# Cancer Research UK Response to National Data Guardian for Health and Social Care: a consultation about priorities

Cancer Research UK (CRUK) is the world's largest independent cancer charity dedicated to saving lives through research. We support research into all aspects of cancer which is achieved through the work of over 4,000 scientists, doctors and nurses. In 2017/18, we spent £423 million on research in institutes, hospitals and universities across the UK. CRUK wants to accelerate progress so that 3 in 4 people survive their cancer for 10 years or more by 2034.

1 in 2 people born since 1960 will be diagnosed with cancer in their lifetime, with that proportion expected to rise. Making the best use of health and social care (HSC) data, in service design, research, and through emergent data-driven technology such as artificial intelligence will be fundamental in ensuring improved outcomes.

Cancer Research UK welcome the opportunity to contribute to this consultation on the NDG's future priorities. Looking forward, CRUK hopes to continue to support the NDG's work, recognising the important role she has to play in providing guidance and ensuring compliance for appropriate uses of patient data, and fostering public trust in patient data use across the health and social care sector.

## 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?

Giving people access and control of health and care data should be an important priority for the NDG going forwards. There have been welcome efforts to shift towards a digitally-led service, for example in the Long Term Plan for the NHS, published in January 2019. Local Health and Care Records are also in development, and NHS Digital is creating a tool which will allow patients to see who has accessed their health and care records for secondary uses. These are important and positive developments which have the potential to not only empower patients through a greater knowledge of their condition and care, and correct errors in their own records, but also increase transparency and openness, which are crucial in building and maintaining public trust.

This is particularly important for cancer. There was an ambition in the Cancer Strategy for England is for all cancer patients who consent to have online access to their test results and other communications involving secondary or tertiary care providers by 2020[1]. This has the potential to increase accessibility for patients with cognitive issues (for example, up to 40% of older patients[2]), and make it much easier to access and track results for cancer patients who may have repeated ongoing diagnostic test to monitor disease response.

There is much potential in a more digitally led health and care system, and Cancer Research UK wants the NHS to be a world-leading adopter of innovation – but it is essential that patients have easy and equitable access to health services and that a move to more digital interactions with health and care systems does not exacerbate or add barriers to seeking help. For example, only 10% have used online service to book appointments, even though over 40% are aware they can do so[3].

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[1] Independent Cancer Taskforce (2015). *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020.*

[2] Cancer Research UK (2018). *Advancing Care, Advancing Years: Improving Cancer Treatment and Care for an Aging Population*. Accessed March 2019 via https://www.cancerresearchuk.org/sites/default/files/advancing_care_advancing_years_full-report.pdf.

[3] NHS England (2018). *GP Patient Survey 2018*.Accessed March 2019 via https://www.england.nhs.uk/statistics/2018/08/09/gp-patient-survey-2018/.

The NDG should play a role in monitoring the real-life impacts of efforts in promoting digital access, and monitoring the situation to ensure changes don't exacerbate inequalities. For example, the NDG could explore what needs to be done to ensure all patients and the public can access the benefits of greater access and more transparency, in order to build broad-based public support and take-up.

2. Are the outlined areas of NDG interest the right ones for the NDG?

Yes, these are both important ambitions. In addition, as patients are given greater access to their health and care records, there also needs to be proactive, ongoing and positive efforts made to explain and promote the secondary use of patient data for research. In an increasingly digital health service it is vitally important that the way the NHS uses and shares data is trustworthy, transparent and well communicated. All organisations that use patient data have a role to play in facilitating this – including the NHS, charities, industry and the NDG.

Patient and public understanding of uses of health and care data is not currently high. As part of the 2016 Review of Informed Choice for Cancer Registration, an online survey of people with cancer and the general public we commissioned from Ipsos MORI found just six per cent of people with cancer said that they knew a great deal or a fair amount about the cancer registry; three quarters had never heard of the registry (74 per cent). [4] However, the desire from people affected by cancer to be given information about the cancer registry is clear: 83 per cent in our commissioned research and 93 per cent in our in-house survey said it was important that patients were informed. Furthermore, of the members of the public surveyed, 74 per cent thought it was important that people knew about the cancer registry regardless of whether they themselves had a cancer diagnosis, demonstrating a public desire to know more about how their health and care data is used.

Most people are supportive of patient data being shared for their own individual care, and a high proportion of people are also happy for patient data being shared where there is public benefit as a result[5,6]. However, there can be significant variation on support for data sharing depending on who has access to patient data, and how it is used. Therefore, it is important that there is meaningful engagement with patients and the public, to increase understanding of secondary uses of patient data for research, and make the positive case for this.

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

The NDG should make sure that the NHS is exploring and implementing models for greater patient control over their health and care data, and that these models are implemented in a way that empowers the public and builds transparency into the system so that public confidence is built and maintained.

It would also be valuable for the NDG to encourage organisations that handle health and care data to have systems in place to proactively respond to data breaches. This should include informing and empowering patients so that they understand the risks and benefits of data sharing.

## 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?

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[4] Ipsos MORI (2016). Perceptions of the Cancer Registry. Accessed March 2019 via https://www.cancerresearchuk.org/sites/default/files/16-036870-01_perceptions_of_the_cancer_registry_survey_report_-_final_-_v2_public.pdf.

[5] Administrative Data Research Centre Northern Ireland, Access Research Knowledge (2017). *Public attitudes to data linkage and sharing*. Accessed March 2019 via http://www.ark.ac.uk/publications/updates/update108.pdf

[6] Wellcome Trust (2015). *Wellcome Trust Monitor Report Wave 3 Chapter 6*. Accessed March 2019 via https://wellcome.ac.uk/sites/default/files/monitor-wave3-full-wellcome-apr16.pdf

Yes, this should be the top priority for the National Data Guardian. Patient data is essential for improving cancer outcomes through research. The information held about patients in their medical records, in cancer registries and other databanks can be used to research the causes of cancer, study the effectiveness of treatments and interventions such as screening, and follow up of patients in clinical trials. Emergent data-driven technologies also have much potential to further improve patient outcomes and care, however it is crucial that there are the right safeguards in place, and that patients' wishes are kept at the heart of any new developments.

Our past research with Macmillan Cancer Support has found that people with cancer are largely very supportive of their data being used for research: for example, 94% of people with cancer supported their cancer data being used for research.[7] However, whilst new data-driven technologies have great potential, there must be trustworthy systems are in place to manage patient data, so that public trust is maintained. The NDG can play a crucial role in holding the organisations that process patient data to account, so that public awareness and support keeps pace with the changing way that data is used. For example, the NDG's past interventions in the use of health data by commercial organisations has been valuable, as a source of independent pragmatic and legally sound advice[8].

In future, we would particularly welcome a focus by the NDG on innovations which involve genomic data. This is a particularly complex area which requires careful communication with patients, the public and health professionals. There is already significant work underway being undertaken by Genomics England and the Genomics Education Programme[9], however there is a valuable role for the NDG in ensuring organisations using genomic data does so in a way that keeps patients' wishes at the heart of their decision-making.

### 5. Are the outlined areas of NDG interest the right ones for the NDG?

In the past, the NDG has placed a strong and welcome focus on the need for effective communication about healthcare data with the public, as well as patients. The 2016 NDG review's assertion that "the case for data sharing still needs to be made to the public" remains correct. It should remain an ongoing priority that information on data sharing is communicated to the public and makes clear the patient benefit of patient data being used in research. Importantly, to avoid damaging public confidence, it is crucial to ensure that uses of patient data reflect public expectations and understanding.

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

The NDG is well placed to facilitate a dialogue with the public on the uses of health and care data, shaped around the views, expectations and concerns of the public. This must include innovative uses of data as they emerge. As the Government develops guidance to govern uses of NHS data for research and innovation, for example with respect to commercial agreements on the use of NHS data, the NDG should advocate for this active and ongoing communication and consultation with the public.

More broadly, the NDG can play a role in promoting guidance and best practice in data use, which reflects public expectations. As an advocate for the responsible use of patient data, the NDG should also work closely with regulatory bodies such as the Information Commissioner's Office to challenge

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[7] Ipsos MORI (2016). Perceptions of the Cancer Registry. Accessed March 2019 via https://www.cancerresearchuk.org/sites/default/files/16-036870-01_perceptions_of_the_cancer_registry_survey_report_-_final_-_v2_public.pdf.

[8] The Guardian (2017). Google DeepMind 1.6m patient record deal 'inappropriate'. Accessed March 2019 via https://www.theguardian.com/technology/2017/may/16/google-deepmind-16m-patient-record-deal-inappropriate-data-guardian-royal-free.

[9] https://www.genomicseducation.hee.nhs.uk/

bad practice and misuse and 'call out' this misuse in the interest of transparency, both privately and publicly, to maintain public trust – as highlighted above.

## 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?

Yes, this is an important priority that will underpin much of the other work towards ensuring responsible use of patient data that improves outcomes, particularly as innovative and complex new data-driven interventions come into use in the NHS. To fully unlock the potential of health data, it must be accurately recorded, clean and be able to be shared across different NHS organisations. To be of most use, data must be findable, accessible, interoperable, and re-useable. This is a pressing issue for cancer. The English cancer registry is a world-leading database, containing data on over 14 million current and historical tumours. Patient level data on chemotherapy and radiotherapy provision is also held by Public Health England, in extensive datasets[10].

Interoperability of data and systems would facilitate better sharing of data across the pathway. In primary care, if a move to a digitally-led service in results in GPs serving patients across a wider geography to deliver digital consultations, records from these interactions must be linked to a patient's GP records to ensure continuity of care and appropriate safety netting. Currently there is not the infrastructure in place to facilitate such a move. Furthermore, research commissioned by Cancer Research UK has found that clinicians in primary and secondary care settings find it difficult to communicate directly and in a timely way, and that current channels for communication mean that important information such as age and comorbidities is missed[11]. These changes would mean that people with cancer would not have to repeatedly explain their condition to different clinicians. This could have a positive impact on patient experience and also improve the efficiency of cancer services, by helping patients move more smoothly through diagnosis and treatment.

To access the most benefit of patient data, it is crucial that there is data skills training for the workforce, who record patient data, will deploy data-driven technologies and engage with patients and the public on data use and sharing. Better, more complete datasets will also support research. purposes

### 8. Are the outlined areas of NDG interest the right ones for the NDG?

To encourage better sharing of patient data across current boundaries, the NDG should promote best practice from across the health system, for example in the world of the Global Digital Exemplars (GDEs), and NHS England's Local Health and Care Exemplars (LHCREs) programme. Spreading innovation that develops best practice in NHS Test Beds that would benefit patients across the health system should also be encouraged by the NDG.

Ensuring the safe use and sharing of patient data requires staff having the skills and knowledge to do so. The recently published Topol Review set out a number of recommendations for an NHS workforce to unlock the benefits of health technology. These recommendations set out a positive way forward, and the NDG should seek to support this vision and the implementation of its recommendations.

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[10] The Systemic Anti-Cancer Therapy (SACT) dataset and the Radiotherapy Dataset (RTDS), Public Health England

[11] Cancer Research UK (2018). *Advancing Care, Advancing Years: Improving Cancer Treatment and Care for an Aging Population*. Accessed March 2019 via https://www.cancerresearchuk.org/sites/default/files/advancing_care_advancing_years_full-report.pdf.

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

Interoperability requires standardisation of data itself, but also systems, infrastructure and the frameworks in place that govern the sharing and use of data. The NDG is well placed to support organisations across the health and care system to develop shared understanding of data use and sharing, as well as more effective ways of working that will facilitate more effective data sharing.

Related to this is the still significant work to do to inform the health workforce about patient data. In the case of cancer data, our 2016 report found that just 55% of health professionals interviewed had some awareness of cancer registration, whilst most health professionals never discuss cancer registration with their patients (83%)[i]. The NDG providing information and support to healthcare professionals (HCPs) would empower HCPs to advocate for the value of patient data to patients and the public. We recommend that existing information governance training includes more information about how the NHS uses cancer data as well as other types of patient data.

## Safeguarding a confidential health and care system

10. Should Safeguarding a confidential health and care system be one of the NDG's top priorities?

Safeguarding data is key to ensuring that patients feel comfortable and confident sharing personal information vital for their treatment with healthcare professionals. Concerns that healthcare data may be used in ways, or shared with government or other bodies, that patients would consider inappropriate risks damaging confidence in data sharing and potentially heightening health inequalities by dissuading at risk groups from accessing healthcare. Ensuring transparency in the way that data is used and shared, and consulting with patients and the public to understand what they consider legitimate uses of healthcare data, could serve as useful ways to reduce concerns.

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

We support to approach put forward by the NDG in relation to genomic data of 'no surprises' to patients about how their data has been used. The NDG is well placed to explore what the boundaries of acceptability in data sharing are for the public, and further use this insight to advise healthcare organisations about appropriate sharing of data. More fundamentally, the NDG is best equipped to advise NHS organisations on current legislation and regulation of data protection and safeguarding. Efforts by the NDG to inform and engage with healthcare professionals, NHS organisations, patients and the public should be proactive and ongoing, and designed to be audience-appropriate.

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[i] Cancer Research UK, Macmillan Cancer Support (2016), *Improving awareness of the English cancer registry among patients, health professionals and the public*, accessed March 2019 via https://www.cancerresearchuk.org/sites/default/files/riccr_201609_amended.pdf