being stolen. Rules are required on when data is destroyed and the information provided on how long data kept for and where it is stored.
- **Transparency** was important. HCPs expect there to be a code of conduct that technology companies adhere to which covers accuracy, risk and data security in terms of ethical approval and consent and a clear rationale for data requests subject to approval. There needs to be transparency on how de-personalised vs. personally identifiable data is used.
- The future data-driven technology has to be tried and tested with HCPs being involved in the **licencing and governance of new devices and algorithms**, to ensure they perform as expected.
- Also, a rigorous cost/benefit analysis would need to take place to ensure the future data-driven technology **makes a difference to care**; or creates new knowledge, or efficiency savings; whatever was promised when it was first introduced.
- Finally, patients and public asked to be able to **consent** to how their personal data is used with an option to opt out and the option to withdraw certain information. Different levels of consent are required e.g. to decide how much/what personal data you want to share. Also, the ability to **review consent over a period of time** to update data – i.e. not just consent once.

Participants see the NHS as **responsible and accountable** for putting the correct data sharing agreements in place. Ultimately, public and patients wanted to see the NHS ‘in charge’ of commercial relationships, taking ultimate responsibility for the use of new technologies, on behalf of the public, prioritising patient care, safety and social benefits.

¹¹ <https://www.channel4.com/news/factcheck/cambridge-analytica-the-allegations-so-far>

2.5. Overall differences in responses

Public

A spectrum of different attitudes was expressed by the public in these workshops. It is possible to identify some similar attitudinal groups. However, attitudes did not divide by variables such as geography or by ethnicity or gender. The urban and rural members of the public did not express significantly different perspectives.

There was some difference by age and life stage; in general, younger participants tended to be more indifferent about privacy and data sharing compared to older participants and patients. Parents tended to be more positive about data sharing when it could relate to the healthcare their children could be offered.

Socioeconomic status did make a difference to attitudes. There were different attitudes expressed by those with higher or lower levels of education, and more or less comfort with using technology. Types of employment also made a difference, which correlates somewhat with socioeconomic status. For example, participants who are more exposed to technology during their work (e.g. machine learning used in accounting software) had a better understanding of how future data-driven technologies might be used in healthcare.

Patients

Responses from patients differed by illness type, more than it did by gender, ethnicity, geography and the other criteria by which they were selected.

Patients with mental health illnesses focused on the importance of empathy in the clinician-patient relationship and therefore were the most concerned about the potential erosion of this relationship by future data-driven technology.

Overall, patients had a much greater understanding of the role of data in healthcare as compared to general public, and were more positive generally about it. Those with one or more long term conditions were more aware of the advantages of data sharing generally, particularly through improved data linkage which they saw as saving patient and HCP time and making the NHS more efficient.

All patients were concerned with their own care. However, compared to the public, they were more open to the potential of patient data sharing via new technologies for the greater good of society.

Patients had particular concerns around equity and availability of future data-driven technology to all.

Healthcare professionals

Healthcare professionals were the most positive about all the data driven technologies described. They felt it is crucial for future data-driven technology to be rolled out universally, not at a different level depending on uptake from each NHS Trust. However, when HCPs were asked about the immediate practical applications of future data-driven technology; some pointing out that they are looking for more reliable indicators so anything that works is welcomed. In fact, some doctors pointed out that their medical ethics required them to use the best approaches available so they were keen to know how future data-driven technology would help.

Both public and patients have concerns that healthcare professionals might be the victims of aggressive marketing by commercial companies in healthcare, if greater data sharing takes place and new marketing opportunities are uncovered. HCPs acknowledge that they are already subject to marketing pressure, and feel they are able to manage this. They told us that they take an informed view of any communications they receive and weigh up the benefits of new information, with their eyes wide open to any hidden agenda. They feel that the benefits of having exposure to new ideas and new technologies outweigh these disadvantages.

3. Response to new types of data gathering, analysis and delivery

3. Response to new types of data gathering, analysis and delivery

After initial discussion of healthcare, patient data, and an introduction to the new technologies, participants and HCPs were shown case studies representing the different ways that their data could be gathered, analysed and applied by using modern technologies in healthcare. In total, eight case studies of new or emergent technologies applied in different clinical scenarios were shown.

Brief descriptions of each case study used in the workshops;

1. Machine Learning and Artificial Intelligence used to create a 3D automated antenatal scan for pregnant women, for quicker and more accurate scans.
2. A Machine Learning programme used to analyse an electronic patient record to identify undiagnosed kidney disease, whilst the patient is in hospital for a different, unrelated medical reason.
3. A finger sensor used to record a patient's tremor, to measure the risk of Parkinson's, during their stay in hospital, even if the patient is in hospital for other reasons.
4. A camera used in a patient's own home, fitted underneath their bed, to take photographs of their feet to monitor the risk of heart failure, post-operation.
5. An insulin implant which constantly collects readings, and administers insulin automatically. The implant is linked to a smartphone app which feeds back to clinicians, and alerts both the user and clinicians when the readings suggest the patient is becoming ill.
6. Natural language processing used (on written notes, or on other materials) during or after a consultation to spot and diagnose psychosis, and to flag when someone with a mental health condition is at risk.
7. A machine learning programme putting patients into different cancer treatment groups based on their genetic data.
8. NHS trust sharing results from electronic patient records, which illustrate drug efficacy differences for different groups of patients, with commercial companies.

The case studies were first assessed as individual examples, and participants expressed their views on how they would like to see technologies like this used in healthcare and their expectations for the use of patient data. Then, principles underlying each were drawn out. Facilitators pushed participants to identify their 'red lines' and cut off points on how data should ideally be gathered, analysed and delivered when used in new technologies.

The discussions around the case studies raised many ethical issues around healthcare; but in most cases these were issues which are not unique to the deployment of new technologies (e.g. debates over clinical equipoise, when to test and treat and when not to; as well as debates over privacy and commercial interests in healthcare).

This section sets out the issues specific to the application of these future data-driven technologies, and is themed on the major issues we identified in analysis. These themes emerged through discussion of all the case studies, and relate to data gathering, data analysis, and data delivery.

3.1 Universal support for data-driven technologies which are based on scans and imaging automation for diagnosis

One case study related to machine learning and Artificial Intelligence creating a 3D antenatal scan in a shorter timeframe with increased accuracy and speed of reporting. Examples of automated diagnoses of eye scans and lung scans were also given during the discussion.

Generally, public and patients were aware that an automated process of collecting, analysing and applying data would be a more **efficient, faster, probably more accurate process**. They felt that the way the technology worked was easy to understand, and that it was clear why personally identifiable data would be required both in building and using Machine Learning applications. Any **risk to the individual from sharing personally identifiable data was seen as low** compared with the benefits to every patient.

Some HCPs were very keen to see Machine Learning rolled out as quickly as possible to help improve the quality of diagnoses in many areas. Some raised the issue of deskilling, but felt automation would lead to efficiencies and better care.

“We see missed diagnoses from scans... scans showing missing hands for babies which aren’t the case when they are born. The sonographer could say it is normal, but a computer could process the data and show something different that needs to be rectified.”

HCP, London, event 2.

“AI might be better at predicting skin cancer than a bunch of specialists, and if that’s the case, then you have to ask people what they want. I think people would still want the best. I don’t think deskilling is a big problem, I don’t feel deskilled because of technology, in fact I feel more skilled because I don’t have to spend lots of time doing the basics, I can actually use my training effectively.”

HCP, London, event 2.

3.2 Incidental findings from new technologies should be treated no differently from incidental findings discovered by other means

One issue raised was how **incidental findings, arising either through observations over time or through a single automated data collection and analysis process**, should be handled. Examples discussed included:-

- Sensor on a patient’s finger in hospital identifies Parkinson’s disease tremor and hence risk of developing the disease.
- Machine Learning programme analysing electronic patient record to identify undiagnosed kidney disease.

Some participants expressed a desire to know about **undiagnosed diseases and illnesses** for quicker treatment. Others pointed out that knowing potential risks would help vulnerable people or those with undiagnosed illnesses.

“The savings in early detection, for things like heart problems, are just immense. Not just saving lives, but saving people from having months of treatment.”

Sheffield, event 2.

“If you were in hospital already, why wouldn’t you be told? It depends on the situation. If something was to be flagged up while I was at home, then I would rather go to see my GP than have somebody call me up to say, ‘We’ve found that you’ve got a kidney problem.’”

London, event 2.

Opinions changed when the information given was about risk of disease, rather than a definite diagnosis. The idea of being told you are at risk of Parkinson’s disease when undergoing routine monitoring for a different purpose, even in

hospital, seemed a step too far. Some participants aspired to **preserve a right to privacy** and even a **'right' to exist in a state of less than optimal** health if they did not seek care, so did not want additional incidental findings, which a machine might discover, to be disclosed to them.

“Some people don't want to know, so wouldn't want to be told that they might have Parkinson's if they haven't consented to being checked. It's different from going for a breast cancer screening, which you have chosen to go to.”

London, event 1.

For these participants, **the fact that incidental findings were discovered using future data-driven technology was not a good enough reason for these findings to be passed on to patients automatically**. They would prefer the findings to be passed to clinicians for them to use their judgement, as with any other incidental findings.

It is particularly important, where new technologies have been used to identify incidental findings, that **clinicians should talk to the patient**, to explain how the diagnosis had been arrived at and what to do next. This was seen as particularly important if the machine learning algorithm could not itself explain how it had arrived at its conclusions.

“If the machines know about me, and it's following some algorithm, it'll know why I'm sick and how my body is...I trust the data... but I would prefer to have a human next to it.”

Cardiff event 1.

“It's murky territory where there could be 5 different outcomes. How does the machine assess each outcome? If the machine learning algorithm has made a decision, the doctor holding the machine learning 'box' doesn't know how it got there...what if the box never tells you what its thinking is?”

HCP, London, event 2

3.3 New technologies which perform continuous observation were seen as acceptable in hospital, but more contested in everyday life

The case studies included various examples of **observing or collecting data** over time by new technologies. Examples included:

- Analysis of hospital in-patient data using machine learning to identify an acute kidney injury. via incidental findings from the electronic patient record.
- Taking photographs of feet in a patient's own home to monitor risk of heart failure post-operation.
- Using an insulin pump or epilepsy monitor which collects readings all the time and alerts the user and clinicians when readings suggest the patient is becoming ill.

Overall, participants felt that this could be beneficial for both individual health care and public health.

However, acceptability varied depending on: whether the subject was in hospital already; the kind of data (i.e. numbers, observations or photographs/films); and whether the subject was aware, or unaware, of each acquisition of data at the moment it happened.

In terms of **data gathering**, public and patients presumed hospital admittance inherently includes consent for any type of health monitoring. This could include being linked up to sensors all the time, or having readings or tests taken periodically. The idea that this collection could be done in an automated way, with future data-driven technology, did not throw up any new ethical challenges.

“It would feel almost routine because you're in the hospital.”

London, event 1.

Collecting data at home was felt to be very useful, create efficiencies for the NHS and would probably improve the patient's quality of life, as they could leave hospital. Patients and public felt that photos of their feet, or other non-

identifiable body parts, taken in their home, with their consent to install the camera, would be acceptable and beneficial.

Some, however expressed concern that they would want to know exactly when the camera was taking its photos. This related to a need to control images of yourself or know when data collection is occurring.

“I’d prefer it if it were something that you press a button to operate, rather than have it running all the time. You know then that it’s only taking pictures of your ankles when you want it to. Your bedroom in your home is a very personal space.”

London, event 1.

Importantly, when this included **photos of a patient’s face**, this was seen as intrusive and participants would need a lot of reassurance about the security of the data and its transmission for their clinical care. Participants were not concerned about statistics about themselves put together in depersonalised aggregate with others’ data; but did not want *images* of themselves being available for wider usage that they could not control, which could lead to them being recognised or identified.

“If someone sold all my medical records to a company for business purposes, that wouldn’t be as bad as if it’s a photo of you. That feels more personal.”

Cardiff, event 1.

There were mixed views when discussion turned to using **cameras in private care-homes** to collect data on residents (e.g. to flag up if they became ill). Some felt that vulnerable populations, who had agreed to live under the care of the home, had given their consent to, and would benefit from, constant observation. These participants felt there was no difference between a care assistant and a camera performing the observation. Others, however, felt there was something different about a camera collecting data constantly, which made it too intrusive.

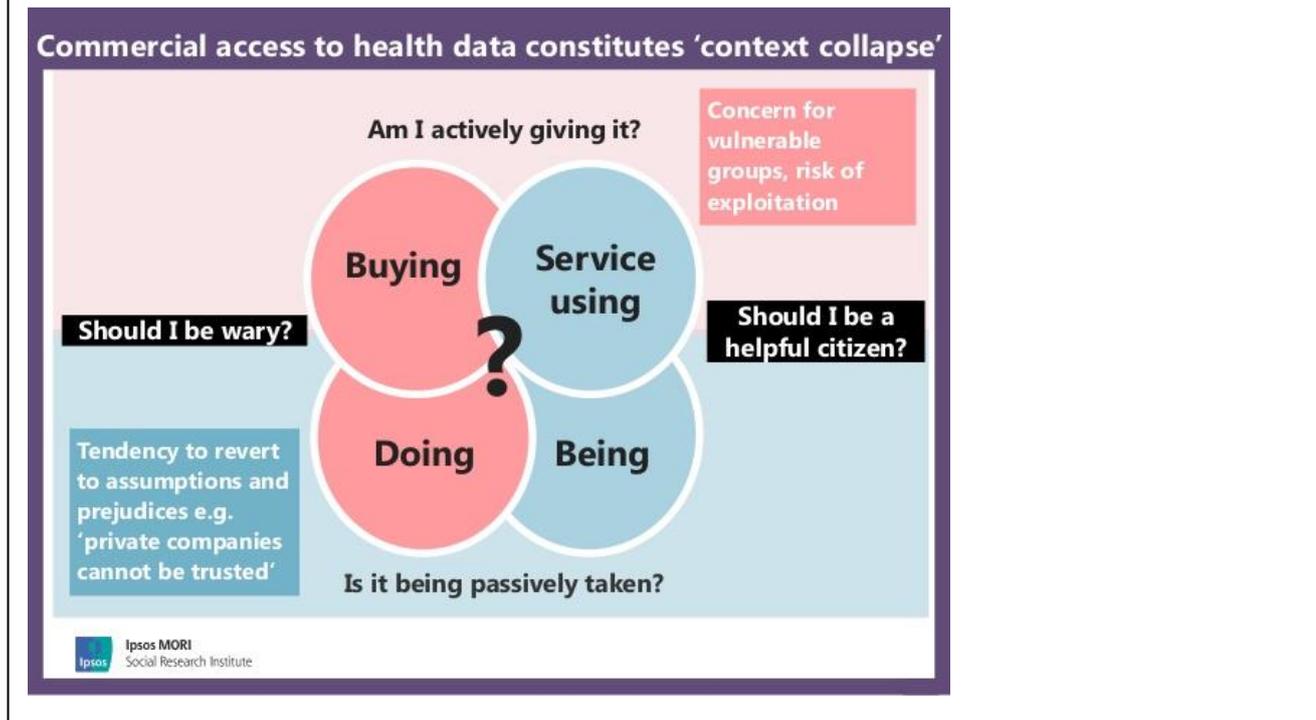
We explored the ‘extremes’ of this concept of surveillance by suggesting that in future cameras might be able to collect data about your health in public places and feed back to clinicians. In general, participants found monitoring of public areas using cameras to identify potential health issues unacceptable, whether the data generated was personally identifiable or depersonalised. There was a ‘gut reaction’ of **distaste for continuous discreet data capture taking place when people go about their lives**, for example the reaction of laughter and horror to this comment:-

“Amazon is developing apps which will recognise if you’re enjoying a book, looking at your face as you read, seeing what page you finish on. Facial recognition will know if you like the book, and they’ll use it to create more books that you’ll love.”

Cardiff, event 1.

This chimes with the findings from the Wellcome Trust study¹² relating to the ‘context collapse’.

The Context Collapse is a model which describes people’s expectations of privacy in different circumstances when they are sharing data. People have traditionally felt that they have an **expectation of privacy and anonymity in shared public spaces**, and so *would not* expect data collection of personally identifiable data to take place. If they see themselves as **engaged in a commercial transaction**, such as using a mobile phone map, they expect that data collection *will* take place. When these contexts blur, people feel uncomfortable; as in the case of commercially-generated data about everyday life or actions being linked with patient data.



There were some interesting discussions over the **ethics of surveillance**; some felt that accepting monitoring as you walk by, could actually be something you agree to as part of the social contract of healthcare. This would fall into the category of being ‘nudged’ by the state to take better care of yourself, which it had a right to do as it was providing your care, and a responsibility to provide it as efficiently as possible. This started to become a discussion about the future of preventative healthcare, and the way in which all of our social space would become a ‘medical’ sphere, if a truly preventative approach was taken to public healthcare, enabled by technology.

“I’m a bloke and we all know blokes don’t go to the doctor. So if there was something in my daily life, that I don’t have to do anything about, and it would remind me or look at if something’s wrong with me- I’d be up for that.”

Cardiff, event 1.

For most participants, the idea of linking publicly-collected imagery to their own personally identifiable healthcare data would be a step too far. Even if data is depersonalised, this felt intrusive.

“At the moment, you tell the doctor what your symptoms are and they tell you what’s wrong with you, but here you’re going into a territory where the doctor is sort of watching you. Does that psychologically soften us and get us ready for the next step where there are cameras in the street diagnosing us?”

London, event 1.

¹² <https://wellcome.ac.uk/sites/default/files/public-attitudes-to-commercial-access-to-health-data-wellcome-mar16.pdf>

However, response was a lot more positive when there were seen to be **immediate benefits to the patient's individual care**, for example in the case of an insulin pump or epilepsy monitor feeding back data continuously. In these cases, the benefit was felt to be so considerable that any privacy loss was worth it.

In terms of data analysis, **participants did not want this data to be used or reanalysed by companies outside the NHS**, nor linked to other lifestyle data. If private companies are contracted to collect data for the NHS in this way, participants wanted to ensure that analysis was done by the NHS where possible, whether the data was in personally identifiable or depersonalised form.

This was partly a result of lack of knowledge of the parameters which these technologies might need to operate, and partly related to the desire to **preserve the clinician's control over decision making**. In any case, this reaction reveals that the public and patients wish the NHS to keep control of as many analytic functions as possible.

For most, the acceptability of this whole idea was predicated on the idea that **commercial interests would not be allowed to re-use the images collected**, (whether personally identifiable or depersonalised), for example to further stratify social groups, leading to higher insurance premiums or intrusive marketing.

These discussions were based on the assumption that new technologies might be able to sift through data about individuals to **draw conclusions about public health as well as individual behaviours**.

Participants felt if these technologies were to be deployed for this, or for individual care, they would want to know a lot more about them and have a much more informed public debate.

3.4 Desire to preserve the valued clinician-patient relationship. Technologies should support clinical judgement and not overrule it.

A key concern across all three locations, when discussing all the case studies relating to Machine Learning, was how any outcome would be conveyed to the patient. This was more concerning in personal and complicated outcomes.

In the example of automated antenatal scans, we did not immediately discuss removing a sonographer, but described the case study in a variety of ways. The discussion nevertheless led participants to think about how they would feel about having Machine Learning or AI replace a human sonographer. There was the strong view that a human sonographer, although potentially less accurate, would be much preferred over an automated processor, as a richer, more empathetic interaction between a sonographer and a patient is viewed more favourably over a more efficient service.

"It's not only the interpretation, it's the psychological factor, how someone presents the fact, how they present to you. People are different, they have different views on life. The doctor needs a psychological approach to motivate you to treatment."

Cardiff, event 1.

Some HCPs had a more nuanced view. They could imagine a tiered approach depending on the outcome of the automated scan and the medical history of the patient.

'The algorithm may have a 'green', 'amber', or 'red' report. If it's green, the patient can go on their way, but if it's amber or red, that might allow you to have one sonographer, or a skilled professional, who maybe runs a suite of 3 scanners, so that when he or she does need to spend time with you, they actually have 20 minutes, instead of 5.'

HCP, Sheffield event 2.

HCPs understood how a machine could provide the reasons why a patient had developed a disease or illnesses, but still felt the clinician-patient relationship would always be required, to explain and reassure the patient after the machine had provided the diagnosis.

“The machine can give you your data and a percentage, but my patients will be straight on the phone wanting to talk through the thousand questions in their head, which the machine won’t be able to answer.”

HCP, Sheffield, event 2.

The relationship was felt to be particularly important when discussing incidental findings or conveying **risk, as in the Parkinson’s example.**

Public and patients also felt that the **clinician should not be overruled by the results of automated programmes.** A particular example occurred during discussion of the Machine Learning programme which could identify acute kidney injury from electronic patient records. In London, doctors in the room pointed out that if the technology identified this problem, it would mean that an operation could simply not take place, whether the surgeon wanted to operate or not. But public and patients still thought the technology should only be used to flag up a problem, and the surgeon should decide, rather than be prevented ‘by the machine’.

There were also many comments made to the effect that even if some algorithms were more accurate than a doctor, public and patients would trust the doctor’s judgement more. (This was particularly the case with the mental health diagnosis examples).

Ultimately, public and patients felt that even if the Machine Learning algorithm was more accurate than a clinician, it should still be used to **support shared decision** making rather than overrule the clinician.

3.5 Linking non-NHS data with patient data is potentially beneficial, for example data from wearables could give patients autonomy and responsibility over their own health.

One case study (the smart insulin pump) represented how data from wearables, collected outside the NHS, could be linked to an individual’s NHS patient data. In the sessions, facilitators extrapolated the idea to test more extreme uses, for example to ask participants about linkages to their patient data from other sources, for example from records of their supermarket purchases.

Participants felt that linking data from their wearable devices to patient data, in general, would be a very good idea to **tailor personalised treatment and enable people to monitor their own health, in partnership with clinicians.** These put responsibility back on the individual for monitoring their own health, and provide easy and accurate ways of collecting data in ways that have not been possible before now.

“If you did opt in to all these things, it would give you a bit of accountability, so maybe you would want to change and improve your lifestyle. You can’t just pretend you did it.”

London, event 1

However, all groups pointed out that future data-driven technology might provide barriers to operation for older people, people on limited incomes who could not afford devices, and people with learning disabilities or without digital literacy who might not be able to operate them. Even if the wearables were supplied by the NHS and required no skill, participants felt some users might be daunted even by the idea.

They felt it would **not be possible to roll out such new devices fairly as a standard part of healthcare, and it might lead to a two-tier health system relating to data.**

Collecting data from outside the NHS, then, might mean richer data might be collected about some types of patients, which would lead to them getting higher standards of care than others, and would also **bias national datasets** as the datasets would not include everyone. This would make wider analysis less effective.

When it came to **linking self-collected data (e.g. from a Fitbit) to patient data in the NHS,** participants were wary of the unintended consequences of doing so. In particular, participants did not want data from wearables to play a part in

determining future access to treatment e.g. if the wearable measured exercise levels, and the fact they had not exercised enough in a given time period impacted which treatments they could access.

As mentioned at 3.3, the ethics of surveillance came into play here. Patients and members of the public did not want to provide data in detail about their health behaviour and lifestyle choices, if it would lead to clinicians judging them, or making them feel 'shamed' for any unhealthy choices they choose to make.

Facilitators did attempt to discuss the benefits of linking health records and other records in a depersonalised way, but participants struggled to see how this could be useful. Identifying trends in diet and health was one opportunity, and participants would be happy to see their data linked for these reasons.

“The way computers have evolved, with things like AI, these decisions and results will be gathered quicker. Finding out about things like too much sugar, too much salt, and so on. Once that’s collected we will get a better picture quicker. Rather than ‘we did a study 5 years ago’”

Cardiff, event 1.

3.6 Very little awareness of, and belief in, the potential of natural language processing to structure data for analysis

Future data-driven technology is being taught to identify diagnoses or concepts that can then be used to augment diagnoses or identify patterns in symptoms that might identify subtly important differences in illness patterns. In the workshops, the case study referenced mental health, using an example of natural language processing in order to identify and diagnose psychosis. However, there are many other uses of this technology.

Due to the focus on mental health, discussions around this example lead to participants expressing that mental health treatment requires human clinician-patient interaction, and the thought of machine learning replacing this interaction is a real concern for many. In general, participants saw mental illness of any kind as something not amenable to automated diagnosis or treatment, but based on a human’s perception of how another human is feeling; rich personal relationships between patients and caregivers were seen as essential to mental health.

So for a minority, even if this technology worked perfectly, it would still be damaging something essential about the human spirit.

“Because of my spiritual beliefs, even if it worked and it made me feel better – then I would start to question myself, I’d start to question what I am, and what it means to be human. I have felt empathy from a machine.”

Cardiff, event 1.

This particular example, then, made it hard to disentangle views of natural language processing from the conception of mental health. However, beyond the specific example, there did seem something difficult for participants to grasp about how an Artificial Intelligence might actually perform a text analysis, and how it could draw conclusions. The terminology was unfamiliar, as many were unsure of the meaning of structured or unstructured data, or 'free text'.

Potentially, greater understanding of how the technology might work could lead to a more informed expectation of what it might deliver, and allay concerns. For now, participants would accept this technology only if used as a guide by clinicians; of all the examples given, it was considered the least reliable for diagnosis.

“I think we’ve come a long way with mental health in recent years, but this does depersonalise it by looking for common themes. We don’t want to lose the personal aspect and the individual treatment. There are feelings involved and you don’t want to overlook these.”

London, event 2.

3.7 Support for analysing big datasets to stratify patients into groups, but questions around how this should be used in the future of genomics

The case study used to represent data being used to stratify patients for treatment, described a cancer trial deploying Machine Learning to identify which patients were more likely to benefit from specific treatments. This would enable patients to be offered more targeted treatments based on information about their likely response to treatment derived from their genetic data.

Stratifying patients genetically for better results of trials, and better results possibly for the individuals within the trials, was seen as highly beneficial by all participants.

“There’s a history of cancer in my family, and if your genes are checked then they could take action sooner to prevent it or treat it if you’re more likely to get cancer.”

Cardiff, event 1.

Participants were generally comfortable for depersonalised data to be collected about them, and understood how this could be collected and used to benefit the population and themselves. However, it was clear they were **not comfortable for any personally identifiable information to be used, unless they themselves were part of the trial**. This relates to the challenges described in section 2.4, where participants found it hard to conceptualise the benefits of sharing personally identifiable data unless they saw benefit to themselves as individuals.

“If it’s aggregate data, then wonderful, because it’s helping everyone.”

London, event 2.

The example given related to patient data within trials, but participants moved on to talking about Machine Learning analyses of genetic data possibly being used in wider contexts in future.

There were some specific caveats around future new technologies working with **datasets of information derived from genomics**. Linking genomic data and other datasets (e.g. lifestyle data, financial, shopping...) is likely to uncover unprecedentedly rich data. Even if the patient data was depersonalised and aggregated, participants felt any learning from genetic analyses potentially could **uncover new knowledge about hidden genetic stratifications of our society**.

Once known, this information would have seismic consequences for the way we think about healthcare and health insurance, and possibly change some fundamental aspects of society overall. The implications of gene mapping on employability, insurance and mortgages were mentioned with suggestions for regulation in the vein of the current Disability Discrimination Act.

“If someone is more disposed to killing themselves or other people, and the technology exists to make these analyses, then it’s only a matter of time before insurance companies start demanding to know this information.”

London, event 2.

“If genetic screening became the norm, it would pay a part in people meeting other people [romantically]. It would be a bit weird.”

London, event 2.

“People would be written off. In my lifetime your whole gene will be mapped out and you know what disease you’re going to get; would you want to know? There are all sorts of ethical considerations.”

HCP, Sheffield, event 2.

4. Raising public awareness on data and new technology

4. Raising public awareness on data and new technology

4.1 Gaps in public and patient awareness

“There were all sorts of categories that technology could help for, which never would have crossed my mind.”

Sheffield, event 2.

Many participants were in the same position described by this member of the public at Event 2; interested in the new technologies, but experiencing a steep learning curve, due to confronting issues that they had never thought about before.

The public, in particular, are currently far from the world of new technologies and the management of data. If the NHS and policymakers wish to include public voices in the decision process about these new ways to improve healthcare, there may be a need to raise public awareness, to communicate about new technologies in ways which resonate with people, and crucially, to help the public understand and comment on any practical or ethical dilemmas around their application.

Even after many hours of discussion and information provision, some public and patients did not grasp the nub of the issue around data-driven technologies and the ways they might use patient data.

Participants overall expressed views which were in line with what has been heard in recent dialogues on attitudes to big data and Machine Learning; such as Ipsos MORI’s dialogues on Machine Learning for the Royal Society¹³ and on the Ethics of Data Science in Government for the Government Data Science Partnership¹⁴.

Participants in this project expressed similar concerns to participants in previous dialogues:

“Participants were often unsure and cautious about the practicalities of how data is, or could be, collected and analysed. They were also sceptical of why data science was being considered in some circumstances, and how results might be used by government for policy-making and planning services...

With very low level of baseline awareness of how data science works in any context, many initially struggled to see the value of using computer analytics (as opposed to more traditional methods) without further information about how these work in practice.

There was:-

- Low awareness of how data sets are collated.
- Doubt as to whether computers can make better decisions than humans.
- Caution about techniques that cluster individuals or use of correlations between datasets that initially appear unrelated.
- Ambiguity about the level of control and automation that can or should be given to a computer.”

From the Executive Summary, Public Dialogue on the Ethics of Data Science in Government

In the discussions for this study:-

- The way that **personally identifiable data could be translated into depersonalised and aggregate data** was not understood, especially in the Sheffield workshops. Some struggled to understand how aggregated datasets could give any useful learning about individuals. These participants basically disbelieved that large datasets can tell you anything that could have bearing on an individual specifically. There are seen to be too many ‘what ifs’ – culture and background, for example. Individual behaviour was seen as being about ‘more than data’ –

¹³ <https://royalsociety.org/~media/policy/projects/machine-learning/publications/public-views-of-machine-learning-ipsos-mori.pdf>

¹⁴ <https://www.ipsos.com/sites/default/files/2017-05/data-science-ethics-in-government.pdf>

especially where health is in question, as an **individual's perception of wellness and illness was seen to be unique to them.**

"[If the feedback to the drug company is on a population level], that's why we don't need to wear a band [wearable monitor to capture our own health feedback]. We don't need that information about individuals. They just need more general information".

Sheffield event 1

This meant that participants rejected ideas which involved **conclusions about behaviour being drawn from combined datasets**, such as shopping and health data, which would lead to recommendations – people felt they were more than statistics, and would need a clinician to interpret their data before deciding what to do about it.

- More specifically, many did not grasp that **some new Machine Learning technologies require training data, and that the quality of the data will determine the accuracy of the results**; missing records systemically from groups of patients will lead to a biased set of findings.
- Algorithms were imagined as being **precise ways of looking at something**, and the **learning** element of Machine Learning was not grasped. Therefore the technologies which were most welcomed were those seen as best at identifying detailed images which might elude a human observer (such as differences in scan images) or to control precision instruments where human error might otherwise creep in. When participants viewed future data-driven technology as performing these kinds of tasks, it was generally welcomed.

The learning from this project adds to the body of dialogue on related topics, and reveals a need for **greater public literacy around statistics** and data science, to help people conceptualise the benefits and risks of data sharing.

4.2 Machine capabilities judged by the standards of human capacities

A theme throughout the discussion was the idea that participants **did not want human roles replaced by machine roles within the health service**. This view persisted, despite the different potential roles of machines and humans being introduced by facilitators in many different ways through the dialogue.

There may be a need for a wider public debate about how knowledge from Machine Learning should be positioned relative to human knowledge. While participants did not use this terminology, the concept of 'System 1 and System 2 thinking' is useful here.

Without necessarily saying this explicitly, participants believed **good clinicians are always using both 'System 1 thinking' (fast, instinctive and emotional) and 'System 2 thinking' (slower, more deliberative, and more logical)**. These two modes of human mental analysis were originally put forward by Daniel Kahneman¹⁵.

Machine Learning was **perceived in the light of these human modes**. In reality, the process of Machine Learning calculation uses neither system, but instead models information very rapidly in a rational way, but at the same time can amplify biases in data in the manner more associated with system 1; so these modes are not helpful. We introduce the idea, however, because participants **tried to map their understanding of human intelligence to this new domain of machine intelligence**.

Because many participants also found it hard to grasp that **Machine Learning would be able to identify relationships between variables that humans cannot**, there was an underlying feeling that **important intuition would inevitably be lost** ('System 1') if clinical judgement was replaced by machine analysis. This would mean that machines would take different 'judgement calls' from humans. Participants did not want machines to make diagnoses in areas which are not

¹⁵ Kahneman, D. (2011). **Thinking, fast and slow**. New York: Farrar, Straus and Giroux.

‘black and white’ for example in mental health, or to perform calculations of risk in cases where individual patient behaviours and values are some of the variables.

“I would like there to be some process by which I can question it. What worries me is that the machine gets it wrong, and without a professional human interfering at some point it just continues to get it more wrong.”

London, event 2.

“This is sharing your personal data with machines. It’s frightening. It’ll be a higher power than us, a higher intelligence, we’ll be in a position of vulnerability.”

Sheffield, event 1.

There may be a need to create **greater depth of understanding of the process by which Machine Learning creates knowledge**, in order to have an informed public debate about how it should support clinicians.

4.3 NHS bears considerable weight of public expectations around responsibility for patient data

There may be a need for **further dialogue on the nuances of the NHS’ contractual responsibilities**, and the challenges it faces in **drawing up contracts on novel technologies**. It was notable in this dialogue that participants were relatively uninterested in safeguards and governance, and we judge in analysis that this is because they have **implicitly devolved this responsibility** to the NHS, which they trust unequivocally to protect their data.

“The NHS must have absolute ownership of the process all the way through, even if the data is being used by a private company, the NHS must lay down the rules and ensure others are adhering to them.”

London, event 1

Designing new data-driven technology demands specialised skillsets. There may be a need to raise public awareness of this. The NHS has **never before needed to possess this knowledge in-house**; indeed, few specialists may yet exist who can competently work in this new area.

There may be a need for public discussion of how we can equip the NHS with the skills necessary to negotiate with technology companies around the design of new technology, given that some implications of new technology use may go beyond questions of data access to more complex ethical considerations.

“What new roles and responsibilities do the designers and developers of such apps take on, and how do the ethical responsibilities at the heart of the medical profession get integrated into these differing design and engineering contexts?”¹⁶

– Crawford, Whittaker *et al*, The AI Now Report: The Social and Economic Implications of Artificial Intelligence Technologies in the Near-Term

¹⁶ https://ainowinstitute.org/AI_Now_2016_Report.pdf

5. Conclusions: criteria for new technologies working with patient data

4.

5. Conclusions: criteria for new technologies working with patient data

Several criteria are highlighted by patients, public and HCPs as needing to be considered in the development and deployment of future data-driven technologies with the NHS.

Overall, there were few **new** considerations around patient data in the context of new technologies which were not already concerns around the use of **patient data in healthcare in general**.

Those that did exist, however, were seen as important issues for healthcare policy.

Patients, public and HCPs **wished the Academy to take their views on board** when considering the three aspects of focus for the study.

- **Data gathering:** Wearables and continuous observation devices have great potential but be careful about how images of people especially faces are stored and shared. Be aware of the 'context collapse' (i.e. that people will feel uneasy about being observed in places they consider to be private); and the impact of this on consent.
- **Data analysis:** Linking data from wearables, other data, and data collected outside the healthcare systems, with patient data is potentially beneficial. There is universal support for Machine Learning analysis of scans or other data, though natural language processing may need some more explanation of how it works and the benefits. Push forward with stratification of patients into groups where this can help deliver personalised medicine, but be wary of the unintended consequences of developing stratified genetic datasets which could create bad social outcomes.
- **Data delivery:** Do not erode the capacity for patients to choose treatments, or the relationship between patients and human NHS staff. Do not allow technology efficiencies to lead to cuts to clinician-led services. Human interactions are valued more than faster and cheaper processes. Explain how diagnoses inform delivery of healthcare especially when machines are empowered to diagnose.
- Overall, **any new use of data needs to have a proven social benefit to make it worth sharing patient data with commercial companies** (especially personally identifiable data).
- **The NHS should be in charge of patient data** and administer it for public benefit. **Make sure the NHS has the skills to protect the public interest** – the public are not thinking too deeply about safeguards and assume the NHS can handle it. Is the NHS equipped to negotiate in our best interests?

Finally, there is scope to further **raise public awareness on how data science and machine learning work**, in order to have more informed discussions of these technologies as they are rolled out in the future.

6. Appendix

6. Appendices

6.1. Steering group members

6.2. Stakeholder group members

Juliet Tizzard (HRA); Valerie Field (MHRA); Rob Frost (GSK); Harry Evans (King's Fund); Catheryn Meaden (DeepMind Health); Tim Hubbard (AHSC); Hugh Lloyd-Jukes (Oxehealth); Dr. Charles Gutteridge (Barts Health); Sam Smith (MedConfidential).

6.3. Sample frame

London Workshop Event 1	Quota Categories	Frequency
Participant	Patient*	7
	Public	11
Gender	Male	7
	Female	11
Age	21-30	8
	31-45	6
	46-65	4
Ethnicity	White	11
	BAME	7
Social Grade	AB	6
	C1C2	9
	DE	3

Sheffield Workshop Event 1	Quota Categories	Frequency
Participant	Patient*	10
	Public	12
Gender	Male	9
	Female	13
Age	21-30	6
	31-45	7
	46-65	9
Ethnicity	White	16
	BAME	6
Social Grade	AB	8
	C1C2	4
	DE	0
Area	Rural (Sheffield Suburbs)	5
	Urban (Centre Sheffield)	17

Cardiff Workshop Event 1	Quota Categories	Frequency
Participant	Patient*	6
	Public	7
Gender	Male	4
	Female	9
Age	21-30	4
	31-45	3
	46-65	6
Ethnicity	White	8
	BAME	5
Social Grade	AB	13
	C1C2	0
	DE	0
Area	Rural (Cardiff Suburbs)	7
	Urban (Centre Cardiff)	6

*Patients are defined by either having life limiting illnesses, long-term conditions, and/or mental health issues, and includes both in-patients (admitted to hospital for treatment, and out-patients (attended hospital for treatment but did not stay overnight)

Workshop Event 2	Healthcare Professionals (Frequency)
London	6
Sheffield	4
Cardiff	5

6.4 Case studies shown to participants

1. Automated ultrasounds for pregnant women

Purpose: quicker, high quality scans, for your care

Technology: machine learning, 3D

Where, how, data is collected? During the scan

Which data is collected? All the usual scan data and more

Antenatal ultrasound is performed in the UK by a skilled sonographer at 8-14 weeks pregnancy, and 18-21 weeks. The sonographer will give results to the woman at the time. If there are any abnormalities detected the sonographer can ask for a further review by a colleague and for further scans and tests.

A combination of 3D and automated reporting (AI) could speed up the time to scan, increase accuracy and speed of reporting.



2. Identifying patients with acute kidney injury

Purpose: revealing kidney injury when the patient doesn't know about it

Technology: machine learning, linking records

Where, how, data is collected? During the stay in hospital and GP record

Which data is collected? Blood tests, vital signs, blood pressure, scans, drugs

Electronic Patient Records are beginning to be used in UK hospitals. They record data about every patient during their hospital stay.

Using big data analytics, and machine learning, patients who have undiagnosed acute kidney injury could be diagnosed



3. Sharing drug efficacy with companies

Purpose: revealing kidney injury when the patient doesn't know about it

Technology: machine learning, linking records

Where, how, data is collected? During the stay in hospital and GP record

Which data is collected? Vital signs, blood pressure, scans, drugs

Electronic Patient Records are now used in every UK hospital. They record and store the vital-sign data, blood tests, blood pressure, scans and drugs for every patient during their hospital stay.



Using big data analytics, and machine learning, the hospital can find out the efficacy of particular drugs at lowering blood pressure, for different groups of patients.

The Trust could share the data with the companies that make drugs to help.

4. Linking your insulin pump data with lifestyle data

Purpose: helping diabetics manage their condition by getting a broader picture of their lives

Technology: wearables, apps, data stored in cloud

Where, how, data is collected? All the time through wearable

Which data is collected? Vital signs, blood pressure, scans, drugs

The system measures blood glucose, delivers insulin when it detects a blood glucose swing, then records the results through a sensor and wireless connection to smartphone. Patient, healthcare team, and family can all see results if desired through an online portal

In the future, a patient might be able to allow the app to link their health data with social media data, supermarket loyalty card, or other data.



5. Identify patients at risk of Parkinson's

Purpose: finding out if someone is at risk of Parkinson's

Technology: finger sensor used for pulse record in hospital

Where, how, data is collected? All the time during the stay, in Electronic Patient Record

Which data is collected? Tremor and movement

Capturing tremor and then modelling the likelihood of Parkinson's development, using ML.

This could be carried out for patients who have come into hospital for other reasons.



6. Spotting early signs of psychosis

Purpose: finding out if someone with a mental health condition is at risk

Technology: natural language processing, ML

Where, how, data is collected? During a consultation

Which data is collected? 'free text' – their usual speech

Using the free text (writing) of patients suffering from mental illnesses.

Natural language processing and machine learning can extract information about their state of mind.

The programme can flag up signs of a deteriorating condition.



7. Monitoring at-risk patients in the home

Purpose: early intervention if a post-op patient starts to be at risk of heart attack on their own at home

Technology: camera sensor, app.

Where, how, data is collected? All the time at home

Which data is collected? Images and videos

People with a heart attack may develop heart failure which shows by ankle swelling. A camera can identify presence of or increase in swelling and enable medications to be adjusted in a timely manner.

A monitoring camera is fitted to the underneath of the patient's bed, with their consent.



Each day as their feet land on the floor a snapshot of the size of their feet is sent to the clinical team. The app flags up any changes.

8. Putting patients into different treatment groups

Purpose: put patients into groups based on genetic data

Technology: Machine learning based on data about their genes and their cancer's genes

Where, how, data is collected? As part of the clinical trial

Which data is collected? Results from DNA tests of the blood and biopsy

This clinical trial looks at different new drugs to treat non small cell lung cancer. The treatment people have depends on changes to genes in your cancer cells. The researchers identify the genetic makeup of your cancer cells.

Machine learning could be used to decide on the different groups and give patients different drugs, which can be matched to the gene changes they have.

The researchers are hoping that machine learning will be able to predict which drugs work best for different groups.

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About Ipsos MORI's Social Research Institute

The Social Research Institute works closely with national governments, local public services and the not-for-profit sector. Its c.200 research staff focus on public service and policy issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. This, combined with our methodological and communications expertise, helps ensure that our research makes a difference for decision makers and communities.