Data saves lives: reshaping health and social care with data

Response from the British Heart Foundation

July 2021

About the BHF

The British Heart Foundation (BHF) is the largest independent funder of research into heart and circulatory disease and the third largest charitable funder of medical research in the UK. Each year, thanks to the generosity of our supporters, we are able to fund around £100 million of new research across the UK and in all four nations.

We support an extensive portfolio of projects focused on the use of health and care data, which has grown substantially in recent years. For example, in 2019 we announced the launch of a £10 million BHF Data Science Centre (BHF DSC) in partnership with Health Data Research UK (HDR UK). The Centre was established to work in partnership with patients, the public, the NHS, researchers and clinicians to promote the safe and ethical use of data for research into the causes, prevention and treatment of all diseases of the heart and circulation. The Centre has already risen to the many challenges of the Covid-19 pandemic and is leading several largescale data projects that aim to better understand the relationship between Covid-19 and cardiovascular diseases. In April 2020, the BHF and the BHF DSC supported the development of a paper that fed into SAGE decision-making,[1] which proposed a way to share data among researchers to rapidly explore the answers to Covid-19 related research questions, across the four nations, using cardiovascular disease as an exemplar.

The BHF also provides significant core funding to both HDR UK and the UK Biobank (currently £2 million and £3.2 million over five years, respectively), and has supported 12 BHF/Alan Turing Institute Cardiovascular Data Science Awards to date, at a value of over £0.5 million. This is a joint funding scheme to support collaborative research between cardiovascular investigators and data scientists seeking to generate data science solutions to key cardiovascular problems. In addition to these strategic investments, as of November 2019 we were supporting approximately £16m across other ongoing data science, machine learning and artificial intelligence research activities.

Introduction

The BHF welcomes the opportunity to respond to the invitation to share our thoughts and experience of using data in health and care, in support of the Strategy currently underway within Government. We work to drive forward the effective use of health data in the fight for improved heart and circulatory disease research, treatments, care and prevention, and recognise the importance of its safe and ethical use informed by, and communicated to, patients and the public. It is vital that regulators and law-making bodies act promptly, ensuring that laws keep pace with technological developments, and that effective oversight and trustworthiness stand at the heart of how data is governed and regulated. We are committed to realising the potential that comprehensive, nationwide, representative data has in this exciting era of personalised medicine and digital innovation through our considerable investment in data science programmes.

We are privileged to work with a world-class community of researchers who utilise the considerable health data asset of the UK on a day-to-day basis. Our expert patient data panel ensures that our data and data science work is always supported by a strong patient voice, encouraging, and challenging us on matters of engagement and transparency.

While we welcome the commitments outlined in this Strategy, the Government will need to provide additional details around implementation, and how these ambitious goals will be realised. In our response, we note that many of the timescales associated with the commitments are very ambitious given the scale of implementation and need for associated cultural change or public engagement. Greater detail on how such timescales would be achieved would be welcome. There is also, as yet, no indication of relevant funding and prioritisation for where this would be targeted.

Finally, we would like to greater investment in education and engagement activities to raise awareness of how communities' health data is used in the medical research context, liaising with charities and patient representation groups to support increasing the profile of high quality research driven by UK health data and its impact and benefits. Much of UK health data is derived from publicly funded health and care services; patients and the public rightly expect their data to be managed securely and be utilised for the benefit of services and the nation's health. Effective, ongoing representative public engagement is vital in continuing to build our understanding of public concerns and views relating to the use of health and care data in research.

Survey response

To what extent do you agree or disagree with the following vision statements for use of data in

health and care?

1. Our most important responsibility is to deliver truly patient-centred care, which puts people

before systems, so people will have better access to their personal health and care data and

understand exactly how it is used

Disagree / Partly disagree / Neither Agree nor Disagree / Partly Agree / [✓ Agree]

2. Staff can only do their best when they have the right information, so staff will have easy

access to the right information to provide the best possible care

Disagree / Partly disagree / Neither Agree nor Disagree / Partly Agree / [✓ Agree]

3. Leaders and policymakers have a responsibility to continually improve how the people we

serve receive care, so leaders in every community will have up-to-date sophisticated data to

make decisions and help the health and care system run at its best

Disagree / Partly disagree / Neither Agree nor Disagree / Partly Agree / [✓ Agree]

4. Service users and their carers will have high quality, timely and transparent data to improve

outcomes, and can easily access to help them make choices about their care

Disagree / Partly disagree / Neither Agree nor Disagree / Partly Agree / [✓ Agree]

5. Our researchers can only deliver results based on the information available to them, so they

will be able to safely and easily access data to provide innovative solutions to health and

care issues for the benefit of every citizen in every community

Disagree / Partly disagree / Neither Agree nor Disagree / Partly Agree / [✓ Agree]

6. To maximise the efficiency and effectiveness of our infrastructure, we will ensure the data

architecture underpinning the health and care system can easily work together to make

better use of data, no matter where it is kept

Disagree / Partly disagree / Neither Agree nor Disagree / Partly Agree / [✓ Agree]

7. Time and safety are both essential, so innovators will be supported to develop and deliver

new solutions safely and sensibly for the benefit of all citizens, staff and the system

Disagree / Partly disagree / Neither Agree nor Disagree / Partly Agree / [✓ Agree]

Do you have any comments on the vision statements as set out in the strategy?

We feel that the vision statements in the strategy are generally well laid out - the use of case studies allows the reader to understand how these vision statements translate to tangible and meaningful action – the BHF was happy to see many cardiovascular specific examples rightly illustrate the huge progress and impact the research and clinical community are making with the tools provided by data science. We would, however, encourage NHSX to be more explicit about how these vision elements are interdependent; perhaps consider the use of infographics to summarise across all 7 vision statements to make clear that this is a data ecosystem and all these interrelated elements are crucial to its success.

Below are specific comments on the statements for each chapter:

- **Chapter 1 Bringing people closer to their data:** We are pleased to see the patient experience at the centre of the vision and wholeheartedly support the joined-up care that this vision will help underpin. It is critical that we ensure that effective provision is made for those without access or ability to utilise digital solutions; CVD and digital inequality share a similar demographic profile. We think this vision statement would be strengthened with more specific reference to data quality and the role patients can play in ensuring this.
- **Chapter 2 Giving health and care professionals the data they need to provide the best possible care:** We welcome the focus on health and care staff who we know do not always have the best experience with data systems. The vision could be strengthened by explicit reference to access to reliable remote consultation and monitoring infrastructure to support the best of new ways of working introduced during the pandemic. In addition, we have found that data access processes and analytical environments are often designed with the needs of the data provider put first. We would like to see this shift towards a more user-oriented approach. Designing processes and environments with the needs of users in mind, could involve providing clear and accessible training and professional expertise to support researchers use health data assets effectively and appropriately. This is well exemplified in NHS Digital’s Data Access Environment which, in partnership with the BHF Data Science Centre, makes dataset expertise and analytical support available through a dedicated data scientist, specific support channels for analysts and researchers and comprehensive documentation and ‘how to’ guides. Finally, the BHF suggests that ensuring multiple uses of the data are optimised (‘enter data once, use many times’ principle) should be a key principle to reduce the burden of entering the same data multiple times.
- **Chapter 3 Supporting local and national decision makers with data:** The vision for this chapter rightly has a focus on data availability; however, although addressed in the main body of the text, we believe the vision will be strengthened by inclusion of analytical skills and capabilities development goals to complement the data availability statements. Local and national leaders will only be able to unlock the promise of data science when it is matched with access to a well-trained professionalised body of analytical expertise.
- **Chapter 4 Improving data for adult social care:** We are really pleased to see a strong vision for adult social care, but question why this is only applied to adult social care. As is well established, support from social care in childhood is strongly correlated with better health outcome in adulthood. We would like to see the strategy reach across government to include children & young person’s social care in the vision. Additionally, the BHF suggests splitting this chapter into elements that are relevant to service users and those that are relevant to professionals; the vision of for each is different and this will help make that clear.

- **Chapter 5 Empowering researchers with the data they need to develop life-saving treatments, models of care and insights:** The BHF was pleased to see that strong consideration from Government of the Goldacre Review, still due to be published. We look forward to final publication of the review and hope that the Government gives strong consideration as to how to continue building on public trust and ensuring patient engagement in decision making when sharing their data. Additionally, we believe the vision statement could be strengthened with the word 'linked' as it is the linkage of these various named data sets that add value. We would also like to see inclusion of standardised, easily understandable data access standards and protocols for all health and care data as a key part of the vision.
- **Chapter 6 Helping colleagues develop the right technical infrastructure:** The ambitions in this section are correct but this must be matched with the appropriate level of investment needed to deliver this. The development of a unified tech fund with a long term vision to fund ICS up front for tech development should be referenced and built upon moving forward. Also, reference to plans for national digital infrastructure development (e.g. the Digital Connectivity Infrastructure Accelerator or the Gigabit for rural areas) would illustrate joined up thinking and show relevance for community based health care providers that may be reliant on off-premises connectivity. While per capita investment in infrastructure is a strong ambition, there will still be a wide variation in need in various regions in England that must be addressed to allow the promise of data science to be unlocked.
- **Chapter 7 Helping developers and innovators to improve health and care:** We believe there is an opportunity to add to this vision that output and outcomes from new developments and innovation should be shared with the public. There is an opportunity to strengthen the link between this vision for chapter 7 and that of chapter 1 both in terms of transparency but also patient engagement and involvement; currently, the chapter 7 vision seems divorced from that of chapter 1 when in fact part of bring patients closer to their data also means giving everyone a chance to be a part of, or even drive, the innovation.

How do you rate each of the three priorities outlined in the strategy?

- To build understanding on how data is used and the potential for data-driven innovation, improving transparency so the public has control over how we are using their data

  Not at all important / Slightly important / Moderately important / Very important / [✓ Extremely important]

- To make appropriate data sharing the norm and not the exception across health, adult social care and public health, to provide the best care possible to the citizens we serve, and to support staff throughout the health and care system

  Not at all important / Slightly important / Moderately important / [✓ Very important] / Extremely important

- To build the right foundations - technical, legal, regulatory - to make that possible

  Not at all important / Slightly important / Moderately important / Very important / [✓ Extremely important]

Please indicate how much you agree or disagree that the commitments in each chapter of the strategy are the appropriate ones to pursue.

1. Chapter 1: Bringing people closer to their data commitments

Strongly disagree / Disagree / Neither agree or disagree / Agree / [✓ Strongly agree]

2. Chapter 2: Giving health and care professionals the data they need to provide the best

possible care commitments

Strongly disagree / Disagree / Neither agree or disagree / Agree / [✓ Strongly agree]

3. Chapter 3: Supporting local and national decision makers with data commitments

Strongly disagree / Disagree / Neither agree or disagree / [✓ Agree] / Strongly agree

4. Chapter 4: Improving data for adult social care commitments

Strongly disagree / Disagree / Neither agree or disagree / Agree / [✓ Strongly agree]

5. Chapter 5: Empowering researchers with the data they need to develop life-changing

treatments, models of care and insights' commitments

Strongly disagree / Disagree / Neither agree or disagree / Agree / [✓ Strongly agree]

6. Chapter 6: Helping colleagues develop the right technical infrastructure commitments

Strongly disagree / Disagree / Neither agree or disagree / Agree / [✓ Strongly agree]

7. Chapter 7: Helping developers and innovators to improve health and care commitments

Strongly disagree / Disagree / Neither agree or disagree / [✓ Agree] / Strongly agree

Do you have any comments on the priorities as set out in the strategy?

The priorities are sensible and provide a good rubric for meaningful change, should this work be delivered to the timescales outlined with appropriate financial support to deliver them. However, while public engagement is recognised within the draft strategy, there is little detail to explain further continued engagement. Understanding Patient Data's (UPD) 'Foundation of Fairness' highlighted that people see the benefits of health data being used by researchers, charities and industry but remain concerned about accountability and the potential exploitation of the NHS by private companies. UPD suggests strong policy recommendations that we would have expected to be built into the draft strategy. Additionally, further clarity can be built into the strategy by illustrating how all three priorities support one another.

Which commitment(s) do you agree with most? Can you tell us why

We welcome the commitments outlined in the strategy; as a major research funder and representative of people affected by heart disease we are particularly pleased to see:

- "*Give citizens the ability to see what research their data has informed, and who has had access to their data, as soon as the technology allows*"

The benefits of using patient data for high quality research has not always been well communicated and/or publicly understood. This commitment will make clearly transparent both the benefits of using health data in research and the commitment of the research community to using patient data safely. We are keen to see researchers and research institutes working in partnership with NHSX to engage with the public in understanding the benefits of using health data in this way.

- "*With the Health and Care Information Governance Panel, create fit-for-purpose rules around different types of data (such as pseudonymised), so that staff can clearly understand rules around the use of data*"

Information governance is often experienced as a blocker for access to data for legitimate research for public benefit; a commitment to a standardised set of clear rules is very welcome to help overcome this barrier

- "*We will introduce legislation in due course to create a statutory duty for organisations within the health and care system to share anonymous data for the benefit of the system as a whole*"

This commitment is long overdue. It helps to brings clarity to information governance issues, as alluded to above, and supports the one extract, many purposes principle. We would like to see this commitment explicitly extended to include research purposes in addition to the reference to 'system' benefit.

- "*We will work across central government, including with colleagues in MHCLG, DfE, the Cabinet Office, MOJ, DWP and across the devolved administrations to improve appropriate data linkage to support people's health and wellbeing*"

Data from areas that help us understand the wider determinants of health and the impact these have on patient outcomes and disease processes is critical for joint planning, effective services improvement and longer-term research. We also see this as a major step forward in the effective and meaningful analysis, monitoring and targeting of health inequality, which is of particular interest in relation to heart health and heart disease prevention.

Which commitment(s) do you disagree with most?

As stated above we welcome all the commitments outlined in the strategy. However, they are very broad in their current scope and we would welcome additional detail with regard to implementation before commenting on some. In general terms, some of the timelines appear very challenging particularly those commitments that are reliant on significant cultural change or public engagement.

On the other hand, some commitments could be more ambitious – for example,

- We would like to see greater commitment to engaging with non-NHS health analytics staff in, for example, charities, think tanks and academia as part of the building analytical and data science capability work. Inclusion of this wider resource-pool in the analyst workforce observatory census, and engagement with the 'Developing Data and Analysis as a Profession' board would enrich the discussion and we believe enhance the professional development offer within the health analytics community. Much of the early analytical capability development work in the NHS was undertaken by non-NHS organisations (e.g. Health Foundation) and these early experiences will have much to teach future development.
- We would like to see more detail on the commitment to shared care record implementation beyond ICS boundaries, with a target date for delivery, prior to the proposed national scale-up in 2024. Patient should know and understand when to expect regional shared care records. As a UK wide charity, the BHF is also keen to ensure that patients crossing UK nation borders for care are not disadvantaged; given the variation in policy and strategy in relation to data between the nations, detail on how this could be achieved would be most welcome.
- We believe that extending the commitment to give citizens the ability to see what research their data has informed should be made mandatory for all data users – this could take the form of a national registry that captures the outputs/outcomes of the work. While we are not prescriptive in the final structure, we believe that empowering people to understand how sharing their health data has been used will only further engender trust from patients and the wider public.
- We believe we can be much more ambitious than 'create partnerships between academic researchers and frontline analytical teams' and instead seek to integrate more purposefully where possible and use research programmes to support and drive policy development and planning (e.g. BHF/NHS Digital partnership)

Please provide any additional comments about why you disagree with any of the commitments:

It is difficult to disagree with these commitments given their breadth at this stage; all contribute towards a multi-layered strategy that address challenges across the health and care data ecosystem. However, the commitments currently remain high level – it would be helpful to have more detail on implementation. Additionally, many of these timescales associated with the commitments appear very ambitious given the scale of implementation required in such a varied landscape. Greater detail on how such timescales would be achieved would be welcome. There is also, as yet, no indication of relevant funding and prioritisation for where this would be targeted- without sustained funding and an appropriate, detailed implementation plan, the ambition contained within this strategy will be curtailed.

6. Is there anything obvious that is missing from the commitments that you feel is important?

We found it discouraging not to see an explicit commitment to develop trusted research environments (TREs) as the go-to means of safe and secure access for analysis and research, particularly given recent comments by the Secretary of State, in relation to GPDPR, assuring Parliament that any data would only be accessible within a TRE. The HDRUK-led Green Paper on TREs, referenced in the text of the strategy, provides an ideal jumping off point for rapidly setting standards and governance that can provide the bedrock for a range of different TRE models. There is much learning from pandemic period that can be brought to bear to this, including from BHF Data Science Centre experience working with NHS Digital's TRE.

Improving data quality is not explicitly mentioned in these commitments; great infrastructure, securing sharing, improved data access etc. is meaningless if the data quality is poor. Recent focus on health inequalities and the role data can play in both perpetuating and solving such issues should be incorporated into a specific and clear commitment that links to the commitment to patients having access to data and validation at point of entry.

7. What key themes do you think we should be focusing on in our broader public discussion? Tick all that apply but if you chose other, please specify:

As stated previously, we strongly believe in both the great potential health data hold for research and the betterment of general health but also in the need for transparency and accountability to be enshrined as the founding principle of any patient data sharing. Additionally, we are committed to the principle that UK health data derived from the NHS and other services funded through taxation is a public resource, and as such the outputs from its use should be made publicly and freely available where legally permissible. This should include publication of relevant analytic code and other supporting information under licensing agreements to support credited reuse, not for commercial gain. Recent projects such as OpenSafely and work from the Health Foundation, among many others, exemplify commitment to transparent approaches. Such examples support the creation of a 'commons of knowledge' and continues to rapidly build a collaborative culture to foster innovation and capacity building. Furthermore, such transparency supports public trust and fosters greater understanding of benefit. These principles are well understood and discussed extensively in the context of health data provision and research; however, transparent approaches are not the default. There are ongoing issues with variability in the timeliness of publication and ensuring publications are accessible and usable, for example in stable, machine readable format and clearly linked from searchable web pages. Such issues can have the result of 'transparency' being achieved in theory only, with researchers, and the public, frustrated by ever changing publication locations, definitions and formats.

8. What are the three most important things that will help us deliver the strategy?

More than three, but in order, 1 being the most important:

1. Transparency with the public, services and stakeholders at each stage in implementation; NHSX must be seen to work in the open
2. Standardisation, for example in access policies, IG guidance, open standards

3. Targeted investment in infrastructure
4. Consideration of *the entire* data ecosystem and those working in it; meaningful partnership and collaboration with (e.g.) charities and academia
5. Early engagement with key vendors

9. What are the three most significant challenges that could prevent us from delivering the strategy?

More than three, but in order, 1 being the most important:

1. Lack of or ineffective public engagement and dialogue- significant lessons to be learned from the furore over GPDPR that are not alluded to in this strategy. Clear frameworks, standards and guidance on data use are welcome but must ultimately result in the benefits realised being fed back into the public domain.
2. Underestimation of the journey you'll need to take frontline staff on to realise the benefits of what for many will be a fundamental change to how they work.
3. A lack of clear accountability for delivery of different elements of the strategy.
4. Funding doesn't follow strategic priorities.

10. Do you have any further comments on the strategy?

Chapter 1 and Chapter 7 could currently be seen as contradicting each other. Chapter 1 states clearly that data is only made available where there is clear benefit for health and care system, and that it is not made available for the benefit of private companies. But this is demonstrably not true; innovators supported by the commitments in Chapter 7 are often commercial companies that do seek to make a profit, to which NHS data will be a contributing factor. This isn't an issue *per se*, but this strategy should be clear and honest on this point and talk about financial value, where relevant, in the context of creating fair returns in data partnerships. Evidence from Wellcome showed that 61% of people in a research study would rather commercial companies access data than miss out on research benefits; this suggests that with appropriate, honest and meaningful transparency the visions of both chapter 1 and chapter 7 can co-exist.