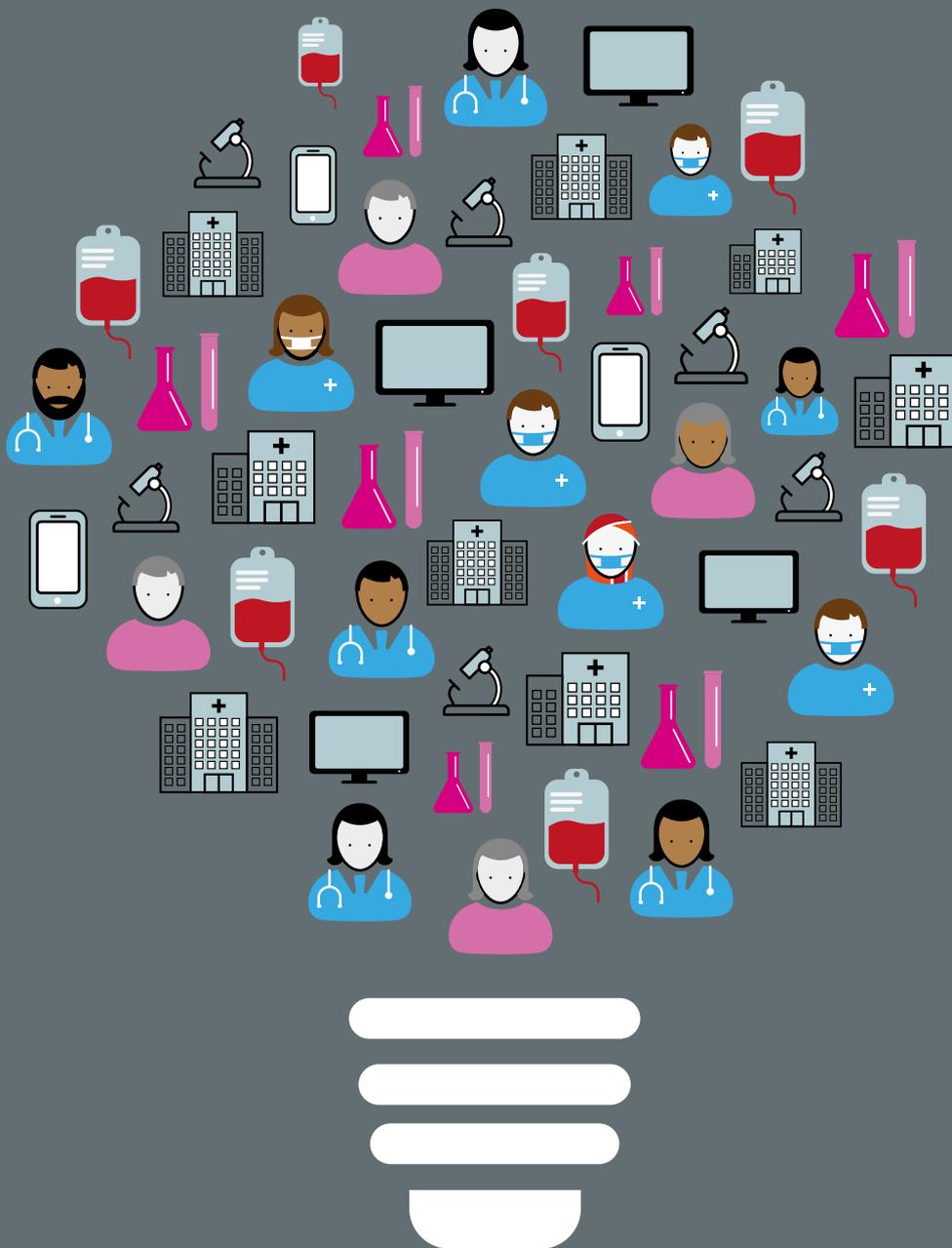


REFORMER THOUGHTS

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A data-driven approach
to cancer care

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Reformer Thoughts brings together the opinions of leading experts from academia, business and government; frontline practitioners and public service users, to provide readers with valuable insight into the challenges shaping the policy debate. The series aims to give a platform to innovative ideas and facilitate an open and informed conversation about how we can improve public services.

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We work on core sectors such as health and social care, education, home affairs and justice, and work and pensions. Our work also covers issues that cut across these sectors, including public service design and delivery and digital public services.

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Introduction

Transforming cancer care: making the most of data

Progress in cancer care delivered by the NHS has meant that more people are surviving and enjoying a better quality of life. Advances in prevention, diagnosis and treatment have led to remarkable improvements. However, there is still a long way to go. More than one in three people in England will develop cancer and there is considerable variation in survival rates across the country.

In the NHS's [Long Term Plan](#), cancer care is a key priority. It committed to diagnosing three in four cancers at an early stage by 2028, providing more support to help smokers to quit, offering genetic testing to children with cancer and conducting more research to develop innovative treatment. These commitments build on the 2015 Cancer Strategy, which aims to improve survival rates through faster diagnosis and treatment.

An effective use of data is essential to achieving the aims of the Cancer Strategy. Data can be used at every stage of the treatment journey, from prevention and diagnosis to treatment and recovery. Making better use of data can help to improve cancer outcomes. It can provide the NHS with a clearer understanding of the disease and the specific needs of the individual. For example, it can help to predict groups who are most at risk to enable more targeted interventions and the development of personalised treatments.

The NHS has access to a wealth of data that are collected throughout a person's lifetime. For cancer care, there are several datasets that record information on diagnosis, outcomes and patient experience.

The NHS is already making strides to make best use of this data. In addition to the cancer dashboard, which is an online interface for all cancer related information, a new data service for cancer alliances has been introduced – bringing together data that track a cancer patient's journey.

Reform research has shown, however, that the sheer amount of data has created a confusing landscape that can be difficult for clinicians to navigate and use effectively. Furthermore, there are still missing or incorrect datasets that make it difficult to form a clear picture of a patient. An improvement in the NHS's data architecture, better data collection and effective data linking between services could help the healthcare system to realise the potential of data.

This *Reformer Thoughts* brings together healthcare experts to discuss the potential of a data-driven approach to cancer care. The articles show how data are currently shaping the delivery of cancer care, how to gain the most from the data that are currently available and how to maximise the potential of this data in the future.



Dr Luke Heselwood
Senior Researcher
at Reform

"An improvement in the NHS's data architecture, better data collection and effective data linking between services could help the healthcare system to realise the potential of the data available."

Health inequalities data tell an unjust tale of two cities

Conversations around cancer and health inequalities struggle to move past 'lifestyles'. It's true that smoking, drinking, and obesity occur on a greater scale in socioeconomically deprived communities, correlating with higher rates of cancer and higher mortality. However, six in ten cancers are not preventable, meaning there are over 1.1 million people living with an unpreventable cancer in England.

That number is rising. By 2030, 4 million people will be living with cancer, many for decades, as the odds for surviving cancer for ten years continue to increase. Too many of these people will have their experience, outcomes and quality of life unjustly impacted by who they are, what they earn and where they come from.

Macmillan have launched a national discussion on health inequalities – starting with a report, *Time to Talk*, analysing the unjust variation that people can experience. What we have found is a 'tale of two cities' – or towns, or villages - where deprivation defines experiences and outcomes. Data have reflected shocking realities: people in the most deprived areas in England are 20 per cent more likely to have their cancer diagnosed at a late stage than those in the least deprived areas. These areas also have half the referrals to early stage clinical trials, and are twice as likely to need emotional and practical support.

Data in this instance are key to identifying health inequalities that exist on a regional basis, and our analysis has found shocking variation in cancer outcomes.

To exemplify this, compare Blackpool and Test Valley. Blackpool is the second most deprived locality in England, and cancer services in Blackpool Clinical Commissioning Group (CCG) were deemed 'inadequate.' Contrast this with Test Valley, one of the ten least deprived localities in England.

Test Valley comes under West Hampshire CCG, where cancer services were deemed 'outstanding' for the past two years. The data reflecting variation in cancer outcomes between Blackpool and West Hampshire CCGs is bleak. From the outset, Blackpool's cancer incidence rate dwarfs that of West Hampshire's, with 670 incidences per 100,000 people compared to West Hampshire's 596.

A concerning continuity in deprivation then occurs – cancer prevalence is far higher in Blackpool, yet outcomes and patient satisfaction are worse. Twenty per cent of patients in Blackpool were diagnosed through emergency presentation compared to 19 per cent in West Hampshire, suggesting worse access to primary care. Similarly, 52 per cent of people living with cancer in West Hampshire were diagnosed at stage one or two, compared to just 44 per cent in Blackpool. Given survival rates greatly increase with early stage diagnosis, this is worrying.

Post-diagnosis, 72 per cent of people diagnosed with cancer in West Hampshire survived for one year, compared to just 67 per cent in Blackpool. An overarching theme throughout is people from deprived communities experiencing worse care – West Hampshire scored 8.66 out of 10 for overall experience of care compared to Blackpool's 8.52.



Zahra Wynne
Policy Officer (Health Inequalities) at
Macmillan Cancer
Support

"Outcomes and quality of life whilst living with cancer should never be unjustly determined by who you are, or where you come from."

It is welcome that the recent NHS [Long Term Plan](#) acknowledged health inequalities and endeavours to challenge them, but further action is necessary. Resources, a local and national vision, and targeted interventions prioritising excluded groups are needed. Outcomes and quality of life whilst living with cancer should never be unjustly determined by who you are, or where you come from. The onus is on the Government to set a vision, allocate resources, and ultimately improve outcomes for the millions who will receive a cancer diagnosis in the future.

The future of the NHS is rapidly moving towards the digital sphere, and data here can play a key role in challenging health inequalities. The development of local health and care records, disaggregated Cancer Patient Experience Survey responses and holistic needs assessments can clearly demonstrate areas in which targeted interventions are needed to reduce the unjust variation in cancer outcomes that currently exist. If the NHS is committed to ending health inequalities, they must use existing data sets to target resources towards the most deprived areas and groups.



Simple changes could improve cancer care now

There is huge potential for improvement in diagnosis, treatment and outcomes for men with prostate cancer from the way we collect and use data. Like other types of cancer, we can look forward to being able to match specific types of prostate cancer or patient characteristics to the most effective individual way of treating the disease.

At Prostate Cancer UK we are working hard to achieve a risk-based approach to diagnosis, understanding how men's clinical and genetic characteristics can help to target testing for a disease where the early stages are unlikely to have any symptoms. The linking together of datasets from some large-scale trials creates opportunities to understand this complex disease in a way that we have never achieved before.

We must be careful, though, to avoid becoming so gripped by the possibilities of the future that we forget to look at simple, pragmatic things that can be done now with data which would make a big difference.

Effective collection and recording of data could help to improve our understanding of how the Prostate Specific Antigen (PSA) test is being used. The test is used in detection of prostate cancer, as well as to monitor the status of the disease after treatment. It would be really helpful to be able to follow trends in the use of the PSA test for men who are not already diagnosed and be able to see how this links to other factors across the UK, such as local awareness campaigns. However, we cannot do this because there is no recording of whether a test is done for detection or monitoring reasons. This would be so simple to fix – it would just need PSA testing data to be linked with data showing whether men are diagnosed with prostate cancer.

Another example is a lack of recorded data showing how many men experience recurrence after treatment for early-stage prostate cancer. This information is critical for understanding which men are most at risk of recurrence and what the most effective treatments for them are. Solving this requires the inclusion of a 'recurrence' code in the Hospital Episode Statistics (HES) database, which contains details of all admissions, and its equivalents in the devolved nations. Ideally, this data recording would distinguish between biochemical recurrence, where no cancer is visible on scans, and recurrence which can be seen on a scan – this would tell us whether the recurrence is in the area of the prostate or not.

Taking this a step further would be clear tracking of an individual patient's journey from first test to death. This would show us exactly why men die from prostate cancer, so we could ensure that research and clinical resources are specifically and appropriately placed. It would also enable us to answer the right questions to significantly reduce the number of deaths from this disease.

Over 11,500 men die of prostate cancer each year in the UK and that number is rising. Data will play a key role in extending and improving the lives of individual men, and giving us the new knowledge and understanding that will enable the step changes in outcomes for the future.



Heather Blake
Director of Support and
Influencing at Prostate
Cancer UK

"We must be careful, though, to avoid becoming so gripped by the possibilities of the future that we forget to look at simple, pragmatic things that can be done now with data which would make a big difference."

The right data?

At Breast Cancer Care and Breast Cancer Now we know that being able to access the most effective drugs is one of patients' biggest priorities. And with good reason. For women with incurable secondary breast cancer this can mean extra months or even years of quality time with their loved ones. For women with early breast cancer it can reduce the risk that their cancer will return. We need the best new drugs to get to patients quickly – and at a price the NHS can afford.

Data are critical to this ambition. It informs decisions on both whether a drug should be available – and whether it should be available on the NHS.

Lack of the 'right' data can prevent a drug being made available on the NHS. Decisions rest on the length and quality of life that it provides. But data on overall survival can take a long time to collect, leaving a drug that may offer other benefits that we know patients value highly – such as increasing the amount of time before their condition progresses – sitting on the shelf, just out of their reach. This is increasingly likely to be the case as we move towards a future of personalised medicine, with more complex treatments targeted at smaller numbers of people.

The new [Cancer Drugs Fund](#) (CDF) is helping to address this problem – at least for cancer drugs. Drugs that currently have uncertain clinical benefit, but have the potential to be cost-effective can be recommended for use on the Fund whilst further data is collected, and a final decision made.

Since the Fund launched in 2016 nearly 30 drugs that might not otherwise have been accessible to patients have been made available through it. Drugs that are recommended for use on the CDF are now also made available to patients in Wales through the New Treatment Fund, and in Northern Ireland through the normal processes.

But we also need to ensure that decisions about which drugs are available on the NHS reflect the outcomes that are important to patients. This means knowing what is

important to patients and collecting data on it where possible. Patients must be involved at the early stages of clinical trial design. Collecting data on the impact of a drug in the real world can help to address this too. And evidence from patients can give real insight into how drugs measure up.

Real-world data could also help ensure that drugs are available at a price the NHS can afford by enabling the price to be adjusted based on the value it provides to patients and the NHS in routine clinical practice – which we know can differ from clinical trials. The [Accelerated Access Review](#) and [Life Sciences Industrial Strategy](#) both recommended the use of flexible pricing models to help support quicker adoption of innovation. Work is already underway to look at how outcomes-based pricing might be more widely implemented in the NHS.

We now have some tangible opportunities to help make all of this happen. A review of the methods NICE uses to decide whether drugs should be available on the NHS is just getting started. This needs to ensure that drug decisions take sufficient account of outcomes that are important to patients, and that patient evidence is central to the process and not just a tick box exercise. And NHS England is currently developing a framework that will provide companies with greater commercial flexibility, which could enable the introduction of outcomes-based pricing and other models.

It is vital that these opportunities are taken.



Baroness Delyth Morgan
Chief Executive at
Breast Cancer Now

"We need the best new drugs to get to patients quickly – and at a price the NHS can afford."



The evolution of cancer data to improve patient care

In Public Health England we are responsible for much of the data collection, reporting and analysis that drives the work of the whole cancer system in England, from public health to healthcare to research. Data are at the heart of everything we do: to quote a popular public engagement campaign that highlights the positive use of patient data to improve health services, Data Saves Lives.

Data underpins the NHS Long Term Plan and nowhere is this clearer than in the new ambition it sets for cancer: that by 2028, the proportion of cancers diagnosed at stages one and two will rise from around half now to three-quarters of cancer patients. There are two parallel challenges inherent in achieving this ambition: knowing the stage of all cancers diagnosed and identifying initiatives that will enable diagnosis at an earlier stage.

Despite the stage of a cancer being an essential piece of information used by clinical teams to decide on the best care and treatment for patients, the recording of this data was historically incredibly low. Just ten years ago we only had stage information on One in five cancers diagnosed in England. In 2012 the England Cancer Registry, now called the National Cancer Registration and Analysis Service (NCRAS), galvanised attention on improving the completeness of this data. This would mean that we would be able to accurately monitor cancer stage across the country, and better understand why some patients were being diagnosed when their cancer was at an advanced stage, when fewer treatment options are available.

We now have stage information on almost nine of out ten cancers, and are able to publish more regular data at a more granular level; a remarkable achievement and one that means we can confidently track progress against the new ambition set out in the Long Term Plan.

But how can this ambition be achieved? Good data is again essential. We need to take a data-driven approach to identify which advances will bring the most benefit to patients. This will mean exploiting the use of Artificial Intelligence techniques such as Machine Learning to link and analyse Big Data and uncover insights relating to earlier diagnosis. For example, looking at patterns of prescribing and visits to GPs prior to a cancer diagnosis.

Stratified screening programmes, based on the factors that we know increase the likelihood of a cancer diagnosis, will enable cost-effective targeted health checks for those most at risk of developing cancer. The expansion in our understanding and recording of molecular and genomic data will also enable tailored personalised diagnosis and treatment, not just for cancer but for many other health conditions.

Cancer treatment is an area where data has been used for many years to monitor outcomes, track trends over time and uncover unnecessary variation. There is a long track record of using surgical data to identify unwarranted differences in care. In recent years, NCRAS has expanded its focus to the whole of the care pathway, including examining the use of chemotherapy and radiotherapy on a national scale.



Lucy Elliss-Brookes
Head of Cancer Analysis at
Public Health England

"We should always remember that cancer data are about people as well as numbers... Without patient support, much of this work would not be possible"

The Systemic Anti-Cancer Therapy (SACT) dataset can be used to assess whether the outcomes of clinical trials are as good when the chemotherapy treatments are made available to a wider range of cancer patients. The toxicity of chemotherapy drugs can be measured consistently, and the side effects of treatment can be monitored across the country. The resulting data can be used to better inform clinical guidance and decision making, and thus support patients in making informed choices about the treatments available to them.

We should always remember that cancer data are about people as well as numbers: our work relies on patient-level information collected by the NHS, as part of the care and support of cancer patients. Without patient support, much of this work would not be possible.



Accelerating research and improving patient care

At The Christie we are constantly trying to improve cancer care so that each patient can have the most modern treatments precisely tailored to that person's genetic, social and physical circumstances.

We are increasingly able to say to patients "this is the very best treatment for you" rather than "this treatment works in the average patient but may or may not work in your case." This personalised approach also allows us to give people treatment that works and improve quality of life by avoiding toxic treatments which we know will not help a particular patient.

We can do all this because data-led technologies and innovations are transforming our understanding of cancer medicine. New ways of linking and analysing patient data are driving cutting edge research, transforming clinical practice and improving patient outcomes. Partnerships between the NHS, academia and industry – recently given a boost by [The Office of Life Sciences](#) – also allow us to pool ambition, insight and capabilities so that we can become demonstrably world leading in this field.

As an NHS Foundation Trust, The Christie works very closely with the University of Manchester, Cancer Research UK and industry partners to co-develop and deliver data driven ground-breaking research.

One example is the [Tumour Characterisation to Guide Experimental Targeted Therapy Trial \(TARGET\)](#) which uses analysis of a simple blood test (liquid biopsy) to provide the detailed genetic analysis required to help match patients to clinical trials and treatment.

This revolutionary approach detects circulating tumour DNA (ctDNA) shed into the blood stream. Traditionally, a tumour's genetic makeup has been determined from a biopsy, obtained through procedures which are not only invasive but also cannot always be repeated to follow changes during treatment. The use of blood samples makes it easy to obtain samples and to gather data about how the tumour changes genetically with different treatments. This means that from a simple blood sample we can determine the genetic make-up of a cancer and match the patient to either an established treatment or a trial of a new treatment.

Another example is adoption of the continuous learning health systems (CLHS) model which uses clinical, genomic and other data. Built originally on the concepts of evidence-based medicine and practice-based evidence, CLHS brings together science, research, informatics and culture to continuously improve patient care. It allows the use of Real World Evidence (RWE) – derived from data stored on Electronic Health Records (EHRs) – to represent patient populations of a particular disease which, because of exclusion criteria, cannot adequately be accounted for in clinical trials. RWE provides potential answers to these problems and helps answer the question "how did other real patients just like me respond to this treatment?"

The Christie, in conjunction with the pharmaceutical industry, have adopted the CLHS approach to give real-time access to meaningful data at scale combined with "advanced analytics" capability. The partnership uses genomic, clinical and patient reported outcome data from real patients to deliver faster and more efficient clinical trials. By speeding up research efforts we can improve treatment and outcomes for cancer patients now and in the future. Through this unique partnership, the ambition is for The Christie, and by association, the UK, to become a world leader in RWE driven research, discovering and developing the next generation of cancer medicines, realising the benefits of personalised healthcare and contributing to the fulfilment of the UK Government's Life Sciences Industrial Strategy ambition.

We are proud to be at the forefront of the personalisation revolution in cancer care. Working with University of Manchester, industry and charitable funders such as Cancer Research UK we are able to address real world questions with real world data and ensure that our philosophy of "team science" is brought to bear on ensuring that each of our patients receives the precise treatment that they need.



Roger Spencer
Chief Executive at
The Christie NHS
Foundation Trust

"We are increasingly able to say to patients "this is the very best treatment for you" rather than "this treatment works in the average patient but may or may not work in your case."

Building a picture of patient benefit

The number of cancer drugs approved for NHS funding has increased significantly in recent years. The UK is matched only by the US and Germany in access to oncology drugs launched between 2012 and 2016.

While improvements can still be made today, we also need to future-proof routes to access, and get a better sense of how much existing drugs are helping patients once they've been prescribed.

Cancer Research UK thinks a different approach to drug pricing, known as outcome-based payment (OBP) – which links the price the NHS pays for a medicine to the treatment outcomes for NHS patients taking the medicine – could help to achieve this.

Our recent report in partnership with Greater Manchester Health and Social Care Partnership, *Making Outcome-Based Payment a Reality in the NHS*, sets out how this model could benefit the NHS, medicines manufacturers, and patients.

Linking payment to patient outcomes can promote value for money for the NHS and ensure efficient spending. It can also support innovation, by signalling to manufacturers that the most clinically effective products will continue to be rewarded at a fair price. And by using post-approval NHS data, OBP can provide much-needed flexibility when the NHS is deciding whether to fund new drugs, which are increasingly coming to market with less complete evidence of their effectiveness from clinical trials. This could help resolve price negotiations with manufacturers faster – accelerating patient access to some new medicines.

However, OBP relies on comprehensive and high-quality data collection on NHS patients' treatment outcomes. We undertook focus groups and a patient survey to understand the views of people affected by cancer on which outcomes should be used to determine prices. The outcomes patients cared about most were mainly "clinical" outcomes, such as overall survival. Tracking of these outcomes is already well-established, through datasets such as SACT.

But for other outcomes – in particular long-term side effects or successful return to normal activities – it's not clear how widely or accurately this data are captured. Even where data are captured, it needs to be easily linked to other datasets for patients' outcomes data to be aggregated in the way OBP requires.

Implementing OBP, with a focus on building this more rounded picture of patient benefit, would therefore require more routine collection of this data, and strong links to be established between individual datasets.

Ultimately, this would mean more systematic data collection to develop a more holistic assessment of how a drug is (or is not) benefitting individual patients, and ensure they are receiving the most appropriate treatment for them. At a system level, this would also allow for a national-level assessment of the value delivered to NHS patients by a drug, and re-evaluation of the price the NHS pays for the drug.

Interviews we conducted with key stakeholders (including NHS, Government and industry figures) as part of our research found differing opinions on the degree to which such holistic data collection infrastructure already exists and is being used. That's why we'll soon be taking forward a new phase of research into OBP to identify what data are available within the NHS to support an OBP scheme based on the outcomes we highlighted in our report, and understand the options for collecting further data to fill in any gaps.

Introducing OBP is a system-level reform. But by focusing on collecting the right outcomes data, with the aim of promoting access to future medicines, OBP could be a crucial step towards a more data-driven and personalised approach to patients' experience of care – on the scale of the individual.



Emma Greenwood
Director of Policy and
Public Affairs at Cancer
Research UK

"Outcomes-based payment could be a crucial step towards a more data-driven and personalised approach to patients' experience of care – on the scale of the individual"

How NICE can keep pace with science

The pace of innovation in cancer care is unprecedented. But as science evolves, the National Institute for Health and Care Excellence (NICE) is being challenged to keep pace in its delicate balancing act of appraising innovative treatments that advance patient care in the context of an NHS with competing funding pressures.

The NICE Methods review is a unique opportunity to bring the NICE Appraisals process up-to-date. We must use this review to ensure patients receive the full benefits of breakthrough cancer innovations.

Our scientific understanding of cancer has improved, leading to the development of ever more targeted and sophisticated treatments. From the use of immunotherapies, cell therapy, combination and precision medicines we can help people with cancer live longer with a better quality of life. Progress is being made in the most challenging cancers where no improvements have been achieved in years and sometimes decades.

At the same time budgetary pressures, an ageing population and NHS capacity challenges, mean that choices around spending must be focused on the value-add a treatment can bring to both the patient and the NHS. NICE was created in 1999 and has played a crucial role in balancing the fiscal constraints whilst approving medicines to improve patient outcomes. Since its formulation, NICE has approved many crucial and life-saving medicines through its appraisals process.

Innovations are critical to advancing healthcare for patients – consider the examples of HIV and AIDS, and Hepatitis C where major advances have been made. A number of cancer medicines have also been made available via the Cancer Drugs

Fund which is a partnership between NHS England, NICE and pharmaceutical companies to provide interim access to new cancer drugs in England.

However, as it celebrates its 20th year anniversary, it is clear that the next wave of innovation is challenging NICE's historical processes and systems. The evolving nature of personalised medicines means that the evidence base is smaller. Scientific advances unlock new opportunities for more targeted therapies, which in turn address smaller patient populations, resulting in less mature data at the time of regulatory approval. In its current form, which has not undergone substantial reform since its inception, the NICE process is no longer able to assess adequately the value to patients and the NHS of these new treatments which have more data uncertainty.

These issues are in sharp contrast to the evolution of flexibilities adopted by regulatory agencies in the UK and across the globe who have taken steps to modify and accelerate the approval of medicines, particularly in areas of high unmet need. For example, the US Food and Drug Administration (FDA) has already approved several medicines that are not specific to a certain cancer type and it is increasingly common for medicines to be approved on what are known as surrogate endpoints (which are taken as indicators of a drug's efficacy, for example tumour shrinkage in a cancer).



Pete Williams
Business Unit Director,
Oncology Division at
AbbVie UK

"The pace of innovation in cancer care is unprecedented. But as science evolves, the National Institute for Health and Care Excellence (NICE) is being challenged to keep pace"

NICE should take account of potential limitations of the scope of clinical trial data and be reformed to accommodate more sophisticated and complex treatment regimens (e.g. precision medicine, multi-indication, and multiple-combination treatments).

NICE should also work with NHS England to enhance the positive impact of early access programmes like the Early Access to Medicines Scheme and the Accelerated Access Collaborative by allowing transformative medicines a greater flexibility when considering the likely data uncertainties. By making these reforms, NICE can cement its status as a world leader in health technology assessment and guidance whilst ensuring patients continue to access the latest cancer innovations.

Conclusion

The potential of data-driven approaches to cancer care

Advances in diagnostic and therapeutic technology in cancer care are creating unprecedented opportunities for improving clinical outcomes for patients and populations, allowing for early detection, improved diagnosis and better treatment design.

Cancer survival rates in the UK have doubled in the last forty years, however there is still significant variation in survival between cancer types. The NHS Long Term Plan has set out ambitious goals for improving cancer survival rates, committing to accelerate access to diagnosis through better screening as well as supporting those at increased risk of cancer. It is expected that by 2028, 75 per cent of cancers at stages one or two will be diagnosed, giving patients timely access to treatment and greater chances of recovery.

Effective use of data will be crucial to achieving these aims. The NHS holds comprehensive data on the health of the population, including information on diagnosis, treatment, outcomes and patient experience. Appropriate use of data could help redesign care pathways, develop new approaches to public health, and inform future research. As discussed by Macmillan, better use of data could help monitor incidence rates for cancers, as well as to uncover health inequalities in cancer care outcomes across the country. Similarly, as highlighted by Prostate Cancer UK, linking data from large-scale trials and clinical datasets could help build a more comprehensive picture of the patient journey, helping identify the recurrence of some cancers as well as monitoring the status of the disease.

There are also opportunities for harnessing new sources of patient data. As emphasised by Public Health England and The Christie NHS Foundation Trust, collecting outcomes data from real-world studies can help enrich clinical trial data and generate evidence on the impact of drugs. Wider use of 'real-world evidence' could help the NHS build a better understanding of how treatments impact people in their everyday lives, therefore helping deliver more personalised care.

However, data alone will not deliver long-term transformation. As highlighted by Breast Cancer Care and Breast Cancer Now, access to accurate, comprehensive and high-quality data is essential, with cases such as the Cancer Drugs Fund showing how an agile model for generating evidence can help bridge gaps.

Delivering a data-driven model for cancer care will also require current models for assessing the value of cancer treatments to be reformed. As argued by AbbVie UK, this will not only be essential for ensuring that patients benefit from the latest cancer innovations, but for innovations to deliver value both for patients and the NHS. Finally, for innovations to be meaningfully adopted, the NHS must implement pricing models that enable commercial flexibility and account for the outcomes that matter to patients. In this respect, systematic and high-quality collection of data on patients' treatment outcomes could help to develop outcomes-based payment models. As argued by Cancer Research UK, such a model could help accelerate patient access to new drugs, inform pricing models, and help monitor the outcomes they achieve for patients.



Claudia Martínez
Research Manager
at Reform

“Appropriate use of data could help redesign care pathways, develop new approaches to public health, and inform future research”

Related content

In October 2018, Reform published *A Data-Driven Approach to Personalised Cancer Care*. The report was kindly supported by AbbVie UK.