A number of studies have explored how people feel about the use of patient data, with fairly consistent findings.

People are generally comfortable with anonymised data from medical records being used for improving health, care and services, for example for research, provided there is a public benefit. The more informed people feel, the more they are likely to support these uses. Many are uncomfortable with the idea of commercial companies accessing their health data, and there are particular concerns about information being passed on for marketing or insurance purposes.

The list below includes references and summaries of studies on public attitudes to patient data.

Joined Up Yorkshire and Humber (2019)

This research with nearly 2,000 people was commissioned to inform the Yorkshire and Humber Care Record. People gave views on how health and care records could and should be used, their boundaries and their concerns. The mixed-methods included a survey, focus groups, case studies and workshops. Engagement took place on buses and trains and in cafes and leisure centres. Findings include that many people were unaware of the role of local councils in planning health and care services. Therefore, they were concerned about local council having access to medical records. 95% of survey participants supported some uses of data beyond their individual care. Some supported using data from records to intervene before people develop a health condition.

Joined Up Yorkshire and Humber

Use of free-text health data (2018)

Brighton and Sussex Medical School and Healtex commissioned a citizens' jury of 18 people held over 3 days to judge how patient data should be used for research. Participants judged scenarios that included both coded and free-text patient data. The report includes how the citizens' jury was designed and carried out as well as the results. Following evidence hearings, participants were all either strongly or fairly supportive of the use of free-text data in research. Participants were guided to consider academic and NHS research rather than research by private companies when answering this question. Views varied on what choices patients should have around uses of both coded and free-text data in research.

Use of Free-Text Health data

Future data-driven technologies and the implications for use of patient data (2018)

Academy of Medical Sciences commissioned Ipsos Mori to hold dialogue workshops with members of the public, patients and health care professionals on awareness, aspirations, expectations and concerns around uses of patient data in future technologies. This research informed workshops on policy implications and principles for uses of data-driven technology. Findings include optimism about uses of new technologies in healthcare, gaps in patient and public awareness impacting views

about the utility of some technologies, that acceptability of some technology uses are context dependent and that the NHS should be in charge of new uses of data with proven social benefit.

[Future data-driven technologies and the implications for use of patient data: Dialogue with public, patients and healthcare professionals](#)

Who benefits and how? (2018)

In this research deliberative workshops were held with Scottish participants from a cross-section of the population to discuss public benefit from research using patient data. Discussions included understandings and expectations of health research, who "the public" are who should benefit from research, and how they should benefit. Participants felt that benefits should reach all, whilst the value of research focused on vulnerable groups was also acknowledged. A focus of discussion was participants' levels of confidence as to whether potential benefits would be realised.

[Who benefits and how? Public expectations of public benefits from data-intensive health research](#)

Great North Care Record public engagement report (2018)

Connected Health Cities, Teeside University and local Healthwatch groups in the North East and North Cumbria engaged 314 citizens across 23 engagement sessions. They explored data sharing, and specifically the Great North Care Record, in order to identify citizens' concerns, hopes and expectations. The report summarises citizen values and expectations around how data about them should be shared, focused under the following headings: reciprocity, fairness, agency, privacy, transparency and trust.

[Great North Care record public engagement report](#)

Great North Care Record sharing health records and setting levels of health record privacy (2018)

This YouGov poll surveyed over 800 people in the North East on behalf of Teeside University following the introduction of the *Great North Care Record*. People were asked about attitudes to sharing data from their health care record and on the importance of being able to set and change health care record privacy settings. After watching a video, 94% surveyed would agree to their health care record being shared within the NHS and 53% would agree to sharing with researchers. 86% of people said being able to control the privacy settings of their health record was important.

[Sharing health record data and setting health record privacy](#)

Public views on what are reasonable expectations around sharing patient data (2018)

The National Data Guardian and Connected Health Cities jointly commissioned a three day citizens' jury to explore when people would normally expect their patient data to be shared, and when they would not. The majority of jurors' thought most examples were reasonable but less supported data sharing with administrative staff and with university researchers developing artificial intelligence

software. For less familiar uses, jurors' views changed where they could speak to those who use patient data. Jurors' tended to naturally assess the desirability of data sharing based on the purposes for using data rather than by what was reasonable to expect.

Reasonable Expectations Report

Article on the National Data Guardian and Connected Health Cities

Health data storage and public cloud use (2018)

ComRes interviewed over 2,000 people as part of the Corsham Institute report about health data storage and public cloud use. 70% of people polled were confident NHS patient data is stored securely. Only 23% of people were comfortable with their data being stored on global clouds, particularly if these might be stored in the European Economic Area rather than the UK. 73% were comfortable with data being stored in local NHS branch computer servers and 69% with data being stored on a national computer server for all NHS networks in England.

Adoption of public cloud services in the NHS

Data sharing and technology (2018)

Asthma UK explored people with asthma's attitudes to the sharing of personal health data for research and NHS service improvement, alongside their views on the use of new technology and data in their asthma care. They found willingness for people to share data. 88% of people with asthma would be willing for their confidential health data to be used for service improvement. 94% of people with asthma would be willing for their anonymised health data to be used by an analytics company, in partnership with the NHS, to better identify people at risk of an asthma attack.

Data sharing and technology

Data being shared by the NHS (2018)

A Healthwatch England survey found that, overall, most people would be happy for the NHS to use their confidential patient information to improve healthcare treatment of others. However, that two thirds of these people felt they may later regret having their data shared with organisations such as companies and universities. In addition, they found that people were more aware of negative data scandals, such as the WannaCry hacking, than positive data initiatives, such as the 100,000 genomes project.

Healthwatch England survey results

Public views on NHS sharing patient address details (2018)

A survey by NHS Digital found that while the majority of people think tracing people suspected of immigration crime is important (86%) even more say it is important to treat patient address details as confidential (97%). Despite the high importance placed on patient confidentiality, the public do support the NHS sharing patients' address details with: police to trace individuals suspected of serious crime (85%); the Home Office to trace an individual suspected of immigration crime (72%), and; other government departments to trace an individual suspected of another type of crime (71%).

NHS Digital poll

Should patients control access to patient records for research? (2018)

Two citizens' juries were held over three days each to find out what control people want over the use of health records for research. When informed of both risks and opportunities associated with data sharing, citizens believe an individual's right to privacy should not prevent research that can benefit the general public. Many, but not all, jurors became less skeptical about health data sharing, as they became better informed of its benefits and risks.

Citziens' juries

Attitudes towards health research (2018)

A study by the Health Research Authority and National Institute for Health Research found that eight in ten people think health research is very important. But confidence varied greatly depending on ethnicity, social class and working status. Compared to a similar study in 2013, there was a rise in confidence that personal data would be held securely if they were to take part in research. People had the greatest confidence in health research funded by the public sector including the NHS. There was less confidence when research was undertaken by the pharmaceutical industry. But if pharmaceutical companies partnered with the NHS in studies, then confidence did increase.

Attitudes towards health research

Attitudes to sharing personal data (2018)

A survey conducted by YouGov for the Open Data Institute (ODI) found that respondents trusted the NHS and healthcare organisations more with their personal data than local government, banks, their friends and family and online retailers. Almost half would share medical data about themselves, if it helped develop new medicines and treatments. However, discomfort around sharing personal data remained high. A third wanted better explanations of how organisations intend to use or share the data and 34% said nothing would make them feel more comfortable.

Sharing personal data

Giving something back (2018)

This systematic review looked at 20 public attitudes studies. It found that there is widespread willingness to share health records for research for the common good; however, this support was never unconditional. The public evaluates the trustworthiness of research organisations by assessing their competence in data-handling and the motivation for accessing the data.

Giving something back

Joined-up Leeds (2016)

This research by Brainbox was commissioned by Leeds Informatics Board. Public engagements held included conversations, facilitated workshops, social media, uses of case studies, journey mapping, surveying and featured various settings, including pubs and community centers. Through a range of citizen engagement, it explored attitudes to health data sharing and how it could best be shared; insights into individuals' personal interest in and views on the potential impact of personal health records; professionals' views, interest in and expectations of personal health records.

Joined-up Leeds report 1 (data sharing) and summary

Joined-up Leeds report 2 (personal health records - citizens) and summary

Joined-up Leeds report 3 (personal health records – care professionals)

Citizens' Juries (2016)

Two citizens' juries explored the planned and potential uses of health data by Connected Health Cities, to judge whether the proposals were acceptable to the public. The jurors examined expert witnesses and carried out group exercises over four days, before reaching conclusions together.

Jury reports

Attitudes towards cancer data collection (2016)

Cancer Research UK and Macmillan Cancer Support commissioned Ipsos MORI to find out what people living with cancer and the general public think about the current process of cancer data collection. While there was very low awareness of the cancer registry, there was overwhelming support for collecting cancer data in this way as well as a desire to learn more about the use of data more broadly.

Review of informed choice for cancer registration (CRUK)

Awareness of the English cancer registry (Macmillan)

Public responses to sharing and linking health data for research (2016)

This systematic review looked at 25 public attitudes studies. The review found there is widespread support for the uses of data in research; however, this support is never unconditional. Most importantly, it found that the public want more information about current data sharing practices, governance systems and safeguards. If empowered by knowledge and information about the processes and safeguards in place, the public felt that consent and opt-in mechanisms may not always be necessary.

Public responses

Public engagement in the Scottish Health Informatics Programme (2016)

The Scottish Health Informatics Programme was a research programme exploring ways of collecting, managing and analysing electronic patient records. It conducted eight focus groups and a stakeholder workshop to explore the public's trust in research and researchers as well the trustworthiness of research. It found that public engagement should be aimed at improving the trustworthiness of science and explored the importance of transparency.

Moving from trust to trustworthiness

Attitudes to use of medical free text data in research (2016)

This study includes a literature review of recent work on patient and public attitudes, with a particular focus on views on uses of free text. The aim was to inform and develop a governance framework for the use of medical free text for research.

Attitudes to use of medical free text data

Public attitudes to commercial access to health data (2016)

Wellcome commissioned Ipsos MORI to conduct an in-depth study of views about commercial access to data. The report suggests a slight majority (53 per cent) of people would be happy for their data to be used by commercial organisations if it was for research, but most people were extremely wary of insurance and marketing companies accessing even anonymised information.

The One Way Mirror

Public and professional attitudes towards the confidentiality of patient health information (2015)

OPM were commissioned by the General Medical Council to review literature on both public and patient and professionals' attitudes towards the confidentiality of healthcare data, depending on the purpose for the use. Main findings on public and patient attitudes were fairly consistent with other attitudes work around lower levels of trust in commercial companies, concerns around safeguards

and willingness to share data for public benefit. Professionals were more accepting of sharing patient data than the public.

Public and professional attitudes towards confidentiality of healthcare data

Wellcome Monitor (2015)

Almost four in five of the public (77 per cent) say they would be willing to allow their medical records to be used in a research study if they were anonymised. This figure was higher than the equivalent question in the previous two surveys.

Wellcome Monitor (Wave 3)

Sharing data between health and care professionals (2015)

Healthwatch Surrey found there is strong support for sharing of all, or part of, people's records with health and care professionals involved in their care. Participants wanted reassurances on the procedures in place to ensure security, confidentiality and accuracy and there was a strong desire for people to be involved in decisions about the sharing of their records.

If I've told you once

Sharing data for purposes beyond individual care (2015)

The BMA contracted BritainThinks to run a workshop with the public as part of research into what the public think about the sharing of healthcare data for secondary purposes.

Secondary uses of patient data

Privacy of health records (2015)

RAND Europe carried out a pan-European survey to find out citizen's views on storing personal health data. The results showed that the UK citizens prefer storage of information related to all health conditions and identity as well as basic health status information. Apart from doctors and nurses, respondents also wanted paramedics to have access to health records.
However, respondents were averse to those other than medical specialists viewing health records, disliking private-sector pharmaceutical companies the most followed by academic researchers and health insurance companies.

Privacy of health records

Trust in data sharing (2014)

A survey by Ipsos MORI for the Royal Statistical Society found a general 'data trust deficit', where people had less confidence that an organisation would use data appropriately than their level of trust in that institution generally. The NHS and GPs had the highest levels of general trust, but still only 36 per cent of people trusted the NHS to use data appropriately. Public support for sharing personal data depended on who it is being shared with, and for what reason.

The data trust deficit

Public attitudes to research including exploring issues of consent and selection bias (2013)

This study included two methods. The first, a systematic review on public awareness and acceptability of patient data uses in research. The second, a focus group of older men exploring if information about selection biases affected their attitudes to the acceptability of non-consent research methods. The review found that males and older people were more accepting of research using patient data. The focus group found that participants were more accepting of research which used data without consent when informed about selection bias and research processes.

Let's get the best quality research we can

Attitudes to using and linking administrative data for research (2013)

ESRC and Office for National Statistics commissioned Ipsos MORI to explore the public's views on using linked administrative data for research purposes. By the end of the second day of dialogue, participants were comfortable with administrative data being linked by the Administrative Data Research Network, provided the data was fully de-personalised, kept secure at all times, and only linked for socially beneficial purposes.

Dialogue on Data

Comparing attitudes to different types of data (2013)

CM Insight conducted qualitative research to explore whether health data is viewed differently from other types of data, and the perceived risks and benefits, to individuals and society, of linking different kinds of data for research purposes.

Public attitudes to linking personal data

Public support for research in the NHS (2011)

Ipsos MORI research for the Association of Medical Research Charities found that 80 per cent of the public were definitely or probably happy to be approached about health research that would involve allowing a researcher confidential access to their medical records.

Public support for research in the NHS

Electronic patient records in the NHS (2010)

The New Economics Foundation carried out a mass public engagement exercise on the use of electronic patient records in the NHS, engaging with over 6,000 people over a two year period.

[Who sees what?](#)

Young people's attitudes (2010)

The Royal Academy of Engineering's report explores young people's attitudes to privacy, security and possible abuses of electronic patient records.

[Privacy and prejudice](#)

The use of personal health information in medical research (2007)

Ipsos MORI research for the Medical Research Council found that public awareness of the use of personal health information for the purposes of medical research is low but, in general, the more informed the public feel, the more positive they are towards it.

[The use of personal health information in medical research](#)