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.

**Emma Greenwood**, Director of Policy and Public Affairs for Cancer Research UK. Emma is responsible for the charity’s influencing work across a wide range of public policy issues – including early diagnosis of cancer, NHS services, access to treatments, and the UK research environment.

In 2015 Emma was the Programme Lead for the Independent Cancer Taskforce, who developed the Cancer Strategy. The NHS in England is now delivering cancer services to the vision set out in the strategy.

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**Interviewees**

The author would like to express her gratitude to the following people and organisations who kindly agreed to be interviewed as part of the research for this paper and were happy to be acknowledged:

Melanie Sturtevant, Policy Manager, Breast Cancer Now
Dr Mieke Van Hemelrijck, Academic Lead of Translational Oncology and Urology Research (TOUR), King’s College London
Dr Navin Ramachandran, Consultant Radiologist, UCLH and member of the IOTA foundation
Dr Niamh Lennox-Chhugani, Healthcare Lead, Optimity Advisors
Nicolaus Henke, Co-Lead, McKinsey Digital & Analytics and Chairman of QuantumBlack
Professor Peter Clark, Consultant Medical Oncologist, The Clatterbridge Cancer Centre
Roger Spencer, Chief Executive, The Christie NHS Foundation Trust
Sean O’Neill, Chief Reporter, _The Times_
Steve Williamson, Consultant cancer pharmacist, Northumbria NHS Foundation Trust
Two representatives from AbbVie
A representative from NICE

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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³ C R Smittenbaer et al., ‘Cancer Incidence and Mortality Projections in the UK until 2035’, *British Journal of Cancer* 115, no. 9 (October 2016).
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, ‘RCoR Responds to the Prime Minister’s Announcements of a New Cancer Strategy and Focus on Early Diagnosis’, Press Release, (3 October 2018).
¹⁴ Matt Hancock, ‘My priorities for the health and social care system,’ Speech, (20 July 2018).

1
The new cancer care model

1.1 The game changer: getting data right
   1.1.1 Driving meaningful change: the cancer dashboard
   1.1.2 A local approach to data sharing
   1.1.3 Improving transparency
The NHS “holds millions of electronic medical records on the health of the population from birth to death.”\textsuperscript{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).\textsuperscript{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**

<table>
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<tr>
<th>Prevention and early diagnosis</th>
<th>Personalised treatment</th>
<th>Supporting patients long-term</th>
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<td>Using data to identify those most at risk of the disease. Targeting interventions, like screening, to encourage earlier diagnosis.</td>
<td>Using genomic and outcomes data to personalise treatment and give patients as much choice and control as possible.</td>
<td>Using apps and wearables to help patients live the healthiest lives possible after the disease and prevent recurrence.</td>
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This new model will be underpinned by the cancer dashboard


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”.\footnote{Sir Michael Barber, Delivering Better Outcomes for Citizens: Practical Steps for Unlocking Public Value, 2017, 21.} 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.\footnote{Sarah Neville, ‘Big Pharma Takes a Gamble on NHS Experiment’, Financial Times, 28 August 2018.} 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.\footnote{‘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).} 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.
Figure 2: The cancer care data landscape

**Key**
- **Always share information**
- **Sometimes share information**
- **Patient-level data**
- **Population-level data**
- **All data available to patient**
- **Some data available to patient**

**Public Health England (PHE)**
- Responsible for collecting and analysing cancer data
- Data collected and analysed includes: Cancer Outcomes and Service Dataset (COSD), Systemic Anti-Cancer Therapy Dataset (SACT), Cancer Alliance Data, Evidence and Analysis (CADEAS)
- Database sits within PHE
- Manages the Cancer Registry
- Data collected includes: diagnosis, treatment, outcomes and patient experience
- Ways for patients to access this data via the PHE patient portal

**National Cancer Registration and Analysis Service (NCRAS)**
- Database sits within PHE
- Manages the Cancer Registry
- Data collected includes: diagnosis, treatment, outcomes and patient experience
- Ways for patients to access this data via the PHE patient portal

**NHS England**
- Lead organisation for implementing cancer strategy
- Data processed includes: cancer waiting times, NHS outcomes framework

**NHS Digital**
- Collect data on behalf of Department of Health and NHS to measure success of cancer strategy
- Data collected includes: Cancer outcomes and Service Dataset (COSD), Systemic Anti-Cancer Therapy Dataset (SACT), Cancer Alliance Data, Evidence and Analysis (CADEAS)

**General Practitioners**
- Where patient first presents with symptoms
- Data collected includes: patient records and diagnostics

**NHS Trusts**
- Where patient treated
- Data collected includes: Radiotherapy Dataset (RTDS), cancer waiting times

**Academia**
- Data collected and published from research and randomised control trials (RCTs)

**Pharma**
- Data collected and sometimes published from clinical trials
- Sometimes receives data from NCRAS for post-market surveillance

**Cancer Alliances**
- Access to CADEAS (in development) for evidence based local decision making

**Cancer Charities**
- Data collected from own research and online member forums
- Data published on:
  - incidence, mortality, survival rates
  - clinical trial results
  - available treatment options

**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

29 Ibid.
30 Reform interview.
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. 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.

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. 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. This database has been linked to improvements in clinical care. 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.

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. 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”.

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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.
38 Stattin et al., ‘The National Prostate Cancer Register of Sweden’.
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. 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. 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. Yet as a recent Reform report argued, 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. 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. In addition, there is low public trust in the Government securely holding and sharing data. Indeed, the 2014 care. data programme, designed to allow anonymised primary care health records to be

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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{51} It has launched DataWell, a software system that allows the secure exchange of patient electronic information across primary, community and secondary care.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{55} Currently, however, there are issues with transparency and bias over clinical trial data.\textsuperscript{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.\textsuperscript{57}

Efforts by campaigns and initiatives such as TranspariMED are accelerating progress in improving clinical transparency.\textsuperscript{58} In addition, charities and pharmaceutical companies now have public online depositaries containing trial results and further information.\textsuperscript{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.

\textsuperscript{50} Sarah Timmis, Luke Heselwood, and Eleonora Harwich, Sharing the Benefits: How to Use Data Effectively in the Public Sector.
\textsuperscript{54} World Health Organization, ‘Clinical Trials’, Web Page, (8 October 2018).
\textsuperscript{56} Ibid.
\textsuperscript{57} AllTrials, All trials registered. All results reported, 2013.
\textsuperscript{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).
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, 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. 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. 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.

Advancements in mining ‘Big Data’ – defined as the ability to combine and analyse large amounts of different information at the same time – 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. 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.

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. 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’. 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.

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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).
67 Ibid.
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. Yet screening is an essential part of the treatment pathway. Evidence indicates that breast screening prevents approximately 1,300 deaths per year. To put this figure into context, this equates to around 10 per cent of the total number of deaths from breast cancer annually. Cervical screening prevents almost 4,000 cases of cancer per year, meaning it is preventing over half of what would be new cases (3,126 new cases are diagnosed a year).

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. 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).

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

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). For bowel cancer, the lab has investigated how to reframe the screening marketing into a more positive message such as ‘looking after your...

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.\textsuperscript{77} Given that cancer care reform is
operating in the wider context of an NHS with stretched resources\textsuperscript{78}, 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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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 halve wait time for patients.\textsuperscript{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.\textsuperscript{83} This could be a promising
development for cancer care given current issues with workforce capacity.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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).\textsuperscript{87}

\begin{itemize}
  \item \textsuperscript{77} Ibid.
  \item \textsuperscript{78} NHS England, \textit{Five Year Forward View}.
  \item \textsuperscript{79} Ian Tucker, ‘AI Cancer Detectors’, \textit{The Guardian}, 10 June 2018.
  \item \textsuperscript{80} Archie Bleyer and Gilbert Welch, ‘Effect of Three Decades of Screening Mammography on Breast-Cancer Incidence’,
  \item \textsuperscript{81} Ryan O’Hare, ‘Research Collaboration Aims to Improve Breast Cancer Diagnosis Using AI’, Press Release, Imperial
  \item \textsuperscript{82} Jenny Cook, ‘GPs “as Good as Consultants” at Referring for Cancer Tests’, \textit{GP Online}, 14 August 2018.
  \item \textsuperscript{83} Health Education England, \textit{The Topol Review: Preparing the Healthcare Workforce to Deliver the Digital Future. Interim
                  Report June 2018 – A Call For Evidence}.
  \item \textsuperscript{84} Cancer Research UK, \textit{Proposals for the NHS 10-year plan}, 2018.
  \item \textsuperscript{85} Genomics Education Programme, ‘Personalised Medicine in the NHS: What Will It Mean?’, Press Release,
                  (26 September 2016).
  \item \textsuperscript{86} NHS England, \textit{Improving Outcomes through Personalised Medicine}, 2016, 7.
  \item \textsuperscript{87} Ibid.
\end{itemize}
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.


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. 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. This means local areas pay for medicines when they achieve outcomes appropriate to their local population, rather than the current practice of paying an upfront set price agreed between the manufacturer and the NHS. 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.

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.

\(^{100}\) 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. 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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