



National Data Guardian Consultation On Future Priorities

Future Care Capital Response

22 March 2018

About Us

Future Care Capital (FCC) is a charity which uses evidence-based research to advance ideas that will help shape future health and social care policy and deliver better outcomes for individuals living in the UK. Beginning life as the National Nursery Examination Board in 1945, the charity has evolved throughout its 70-year history and we continue to have Her Majesty the Queen as our Royal Patron.

Our work to enable key stakeholders to harness the value of health and care data has involved extensive research, policy development and advocacy activity over a period of two years - related publications include: [Intelligent Sharing](#), [Facilitating Care Insight](#) and our [parliamentary briefing](#) for the House of Lords debate on September 6th 2018.

FCC's response to this consultation focuses upon the National Data Guardian's proposed priorities for action having been placed on a statutory footing in December 2018.

Priority 1 Encouraging access and control: individuals and their health and care data

1. Should giving people access and control of health and care data be one of the NDG's top priorities? **Yes**
2. Are the outlined areas of NDG interest the right ones for the NDG?
 - *Encouraging greater /easier access for patients to see their health and care records and who has viewed them;*
 - *Greater transparency for patients to see tailored information showing how data about them has been used for reasons other than their own individual care, for example how it has been used to improve health, care and services through research and planning; and*
 - *Exploring models for greater patient control over data.*

Re the scope of health and care records and encouraging greater access – we would like the NDG to

(a) continue to call for compliance with pertinent provisions in the Data Protection Act (2018) working with the ICO – in particular, those relating to Subject Access Requests, 'data portability' and the 'right to be forgotten', echoing the recently published [recommendations](#) of HMT's Expert Panel on Digital Competition and anticipated findings of DCMS's [Smart Data Review](#);

(b) encourage relevant bodies to integrate health and care data so that individual data subjects and the professionals who care for them can access as comprehensive and accurate a data set about them, in as broad a range of health and care settings as

possible, in the interests of providing high quality and person-centred services; and

(c) acknowledge the limitations of 'channel switch' for vulnerable groups – for example, individuals with poor literacy skills, mental impairments and/or people who may be digitally excluded – and champion appropriate mitigation strategies.

Re ease of access and transparency about who, in addition to the data subject, has viewed health and care records about them – we would like the NDG to

(d) explore the scope for distributed ledger technologies to better facilitate self- and supported care as well as transparency and 'auditability' in the interests of promoting and maintaining public trust – generating such advice and guidance as may be deemed appropriate to better inform individuals and providers about its potential (or otherwise).

Re greater transparency or 'auditability' where health and care data is used for reasons other than an individual's care (e.g. to improve services through research/planning) – we would like the NDG to

(e) promote the development of readily intelligible 'feedback loops', proactively disseminated at regular intervals, so that individual data subjects are appraised of the ways in which data about them is 'making a tangible difference' and, thereby, encourage what we have termed 'data philanthropy'. Here, the Data Commons Blueprint generated by the New Zealand Data Commons Project <http://datacommons.org.nz/> is instructive, as is the approach to tailored feedback about research of relevance to individuals deployed by Midata.coop in Switzerland <https://midata.coop/>

Re exploring models for greater patient control over data – we'd like the NDG to

(f) explore and promote greater understanding of the scope for distributed ledger and blockchain technologies - like Medical Chain <https://medicalchain.com/en/> - to empower individual data subjects in respect of accessing and/or controlling access to health and care data records about them;

(g) champion the establishment of a programme to pilot the development of health and care Data Cooperatives, Data Communities and Data Collaboratives in order to promote a culture of data philanthropy – this would be through the demonstration of tangible health and care outcomes, delivered by a range of 'trusted vehicles', pursuant with the examples and recommendations in our report: Intelligent Sharing - <https://futurecarecapital.org.uk/policy/healthcare-data/>;

(h) work with pertinent bodies and agencies to explore the potential to design and develop 'data trusts', with appropriate consents and safeguards, to link data that are currently controlled by public and private entities with a view to improving health and care outcomes. We note, for example, the potential to harness banking data to better identify vulnerability in a [report](#) recently prepared for Barclays, and we are actively talking to social care commissioners and mental health charities about whether/how such 'data trusts' might be piloted in order to benefit geographic communities;

(i) work with the ICO to develop guidance about new and emergent technologies – like Hu-Manity <https://hu-manity.co/> - which are explicitly designed to incentivise health and care data brokerage. Here, we are concerned to ensure that the general public is made aware of and understands the potential 'pros' and 'cons' of engaging with such initiatives, so that individual data subjects can provide meaningful and explicit consent in respect of the same - we would also like Government to take steps in the interests of safeguarding vulnerable and less affluent groups in this regard; and

(j) produce guidance, working with the ICO and Centre for Data Ethics and Innovation (CDEI), about the optimum approach to treatment of patient data impacting multiple data subjects and/or after an individual's death. In respect of the former, we are explicitly concerned about the current limits to 'consent' as a mechanism, given the growth in take-up of private genetic testing services. In respect of the latter, we wish to ensure that patient data that could help save lives and/or improve services may be donated for those purposes, in much the same vein as a person's organs.

3. What would you like to see the NDG do in this area? **N/A**

Priority Two - Using patient data in innovation: a dialogue with the public

4. Should use of patient data in innovation be one of the NDG's top priorities? **Yes**

5. Are the outlined areas of NDG interest the right ones for the NDG under this priority?

- How do patients want and expect data about them to be used within health technology?

- Is there understood to be a reciprocal relationship, whereby those receiving care allow data usage to facilitate improvements? What are the boundaries that people would put around this?

- How far do public expectations of data usage match reality, for instance in NHS apps and non-NHS health apps? What should be done to ensure expectation and reality are brought closer together?

The Wellcome Trust has undertaken extensive public engagement work through its [Understanding Patient Data](#) initiative to better understand how and by whom patients want and expect health data about them to be used. There is, however, more to do where the general public's awareness and 'buy-in' to the use of their data to develop new technology is concerned, as we made plain in a recent Lancet [article](#) to which FCC's Director of Policy and Strategy contributed.

We believe it is important to distinguish between:

- the use of patient data in more traditional clinical trials to develop new pharmaceutical treatments;
- the use of patient data to develop leading-edge healthcare products; and
- the use of patient data to develop but, also, crucially, 'fuel' digital technologies.

In respect of the latter, DHSC continues to evolve its [Code of Conduct for Data-Driven Health and Care Technology](#). The Office for Life Sciences is also consulting on commercial principles which are expected to inform a related policy framework, linked to the prospect of a National Centre of Excellence to support NHS organisations pursuing commercial opportunities, pursuant with the most recent [Life Sciences Sector Deal](#).

From our perspective, it is vitally important the NDG works with pertinent bodies to guarantee the highest ethical standards are maintained. The public must be engaged in a meaningful dialogue because individual data subjects ought to be able to understand and, ideally, have a say in how the value of data about them is being harnessed via a readily intelligible feedback loop – without which, there is a risk the NHS loses their trust over time.

6. What would you like to see the NDG do in this area?

Our position, above, flows from primary research underpinned by a FOI request issued to all NHS Trusts in England back in December 2018 – the detailed findings of which are forthcoming but summarised below in the interests of transparency and timeliness:

- NHS Trusts are not currently required to record data about requests to access/use the data they control for research and/or commercial purposes in a consistent manner for the purposes of reporting;
- Acute and Mental Health trusts receive up to **x10 as many requests** to access/use the data they control for research and/or commercial purposes each year as Ambulance and Care trusts;
- Foundation Trusts (FTs) received **x2-x3 times as many requests** as non-FTs;
- Trusts in the West Midlands, London and the North West received **more requests than other regions** in the three financial years we asked about and demand, generally, mapped to the presence nearby of a Russell Group university;
- The **majority of requests received by Trusts were approved** (almost 90%);
- Around **1/3 trusts claimed not to have received any requests** to access/use the data they control for research or commercial purposes;
- The **majority of recorded requests came from HEIs and other NHS organisations** rather than (other) commercial entities, but we are unable straightforwardly to assess the relationship between HEIs and the corporate entities with whom they work; and
- Circa **1/3 of requests resulted in a financial/commercial relationship** between the Trust and the requester. Trusts from London, the West Midlands and the North West were most likely to enter into such relationships.
- NIHR Clinical Trials are about giving research opportunities to all patients in the NHS, but **70 trusts (30%) had 30 or fewer studies attached to them in 2017/18**
- Only **50% of NHS Trusts appear to have developed and published an Intellectual Property (IP) policy** – there are **no STPs that are fully covered** in terms of IP policies
- Most IP policies **refer to guidance published and not updated since 2002** and **very few make explicit reference to data protection** and/or GDPR.

What is readily discernible from our research is that there appears to be a significant discrepancy in the potential for NHS Trusts of different types and in different places to use patient data for the purposes of innovation – whether we are talking about providing access to existing data that Trusts control OR new data that Trusts might work with third parties to generate through participation in clinical trials OR simply having an appropriate intellectual property policy (and, with it, a transparent approach) in place.

There might be a tacit (or explicit) acceptance that 15% of NHS Trusts – and the overwhelmingly urban populations they serve – will benefit disproportionately from any data-driven innovation revolution by dint of their proximity and ties to Russell Group universities and the R&D ecosystems in which they're involved and invested. Then, again, there might not... 'the future is here – it's just not evenly distributed' and we are firmly of the belief that that needs to be reflected in any dialogue with the general public.

Ultimately, our research points toward the need to mandate standard returns to render data supply, demand and commercialization efforts **transparent** – without which, it will be difficult to derive criteria for success and monitor the progress of any National Centre of Excellence established in keeping with provision for the same in the Life Sciences Sector Deal. Crucially, in the absence of transparency, Government is unable to provide the general public with the means to **consent/audit/trust** how data about them is being

used in respect of innovation. The NDG should consider carefully how her office might help introduce related measures into the already complex landscape for mapping, managing and accounting for NHS controlled data and the Intellectual Property it will, increasingly, play a role in developing.

The NDG should also consider how best to inform the general public of potential pros and cons of using health apps, pace the findings outlined in the BMJ this month: <https://www.bmj.com/content/364/bmj.l920>

Priority Three - Getting the basics right: information sharing for individual care

7. Should Getting the basics right: information sharing for individual care be one of the NDG's top priorities? **Possibly**

8. Are the outlined areas of NDG interest the right ones for the NDG under this priority?

- *Working with bodies leading on education and training to ensure that those working within the health and care system are equipped to handle and share data with confidence*
- *Encouraging better sharing for individual care across boundaries, particularly between health and social care*
- *Reviewing existing Caldicott guidelines with a view to giving further clarity or guidance which would support appropriate sharing*

The NDG has already devoted considerable time/energy in this regard, and whilst we believe there is merit in consolidating such efforts, we would wish to emphasise the proviso outlined below in response to (9) as well as those other areas of interest the NDG might usefully explore we've listed in response to (13).

9. What would you like to see the NDG do in this area?

In 2018, we worked in with Cambridge Econometrics to explore the risks and opportunities different parts of the country face in planning and managing adult social care provision. Four local authorities worked with us to discuss the particular challenges they are grappling with at a local level: Brighton and Hove City Council, Essex County Council, Leeds City Council and Nottingham City Council. The research found that local areas are underpinned by different 'care infrastructures' that result in broad-ranging challenges as well as opportunities to transform outcomes for individuals. We concluded that national health and care policy needs to better acknowledge local differences if it is to result in tangible improvements to the quality of life people experience.

To do that in practice, local authorities need a much better understanding of when and how people interact with the wider care ecosystem but face significant challenges in assembling pertinent data and evidence to advance contemporary, person-centred approaches. Accordingly, we recommended that:

(a) the Government should support commissioners, providers and innovators to solicit a much better understanding than is currently possible using the traditional data collection methods from which standard 'monitoring' data is derived;

(b) the Government should invest in a new national data analytic capability to improve care insight for commissioners, providers and business and, thereby, support the appraisal as well as product/service design activities needed to expedite the introduction of new care models;

(c) the ONS should improve upon the data it collects, curates and publishes where it impacts upon care insight to better enable others to plan and develop caring economies - in particular, it should ensure that changes to the census result in improvements to data about unpaid carers and internal migration amongst different age cohorts;

(d) the CQC should require and provide access to improved data concerning self-funders – whether they are in receipt of domiciliary or residential care services – to better facilitate care insight for commissioners, providers and business; and

(e) the Government and pertinent funding councils should invest in partnerships between councils, universities and business to explore the potential for new technologies and data science techniques – including machine learning and artificial intelligence – to support the evolution of next generation care services and insight.

If the NDG is to make further progress in ‘getting the basics right’ to improve outcomes for individuals, we think her office needs to devote more attention to data impacting social care planning and provision than has been the case to date, and our recommendations above point toward areas she might usefully explore in more depth.

Priority Four - Safeguarding a confidential health and care system

10. Should safeguarding a confidential health and care system be one of the NDG’s top priorities? **Yes**

11. Are the outlined areas of NDG interest the right ones for the NDG under this priority?

- Clarifying the interplay between the requirements of common law and data protection law with an aim of finding a way to explain this that clinicians and patients can understand

- Progressing the concept of reasonable expectations as an important aspect to shape the boundaries of information sharing

Yes – with the proviso below in response to (12).

12. What would you like to see the NDG do in this area?

With the proliferation of data, new and emergent technologies, there is the scope to transform the way in which we care for ourselves and others if we move to embrace our ‘brave new world’. At Future Care Capital, we believe that that will require us to co-produce a new settlement, fit for purpose in the 21st Century, which we have termed a ‘Care Covenant’. The health and care services brought about by Beveridge and other giants of his age are on the cusp of being massively disrupted – as much by demographic change as by technological advancements being spear-headed by global corporates. We urgently need to redefine how we propose to proceed, in particular, if we are to maintain public trust.

We think a Care Covenant should be underpinned by a ‘digital contract’ so that we guard against the emergence of a digital dystopia. Exploring the interplay between the requirements of common law and data protection law should ensure that Government acts to prevent data-driven discrimination and avoids a situation whereby individuals are left feeling uneasy about the fine line between well-intentioned prediction and heavy-handed surveillance in respect of health and care.

However, we would also like the NDG to take steps to ensure we maintain an appropriate balance between the rights and responsibilities of individuals and pertinent

professionals and those of communities and populations (both now and in the future). We have an ethical obligation to *collectively* steward wellbeing today as well as in the interests of future generations - whereas, too often, emphasis is placed upon the individual and the here and now. If wellbeing is approached as a 'common pool resource', pace Elinor Ostrom's work in respect of other 'natural resources', then, common law ought also to act in defence of a health and care data commons – and a contemporary definition / understanding of 'reasonable expectations' should take this into account.

Additional Questions

13. Looking at all the priorities outlined, are there other areas of work that you would suggest for the NDG?

- the potential for data-driven discrimination in health and care
- the potential to usefully introduce formal provisions related to anonymised data
- investigation of algorithmic developments as they pertain to health and care
- investigation of data-related infrastructure – in particular, cloud provider monopolies and the security surrounding sensitive patient data (genetic, biometric, etc.).

14. Are there any priorities you would remove or change? N/A

15. Please provide any other comments or feedback to the NDG and her team.

There is enormous potential for both health and care data to drive improvements in outcomes as well as innovation in products, services and related systems but, at present, there appears to be far greater emphasis and importance placed upon health and, in particular, 'patient' data by the NDG.

There are, at least, three types of data which ought to be of interest to the NDG from our perspective:

- the data controlled and/or generated by publicly funded and accountable health and care organisations;
- the data controlled and/or generated by private/independent organisations who provide pertinent services to the NHS, local authorities and/or individuals; and
- the data controlled and/or generated by private entities whose core business might not be health/care related but which might, nonetheless, have the potential to generate insights into a population or individual's health/care.

An individual's digital health/care twin involves all of the above, and we would welcome recognition of the interplay between them - together with an ethical framework, pertinent guidance and coherent measures to protect, enhance and deploy them.

Contact information

Future Care Capital
Gillingham House
38-44 Gillingham Street
London, SW1V 1HU

For further information about our submission, please contact Annemarie Naylor, Director of Policy and Strategy: annemarie.naylor@futurecarecapital.org.uk