

A data-driven approach to personalised cancer care

Maisie Borrows

October 2018

#reformcancercare

Reform

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Advisory board

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Dr Charles Alessi, Chief Clinical Officer of HIMSS and Senior Advisor to Public Health England (PHE). Charles is a globally recognised and trusted leader in health care. He brings a wealth of experience, particularly around health systems and the interface between healthcare, social care and the personalisation of wellness. He is a physician in London, with more than 35 years of experience in all aspects of clinical practice in the NHS. He is also the Senior Advisor to Public Health England (PHE), a position leading thought leadership around productive healthy ageing including dementia, targeting risk reduction. Furthermore, he fulfils key roles in PHE around digital interventions, particularly those that involve behavioural change.

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The arguments and any errors that remain are the authors' and the authors' alone.

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Introduction

Cancer is evolving. A disease traditionally seen as a death sentence is now moving towards a controlled, chronic illness.¹ There have been remarkable improvements in treatment and survival rates in the last few decades.

Yet, despite improvements, diagnosis is still devastating, and it affects so many. More than one in three people in England will now develop cancer in their lifetime.² This is partly because of an ageing population – by 2035, people aged 75 and over are projected to account for 46 per cent of all cancer diagnosis³ – but also driven by lifestyle risk factors such as obesity.⁴ Although outcomes have improved,⁵ survival rates in England still lag behind other comparable countries.⁶ What's more, there is a postcode lottery in outcomes with “unacceptable variability” in survival rates across the country.⁷

It is no surprise that improving cancer care is a priority for the Government. A key announcement in the Prime Minister's 2018 Conservative Party Conference speech was the launch of a new cancer strategy to improve survival rates through faster diagnosis and treatment.⁸ This will build on the existing 2015 Cancer Strategy.⁹ The 2015 strategy established the Cancer Vanguard, a partnership between Greater Manchester Cancer, RM Partners and UCLH Cancer Collaborative, along with 19 regional Cancer Alliances, to be the delivery mechanisms for radically improving outcomes across the country.¹⁰ They have made progress in making cancer care at a local level more preventative, personalised and integrated.¹¹ Cancer reform reflects the changing model of care in the NHS more generally, with care shifting from a ‘one-size-fits-all’ approach to personalisation.¹²

Underpinning the success of cancer care reform is the effective use of data.¹³ The Secretary of State for Health and Social Care, Rt Hon Matthew Hancock MP, has highlighted this in his priorities for the NHS, saying the NHS must get “the data architecture right” if it hopes to become a modern, efficient service.¹⁴ The information routinely collected by the NHS, in national datasets and in medical records, is vital for research into the causes of cancer and evaluating the quality of services.¹⁵ Advancements in personalised medicine will enable far more effective treatment for cancer patients.¹⁶ This will be a game-changer for the NHS, but advancements like this will only be possible with a well-designed data infrastructure that can turn inputted data into useful insight.

The NHS can do much more to realise the potential of the vast amounts of data it collects.¹⁷ This paper offers one vision for how it could. Making better use of data will not only improve cancer outcomes but will also enable the Service to manage the disease far more effectively, now, and in the future.

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- 1 NHS England, *Achieving World-Class Cancer Outcomes: Taking the Strategy Forward*, 2016.
 - 2 National Audit Office, *Investigation into the Cancer Drugs Fund*, 2015, 5.
 - 3 C R Smittenaar et al., ‘Cancer Incidence and Mortality Projections in the UK until 2035’, *British Journal of Cancer* 115, no. 9 (October 2016).
 - 4 Katrina F. Brown et al., ‘The Fraction of Cancer Attributable to Modifiable Risk Factors in England, Wales, Scotland, Northern Ireland, and the United Kingdom in 2015’, *British Journal of Cancer* 118, no. 8 (April 2018).
 - 5 NHS England, *Five Year Forward View*, 2014.
 - 6 Claudia Allemani et al., ‘Global Surveillance of Trends in Cancer Survival 2000-14 (CONCORD-3): Analysis of Individual Records for 37 513 025 Patients Diagnosed with One of 18 Cancers from 322 Population-Based Registries in 71 Countries’, *Lancet (London, England)* 391, no. 10125 (March 2018).
 - 7 Jonsson, Bengt et al., *Comparator Report on Patient Access to Cancer Medicines in Europe Revisited – a UK Perspective*, 2017.
 - 8 ‘Theresa May Speech in Full: Read the Prime Minister's Keynote Conservative Conference Address’, *Evening Standard*, 3 October 2018.
 - 9 The Royal College of Radiologists, ‘RCR Responds to the Prime Minister's Announcements of a New Cancer Strategy and Focus on Early Diagnosis’, Press Release, (3 October 2018).
 - 10 The Cancer Vanguard, ‘Cancer Vanguard’, Web Page, (20 August 2018).
 - 11 NHS England, *Five Year Forward View*.
 - 12 NHS England, *Next Steps on the NHS Five Year Forward View*, 2017.
 - 13 HM Government, *Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens*, 2014.
 - 14 Matt Hancock, ‘My priorities for the health and social care system,’ Speech, (20 July 2018).
 - 15 Cancer Research UK, *Cancer Research UK's Proposals for the NHS 10-Year Plan*, 2018, 20.
 - 16 National Information Board, *Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens* (NHS, 2014), 44.
 - 17 Cancer Research UK, *Proposals for the NHS 10-year plan*.

1

The new cancer care model

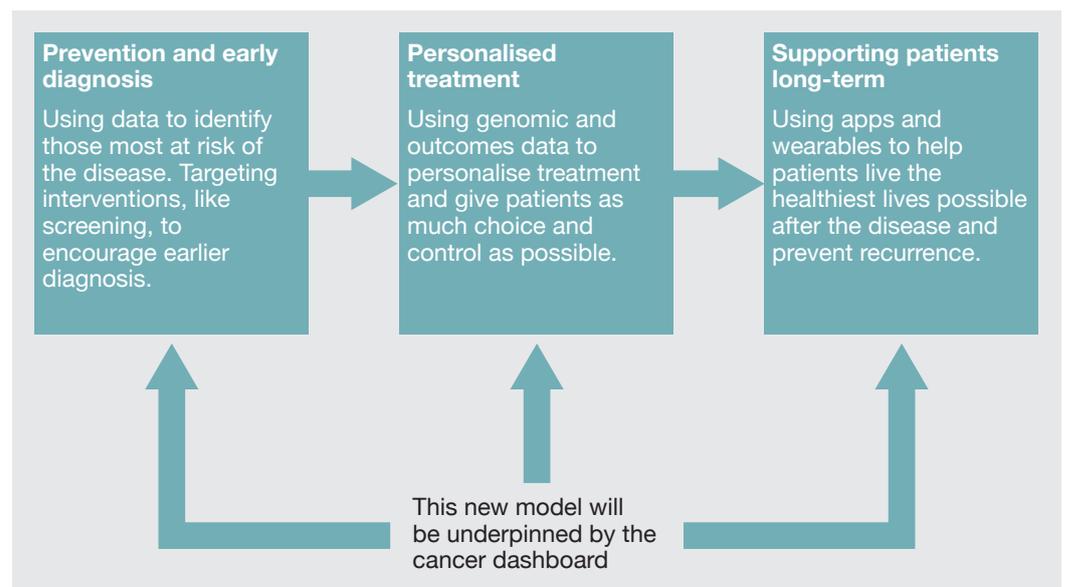
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The NHS “holds millions of electronic medical records on the health of the population from birth to death.”¹⁸ Analysing this data intelligently provides insights that can improve the understanding and management of cancer. A new model of cancer care should examine and use this data at every stage of the cancer patient journey, from prevention and diagnosis through to treatment and recovery (see Figure 1).¹⁹

An interviewee for the paper told *Reform* about the “amazing treatment” they had as an NHS patient. They described it as a “wrap around service”, where everyone from the clinical nurse to the psychotherapy team, worked together to give them the best treatment possible. A data-driven model should recreate this experience across every cancer alliance, sharing data effectively between different stakeholders so that care is truly integrated around the patient.

The patient must be at the heart of the new care model. As one interviewee argued, patients can be more informed and play a more active role in their care. Clinicians should have the necessary insight at their fingertips, so they can ask patients “what are the goals of your care?” and describe the treatment available that can best achieve these.

Figure 1: A data-driven approach to personalised cancer care



Source: *Reform* interviews. NHS England, *Achieving world-class cancer outcomes: taking the strategy forward*, May 2016.

¹⁸ Peter Border, *Big Data and Public Health*, Number 474 (Parliamentary Office of Science and Technology, 2014), 1.
¹⁹ Cancer Research UK, *Cancer Research UK's Proposals for the NHS 10-Year Plan*, 20.

1.1 The game changer: getting data right

The recent *Barber review* recommended that any public service wishing to deliver better outcomes needs “good data to be gathered and analysed in a timely manner to allow an informed decision”.²⁰ The first step, therefore, to improved cancer care is to get the data infrastructure right. Data inputted can then be analysed, and the insight gained used to drive progress.

One of the NHS’s greatest strengths is its comprehensive datasets.²¹ Cancer care is no exception. There is a plethora of different datasets including information on diagnosis, treatment, outcomes and patient experience, and multiple data flows between different organisations.²² However, according to several interviewees for the paper, the quantity of data has created a confusing landscape with the same information often collected twice or not always shared in a timely manner to deliver effective patient care.

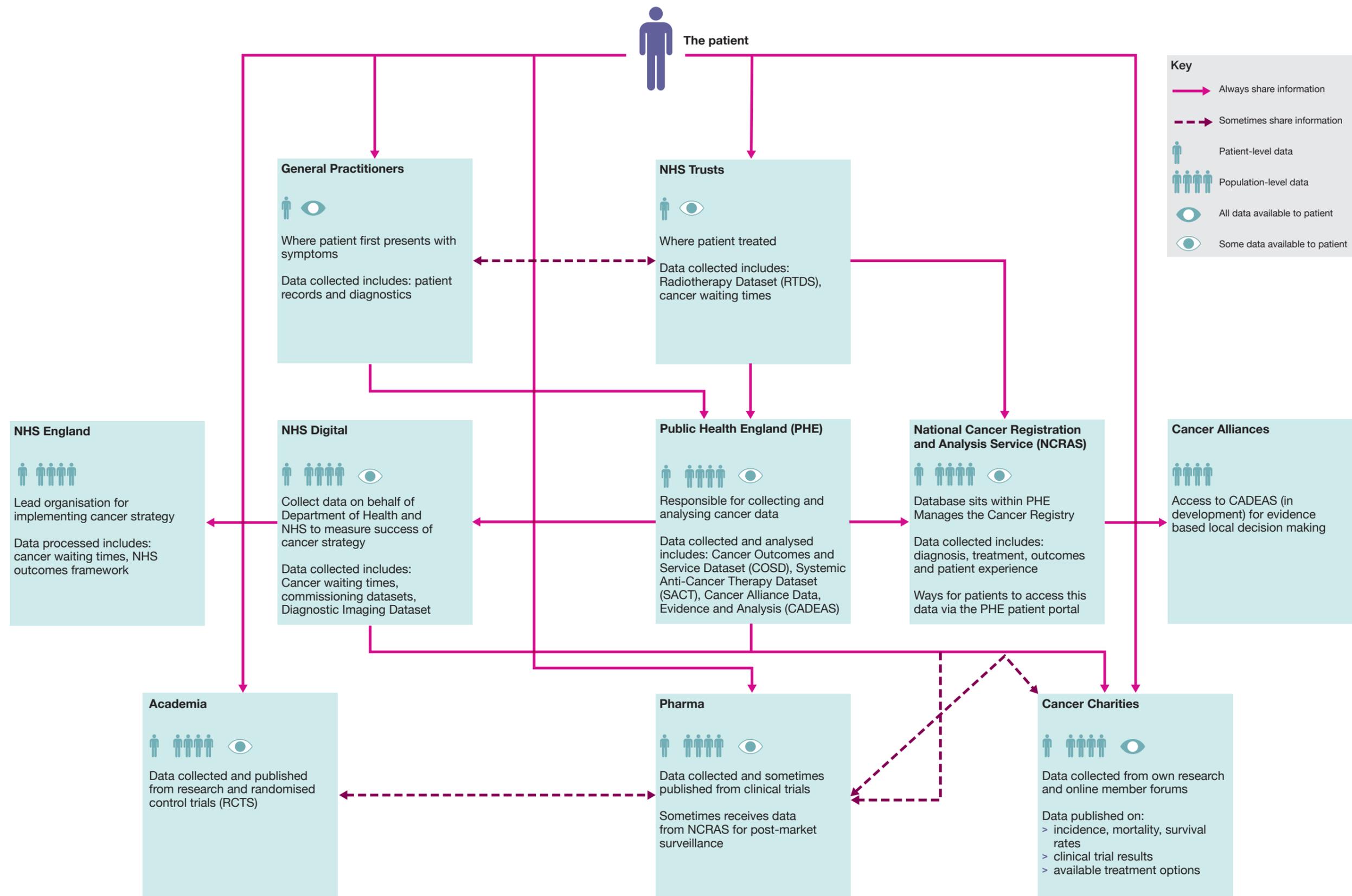
Figure 2 shows the different datasets involved in cancer patient care. It highlights the data flows: where information is shared and where it is accessible to patients. It is not meant to be a completely accurate description. Rather it gives the reader an idea of the vast amounts of data that surround a cancer patient, and pinpoint areas where improvements could be made.

20 Sir Michael Barber, *Delivering Better Outcomes for Citizens: Practical Steps for Unlocking Public Value*, 2017, 21.

21 Sarah Neville, ‘Big Pharma Takes a Gamble on NHS Experiment’, *Financial Times*, 28 August 2018.

22 ‘Data Sets’, NHS Digital, (20 August 2018); Sarah Miller, *Cancer Data Flows in Public Health England* (Public Health England, 2017); ‘Cancer Statistics for the UK’, Web Page, Cancer Research UK, (16 October 2018).

Figure 2: The cancer care data landscape



Source: Reform interviews and research.

1.1.1 Driving meaningful change: the cancer dashboard

As Figure 2 shows, population-level data is collected on cancer outcomes separately by hospitals, Public Health England (PHE), Cancer Alliances, Cancer Charities, the Cancer Registry and pharmaceutical companies. For a single patient, hospital consultants are asked to submit data to four registries with closely related data fields: Cancer Outcomes and Service Dataset (COSD), Systematic Anti-Cancer Therapy (SACT), National Radiotherapy Dataset (RTDS) and National Audits.²³ Interviewees highlighted how this was time consuming for professionals and increased the likelihood of error when inputting data. Even with these different datasets, a recent study by Breast Cancer Now found that one in five hospital trusts were not collecting data on a number of cancer patients.²⁴ Missing or incorrect datasets means it is difficult to form a complete picture of a patient's health status and the impact of care across the treatment pathway.²⁵

Melanie Sturtevant, Policy Manager at Breast Cancer Now, told *Reform* “there is a consensus that we need to do data collection better so that we can see the impact of interventions”. The cancer dashboard should look to do exactly that. This was set up by PHE for the 2015 Strategy as an online dashboard of cancer related information, and should provide insight to help Cancer Alliances drive improvement in cancer care.²⁶ It aims to group different data sources on metrics like one-year survival, patient experience and the number of cancers diagnosed through emergency presentation, so that it can identify where improvements in care are needed.²⁷ However, there are challenges with the current dashboard. Stakeholders have argued that the data collected does not always provide enough granularity to be used as intelligence to make meaningful improvements to the cancer patient pathway.²⁸ Because of this Kent and Medway Cancer Alliance has gone as far as to create their own.²⁹

Going forward, the cancer dashboard should be extended and become the single point of access for cancer outcomes data, in England.³⁰ PHE should make a concentrated effort to improve on the completeness and granularity of data it collects and link this to datasets on medical history, treatment and patient experience. The dashboard in time could make the most of advancements being made by the 100,000 Genome Project in DNA sequencing (see box below) and link with this data, if patient's give their consent,³¹ so it can provide accessible information to clinicians and patients of genetic risk to cancer.³²

23 Open Cancer, 'A Modern Approach to Cancer Data Management', Web Page, (18 December 2015).

24 Breast Cancer Now, *Secondary breast cancer: Part Two: Who's counting?*, 2016

25 Border, *Big Data and Public Health*.

26 Public Health England, 'New Cancer Dashboards – So Much Data; Enough Information?', (13 May 2016).

27 Suzanne Wait, 'Towards Sustainable Cancer Care: Reducing Inefficiencies, Improving Outcomes – A Policy Report from the All.Can Initiative' 13 (September 2017).

28 All Party Parliamentary Group on Cancer, *Progress of the England Cancer Strategy: Delivering Outcomes by 2020?*, 2017.

29 Ibid.

30 *Reform* interview.

31 National Data Guardian, *Impact and Influence for Patients and Service Users* (Department of Health, 2017), 10.

32 Genomics England, 'Why Is Cancer in the 100,000 Genomes Project?', Web Page, (9 October 2018).

Cancer and the 100,000 Genomes Project

The original flagship project set out to sequence 100,000 whole genomes from NHS patients with rare diseases and patients with common cancers.³³ In Autumn 2018, the Secretary of State for Health and Social Care announced ambitious plans for extending the project so that 1 million whole genomes will be sequenced within the next five years.³⁴

Cancer is included in the project because it is a genetic disease. The project is sequencing DNA from a patient's tumour and healthy cells to uncover the genomic changes causing an individual's cancer. It is hoped that this information will help improve diagnosis. This information should also help clinicians choose the treatment most likely to be effective for a person, which is being made possible by the growing use of personalised medicine. Personalised medicine and its potential impact on outcomes are explored further in Chapter 2.

Source: Genomics England, 'Why is cancer in the 100,000 Genomes Project?', 2013.

Using the dashboard as a single point of access should provide meaningful analysis of how different factors impact the likelihood of developing and surviving cancer. To maintain patient privacy, differentiated access controls regulating who can see different datasets could be used.³⁵ This data infrastructure could be modelled on international best practice. For example the National Prostate Cancer Register in Sweden has been applauded for having complete, representative and high-quality data.³⁶ This database has been linked to improvements in clinical care.³⁷ It highlighted the proportion of men with low-risk prostate cancer who underwent an unnecessary bone scan and numbers have now decreased from 45 per cent in 1998 to 3 per cent in 2008.³⁸

The cancer dashboard should not just gather outcomes data from healthcare providers but also collect outcomes data from real-world studies; looking at how treatments impact people in their everyday lives, away from a clinical setting.³⁹ Incorporating this data into analysis will provide a more holistic picture of the cancer patient experience and this information could be used to prevent relapse. The Salford Lung Study (see box below) is one such example of a successful real-world study and has been praised for offering insight on "real world outcomes and real people".⁴⁰

33 Genomics England, 'About Genomics England', Web Page, (9 October 2018).

34 Genomics England, 'Secretary of State for Health and Social Care Announces Ambition to Sequence 5 Million Genomes within Five Years', Press Release, (2 October 2018).

35 Differentiated access controls mean that not everyone will have the same rights to view the data. For example, a nurse would be granted access to data relevant to her work which generally would be less to what a consultant would be granted access to.

36 Par Stattin et al., 'The National Prostate Cancer Register of Sweden', *Tijdschrift Voor Urologie* 7, no. 2–3 (February 2017).

37 Katarina Tomić, Umeå universitet, and Institutionen för kirurgisk och perioperativ vetenskap, 'Data Quality in the National Prostate Cancer Register (NPCR) of Sweden' (2018).

38 Stattin et al., 'The National Prostate Cancer Register of Sweden'.

39 Timothy E. Albertson et al., 'The Salford Lung Study: A Pioneering Comparative Effectiveness Approach to COPD and Asthma in Clinical Trials', *Pragmatic and Observational Research* 8 (2017).

40 Ibid.

The Salford lung study

This study examined the safety and effectiveness of a new treatment for chronic obstructive pulmonary disease (COPD) on over 2,800 patients in Salford and the surrounding Greater Manchester area. It was designed to include patients who would often be excluded from traditional clinical trials, for example patients being treated for other chronic diseases, to be much more representative of everyday practice and the patient population. The study was placed in Salford because of the existing infrastructure of integrated electronic health records. The study relied on bespoke software which integrated the electronic medical records of patients across all of their everyday interactions with their GPs, pharmacists and hospitals. This allowed for close monitoring of patients' experience in near real-time, but with minimal intrusion into everyday lives. Not only has this trial provided a clear picture of how medicines interact with patients' everyday lives, it has also offered a glimpse of the future model for clinical trial design – digitally-enabled and cost-effective.

Source: The University of Manchester, *Pioneering Salford Lung Study achieves world first, 2016.*

With the patient's consent, insight offered from the cancer dashboard could be strengthened by incorporating the "explosion of healthcare data" generated outside of the traditional healthcare settings from wearables and apps.⁴¹ These track vital signs, such as heart rate, blood glucose and blood pressure, and their popularity is increasing. Amongst those who use digital technologies to manage their health, the use of wearables went up from 22 per cent to 31 per cent between 2016 and 2018.⁴² As Dr Navin Ramachandran, Consultant Radiologist at UCLH described, including the data generated from digital technologies would mean data collection moves from the current episodic model (data is only collected when a patient visits a healthcare professional) to a continuous cycle of collection and analysis. This would create a much richer picture of patient experience and how this is linked to long-term outcomes.

1.1.2. A local approach to data sharing

Alongside an improved national cancer dashboard for outcomes, data must be shared effectively and promptly between different stakeholders to ensure patients have the best possible care experience. A cancer patient normally interacts with many different parts of the health service. They might have their cancer diagnosed at their GP, then referred to a district hospital before potentially a specialist hospital, and then receive some of their rehabilitation with social care.⁴³ Yet as a recent *Reform* report argued,⁴⁴ and as Figure 2 indicates, sharing of data across healthcare is variable. This is partly because of technical barriers of interoperability issues and legacy systems.⁴⁵ However, cultural issues also stand in the way with risk aversion to sharing data between different stakeholders because of legal liabilities and different information governance.⁴⁶ In addition, there is low public trust in the Government securely holding and sharing data.⁴⁷ Indeed, the 2014 care data programme, designed to allow anonymised primary care health records to be

41 Joachim Roski, George W. Bo-Linn, and Timothy A. Andrews, 'Creating Value In Health Care Through Big Data: Opportunities And Policy Implications', *Health Affairs* 33, no. 7 (2014).

42 Health Education England, *The Topol Review: Preparing the Healthcare Workforce to Deliver the Digital Future. Interim Report June 2018 – A Call For Evidence*, 2018, 24.

43 Eleonora Harwich, Alexander Hitchcock, and Elaine Fischer, *Faulty by Design. The State of Public-Service Commissioning*. (Reform, 2017).

44 Sarah Timmis, Luke Heselwood, and Eleonora Harwich, *Sharing the Benefits: How to Use Data Effectively in the Public Sector*, (Reform, 2018).

45 Ibid.

46 Ibid.

47 Royal Statistical Society, *Royal Statistical Society Research on Trust in Data and Attitudes toward Data Use / Data Sharing*, 2014.

shared outside the NHS, had to be abandoned after a loss of trust due to the public not being fully informed about how their personal data would be used.⁴⁸

If the NHS is to move into this data-driven model, local areas should drive improvements in data sharing. The 19 Cancer Alliances provide the perfect platform for this, as their remit is to bring together multiple actors across the geography to provide a more joined-up approach to care.⁴⁹ In terms of overcoming barriers to data sharing, regional approaches have traditionally had more demonstrable success in obtaining trust and data sharing agreements, perhaps due to closer proximity with the public and greater input into the data use.⁵⁰ Greater Manchester has recently become a Local Health and Care Record Exemplar, meaning it has been granted additional funding to improve data sharing across its health economy.⁵¹ It has launched DataWell, a software system that allows the secure exchange of patient electronic information across primary, community and secondary care.⁵² Other local areas could look to build a similar software system, tailored to their local population needs. The NHS long-term plan, due out later this year, should ensure local areas have adequate support and funding to do this.

1.1.3. Improving transparency

Transparent reporting of information from clinical trials provides patients with opportunity to receive the newest and most innovative treatments.⁵³ Clinical trials are the foundation of evidence-based medicine; they enlist volunteers into trials to investigate whether drugs, medical devices and treatments are safe and effective for use.⁵⁴ Not only do they inform the decision making bodies like the Medicines and Healthcare products Regulatory Agency (MHRA) as to whether a new drug should be allowed onto the market, they also inform the decision making of doctors and patients to determine the best treatment option.⁵⁵ Currently, however, there are issues with transparency and bias over clinical trial data.⁵⁶ A report into the problem found that that only a fifth of trials registered on clinicaltrials.gov had reported results within one year of completion and trials producing negative results were twice as likely to remain unreported as positive trials.⁵⁷

Efforts by campaigns and initiatives such as TranspariMED are accelerating progress in improving clinical transparency.⁵⁸ In addition, charities and pharmaceutical companies now have public online depositaries containing trial results and further information.⁵⁹ Going forward, the new cancer care model should work with these groups to ensure this information is accessible and understandable to all those involved in patient care, including the patient themselves.

48 Tjeerd-Pieter van Staa et al., 'Big Health Data: The Need to Earn Public Trust', *BMJ : British Medical Journal*, 14 July 2016.

49 All Party Parliamentary Group on Cancer, *Progress of the England Cancer Strategy: Delivering Outcomes by 2020?*.

50 Sarah Timmis, Luke Heselwood, and Eleonora Harwich, *Sharing the Benefits: How to Use Data Effectively in the Public Sector*.

51 Leontina Postelnicu, 'Three Regions Selected as Local Health and Care Record Exemplars', *British Journal of Healthcare Computing*, 23 May 2018.

52 Connected Health Cities, 'What Is the Datawell?', Web Page, (6 September 2016).

53 Joseph M. Unger et al., 'The Role of Clinical Trial Participation in Cancer Research: Barriers, Evidence, and Strategies', *American Society of Clinical Oncology Educational Book. American Society of Clinical Oncology. Annual Meeting 35* (July 2017).

54 World Health Organization, 'Clinical Trials', Web Page, (8 October 2018).

55 Cochrane, CRIT, and TranspariMED, *Clinical Trial Transparency: A Guide for Policymakers*, 2017.

56 Ibid.

57 AllTrials, *All trials registered. All results reported*, 2013.

58 STOPAIDS, HealthWatch UK, Universities Allied for Essential Medicines UK and TranspariMED, 'Science and Technology Committee: Research Integrity Inquiry. Submitted Evidence.' (HC 350, 6 March 2018).

59 GSK, 'Data Transparency', Web Page (12 June 2014).

2

Putting the model into practice

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From a patient perspective this new care model means an integrated and personalised experience. Sharing and analysis of data across local health economies will help identify people most at risk of developing the disease and interventions can be targeted accordingly. A more intelligent use of data will help clinicians decide the most effective treatment options, and transparent reporting of outcomes will mean, where possible, patients have more choice. Wearables and apps will support traditional inpatient treatment, helping people make better lifestyle choices in recovery.

2.1 Prevention

In line with the Prime Minister's recent announcement,⁶⁰ an interviewee summarised to *Reform* that to significantly improve patient outcomes, much more work needed to be done in the initial phase of the new care model. The historic argument for explaining the variation of outcomes across the country is access to care.⁶¹ Interviewees disagreed with this assumption, saying there is a confounding relationship between access to care and lifestyle, where those living in areas with poor access are also more likely to be less educated about lifestyle risk factors.⁶² As Steve Williams, consultant cancer pharmacist at Northumbria NHS Foundation Trust argued, this is because "a more affluent person in the South East may approach their health very differently to someone from a more socioeconomically deprived background in the North East." Smoking causes at least 15 different types of cancer, 15 per cent of new cancer cases in the UK and more than a quarter of all cancer deaths.⁶³

Advancements in mining 'Big Data' – defined as the ability to combine and analyse large amounts of different information at the same time⁶⁴ – provides the opportunity to strengthen prevention efforts. The improved data infrastructure in this new model will make this possible; it can provide intelligence on population groups most at risk of developing the disease. GPs should work closely with those identified as at risk to better manage lifestyle risk factors. Modifying health behaviours, such as smoking cessation, physical activity, eating a healthy diet and adherence to cancer screening guidelines are all known to prevent and control the disease.⁶⁵ New care models such as social prescribing, which connects people with non-medical interventions to help them manage long-term health conditions, could be used to encourage the uptake of healthier behaviours.⁶⁶

This intervention should be given as an option to both those with lifestyle risk factors and/or a genetic risk. There are concerns in the scientific community that predictive genetic testing could lead to adverse psychology and behavioural responses if the right support and information is not in place.⁶⁷ However, studies examining the potential impact of telling people they have a genetic risk to developing a certain type of cancer, such as the risk BCOC for breast cancer, have shown that most people respond proactively to this information and 'try harder to have a healthier lifestyle'.⁶⁸ This new data-driven model should help the public have a multifaceted view of cancer, so they have a better understanding of all the risk factors, and if they do have a particular susceptibility, feel empowered and supported to change their behaviour accordingly.

60 'Theresa May Speech in Full: Read the Prime Minister's Keynote Conservative Conference Address'.

61 Catherine Foot and Tony Harrison, *How to Improve Cancer Survival: Explaining England's relatively poor rates* (The King's Fund, 2011), 17.

62 Saskia C. Sanderson et al., 'Awareness of Lifestyle Risk Factors for Cancer and Heart Disease among Adults in the UK', *Patient Education and Counseling* 74, no. 2 (February 2009).

63 Cancer Research UK, *Cancer Research UK's Proposals for the NHS 10-Year Plan*.

64 Peter Liu, 'How Data Science Enables Early Cancer Diagnosis', *Springboard*, 28 June 2018.

65 Catherine Foot and Tony Harrison, *How to Improve Cancer Survival: Explaining England's relatively poor rates*; NHS England, *Achieving World-Class Cancer Outcomes: Taking the Strategy Forward*.

66 Andrew McConaghie, 'Social Prescribing: Can the NHS Make It Mainstream?', *pharmaphorum*, 26 October 2017.

67 Ibid.

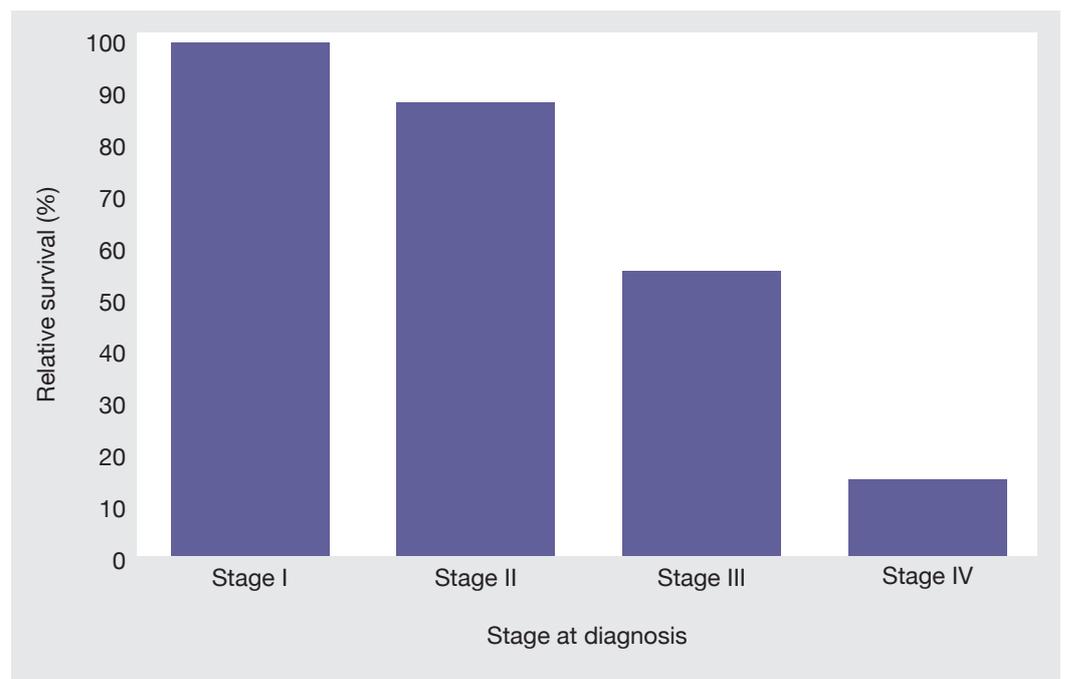
68 Susanne F. Meisel et al., 'Anticipated Health Behaviour Changes and Perceived Control in Response to Disclosure of Genetic Risk of Breast and Ovarian Cancer: A Quantitative Survey Study among Women in the UK', *BMJ Open* 7, no. 12 (December 2017).

2.2 Early diagnosis

Population-level analysis of at risk groups can also be used to develop programmes to encourage people to engage with cancer screening. Notably, take-up of screening is lowest in the population segment with the highest risk of developing cancer.⁶⁹ Yet screening is an essential part of the treatment pathway. Evidence indicates that breast screening prevents approximately 1,300 deaths per year.⁷⁰ To put this figure into context, this equates to around 10 per cent of the total number of deaths from breast cancer annually.⁷¹ Cervical screening prevents almost 4,000 cases of cancer per year,⁷² meaning it is preventing over half of what would be new cases (3,126 new cases are diagnosed a year).⁷³

Earlier diagnosis has a knock-on effect on the rest of the treatment pathway. It makes it more likely patients will receive treatments that can cure cancer.⁷⁴ For breast cancer a survival rate of five years is almost 100 per cent likely if diagnosed at stage I, while the survival rate decreases to 30 per cent at stage IV (see Figure 3).⁷⁵

Figure 3: Early diagnosis of breast cancer leads to better outcomes



Source: Cancer Research UK, *Five Year Relative Survival by Stage, Women (Aged 15-99 Years), Former Anglia Cancer Network, 2002 – 2006, 2012.*

In this personalised model, those at risk of developing cancer should receive communications and information encouraging them to take part in screening. The Imperial College Innovation Lab, the Helix Centre, is looking at how to encourage screening in groups with typically low levels of engagement (normally men and people from lower socio-economic groups).⁷⁶ For bowel cancer, the lab has investigated how to reframe the screening marketing into a more positive message such as ‘looking after your

69 Helix Centre, ‘Bowel Health: Improving Take-up in Bowel Cancer Screening’, Web Page, (20 August 2018).

70 Greater Manchester Cancer, ‘Greater Manchester Cancer: Vanguard Innovation’, Web Page, (16 August 2018).

71 Cancer Research UK, ‘Breast Cancer Statistics’, Web Page, (16 October 2018).

72 Greater Manchester Cancer, ‘Greater Manchester Cancer: Vanguard Innovation’.

73 Cancer Research UK, ‘Cervical Cancer Statistics’, Web Page, (16 October 2018).

74 NHS England, *Achieving World-Class Cancer Outcomes: Taking the Strategy Forward.*

75 Cancer Research UK, *Five-Year Relative Survival (%) by Stage, Adults Aged 15-99, Former Anglia Cancer Network, 2002-2006, 2012.*

76 Helix Centre, ‘Bowel Health: Improving Take-up in Bowel Cancer Screening’.

bowel health' rather than 'screening for bowel cancer' to encourage uptake, and make the home testing kit more practical and easier to use.⁷⁷ Given that cancer care reform is operating in the wider context of an NHS with stretched resources⁷⁸, targeted screening will help the NHS become more efficient with any increase in cancer funding, whilst simultaneously bringing real value to patients.

Using data more intelligently can be coupled with new technology, such as Artificial Intelligence (AI), to improve screening accuracy.⁷⁹ At the moment, thousands of cases are not picked up by mammograms each year, and evidence shows that a high proportion of mammograms yield false positive results when interpreted by radiologists, leading to one in two healthy women being told they may have cancer.⁸⁰ A project led by Imperial College London is exploring how AI could improve breast screening and lead to a more accurate detection of cancers using mammograms.⁸¹ If trials like this are successful, there is much opportunity to increase the efficiency of screening services and improve patient outcomes.

This new model will impact the cancer workforce. Improved data sharing in cancer should strengthen the role of GPs as the gatekeepers to the rest of the treatment pathway. Aside from prevention efforts, GPs should be better informed to help with early detection of the disease. This will be beneficial for patient care; recent research has found that GPs are 'as good as consultants' at referring for cancer tests, and direct access scans – allowing GPs to refer patients for diagnostic testing without first referring to a specialist – have been found to more than half wait time for patients.⁸²

As the interim Topol review argued technology such as AI is likely to augment the work of pathologists and radiologists, rather than replace them.⁸³ This could be a promising development for cancer care given current issues with workforce capacity.⁸⁴ Technology should not only enable the workforce to become more efficient to meet growing demand, but also free up time to allow for more innovation and adaption to new interventions that improve patient outcomes.

2.3 Personalised treatment

If a patient is diagnosed with cancer, a data-driven model of cancer care should enable far more personalised and effective treatment. In time, dependant on a secure system and patient consent, information from initiatives like the 100,000 Genomes Project could be linked to the cancer dashboard to encourage the use of personalised medicine. This will provide the opportunity to choose the best possible treatment for each individual patient.⁸⁵ In the past, cancer patients have been treated by 'blockbuster' treatments based on symptoms. This is where all patients receive the same treatment which is typically 30 to 60 per cent effective.⁸⁶ Personalised medicines move away from this symptoms approach, providing medicines targeted to an individual's genetic and lifestyle uniqueness (see the box below for two trial examples).⁸⁷

77 Ibid.

78 NHS England, *Five Year Forward View*.

79 Ian Tucker, 'AI Cancer Detectors', *The Guardian*, 10 June 2018.

80 Archie Bleyer and Gilbert Welch, 'Effect of Three Decades of Screening Mammography on Breast-Cancer Incidence', *The New England Journal of Medicine* 367 (November 2012).

81 Ryan O'Hare, 'Research Collaboration Aims to Improve Breast Cancer Diagnosis Using AI', Press Release, Imperial College London, (24 November 2017).

82 Jenny Cook, 'GPs "as Good as Consultants" at Referring for Cancer Tests', *GP Online*, 14 August 2018.

83 Health Education England, *The Topol Review: Preparing the Healthcare Workforce to Deliver the Digital Future. Interim Report June 2018 – A Call For Evidence*.

84 Cancer Research UK, *Proposals for the NHS 10-year plan*, 2018.

85 Genomics Education Programme, 'Personalised Medicine in the NHS: What Will It Mean?', Press Release, (26 September 2016).

86 NHS England, *Improving Outcomes through Personalised Medicine*, 2016, 7.

87 Ibid.

PRECISION Panc project

This aims to develop personalised treatments for pancreatic cancer patients, improving the options and outcomes for a disease where survival rates have remained stubbornly low. The researchers will use the molecular profile of each individual cancer cell to offer patients and their doctor a menu of trials that might benefit them.

Source: PrecisionPanc.org, *Our Research*, 9 October 2018.

The Optima Trial

The Optima trial, working with 4,500 women diagnosed with breast cancer, is genetically testing tumours to decide the patients who will best respond to chemotherapy and those who have the specific genetic variation to be given the personalised medicine Herceptin. This trial hopes to result in 7,000 women being spared the toxic side-effects of chemotherapy, while saving the NHS an estimated £17 million.

Source: National Institute for Health Research, *Landmark trial looking at test to predict who needs chemotherapy for breast cancer begins*, Press Release, 26 January 2017.

More information on treatment available should also improve the choice patients have over how they would like to receive treatment. Interviewees explained that new medicines are often in pill form and so can be administered out of the traditional in-patient setting. Interviewees spoke about innovations like chemo buses making new models of ‘closer to home’ care a reality. A branch of LloydsPharmacy in Scunthorpe is providing the breast cancer treatment Herceptin, delivered by a nurse using a subcutaneous injection. For some patients this will be more convenient and is predicted it will save 14 trips to hospital (out of possible 17) per patient per year.⁸⁸ It is important that this new care model recognises that these treatment options will only be suitable for some people and so ensures people are given enough information to choose how to receive treatment in a way best suited to their lifestyle.

Including real-world evidence in the cancer dashboard should benefit the work of Cancer Alliances by informing them of the treatments most effective for their local population. This information could then be used to empower local areas to decide how and what to pay for treatment. Areas such as Greater Manchester are partnering with the pharmaceutical industry to use real-world evidence to trial paying for medicines based on outcomes.⁸⁹ This means local areas pay for medicines when they achieve outcomes appropriate to their local population,⁹⁰ rather than the current practice of paying an upfront set price agreed between the manufacturer and the NHS.⁹¹ Whilst still in development, supporters of flexible outcomes-based pricing schemes argue these will be a ‘win-win’ for all those involved: patients should get faster access to drugs tailored to their specific needs, local health economies can ensure value for money by paying for medicines when they achieve the outcomes they want and industry can have a “more assured and accelerated route to market” if they can demonstrate real value from their medicines.⁹²

88 Neil Trainis, ‘First Herceptin Service Provided in Pharmacy Rolled out in Scunthorpe’, *Pharmacy Business*, 7 June 2018.

89 Cancer Research UK, *Making Outcome-Based Payments a Reality in the NHS*, 2018.

90 Ibid.

91 Leo Ewbank et al., *The Rising Cost of Medicines to the NHS: What’s the Story?* (The King’s Fund, 2018).

92 Sarah Neville, ‘Big Pharma Takes a Gamble on NHS Experiment’.

2.4 Supporting patients long-term

The changing nature of cancer means that this new model must support patients long-term, after treatment and into recovery. Macmillan research revealed that in certain cancer groups, more than 90 per cent of patients now live for more than one year and more than 80 per cent live for more than 5 years.⁹³ Importantly, these patients may face fewer hospital admissions but are still living with the consequences of cancer so need to be informed on how best to manage it. The ADAPT trial at the Christie is looking at the long-term support lymphoma patients need.⁹⁴ Patients and GPs are given treatment management plans, where patients only need to provide hospitals with an update on their condition.

A data-driven model of care can do much to prevent cancer from returning after remission. The TOUR bladder cancer trial at UCL is investigating how exercise can influence recovery.⁹⁵ This builds on similar work, such as Macmillan's Walking for England, which shows benefits of physical activity during cancer treatment.⁹⁶ Apps and wearables can be used to help people live more healthily. The Christie is currently trialling a smartphone app, so patients can record symptoms (such as mobility and energy levels) whilst receiving cancer treatment.⁹⁷ Apps like this could be extended to post-treatment, providing the information and support to help people make better daily choices, which might affect their long-term recovery.

Web-based applications or digital therapeutics take this one step further. They ask patients to record symptoms online and then use algorithms to detect anomalies. Importantly, this allows for far earlier detection of recurrence.⁹⁸ One online therapy worked with advanced lung cancer patients, a group that generally has poor prognosis, asking them to enter subjective measures of wellbeing including pain, energy levels and appetite into a web application on their smartphone. In this trial, patients saw a gain of 7.6 months in overall survival, when followed up after two years of using system.⁹⁹

A data-driven, personalised model of care presents a significant opportunity to gather insights from patients on how cancer care can be improved. The Cancer Vanguard has recognised this and has partnered with the app iWantGreatCare.¹⁰⁰ This system works with 45 NHS organisations, collecting real-time patient feedback on care received at key points of treatment. This is a tangible way to put patients at the heart of the new care model – using their feedback and insight to continuously improve the cancer care for them now, and the care for patients in the future.

93 H McConnell, R White, and J Maher, *Three Cancer Groups: Explaining the Different Complexity, Intensity and Longevity of Broad Clinical Needs*, 2015.

94 The Christie, 'Innovative Models of Care', Web Page, (15 June 2018).

95 Guy's and St Thomas', 'Landmark Bladder Cancer Study Launched', Press Release, (6 June 2018).

96 Ramblers, 'Macmillan Cancer Support', Web Page, (15 June 2018).

97 pharmaphorum, 'The Cancer Vanguard: NHS and Pharma Partnership Improves Patient Experience', Press Release, (7 February 2018).

98 Sarah Neville, 'Digital Therapeutics Show Potential for Healthcare Disruption', *Financial Times*, 24 August 2018.

99 Fabrice Denis et al., 'Randomized Trial Comparing a Web-Mediated Follow-up With Routine Surveillance in Lung Cancer Patients', *Journal of the National Cancer Institute* 109 (April 2017).

100 Jacqui Wise, 'Disruptive Technologies Making Cancer Care More Patient Centred', *BMJ* 359 (December 2017). The relationship with this specific app has not been renewed but the principle of real-time feedback should be taken forward in this new model of care.

3 Conclusion

Cancer is the disease of the modern age. It touches the lives of everyone in some way, so it is right that the Government is ambitious in its aim to significantly improve outcomes.¹⁰¹ The rich insight that the NHS now has from its vast datasets offers the perfect opportunity to do exactly that.

As this paper has explored, a more intelligent use of data will allow for better prediction and prevention of the disease. This should always be the top priority for a sustainable health and care service – preventing a disease from developing in the first place. If the disease does develop, however, data and innovation can help the NHS intervene far earlier in prognosis, giving patients the best possible chance of survival. From then on, if a patient does need further treatment, genetic data and personalised medicines can make care more effective. As this paper has recognised, much of the data needed for a new data-driven model of cancer care is already there. Going forward, the NHS should prioritise improving data infrastructure to provide greater insight leading to better cancer care. The Cancer Vanguard and the local Cancer Alliances are best placed for making progress in data sharing and the long-term plan for the NHS should ensure local areas have the adequate support to do this.

The patient and their best interests should always be at the centre of a new care model. Improving cancer data is one way to progress towards the main goal in cancer care; giving everyone the best possible chance of long-term survival, alongside the best cancer care, during the most challenging part of their life.

¹⁰¹ 'Theresa May Speech in Full: Read the Prime Minister's Keynote Conservative Conference Address'.

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