Written evidence submitted by the Association of Medical Research Charities (AMRC) (DDA0033)

> *Key messages*
> - Connecting data more effectively from different parts of the system holds enormous potential benefits for society.
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> - The use of health data is highly sensitive to the public, and the difficulty of getting data sharing right should not be underestimated.
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> - Public trust cannot be taken for granted. Clear communication and sustained and meaningful public engagement are crucial.
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> - Commercial access to data can bring enormous benefits to patients, but needs an ongoing and open conversation.
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> - Use of health data for purposes beyond health - including sharing data between Government departments and outside of the NHS - must reflect public expectations and consider patient benefit.
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> - Researchers must be able to access data in a proportionate and responsible way.
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> - The impact of missing data on health inequalities must be considered.
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> - Increased emphasis on engagement and trust in the NHS data strategy is welcome, however, much will depend on the detail.
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> - Sharing data will never be completely risk-free. People must be aware of the risks, benefits, and safeguards in place, so that they can make an informed decision about their data.

About the Association of Medical Research Charities (AMRC)

AMRC is the membership organisation for medical and health charities funding research in the UK. We represent over 150 medical research charities, from large to small, including: Cancer Research UK, the British Heart Foundation and Wellcome. Our members have invested nearly £14.5 billion in research in the UK over the last twelve years, supporting nearly half of all publicly funded medical research. Charities play a unique role in the life sciences ecosystem; driven by patient priorities and tackling areas of unmet need, they accelerate the delivery of innovative treatments to patients.

Patient data is crucial in advancing medical research and holds vast potential to deliver benefit to patients. Many of our members are making strides forward in this space; nearly a third hold or support patient data assets, including patient data registries.

Medical research charities have close connections with patients. Whilst many patients are passionate about the importance of using data for patient benefit, others have concerns about how data their data will be used. It is crucial that Government realises the importance of getting this right – the benefits of data for research can only be realised through responsible uses of data that are underpinned by public confidence and trust.

1 The potential benefits, including to research, to effectively use and share data between and across Government, other public bodies, research institutions and commercial organisations

Connecting data more effectively from different parts of the system holds enormous potential benefits for society

The are many benefits of collecting, linking and using data to improve health. Charity-funded researchers rely on information from patient data to understand more about disease risks, to improve diagnosis and to develop new treatments. Notable examples from medical research charities include:

- [Kidney Research UK's work to link GP and hospital data to improve dialysis treatment and outcomes](#)
- [Diabetes UK's work to tackle preventable amputations by linking GP data with hospital data](#)
- [Cancer Research UK's co-funded research that revealed that Black African women in England are nearly twice as likely to be diagnosed with late stage breast cancer as white women in England](#)

Examples like these would not have been possible without the use of patient data in research.

Further, the ability to link and use health data alongside other sources of data has also led to huge benefit – for example the impact on asthma in linking health and environmental data to monitor the effect of air pollution on health.

2 The existing barriers to such data sharing

The fundamental barrier to the use of health data is the **lack of public trust** in its use. Health data is sensitive, so it is crucial that Government recognises the importance of responsible uses of data that are underpinned by trust and meaningful public engagement. This will be covered in more detail in section 4 below (p4-5).

In addition to the problem of lack of public trust, other barriers include:

i)   The impact of missing data on health inequalities

There are huge gaps in health data available for research. Priority must be given to improving the completeness, quality, and interoperability of new and existing datasets.

Improving data quality will require investment of data collection and management including training clinical staff to input good quality data, ringfencing time to enable them to do so, and providing appropriate incentive. Standardising data collection could reduce burden on health professionals and provide more consistent data for use in research.

For some AMRC charities, incomplete data means they cannot do the research they need to do. Patchy data also means it will not be representative of the whole population, meaning research cannot be as insightful as possible, with a risk of introducing bias or exacerbating health inequalities. It is difficult to address health inequalities if there is not the data that demonstrates it.

ii)   Enabling researchers to access data in a proportionate and responsible way

For charities, it is crucial to be able to ensure that researchers can use data in a responsible way, with proportionate processes and governance to support access. AMRC charities welcomed the NHS Data Strategy's commitment to move towards data access through Trusted Research Environments (TREs), to improve the security and privacy of health data and ensure a safe setting for research.

However, the NHS Strategy needs to provide more detail how TREs will be introduced. For example, more detail is needed on where exceptions to TRE data access may be made, for example where explicit consent is given.

It will be crucial that data is accessible and useable by researchers of different disciplines. This may involve designing user-orientated processes or providing training for researchers. It will also be important to ensure that data from different sources (including data from other TREs and data that does not reside in the NHS) will be able to be linked in the TRE.

3 The extent to which data issues are appropriately addressed by the Government's National Data Strategy[1]

Increased emphasis on engagement and trust in the NHS data strategy is welcome, however, much will depend on the detail

The NHS Data Strategy took an overly ambitious and positive tone and assumed a level of public trust that may not exist. The Government was wrong to assume greater public acceptance before the launch of GPDPR and the NHS Data Strategy. Although the pandemic might have improved awareness of how data is used, that does not mean there is a higher level of trust.

We are encouraged to see the increasing emphasis on engagement and communication as the NHS data strategy is revised following consultation. However, much will depend on the detail included in the new version of the Strategy, and how it is implemented. The Government needs to recognise the challenges it faces to rebuild confidence in data use. These must be addressed openly and proactively - transparency is imperative.

Medical research charities are trusted custodians of data and have valuable expertise which can contribute to the debate. Charities must, therefore, be engaged closely in the development of the Strategy – for example through sharing good practice on transparency and ensuring meaningful engagement. Charities not only use data in the research they fund but are also integral conduits for consulting and understanding their patients' attitudes including towards data sharing.

Following the recent announcement of the merger between NHSX/England/Improvement /Digital, it is also important that the NHS Data Strategy maintains momentum and has clear and stable leadership despite the changes to the NHS.

4 The ethics underpinning the use and sharing of individuals' data in health and care contexts

    i)   The use of health data is highly sensitive to the public, and the difficulty of getting data sharing right should not be underestimated

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[1] NB – in this response, we will only be referring to the NHS Data Strategy: 'Data saves lives: reshaping health and care with data', rather than the National Data Strategy.

Health data is sensitive, so it is crucial that Government recognises the importance of responsible uses of data that are underpinned by public confidence and trust.

We know that the public is support for health data being used for research for public benefit; but only within a system they can trust. Public trust in the use of health data must be earned rather than assumed. It is important to keep making the case to the public through sustained public engagement and communications, and to explain the safeguards that are in place.

It is vital that clear accessible information is provided so that the public have a good understanding of how data will be used, who it will and will not be shared with, and what choices are available to them (for example it is important people are well-informed about the option to opt-out).

In order to public trust, continuous, clear public engagement and transparency is vital – one way communication is not enough. Meaningful engagement means actively responding to the findings of any engagement or consultation to address concerns and build confidence.

ii)   Commercial access to data needs an ongoing and open conversation

People are particularly uncomfortable about how data is used by commercial companies. Several studies have explored how people feel about the use of patient data, with fairly consistent findings. People are generally comfortable with data from medical records being used for improving health, care and services, for example for research, provided there is a public benefit. [2]

However, many are uncomfortable with the idea of organisations outside of the NHS – for example commercial companies – accessing their health data, and there are particularly strong concerns about data being passed on for marketing or insurance purposes.

Research suggests that people have two main concerns regarding commercial access to data. First, for themselves as individuals: concerns over invasion of privacy, data being used for marketing purposes, and a loss of control. Second, for society: people feel uncomfortable about companies exploiting data for profit, potential implications for vulnerable groups, and want to see a public benefit from any data uses.

However, commercial partnerships can bring enormous benefits to patients and companies. There are positive examples where commercial companies have used data in partnership with charities, which could be used to showcase best practice and build public trust. For example, the Cystic Fibrosis Trust registry data is used by pharmaceutical companies to conduct research into the long-term safety of new therapies.

It is important to be transparent about commercial access to data and to discuss the reasons openly. This could help alleviate some fears that companies are benefitting from NHS data 'behind closed doors'.

An ongoing and open conversation will be essential to understand the public's expectations of commercial partnerships and to provide information about how the ecosystem works and why commercial access is necessary.

It is vital that those using patient data can demonstrate the public benefit of such uses. The National Data Guardian has carried out important work on how to make sure that health and care data is used in ways that benefit people and society, including their report 'Putting Good

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[2] https://understandingpatientdata.org.uk/sites/default/files/2018-10/Public%20attitudes%20study%20summary.pdf

into Practice: A public dialogue on making public benefit assessments when using health and care data'. The NHSX Centre for Improving Data Collaboration has also been established to ensure appropriate benefit sharing, so the NHS can benefit when companies use data – it will be important to build on this initiative.

It is also important to explain the safeguards that are in place to ensure there is public benefit for any use of data, and the sanctions that are in place to avoid misuse. These need to be clearly explained. In Healthwatch England's polling, they found people lacked confidence that companies would be held accountable if they misuse data.

iii) *Use of health data for purposes beyond health must reflect public expectations and consider patient benefit*

Whilst health data should not be siloed from other data, the use of health data shared for secondary uses outside of healthcare - including sharing data between Government departments and outside of the NHS - is highly sensitive to the public.

For example, controversial policies such as NHS Digital's data sharing with the Home Office severely undermined the public's confidence and support in sharing their health data. We are concerned about the implications that such policies may have on public trust. Different Government departments have conflicting objectives and priorities about data – as demonstrated by the Home Office example.

It is important that the public can trust organisations to hold and process their data in ways that have a clear legal basis, and which are communicated transparently to them.

We support the NDG's principle of "no surprises" in terms of expectations that the public have on sharing health data. The use of health data must reflect public expectations and understanding, and also take into account patient benefit.

Public attitudes research conducted over Summer 2021[3] found that people understand and support the benefits or using data for research and planning, but do not trust that the Government will use their data for this purpose only. Polling suggests that these views are partly formed by wider attitudes towards Government and the Cabinet and the handling of the pandemic.

5 The extent to which appropriate safeguards and privacy are applied in the usage and sharing of individuals' data

Sharing data will never be completely risk-free, meaning people must be aware of the risks, benefits, and safeguards in place, so that they can make an informed decision

It is crucial that the right safeguards are in place to protect people's personal data, and these are explainable to people. Many safeguards are already in place, for example:

- clear red lines on certain uses e.g., data cannot be used for marketing or insurance purposes.
- data being anonymised as much as possible, and researchers are only given access to minimum amount of information needed to answer the research question
- strict controls about how companies can use personal health data, including having a legal basis to access identifiable data, data access committees reviewing all

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[3] https://www.healthwatch.co.uk/news/2021-07-20/patient-data-crucial-planning-health-services-and-so-building-trust-how-nhs-uses-it

applications, and having to sign contracts setting out what they can and cannot do with the data
- robust penalties if data is misused
- audit processes to check who is accessing data

Trusted Research Environments are also an important tool for improving data security and building public trust. TREs operate where data can be accessed, but not held, meaning researchers come to the data rather than any data leaving the system: raw data is not sent out or downloaded only analysis results which are reviewed and approved. This can address some of the concerns of the public through appropriate safeguards on and tracking of the data.

Safeguards can help to minimise privacy risks. However, using data will never be risk free. To be useful for research and planning, data often needs to contain enough detail for new insights to be generated. Even with direct identifiers removed, individual data can potentially be re-identified and linked to an individual. Whilst you cannot remove risk completely, you can reduce the risks as much as possible while still allowing the data to be useful.

It is important to be open about these risks and safeguards and ensure the public have a good understanding of them so that they can make an informed choice about how their data is used.

6 The effectiveness of existing governance arrangements

Within the health and care system, the National Data Guardian has played a vital role in providing an independent and trustworthy voice and must be appropriately resourced.

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