A Blueprint for the NHS – Fixing the problems

A St George's House Consultation

Report

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Executive Summary

A group of cancer and health policy experts convened at St George's House, Windsor (12-13 December 2024) to discuss the future of the UK health system, focusing on cancer care. This follow-up to a 2023 consultation brought together experts from public, private, and third sectors to advise decision-makers on the radical transformation needed to improve cancer outcomes and inform broader NHS reforms.

UK cancer survival rates lag behind other high-income countries. The Covid pandemic severely disrupted cancer care, leading to unacceptable waiting lists. Cancer affects 1 in 2 people, with incidence rising. Cancer care requires urgent reform and remains a major political issue.

Cancer treatment has become more expensive and complex. The challenge is high volumes of patients passing through intricate pathways at speed. These pathways are failing and urgently need to be rebuilt fit for the future leveraging modern technology, scalable processes and with appropriate incentives. Accountable oversight is needed into best value for money based on quality data and a refocusing on improving overall cancer survival and reducing inequalities. The UK still has world class front line staff but so often the "system" does not allow them to do their jobs. The NHS reforms—shifting care from hospital to community, prioritizing prevention, and embracing digital transformation—were agreed as critical for cancer care. However, fundamental changes in the culture, accountability and operating of the NHS is needed. Without this any new national control plan will fail. The data is clear—cancer care has deteriorated over the past five years, and without radical change, the crisis will become unrecoverable.

Key Policy Recommendations for Cancer Care Reform

1. Digital Transformation to improve communication, efficiency, and care delivery.
2. Rapid and decisive technology implementation to recovery and leap forward cancer care
3. Decisive Leadership & Reduced Bureaucracy: Strong leadership must drive reform, streamline decision-making, and cut administrative burdens.
4. Cultural change; at all levels and move from centralised dictats to facilitation of workforce led solutions
5. Implement a common minimum dataset to evaluate the impact of the National Cancer Plan
6. Integration and Partnership with coproduction of care
7. Implement rigorous elimination of wasteful use of resources
8. Integration of research and development and data sharing
9. Value-Based Healthcare: Leverage of high-quality data for national audits and research to ensure cost-effective, patient-centred care.
10. Independent Expert Task Force: Establishment of an expert body of clinicians to oversee strategy development and implementation, remove barriers, and ensure ongoing innovation. Providing real time robust oversight with economic evaluation of healthcare costs and clinical outcomes.

This paper presents a strategic framework based on expert consultation under the Chatham House Rule, distilling key insights from leaders across healthcare, policy, industry, and civil society. It defines the urgent trade-offs and structural reforms necessary to shape the National Cancer Plan and the broader NHS agenda for the next 10–30 years. Since this meeting NHS England has been abolished and there has been further cost savings across ICBs and Trusts. Global economics have now undergone radical change with the shift in American policy on defence and trade. At a pivotal moment for the NHS, this vision provides a decisive roadmap for achieving sustainable, high-quality cancer care and broader healthcare transformation.

1. Introduction

Changes in strategic context

The NHS, established in 1948, has evolved from managing trauma, infection, and maternity care, to offering free inclusive health services funded by taxation. Recent legislation emphasizes the need for comprehensive health services and the need to address inequalities, while the Health and Care Act 2022 aims to reduce bureaucracy and enhance accountability. However, the NHS faces a crisis marked by rising costs, chronic care needs, and increasing demands for elderly care due to an aging population. Local authorities manage social care, but it strains healthcare resources. Reorganizations within the NHS have created confusion in accountability, with significant waste and insufficient funding for effective patient services. The Covid pandemic put further pressure on a failing health system

After the Covid pandemic, it is vital to recognize health as an economic asset rather than merely a cost. Important discussions and political agreement are essential for the long-term planning and radical change which is needed. Simply increasing funding is not a solution; a long-term plan for comprehensive change is necessary. Political cycles continue to create challenges. Addressing social health determinants and engaging in national discussions about the impact of the nation's health on the economy is crucial.

The political importance of the NHS

Participants supported the new government's proposal to be courageous and bold and enable the country to take decisions about the NHS. Long-term cross-party consensus was required to help with delivering unpopular messages.

Cancer care as a template for change across the NHS

It was considered possible to shift cancer positively by the next election with some very specific changes and through uniting people around a common cancer plan. Lessons learnt could help the much harder shifts across the whole NHS.

Background to cancer care

Although UK cancer survival has improved in the past 50 years, it still lags behind many other high-income countries, ranking for example, 28th out of 33 countries with similar wealth and income for 5-year stomach and lung cancer survival. The cancer care pathway broke down significantly after the Covid pandemic and has not recovered resulting in unacceptable cancer waiting lists, with no clear plan to reduce the impact of this. Cancer now affects I in 2 of the population at some time in their lives and there is an expected increase in cancer cases of 30% by 2040. Cancer treatment is complex and needs systems to work efficiently and with good communication. It is unable to work in the way needed and is part of the system that the Darzi report described as 'broken'.

The challenge

Cancer care in the UK is at its most critical point in a decade, with over 500,000 patients waiting beyond the recommended 62 days for treatment over the last ten year and survival rates among the lowest in the Western world. Growing delays have become normalized, competing with broader NHS backlogs and workforce challenges, while cancer incidence is rising. Unlike the radical and well-funded successful Labour 2000–2008 Cancer Plan, today's NHS faces financial and systemic constraints; there is a backlog and cancer care is far more complex and expensive. The recent UK economic forecast and likely need for increased defence funding, as well as global economic concerns adds additional pressure. However, without urgent action, cancer survival rates will continue to decline for decades. A cross-party consensus is essential for long-term NHS reform. Cancer care remains the salient top priority for patients and so remains a major political issue.

Inspiration from abroad

Denmark was highlighted as a positive role model in cancer care. It had initially one of the highest instances of cancer mortality in Europe. However, with an ambitious plan they prioritised cancer and turned their cancer survival around.

However, it was acknowledged that Danish politics is more consensual than the UK's and that consensus about improving cancer care crossed parties. Cross party consensus on the Cancer Plan must be prioritised to remove the repeated upheaval caused by the election cycle.

Announcement of a new National Cancer Control Plan

The Rt. Hon Wes Streeting, Secretary of State for Health and Social Care for the UK, announced his decision in December 2024 to publish a National Cancer Control Plan following the determined work of the Health and Social Care Select Committee in collecting and acting on evidence. The International Cancer Benchmarking Partnership (ICBP) has shown unequivocally that countries with consistent national cancer plans have better cancer outcomes. Since the meeting a call for evidence was announced on World Cancer day on 4 February 2025 and in March 2025 the abolition of NHSE was announced. Geopolitical changes in early 2025 has meant there will be less funding than hoped and the NHS has been asked to live within its means.

2. Where are we now and what happens if we don't change?

- The obesity crisis has resulted in widening health inequalities and is responsible for driving some of the increase in cancer incidence.
- Mental health issues are fuelling an increase in sickness benefits
- We have less people returning full-time to the workforce post Covid.
- Exercise levels across all age groups remain insufficient.

There is growing concern that because the NHS consistently provides for us, we are not taking sufficient responsibility for our own health and therefore not valuing the cost of health care. Poor care is resulting in increased patient safety risks and litigation costs.

Record waiting lists are leading to an increased adoption of private health care plans which are pushing up health insurance premiums, resulting in fewer people being able to afford complete coverage or able to afford their premiums.

However, **the most immediate threat was seen as the collapse of primary care**.

There are solutions available to address some of the identified issues, but this requires brave and decisive action by those who can truly enact change across the wider NHS. Examples include:

- bringing together and coordinating health and social care will transform how we can use our hospitals.
- using 'usable' technology to support seamless patient transitions across the boundaries of care.
- providing clarity to GPs - regarding their responsibilities and to whom they are accountable to.
- driving recruitment in the most at-risk areas including Primary Care
- removing the "sticky-middle" of bureaucracy in the NHS- enabling the right people to make the right decisions.
- removing the estimated 35% financial wastage to free up the resource needed to help fund this new way of working.
- linking commissioning of care (reinstating the link between GP ordering care and commissioning care).
- co-producing and co-ordinating solutions with the public, charities, support groups as well as the front-line workforce in order to amplify resources and improve quality of care.
- using digital technologies to improve communication, productivity, and increase data and feedback to improve patient safety and patient-reported outcomes (PROs) - when implemented appropriately.
- using lessons from the private sector in developing and commissioning value-based cancer pathways focussed on cost, quality and outcome measurements.

- retaining and further enhancing the workforce. The UK has a world class workforce which can deliver if valued and supported.
- accelerating and expanding patient recruitment to UK clinical trials through collaboration with the pharmaceutical industry that improve patient outcomes- navigating the issues that have been identified post Brexit and taking full advantage of the potential opportunities to be disruptively progressive.
- making the UK a more attractive market for a sustainable life sciences industry to thrive in.

The necessary changes can be made but requires change in culture, leadership, accountability, dialogue with the public, infrastructure and vision

3. Guiding principles for the changes needed

Vision

UK health policy needs to be grounded in a long-term, bi-partisan grand vision. This needs to make a frank assessment of the nation's health and the NHS's strengths and weaknesses. It also needs to provide hard-headed answers to the challenges for moving from the current unfit for purpose NHS to one fit for the future. The public need to be engaged in a far more meaningful way with health education, responsibility and co-production and decision making prioritised. Front line staff need to lead clinical decision making and support shared clinical decision making with patients.

The National Cancer Plan needs its own specialist ecosystem to manage rapid access to diagnostics, to enable referrals to the right specialist teams and to access the right treatment. International data suggests that a 4-week delay in treatment can reduce cancer survival by 10%. Within the specialist ecosystem there is a need for high quality and evidence-based treatment choices including access to clinical trials and provision for specialist survivorship and palliative care services.

A National Cancer Plan needs to:

- Have at its core a group of cancer experts, independent of government and the NHS to help drive the plan from conception to implementation and in the rapidly changing environment needs to be nimble and responsive and innovative
- develop a sense of urgency around achieving the short-term objective of reducing waiting times for both diagnosis and initiation of cancer treatment and a longer-term objective of how best to meet an increased future demand for services.
- embrace partnerships with all stakeholders (the general public, patients, NHS staff, community groups, charities, industry, private health care providers and insurers, and the social care sector amongst others including academia).
- shift resources from secondary to primary care providers and the community where linked patient records achieve the necessary continuity of care – the money should follow the patient
- leverage the transformation of real-world data and artificial intelligence towards the identification and implementation of evidence-based value-based care pathways for cancers where survival outcomes have the greatest potential to be improved.
- proactively prioritize risk stratification of patients, earlier disease detection, appropriate application and funding of diagnostics and treatment, and one that enables greater empowerment of patients through enhanced health literacy initiatives that encourage, and support individuals to take greater care of reducing their risk of developing cancer and other diseases.
- reward innovation and timely adoption of best practice treatment and care.
- foster a healthy environment for the life sciences industry where the UK is seen as an attractive market to develop and commercialise new medicines. (The life sciences sector is a UK success story, but in recent years other countries like Denmark have increased capabilities and made progress on cancer at a faster pace. Last year, for the first time since 2012, the UK had no Initial

Public Offerings in life sciences. Unless action is taken, the UK's ability to attract the best researchers, innovative companies and life science investors will be greatly reduced).

- ameliorate inefficiencies through reducing waste, the use of ineffective interventions and practices.
- instil confidence and pride in the Government from the perspective of both its employees and taxpayers alike that it can run an efficient and effective health service that delivers outcomes on par with other countries.

Cultural changes

To underpin all the changes, cultural shifts are required. Without them changes will fail. The UK has shown it can move at pace, such as in the pandemic, but it needs a clear decision on priority, and one person in charge – accountable- to ensure the correct advice is sought and that change is implemented unilaterally. Similarly patient safety needs a culture of openness and valuing lessons learned. Incentives need to be reviewed with the emphasis on improving patient care and outcomes. Collaboration across NHSE, DOHSC and relevant clinical bodies is desperately required.

Funding

The Treasury needs to see health as an asset and investment and not just expenditure[1]. Long-term planning is vital to improve outcomes for cancer patients across England, coupled with reform and funding for the NHS[2]. Mr Streeting acknowledged public anxiety about the level of funding the NHS has as a proportion of government spending. "*It's really important to demonstrate that it is investment for a purpose and to deliver real outcomes, and I think one of the ways in which we do that is to outline - at the same time as the immediate priority of bringing down the elective care backlog, which is going to be a big political focus - we also need to demonstrate that over a longer term period we're making the right choices now to put the NHS onto a more sustainable footing*."[3]

The current funding model in the NHS involves rationing of care either overtly or subconsciously. Difficult but clear decisions are needed to be made as to what the NHS can and cannot provide. This will involve stopping some care to enable other care. This need to be proactive and based on evidence. The Public need to be brought into the conversation.

Cancer care within the current system is becoming unaffordable and will continue to do so with increasing costs of systemic therapy and the increasing numbers of patients being diagnosed and living longer with disease.

Cost Savings

Discussions on finding money from within the current budget provided ample examples of where money could be saved; waste (around 35%) was identified in equipment, medication, contracts, workflow. Examples from industry including private health care where senior managers are regularly and constantly charged with identifying waste and devising solutions to save money (without compromising on services or quality). Being creative rather than relying on the 'we have always done it this way.'

The "sticky middle" of bureaucracy needs to be clearly identified and removed. This will bring about a game change in terms of freeing up resources and time.

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[1] The Health Foundation, Louise Marshall et al, Briefing: The nation's health as an asset Building evidence on the social and economic value of health. https://www.health.org.uk/sites/default/files/upload/publications/2018/The%20nation%27s%20health%20as%20an%20asset.pdf, accessed 9 Jan 2025.

[2] UK Parliament. NHS0023 Written evidence submitted by Cancer Research UK. https://committees.parliament.uk/writtenevidence/113672/pdf/, accessed 9 Jan 2025.

[3] The Royal Society of Medicine, Wes Streeting MP's plan for a more sustainable NHS. Published 18 July 2022,https://www.rsm.ac.uk/latest-news/2022/wes-streeting-mps-plan-for-a-more-sustainable-nhs/ accessed 9 Jan 2025.

Primary Care -List based practice

This model was effective but there was an opportunity to restore the referral and commissioning role of primary care - giving responsibility back to GPs. There will be an opportunity cost, with GPs already overwhelmed and so workforce expansion will be needed. This may be more effective than the current extra layer of commissioning. Downsizing of commissioning structures will save money, time and create more accountability.

Increased taxation on causes of ill health and reduced taxation on good health

Tobacco taxation assisted in the reduction of people smoking. Taxation on vapes – particularly those flavoured which encourage children to take up vaping need to be reviewed.

Ultrahigh processed food as well as alcohol minimum pricing should be introduced to encourage a move to more healthy food choices.

Differential business rates and council rentals should consider favouring local fruit and vegetable shops over betting and vaping shops which currently blight our High Streets.

Blended mixed models

Co-payment models need to be considered. This may be acceptable to the public with evidence that the poorest were protected. It should not be seen as a political stance.

Encouraging patients who have access to private healthcare to use their policies rather than rely on the overburdened NHS. Many patients and GPs prefer to use the NHS for treatments such as cancer believing that the private sector may not be as regulated or have access to the same support systems.

To support patient choice and evidence quality both in and outside of the NHS, data submissions on outcomes must be submitted from all healthcare facilities - so that trends can be identified and early action taken.

Innovation in medicines development and reimbursement

The UK has a unique opportunity post-Brexit to run commercially sponsored registrational clinical trials of cancer medicines in an expedited and cost-effective manner. With its ethnically enriched population and significant experience in participating in clinical trials, it could screen inclusion criteria of clinical trials posted on www.clinicaltrials.gov against the characteristics of patients recorded in electronic patient records to speed up patient identification for such trials. Opportunities should be made available to patients to undergo genomic testing prior to treatment wherever possible and to have this data recorded in the EPRs so that entry into relevant clinical trials of personalized medicines can be expedited. Using genomics appropriately should be both cost effective and beneficial to patient outcomes, extending quantity and indeed quality of life- identifying treatments that are likely to work well and equally importantly treatments that are unlikely to provide benefit, despite their potentially considerable cost.

Genomics should also be driven by family history in the bid to identify those at risk earlier to ensure they are provided with a more focussed screening programme.

Using genomic services via a reputable provider should identify where any suitable and open clinical trial options are available for individual patients. The costs of running randomized clinical trials have risen exponentially due to regulatory and HTA requirements mandating randomized comparisons with standard(s) of care. However, the UK falls behind other countries in granting reimbursement of these medicines at a price that rewards innovation. As a result, UK patients do not get the full opportunity to benefit from scientific advances.

There is an unprecedented opportunity to take full advantage of this opportunity. Speed up patient access to clinical trials in the UK and the regulatory and reimbursement approval of innovative cancer medicines. Remove the regulatory requirement in cancer to undertake RCTs and allow manufacturers to secure marketing authorization on the basis of single arm experimental trials enriched with control arms consisting of patients receiving standard(s) of care using real-world evidence. NICE is well

equipped through its Real-World Evidence Framework to evaluate these types of secondary data for both regulatory and HTA approval4.

The solution involves using existing technology to identify eligible patients faster, utilizing electronic patient records or SACT data to automatically screen patients based on trial inclusion/exclusion criteria. Medicines manufacturers can expedite regulatory approvals by submitting adaptive trial designs to Research Ethics Committees. This will reduce clinical development costs and allow manufacturers to maximize patent duration, creating the first incentive for UK medicines manufacturers to invest in clinical trials.

For innovative cancer medicines that have immature data on patient outcomes (since data on overall survival may take many years to be available), NHS England and NICE could agree to reimburse cancer medicines at a price that falls within an agreed willingness to pay threshold subject to patients achieving a pre-defined outcome from treatment at an agreed time point.

If patients fail to achieve this outcome, then a given % is paid back to NHS England. What this process enables is faster (and a higher rate of positive) reimbursement decisions which can be facilitated under conditions of uncertainty, where the risk is taken by the manufacturer if the outcomes do not deliver. Similarly, if patient outcomes exceed expectations, then it may be reasonable to increase prices accordingly. This creates a more flexible and iterative approach to drug pricing that is value-based and outcomes-focused. Currently, there are financial disincentives put in place by NHS England and NICE that discourage the use of outcomes-based payment schemes by manufacturers. This acts as a barrier to patients being able to access innovative medicines. They penalize medicines manufacturers by forcing them to offer higher price discounts if they wish to use an outcomes-based payment scheme, which does not help the UK achieve value-based healthcare.

Public conversation about choices and improving health literacy

There is a clear need to get the public on-side concerning the choices that need to be made in the NHS. Public conversations in citizens forums could assist. Health literacy needs to be taught as part of the national education curriculum from an early age. General open discussions need to be had about disease causation, dying, the resources available, the psychology of illness. Celebrities have been helpful in many areas in starting these conversations- but these are short lived windows of education and much of the good work can be undone via social media where health content is unregulated and where celebrity entrepreneurs have been identified as spreading health untruths. Sir Nick Clegg (previously at Meta) may be useful to consult with.

The mobile phone is a huge health assistant in our pocket and should be used more to normalize health education, communication and public health. The NHS App was considered to have potential opportunity across the health sector and already has a wide network of users.

Expertise

Front line staff have been marginalized in the management of the NHS over the last 30 years.

Huge concerns have been raised about the amount of time clinical staff are spending on computers satisfying the increasing administration tasks devised by non-clinicians which were supposed to make their processes more streamlined and efficient. One of the most startling changes has been seen with the dismantling of the clinical team structure, meaning a dangerous loss of continuity of care and overall responsibility.

Speaking up and challenging the group think is still often career limiting despite the protections put in place.

The evidence from Covid shows it was front line staff who were responsible for devising so many of the operating solutions- with multidisciplinary teams working freely together for the betterment of patients.

[4] NICE Real World Evidence Framework, Corporate document [ECD9] published: 23 June 2022. https://www.nice.org.uk/corporate/ecd9/chapter/overview accessed 9 Jan 2025.

Policy makers need to listen to these front-line staff who should be empowered to make positive changes.

Amplification

Small changes which have big effects must be sought out, replicated, prioritized and encouraged. Systems where patients can collect their own data 'real time' will be vital. In cancer the wider use of validated patient reported outcome measures could transform the quality of follow up and data gathering. Use of targeted support and information can lead to more streamlined care with patients being signposted to what they need rather than a one size fits all approach.

Mandates from the centre

The public want and need a well-run health service, which means centralised clear decision making rather than the current distributed lack of decision making and accountability.

The Government should be clear on what should be mandated to improve health care; this is the type of care which the tax payer is paying for and expects the NHS to deliver.

Executive power must include: access to timely and accurate patient data for use to support value-based care and from which to derive national policy. This in turn will support access to the latest treatments and techniques and a move away from the postcode lottery access.

Integrated patient-based digital transformation

Technology plays a key role in the future of the Health Secretary's plans for the health service. Both to "improve the back office and to improve the patient experience and the navigation around the NHS," as well as making effective use of "ground-breaking new treatments and technology that's already being rolled out and new developments that are coming down the lines."

Cancer is an excellent example of how integration of digital patient data can improve care at reduced cost. In the past individual oncology patient medical records were often separate from general health care records as the care was multifactorial and integrated. The extended and digital equivalent will allow the individual patient pathway to be followed and monitored; with integrated medical records all care providers will have access to the information required to support decision making. Patients reported outcomes can be collected and integrated with treatment and outcomes. Alerts and side effect information for both patient, family and primary care and others will be available. The system designed for scale will be needed. The NHS is best placed to capitalize on such systems and there are many questions regarding the use of the successful NHS app and how far that can be used to support patients on treatment.

Political engagement

Health and, in particular, cancer care is a political hot potato. Political engagement from all parties is therefore needed so that the 5-year election cycle does not continue to disrupt improvements.

The consultation from St George's House aims to provide expert opinion on which to inform politicians, supporting them with the complex decisions that are required at a time when advances in treatment are coming at increasing speed and with the technology often outstripping the evidence.

General Practice as a single point of failure

Primary care is at breaking point. It is acknowledged that they receive only 6% of the NHS budget yet carry out 90% of the clinical contacts, with increasing workloads delegated from secondary care or caused by delays in secondary care. Some immediate solutions are needed, and suggestions include;

- addressing recruitment and retention
- stopping the unlimited liability for GP practices
- allowing quick implementation of IT that will help remove and short circuit blockers such as Integrated Care Boards (ICBs). ICB staff lack the expertise for tech decisions; centralize and streamline approval to enable quick primary care adoption.

- allowing a mixed economy; NHS GP surgeries should offer private services, like dentists and consultants, to generate funding and support NHS care.
- removing unnecessary reporting; adopting modern clinical computer systems will allow seamless data access and effortless integration
- ensuring GPs are seen as a valued part of the health service
- allowing GMS contracts to be held by LLPs to limit the liability faced personally by GPs who run NHS GP surgeries.

By bolstering primary care, this will enable the shift from hospital to community, sickness to prevention and streamlining commissioning.

With the increasing advances in cancer care the need for care closer to home provided by GPs and their teams will provide more efficient treatment pathways and support more patients to access care outside of hospitals.

4. Strategy in Action: Three questions for cancer care

The National Cancer Control Plan needs to be developed with a wide-ranging expert group and implemented immediately. The goal of how the UK will be within the top 3 European countries for 5-year survival outcomes should be clear. Getting up to the European average will save 18,000 lives a year- but the goal should be better than this.

International evidence is clear on what is needed in a national plan and UK experts have concurred and published widely on this. We know what to do, we just need to make sure it is comprehensive and delivered; the piece meal Covid recovery plans failed. Clinical research infrastructure also needs recovering. Funding needs to be over 5 years and not subject to annual re-negotiation.

The ultimate aim is the improvement in 5-year survival.

Surrogate endpoints will also be required:

- **improvement in the percentage of patients diagnosed at an early stage** will assess the recovery of the screening programmes and patient/GP awareness/functionality.
- **improvements in the 62-day treatment pathway** will be needed to ensure the whole cancer pathway to treatment is recovering.

The planned x3 shifts in NHS strategy were discussed in relation to cancer care.

1. Hospital → Community

A number of changes were needed to make this shift successful for cancer care;

- Clarity of who is responsible for cancer care in the community - this needs to be general practitioners. They need to be given the same parity of esteem as hospital consultants and given the funding to do this.
- Community teams need to be comprehensive, be co-created with professional groups, the voluntary sector and the family and should identify clear lines of responsibility.
- These teams need to be empowered to work flexibly and be available 24 hrs /7 days a week. This will need and increase in the proportion of the NHS budget to Primary care (currently only 6%) and the recruitment and retention crisis will need to be resolved.
- The social determinants of care need to be addressed.
- It was seen as important to get rid of the "sticky middle" to avoid bureaucracy and waste.
- Cultural change and communication are seen as vital. Doctors during their training need to spend quality time in GP practices and nurses need to be given greater scope in their specialist roles.

- Palliative care requires increased support to enable patients to make earlier choices over care, to provide patients with enhanced symptom support outside of the hospital setting and to provide a smooth transition to End of Life Care at the appropriate time.
- Decision making needs to be supported by data using digital technology; patient individual cancer records and AI. Interoperability specifications (already quite clear and mandated) need to be enforced by commissioners. Straight to test algorithms should be introduced. Communication channels with named consultant / key worker in secondary care should be identified.
- Single point of contact needs to be understood and communicated.
- Addressing health inequality is essential. Deprivation in neighbourhoods and investment needs addressing through the collection of data[5], new community workers that are trusted and have cultural input should be introduced to GPs and the wider healthcare community to support improvements.
- Primary care is the only NHS sector not running a deficit due to the partnership model, which should be encouraged to prevent secondary care-style deficits and maintain maximum efficiency within current funding.
- Commissioning roles should include incentives for efficiency and waste reduction, similar to fundholding in primary care so savings made to budgets can be invested in other primary care /community projects.

2. Sickness → Prevention

This is relevant to cancer in terms of screening and prevention. Several factors have been identified that cause ill health and cancer: sedentary lifestyle, diet, smoking, alcohol consumption and social deprivation. More spend will be needed on promoting wellness, with the potential for this to be paid for by taxes on the causes of sickness.

Tackling the obesity crisis which is driving more cancer cases is vital with a range of measures which could potentially include; taxation on ultra-high processed food, introducing a minimum alcohol unit price, rebates on rates and leasing in on healthy eating 'greengrocer' stores. Data needs to be reviewed on the long-term impact of weight loss injections and health inequalities.

Other countries have gone further in promoting a healthy lifestyle. In Singapore rewards are given to people hitting their step count per day. This has also been mirrored by Vitality Health Insurance where customers are rewarded for healthy living. In all areas of government increasing exercise should be prioritised: in schools, in the transport infrastructure, access to leisure centres etc, leveraging communication through social media.

Increase in screening infrastructure is needed with easy access to scanners. A review of how screening takes place should also be reviewed. Is there a way to capture women who attend for breast cancer screening to have their cervical screening on the same day- and be given their FIT test to complete too? Can we make screening easier to access- can we bring it into the community and capture more. A campaign to increase screening for cancer is urgently needed- and our systems should be reviewed alongside this.

Phones in our pockets could be used as an education tool as well as AI and social media.

3. Analogue → Digital

The benefits were recognised but barriers to introduction, and effective integration and use were identified:

- Patients were concerned with data security (cyberattacks) and misuse of data (selling to third party etc). However, it was recognised that many cancer patients are happy to share their data to support

[5] HOUSE OF LORDS Integration of Primary and Community Care Committee Report of Session 2023–24 Patients at the centre: integrating primary and community care. 15 December 2023. https://publications.parliament.uk/pa/ld5804/ldselect/ldcareint/18/18.pdf accessed 9 January 2025.

further research. A national independent oversight authority should be created to resolve such issues and reassure patients of anonymity.

- The secure data environment (SDE) federated platform has been negotiated for the NHS and its benefits and security communicated amongst health care providers.
- The introduction of the Electronic Patient Record has been expensive and poorly executed. Mandate integration of secondary and primary care EPRs using global standards (HL7, MESH, FHIR) to enable seamless data sharing, reduce unfunded workload transfers, and support collaboration through new market entrants. With multiple solutions available no one key solution has been identified as being superior. Implementation of systems continue to take up far too much of provider IT time and there is evidence where operational introduction has caused patient safety issues. Trust IT time devoted to this should be capped to ensure other IT issues were not neglected. A move to individual patient records was needed to put into effect the hospital to home strategy and to maximise data usage to improve patient care.
- Communication between commercial providers of IT infrastructure and migration with clinical need was needed. Not all spoke the same language and the specification of the output could be suboptimal. Centralisation of skill in such interaction would help, particularly for a complex area such as cancer.
- Regulations needed to be reviewed and disrupted. There are many lessons to be learned from how the relaxation of regulations during Covid helped but remained safe and effective.
- The principle of the patient owning the data was secured but there also needed to be a conversation about the need for centralisation and analysis of data for improved patient care as well as for informing policy.
- The implementation of routine capture of patient reported outcome measures (PROMs) needs to be a joint effort between patients and healthcare decision makers. We need to measure what is important to patients and their families as well as what 'we' feel is important.
- NHS Trusts need to be given confidence in the priority of IT implementation.
- Introduction of MedTech-methodology for rapid HTA assessment and adoption is needed and not be confined by inappropriate assessment tools. There should be a national body agreeing and approving rapid roll-out rather than individual local reviews.
- Reduced reliance on the existing duopoly (EMIS and System One) is needed in primary care by promoting new entrants in the clinical system market and require existing providers to integrate with new systems, ensuring seamless data sharing. New clinical systems should use cloud-based architecture and global standards (e.g., FHIR APIs) to enhance cross-organizational data access and continuity of care.
- The NHS must streamline AI tool authorization, overcoming unclear processes and ICB CSO refusals.

5. Conclusions

This expert group were keen to support the Government and DHSC as they navigate through the production and delivery of a National Cancer Plan. Gaining insights from expert leaders independent from government and public bodies is essential. These leaders are deeply aware and appreciate the multiple challenges ahead and are committed to providing the best advice possible. They could also support specialty forums to ensure all voices are represented and to advise on implementing significant changes at grass roots level.

The multidisciplinary expert group was unique in their range of expertise and hope to be of service to the Rt Hon Wes Streeting as he moves his plan forward.

Appendix 1. Summary of individual solutions

Below is a summary of the range of suggested interventions from individual participants. It should be noted that the range of participants expressed a number of ideas and should be emphasised that not every participant signed up to every recommendation.

1. Integration and Partnership

Suggested interventions

1. Develop and implement a healthcare unification theory.
2. Bring back cancer networks linked to ICBs.
3. Link life sciences, medical technology and healthcare to drive growth in life sciences and ensure the benefit of research reaches healthcare.
4. Develop partnership with the private and third sectors and don't just come to them in a crisis. Make partnership business as usual.
5. Strengthen social care buy implementing proposals from reviews such as the Dilnot Commission[6] so that people with multiple comorbidities have the support they need to live independently for longer.
6. Provide better approaches for living with and beyond cancer. Reduce touchpoints for end of life care.
7. Divide healthcare budget into wellbeing and treatment to ensure that the health service focuses on both its missions: to enable health and wellbeing and to care for the ill or dying, in this order.

What will happen if no action is taken

Continuity should be a thread through all actions. At the moment the infrastructure for public health is fragmented. There are too many turf wars with other sectors. Without good integration of systems and partnership with other sectors, the NHS will continue to have more problems dumped on it that previously have been dealt with in other spaces. This is already happening with some mental health concerns such as complex grief. The spaces that used to deal with this have been lost and patients are now going to GPs instead.

Possible objections and barriers

Some participants disagreed with the idea of a separate budget for a health and a wellness service (Intervention 7). They emphasised that these are two different sides of the same coin and need to be linked closely

2. Coproduction

Suggested interventions

1. The cancer plan should involve consultation with both the NHS workforce and the public, to form a bottom-up plan. As many views as possible should be included; they should be listened to and implemented. Patient experience should be at the centre of the plan, including experience before, during, and after treatment.
2. Set up a multidisciplinary delivery board for cancer care with patients and non-clinical members. A national conversation followed by formation of these multidisciplinary groups was suggested to make everyone feel part of the solution.

[6] https://webarchive.nationalarchives.gov.uk/ukgwa/20130221121534/http://www.dilnotcommission.dh.gov.uk/our-report/.

3. Distribute power across the NHS. Empower people in a consistent, national way.
4. Connect government and people to build wellness. (See **Reaching the Public and Education**)
5. Patients should be involved in decision making and research. This needs to happen on both a micro and macro level. Shift NHS culture from 'doctor knows best' to 'patient knows best'. Clinicians should be facilitating not paternalistic. Participants stressed that the NHS is a 'service' not a 'product': it relies on participation of patients in decisions.
6. Give patients and families more control while they are waiting for diagnosis and treatment.
7. Transfer legal ownership of medical records to patients, with a legal allowance for clinicians to use them. This could tangibly change the power balance between people and clinicians.
8. Coordinate a national roll out of Patient Recorded Outcome Measures (PROMs) and Family Recorded Outcome Measures (FROMs)

What will happen if no action is taken

Coproduction is essential for the NHS to truly have people at the centre of what it delivers.

Implementing a top-down cancer plan will result in people asking 'how do you expect me to do that?' Many groups who are voters are engaged with the NHS and if the NHS fails to make them feel engaged this will have a negative political impact (or a positive one if they do feel empowered).

Patients are now entering the consulting room better armed with knowledge about their symptoms and condition. Clinicians need to be able to facilitate this, not see it as a threat. Politically, problems occur when families don't feel in control of their treatment and treatment of loved ones. Getting the family in the right place at the start of treatment also makes a big difference for clinicians.

Possible objections and barriers

Participants warned that there are multiple stakeholders to negotiate, with varying levels of agency, authority, and potential to be helpful for a cancer plan (Intervention 1).

Participants felt that the NHS struggles to devolve power (Intervention 3). Some wondered whether regional plans were more important than a national cancer plan to give people more of sense of control. Others argued that a national plan will allow regional plans to be developed.

Some participants thought that patients should not be direct members of a cancer care delivery board (Intervention 2) because this would simply be tokenism. The people who become patient advocates and board members are better informed than average and more able to take action. Instead, patient voices should be properly sampled for a representative view of their needs, and this should be fed into boards. Samples should be stratified according to the groups diseases affect.

There was a warning that change in culture (Intervention 5) is an output not an intervention. More consideration of what drives culture is needed.

3. Workforce

Suggested interventions

1. Give the workforce a clear signal that there will be positive change for them.
2. Get clinician unions on board in creating change of practice among clinicians.
3. Pay people for the outcomes they achieve based on the cancer plan.
4. Ensure everyone with a clinical qualification undertakes some clinical work to keep their experience current. This experience should include community work, in multiple different locations to ensure experience of diversity. (See **Shift to Primary Care and Community**)
5. Allow recruitment of unemployed healthcare workers, especially GPs, which is currently difficult as it can't be done through core processes. Make it easier to recruit from migrant communities too. This should be done through core GMS contracts as the current dictats allowing and funding only PCNs to employ new GPs has failed. GMS delivers more efficiently than PCNs.
6. Colleges should be more flexible around training and transfer between healthcare settings.

7. Learn from industry how good businesses take their workforces with them when implementing future plans. (See **Integration and Partnership**)
8. Consider the impact of role models.
9. Make sure health care is available 24/7 and combat 5 day working weeks. Disease does not respect clinicians being clocked off.
10. Improve retention before recruitment. Make sure the NHS is a good place to work, where it is easy for people to do jobs they care about. Improve support around emotionally difficult parts of the job, such as giving oncologists better training for having 'bad news' conversations with patients. At the same time get rid of unnecessary training. Review training regularly and make sure it is relevant.
11. Improve the experience for community health workers, who are very low paid but known and trusted.
12. Allow training up of care assistants to nurses on the job. This can be done more quickly than training new cohorts. Give care staff a career pathway with training and benefits.
13. Allow recruitment of unemployed healthcare workers, especially GPs, which is currently difficult as it can't be done through core processes. Make it easier to recruit from migrant communities too.
14. Use technology to cover workforce gaps. Plan for educating the workforce in how to use this technology, and finance this training.
15. Reduce risk averse approaches by getting rid of the 'sticky middle' layer of administrators and low-level managers who want to choose the easier path of not doing something. These can be replaced with technology, providing savings on salaries and more efficient services for the rest of the workforce. (See **Waste and Efficiency**)
16. Family members are an untapped workforce and can support their relatives if given training.

What will happen if no action is taken

Healthcare is currently unsustainable due to lack of workforce. Doctors and nurses are being lost rapidly, including those emigrating, those leaving clinical practice to do something else, and those moving to private healthcare.

The culture in healthcare is currently very defensive, which blocks innovation. Participants felt that care legislation is impeded by a lack of connection between those at the top, who have great ideas, and those at the bottom, who also have great ideas and know the pressures of implementing them. These groups are impeded in implementing ideas by a 'sticky middle' layer of staff that block innovation.

At the moment the situation appears to have no end and no plan for improvement. The government needs to engage everyone in a live cancer plan now to improve morale before it is too late. It is very important to provide hope.

Possible objections and barriers

Some participants felt that the problem of morale in the workforce (Intervention 1) was beyond the scope of this consultation. It does not just result from understaffing but also a loss of respect from patients and managers. Others felt that having a government that has committed to changing things in cancer care will help with morale.

Participants stressed that workforce deficits will not be solved by training more doctors (Intervention 5) because the time frame of that is too long.

Use of technology to plug this gap (Intervention 13) may be impeded by lack of knowledge on how to use the technology and lack of trust for the system.

Some participants were concerned about unemployment caused by the drive to replace bureaucracy with technology (Intervention 14).

4. Leadership

Suggested interventions

1. The national cancer plan should be headed by a CEO and a chair, with the CEO reporting to the Secretary of State for Health, rather than NHS England. Some suggested reinstating a Cancer Czar.
2. Avoid a huge advisory group and have smaller groups for each area instead. Distribute power and responsibility. Delegate power to the lowest level to avoid managers taking all the decisions. (See **Coproduction**)
3. Remove duplicated roles. (See **Waste and Efficiency**)
4. Celebrate good people leaders. Enable resilience in lonely leaders. Leadership should incentivise outcomes. It should be both challenging and supportive, holding people to account and also resourcing them.
5. Give leaders the power to bring together the best people. Get commitment from people with good ideas and give them the executive power and confidence to implement them.
6. Build change through a mass of simple daily actions undertaken by leaders. Leaders should work out each day what small action they can take to get the cancer plan closer to achievement.
7. Consider what things to be authoritarian about and dictate must be done.
8. Continue using list-based practice, which was highlighted as the NHS's strongest business efficiency.
9. Link with the private sector to learn about business management. (See **Integration and Partnerships**)

What will happen if no action is taken

Nothing will happen in the NHS without stronger leadership. At the moment nobody knows who is in charge and who is accountable for what. This results in everyone blaming everyone else when something goes wrong and being ultimately unable to hold anyone to account. This also means that people wanting to introduce innovations don't know who to talk to in the NHS to have impact.

NHS England has become a scapegoat for things that have gone wrong in the NHS, although they were created as an independent board. It is hard to address what went wrong with this, instead of just criticising. Some argued that the problem is that NHS England tries to do everything and suggested working out what it should and should not do.

Possible objections and barriers

Some participants were concerned about leadership that was divided with national champions in different departments (Intervention 1). There was a disagreement about whether one person needed to be clearly in charge and accountable or whether distributed leadership was better. Some were concerned that this would put too much pressure on one person, leading them to fail. Others pressed participants not to be afraid of accountability in leaders. They explained that a single, accountable leader could still practice distributed leadership. However, others suggested that there is a lack of courage for this in the NHS right now. It was agreed that anyone who took on this role would need to be someone at the stage in their career when they wanted to 'give back' to the NHS.

Others felt that the theory of the NHS is about centralisation with an ecosystem that suggests that each individual is not in control. They felt that managers would resist any change that made them lose some of the control they have (Intervention 2). However, others argued that this could be challenged by exposing that the control they do have is an illusion. They argued that these managers already know they don't have control and if this is exposed, they might be more open to devolving more control to lower levels. Some felt that this would require huge layers of integration to make it work and people working in a collaborative manner. If only one part succeeds the whole vision will not work.

Some participants felt that there is a problem with central leadership at the moment due to lack of experience (Intervention 4).

Some participants were wary of taking lessons from industry (Intervention 9) because healthcare has very different working patterns including expectation to work nights and weekends.

5. Commissioning and Referrals

Suggested interventions

1. Some participants wanted to take some budget away from ICBs and impose it centrally to require everyone to do things in a specific way, such as using the same technology interventions for appointment booking. One suggestion was for trusts to agree 80% of budget and localise 20%.
2. Others also wanted to reduce the commissioning power of ICBs, but suggested doing more commissioning through micro decisions made in primary care when GPs decide to refer patients for services. They advocated considering referrals as commissioning acts to reconnect allocation of resources and utilisation. They wanted to set up indicative measures to raise awareness of use of resources through these decisions. They also suggested tracking patients from primary to secondary care to work out where resources should be allocated and consider the allocative value of care when patients move from one place to another. This would be a move from institutional care to value-based care.
3. Digitise the platform for referrals for tests. (See **Rapid Diagnosis and Treatment**). Mandate EPR systems to use global standards for full interoperability and seamless NHS integration.
4. Reduce episodic commissioning.
5. Rethink the definition of severity of disease which is used for commissioning decisions and is a big barrier for cancer spending.
6. The value of care should be in what matters to the people who are served not the system. Introduce hyper-personalised treatment plans.
7. Count outcomes so that the NHS can stop paying for imports and start paying for outcomes. (See **How to Pay for Healthcare**)
8. Allow the NHS to agree gainshare contracts with private companies where the companies are paid a percentage of the savings made through the use of their service, such as a technological intervention which improves surgical efficiency. This allows for payment after implementation.

What will happen if no action is taken

If commissioning is not linked to utilisation the NHS will continue to waste tax on underutilised services.

People in charge of commissioning are defensive rather than solution finding at the moment.

Possible objections and barriers

Participants considered that change in commissioning might be blocked by organisations that are controlled by NHS England (Interventions 1 and 2).

Some participants stressed the need for a definition of value-based healthcare (Intervention 2).

Participants were concerned that measurement of output of GPs and hospitals was confusing as patient contacts are measured differently in hospital than GPs (Intervention 2).

Secondary care organisations are not considering the needs of primary care organisations when it comes to interoperability of computer systems. This needs to be mandated to ensure integration of computer systems for seamless patient care across boundaries.

6. Waste and Efficiency

Suggested interventions

1. Improve efficiency in the NHS to save wasted money rather than asking for more to fund the cancer plan. (See **How to Pay for Healthcare**)

2. Stop non-evidence-based practice, including diagnostics, medicines, and medical technology. The NHS needs to stop doing things which are not helping.
3. Reduce avoidable harm to patients. Fix medical error.
4. Reduce inappropriate prescribing, particularly on antidepressants. De-escalate treatments where people are currently over treated, such as in chemotherapy and radiotherapy. Surgery is also improving meaning that operations are less drastic.
5. Use software tools to predict which patients have the capacity to adhere to a treatment plan, offer them reminders to take drugs, and monitor their adherence, to avoid waste due to non-adherence to treatment.
6. Introduce stricter controls on genomics to avoid inappropriate retesting.
7. Rethink drug dispensation as a lot of unused drugs are thrown out when a patient dies because they have already been dispensed.
8. Introduce deposits on equipment to avoid waste when the equipment is discarded.
9. Reduce duplication of services.
10. Cut out bureaucracy. Software could be used to replace 'sticky middle' managers. (See **Workforce**)
11. Make building efficiencies by turning off computers and lights overnight.
12. Focus on prevention to ensure healthier citizens who need fewer hospital stays. (See **Reaching the Public and Education**)
13. Ask staff to come up with their own ideas on reducing waste. Give money saved back to the people who make savings. (See **How to Pay for Healthcare**)

What will happen if no action is taken

It was suggested that waste in the NHS is greater than the education budget. There is currently a lot of wasted money through missed appointments.

The NHS waits until the last possible moment and treats people in the most expensive place. This is a broken theory of business.

Waste is closely linked to hope and anxiety. It frustrates people who are closer to the patient. (See **Coproduction**).

Some participants questioned how much waste is recoverable (Intervention 1). Others were positive that a lot was easily recoverable and straightforward to gain back. However, it was stressed that there needs to be data to support claims of waste recovery. Particularly, technologies which claim to reduce waste need to be supported by evidence (Intervention 5). We use programs like Scriptswitch and OptomiseRx in primary care. A lot of work is done by primary care clinicians to get best value but a lot of this hard work is often wiped our by fluctuating drug costs due to Drug companies and lack of supply.

Possible objections and barriers

Some participants questioned how much waste is recoverable (Intervention 1). Others were positive that a lot was easily recoverable and straightforward to gain back. However, it was stressed that there needs to be data to support claims of waste recovery. Particularly, technologies which claim to reduce waste need to be supported by evidence (Intervention 5).

Some participants worried about how to take patients along when reducing local centres to streamline health, which often results in protests from people and MPs (Intervention 9).

7. Shift to primary care and community

Suggested interventions

1. Prioritise prevention and participation. Change prevention spend. Invest in community bases. Fund community infrastructure. (See **Reaching the Public and Education**)

2. Detect health problems in the community and fast track to the right place for treatment. Return patients quickly, with responsibility for recovery held by primary care. Include point-of-care biomarkers throughout primary care. Support community clinicians with AI clinical decision support tools to help them work out the best diagnostic tests to order, and to improve trust at handover. Other tools can be used to search through patient records and identify those with risk factors. (See **Rapid Diagnosis and Treatment**)
3. Create one-stop cancer at home centres across the country, which are small and flexible.
4. Some suggested utilising and funding pharmacies to make pharmacists a true part of the health service. In Ireland, people are encouraged to take up a 15-minute health check in their pharmacy and get digital devices in return. Others suggested employee appraisals could be a better site for such a check.
5. Harness the community. Create community teams including GPs, Social Workers, Nurses, with GPs leading so that there is someone for the hospital consultant to hand over to. Shift care home as soon as possible and instigate formal handovers. Get people out of hospitals and keep them well. Liaise with charities and hospices. Create an understanding that your cancer team is not the hospital team but the neighbourhood team. Some also suggested bringing community teams into the hospital to ensure seamless care.
6. Campaign to encourage people to think about who will help them get to hospital rather than just when to call 111. Allow family and friends to stay in hospitals if accompanying someone, so that they can learn about how to care for them. Prepare people to return home and help family and friends to support them. Don't just impose equipment on people. Other countries such as Italy were suggested as examples for this. Engaging families more won't cost a lot.
7. Enable unpaid carers to continue in employment while caring.
8. Partner with community leaders. The NHS can't do everything. Incentivise charities to run health support programmes, perhaps with rent rebates. The charity commission should specifically review these charities with a medical focus. (See **Integration and Partnership**)
9. Some suggested incentivising GPs by paying them based on the wellness of their populations. Wellness should be the standard, not the exception. They suggested holding primary care accountable for the prevention agenda.
10. Others argued that the unlimited liability that GPs hold for primary care means that partners are not retained and practices are failing. They asked for unlimited liability to be ended and for GPs to be allowed to become Limited Liability Partnerships (LLPs) to protect them if something goes wrong.
11. Give GPs equal status with consultants. Challenge anyone who says that GPs are not part of the NHS.
12. Mandate experience in community practice for people working in hospitals so that they understand it and its culture, and have more trust when discharging people. (See **Workforce**)
13. Support patients with managing their own health as the time spent with a clinician is much smaller than the time spent managing their own health. Build good relationships with patients to motivate self-care. There need to be changes in what goes on in every day of a patient's life.
14. Utilise patients' mobile phones as the most important medical device. Engage patients in self-monitoring using wearables and monitoring bloods through their phone. Use technology to hyperpersonalise this, with information presented as voice or video in the patient's own language and accent. Phones can also provide automated alerts to the care team. (See **Reaching the Public and Education**)

What will happen if no action is taken

Currently we have a national sickness service and these actions are needed to move to a national health service. The current health system is reactive and a very small proportion of the budget is spent on prevention. Prevention is fundamental to the wellbeing of communities.

At the moment GPs are doing a large proportion of the work of the NHS with a small proportion of the budget. GPs are not considered a core part of the NHS since they are private practices. However, they do not have enough money to hire who they want. GPs feel isolated and excluded from decision

making. Budget needs to be put back into the community. Primary care is close to collapse and if it collapses the NHS will collapse. There are unprecedented patient numbers in primary care.

Patients are increasingly being discharged earlier and need a reliable system to help them self-manage their recovery. There are changes in the amount of responsibility patients will accept for their care and they need support with this.

Possible objections and barriers

Participants complained that there has been meeting after meeting where people agree that not enough is done on prevention, but nothing changes (Intervention 1).

Participants warned that prevention is more difficult to measure over time than treatment (Intervention 1). In addition, prevention does not provide a story for the media. Even the person who did not get a disease due to prevention does not know that they would have got it otherwise. In contrast, waiting lists for treatment are an obvious scandal.

Some participants suggested that some 'prevention' interventions come too late because they focus on individuals who are already at high risk, for example, community fitness evenings targeted at people at risk of heart disease where they can be screened. There are five levels of prevention in medical understanding and some participants warned that throughout the consultation these levels were conflated.[7] They argued that the strategy must be clear on which level of prevention to focus on (Intervention 1).

Some participants highlighted the need to consider what this shift towards the community would do to hospitals (Intervention 2). Will outpatient services need to close and if so, how?

Participants warned that the business model for pharmacies in the UK is very fragile (Intervention 4).

Participants suggested that there is a lack of trust when discharging people because few hospital clinicians have spent time in community practice (Intervention 5).

Some were concerned that any narrative about more involvement from family members in hospital stays would be viewed as a scandal (Intervention 6). Others worried about people who do not have nearby family or friends who could do this. (See **Health Inequalities**).

8. Rapid Diagnosis and Treatment

Suggested interventions

1. Fast track early diagnosis in primary care and shift everything earlier in the cancer pathway. Provide rapid access to diagnostics. Reduce late diagnosis in A and E and introduce a target to detect more cancers at an earlier stage. This could have an early, obvious impact.
2. Introduce regular health screenings that don't require specialised equipment. Some suggested that targeted long health checks could be introduced earlier: 2025 not 2028.
3. Digitise the pathway to request tests to improve access to diagnostics. Digitise pathology slides too. Some participants suggested that industry partners would be happy to help. They will be motivated by finding people who need their drugs. (See **Integration and Partnership**)
4. Use technology to intervene earlier in health.
5. Conduct vaccines and screenings in community spaces where people already are, for example, swimming pools. (See **Shift to Community and Primary Care**)
6. Encourage screening through nudging on social media and counter misinformation about screening. (See **Reaching the Public and Education**)
7. Improve radiotherapy waiting times.

[7] https://www.ncbi.nlm.nih.gov/books/NBK537222/.

8. Hit the 62-day treatment target to show that the system works once you are in the system. Faster diagnosis is no good if the path to treatment once in the system is delayed.
9. Provide training to deal with anger and resentment about delays in diagnosis and treatment that are happening now. (See **Workforce**)

What will happen if no action is taken

If serious cancers are treated earlier, there are fairly good results. At the moment screening does not start at the age to provide early diagnosis for new presentations of cancers. Currently uptake for breast and cervical screenings is under 70%.[8] Consider the cost of screening compared to the cost of not screening.

There is a diagnostic gap. Early diagnosis measures are not adopted uniformly across the country. There are currently not enough pathologists.

Possible objections and barriers

Participants were worried about how to move things earlier while still delivering the care that is required now (Intervention 1).

Some participants worried that targets around diagnosis of cancers at earlier stages would be impossible to achieve since it hasn't shifted in a very long time (Intervention 1). Participants disagreed about whether an early diagnosis target or a target around rapid treatment was more important. (See **Targets**).

Community Diagnostic Centres were supposed to be located in shopping malls and other community settings. Instead they have been incorporated into existing hospital trusts making them less accessible and also prone to the usual inefficiencies afflicting secondary care.

Participants warned that there are not enough pathologists at the moment and this will not be solved in a 5-year time span (Intervention 3). They wondered how to solve the gap in a different way, perhaps by showing how certain measures would save on pathologists. Participants warned that early diagnosis is only meaningful if you then get early treatment (Intervention 8).

9. Reaching the public and education

Suggested interventions

1. Communicate relentlessly to people that healthcare is moving forwards. Change the story that is being told about the NHS.
2. Have a true national conversation that can be communicated with people. Push back slightly against unrealistic expectations. Some participants felt that these expectations would only take a short time to change. Use a citizens assembly to draw boundaries about what the NHS can and can't do, so that the NHS doesn't keep taking on more than it has capacity for. It might be necessary to say that there are some services the NHS can't offer.
3. Give people a sense of control. Empower them to own their own health. Be enabling and make it possible for people to change. (See **Coproduction**)
4. Get people interested in health through the NHS app, providing coaches to educate people in how to use it. Medical students could be employed as coaches and be available in out-patient waiting rooms. Charities could also help. Medical staff will need training in using and understanding the app. Make the phone the wellness hub for everyone. Offer lifestyle tracking and rewards to gamify health. Train people to be more aware of the body.
5. Educate and inspire people to self-manage health and self-care. This will help to plug the gap in the workforce. (See **Workforce**)

[8] https://www.nuffieldtrust.org.uk/resource/breast-and-cervical-cancer-screening.

6. Allow families to stay in hospital with relatives to learn how to care for them when they return home. Provide a single point of contact for patients and families with questions about treatment. Provide better information on how to care for someone who is dying at home, including how to recognise that someone is dead, so that people don't jump to calling 999 unnecessarily. Talk about dying earlier. (See **Shift to Primary Care and Community**)
7. Provide better information about side effects of treatment and medication, for example through alerts on phones. Give people a book to keep notes on their health record.
8. Messaging to public needs to address patients' focus on targets. (See **Targets**)
9. Keep messaging simple so that media can use it. Use acronyms to help people remember.
10. Regulate cheap food to challenge the obesity infrastructure. Enforce honest labelling and reduce unhealthy food advertising. Tax sugar. Reduce food deserts. Incentivise healthier food. Give low high street rates to greengrocers and high rates to fast food. If the pricing is right people will realise it is cheaper to eat healthily. Educate people that health is wealth.
11. Utilise peer pressure and peer security.
12. Teach children how to cook in school.
13. Aim for people to do half an hour of walking a day. Build on the knowledge that sports are good for mental health. It was pointed out that the Dutch have their Department for Health within their Department for Culture and Sport. Could this be useful?
14. Employ evidence-based research about what will motivate people. Connect with psychology professionals to understand how best to motivate people. (See **Integration and Partnerships**)
15. Pay social media companies to use their algorithms to push people towards healthier lifestyles. They could gamify health using personal information they have access to. Nudge behaviour change. Utilise reliable social media influencers and challenge misinformation.
16. Utilise TV Programmes and popular scientists. Political champions are also important.

What will happen if no action is taken

Some participants felt that behaviour change was more important than policy. Focus on prevention requires education and behavioural change in the population. Obesity is the number one predictor of future chronic disease. There is a tsunami of inflammation caused by too much glucose.

Cancer was seen as an important hook for reaching the public since the risk factors for cancer are the same as other diseases but cancer is attention-grabbing. The public are terrified of cancer.

Demand for the NHS has gone up very much in the last few years. The NHS currently has near infinite demand and keeps having more added, such as mental health. The expectations of the NHS need to be managed.

Current health education was considered appalling by participants. They felt that the medical education industry has infantilised patients through the idea that the doctor knows best. (See **Coproduction**)

Social media currently has a poor impact on mental health. Some participants felt that algorithms make many decisions in our lives now and the people who understand behaviour change are pushing bad things. Perhaps instead, social media could be used for health through the ideas above.

Possible objections and barriers

Some participants suggested that there is a problem with raising expectations about the NHS through portrayal of innovations like precision medicine, which suggests to the public that the most complex problems will soon have solutions (Intervention 1). Meanwhile they can see that the health service can't do simple things. People are worried about waiting lists and access to doctors. It is hard to reconcile their hope with the reality of the situation.

Some suggested that policy makers lack awareness about how unreasonable a very small percentage of the population can be in primary care (Intervention 2).

Participants considered what ways of contacting people should be used, and stressed the need to watch out for people who can't cope with the switch to digital (Intervention 4). Some were worried that increasing use of the NHS app could widen health inequalities. Others saw it as an opportunity to

democratise healthcare. They argued that some people are not digitally excluded but are not making use of the full potential of their digital skills. It was stressed that other media will be more accessible to some people. However, some participants suggested that leaflets are useless, since they are unreadable by many people, and complained that health teams don't teach patients about their treatment journey and just give them leaflets instead. Others argued that phone calls remain effective. Some participants wondered how to reach people who don't engage with the health service, suggesting that these are the populations that have the worst outcomes. They worried that there is often no follow-up when people miss appointments. (See **Health Inequalities**)

Participants stressed that individuals can't just stop eating if there is no good food available in their area and price bracket. Good food needs to be substituted for bad (Intervention 11). Many people don't have control over their lives; they have to eat even if there are no healthy choices. (See **Health Inequalities**)

Some were concerned that there have been public health messages about obesity for many years and yet obesity is going up (Intervention 11). Others pointed out that replacements for glucose, such as artificial sweeteners, are also bad for health. Participants worried about the impact of anti-obesity agents on inequalities based on the idea that obesity in America has plateaued due to educated Americans buying expensive anti-obesity agents. In addition, some pointed out that these treatments lead to loss of muscle mass, producing more frail people. However, others argued that increases in food prices in America have influenced this more.

Participants warned that behavioural change is difficult (Intervention 15). There are many layers of behaviours. Motivating people to do the things they know they should do is very hard. Other participants suggested that evidence around how to motivate people about their health is currently underutilised. Participants stressed that the NHS must *encourage* people to change their behaviours not *make* them. Otherwise all these measures might just irritate the population.

Participants worried that social media companies might not be willing to become forces for good in health as suggested (Intervention 16). Is there a good business model for them here? Would the NHS be able to afford them? However, it was stressed that governments do need to have a robust conversation with these companies about their impact on the population.

10. Health Inequalities

Suggested interventions

1. It was stressed that there is no better way to show commitment to equity than to provide healthcare for all.
2. Connect with or place point people in local communities to get them on board. (See **Shift to Primary Care and Community**)
3. Approach organisations such as Healthwatch to understand local issues relevant to demographics and resources.
4. Understand the complexity of the NHS patient base and realise that there is no one-size-fits-all. Don't assume the same thing will work for everyone. Allow space for people to do what works in specific locations which may have higher deprivation.
5. Use AI to make health messages explainable no matter who you are. (See **Shift to Primary Care and the Community**)
6. Have parallel communication methods so that access is maintained for all. (See **Reaching the Public and Education**)

What will happen if no action is taken

Some participants felt that the NHS commitment to equity underpins the UK political system. If healthcare can reduce inequality, reductions in inequality in other areas of society will flow more easily. If not, democracy may come under threat.

Inequality is the root of many problems in relation to cancer. Countries like Denmark that have done well on improving cancer outcomes were considered to have a more equal society than the UK. Inequalities are a big problem here and some participants worried that growing inequalities would become the norm without a change in approach. There is no mechanism in the NHS to marry up thinking about social determinants of health. This is a challenge to overcome, however, participants stressed that this doesn't mean it is impossible.

Currently there is healthcare rationing in this country, with a growing demographic fracture between people who are working and still can't get the healthcare they need. Some suggested that the UK tilts towards treating younger people rather than the elderly in rationing healthcare, which is discriminatory.

Glucose is a problem that comes from growing wealth and many chronic problems are due to this. Although we live in a richer society, many are food impoverished, while the food industry makes lots of money from this. (See **Reaching the Public and Education**)

Possible objections and barriers

Some participants questioned whether the NHS can decrease inequalities (Intervention 1). Many determinants of health come into play twenty or thirty years before pathology emerges. The NHS would need to go back to this. However, others claimed that the excuse that the NHS can do only 20% to change health inequalities is based on old data.

Participants stressed that there are no blanket ideas that work for all communities (Intervention 4). It was highlighted that deprived areas see a completely different case mix to other areas. However, others argued that ideas should be implemented anyway because the NHS can't let everyone die just because some people can't access interventions. They felt that the NHS needs to stop pretending to offer everything to everyone all the time. Others again stressed that those who can't access standard interventions are often the people who most need care.

People located in deprived areas may also lack digital skills (Intervention 6). Some participants worried about the number of steps through various authentication mechanisms needed to access the NHS app. Others argued that this is not a reason not to work to get the app right. Facial recognition could help with this. Still others stressed that some older people can use technology well and assumptions shouldn't be made. Some were convinced that in the future technology would become ubiquitous. (See **Reaching the Public and Education**)

11. Targets and Standards

Suggested interventions

1. Produce evidence-based targets towards objectives that really matter to professionals and people and support them to be reached. The goals and measures must resonate with staff, taxpayers, and patients. (See **Coproduction**)
2. Produce a vision to drive this, imagining something better and a healthier future for all. One suggestion was 70% long term cancer survival by 2030. Another suggestion was to get cancer survival up to the European average. Quantify how many lives will be saved along the way, since this is what people will be impressed by.
3. Produce both systems measures and clinical measures. These must be objective.
4. Implement reviews.
5. Do analysis when targets are missed and have financial penalties for missing targets.
6. Provide positive incentives for meeting targets.

7. Link targets with incentivisation of primary care to produce wellness in the populations they serve. (See **Shift to Primary Care and Community**)

What will happen if no action is taken

The UK is not performing as it should be. It has not achieved the target for 85% of cancer patients to receive treatment within 62 days of referral since 2015.[9] Participants suggested that the NHS has got used to missing targets. However, in business, missing targets means you won't survive.

Some participants stressed that if it doesn't get measured it doesn't get done, while what does get measured gets improved. There is only a return on investment if it is measured against a target.

Current targets have been set in the absence of a road map to achieve them. They are just a long list of asks without a plan for delivering improved productivity.

Possible objections and barriers

Some were worried about targets set without evidence (Intervention 1). Can suitable precise outcomes be found in cancer to measure the success of the NHS?

Some worried that targets kill initiatives because people stop doing other things to work towards the target (Intervention 1). Some participants were concerned about following practice from industry around targets because in health staff can't just push things through to meet a target like in a factory. In health you can't afford mistakes. They stressed that targets in cancer are quality targets not performance targets. (See **Integration and Partnerships**)

Some participants warned that when the government imposes targets from above, workers say that is not how it works in practice (Intervention 1). Participants wondered whether targets should be imposed nationally or differ around the country.

Participants stressed that thought is needed about what should be categorised as success, considering what good looks like and how to learn from best practice (Intervention 2).

There was concern that targets around wellness in primary care might lead to GPs removing sick patients from lists (Intervention 8).

12. Implementation of technology

Suggested interventions

1. Move from analogue to digital. Move from a reactive health system to a digitally enable proactive one.
2. Use cancer as a model for the integration of technology across the NHS. Improve continuity of technology through cancer care as some aspects of cancer care are already very digital.
3. Improve systems efficiency. Make more intensive use of current technology infrastructure by opening scanners for use at night or buying capacity from private healthcare.
4. Make use of the NHS app, which was considered a very important asset as a single, national, central app. (See **Reaching the Public and Education**)
5. Mandate that 25% of IT systems resources must be spent not on Electronic Patient Records or business as usual, but on implementing new technology.
6. Set up honest conversations with technology companies to understand the potential and help to cross the language barrier between health and technology.
7. Outsource trials for medical technology and conduct them using data and modelling rather than a physical randomised trial, ensuring that technology is still pressure tested. Centralise the results of these trials, perhaps through a central committee so that technologies can be more easily

[9] https://committees.parliament.uk/writtenevidence/113672/html/.

implemented, especially across primary care practices. This will ensure that GPs don't have to individually take on the risk of incorporating new technology.
8. Allow diverse funding models, including gainshare where companies are paid a percentage of savings after implementation. Empower purchasing speed. (See **Commissioning and Referrals**)
9. Create a side group in Lancet Oncology with technology expertise.
10. Implement AI to help with prioritisation of case lists.
11. Link AI into primary and secondary care electronic health records (See **Integration and Partnership**)
12. Use AI to help with decision making in primary care and community settings. (See **Shift to Primary Care and Community**)
13. Use algorithms to transform people to take care of their health better. (See **Reaching the Public and Education**)

What will happen if no action is taken

When you get digital transformation right it will save not only money but time. Workers will not be spending time on administrative issues not related to their skill set. (See **Workforce**)

Introduction of medical technology is very slow due to the need for a randomised trial. Due to the change of government, implementation of approved technology is being delayed due to the budget not being decided. If funding models are not changed this will continue to be a recurring problem.

Technological hardware is lacking in some areas. There is a lack of scanners.

Cancer is getting more complicated. Without AI support, primary care and community settings will not cope with the suggested shift of services to them. (See **Shift to Primary Care and Community**)

Possible objections and barriers

Some participants warned that digital transformation will require deep cultural shifts (Intervention 1). Others worried that moving to digital won't necessarily enhance patient safety.

It was pointed out that cancer care is behind elective surgery in implementation of technology to manage case prioritisation (Intervention 2).

Some participants wondered about hardware and how to change the analysis of medical technology to implement it more effectively (Intervention 3).

Some participants worried about digital exclusion among people who really need to attend healthcare providers (Intervention 4). They criticised a tendency to apply technology across the board without thinking about who should still be approached in other ways. (See **Health Inequalities**)

There was a worry that the NHS is not talking the same language as technology companies (Intervention 6).

ICB's were considered as blockers of technology implementation by some (Intervention 8). (See **Commissioning and Referrals**)

Some stressed that the primary care role should never be automated. They were worried about employing things that act human but aren't human in relationship building (Intervention 12)

13. How to pay for healthcare

Suggested interventions

1. Increase public spending. This could be either through tax or national health insurance. Some participants stressed that there is an international consensus on the benefit of universal health

coverage agree twelve years ago by every country.[10] They argued that privately funded systems are expensive and the poorest don't access them. Others stressed that it is a myth that all UK healthcare is publicly funded at the moment and called for acknowledgement that we have a mixed model.

2. Others suggested introducing capped contributions to healthcare, feeling that the population may not value the health system and simply treat it like a freebie. Some argued for allowing a mixed economy for GPs, who are currently allowed to charge patients for very few things. This would make practices more viable and increase morale. They stressed that people pay for glasses and the dentist, although others pointed out that people struggle to access NHS dentistry because dentists are not reimbursed fully for the costs of NHS treatment, so dentists can't afford NHS patients. Nevertheless, there was a suggestion that rather than offering all healthcare free and no social care, some publicly funded social care could be introduced and some healthcare charged. Some argued that funding the health service while free school meals are cut seems immoral. However, others claimed that while small copayments reduce demand for healthcare dramatically, it is the poorest who stop coming rather than those who take it for granted. Introducing means testing to combat this quickly makes the system more expensive than it is worth.
3. Another suggestion was to introduce risk-adjusted per capita tax to incentivise healthy lifestyles. There could be more tax on things that are problematic for health. It was felt that alcohol is undertaxed, vapes are very dangerous and undertaxed, and purchases over the internet are not taxed adequately. Tax could also be used to tackle obesity.
4. Demonstrate where funding will come from elsewhere in the system. (See **Waste and Efficiency**)
5. Regular funding is important as one-year budgets are very difficult to work with. Make sure the ten-year plan is fully funded.
6. Shift the health service from the debit to the asset side of the balance in the national budget.
7. Funding is needed to build trust in community projects. (See **Shift to Primary Care and Community**)
8. Properly invest in prevention actions like stopping smoking, rather than the exciting things like new scanners. Change the business model to pay for wellness.
9. Fund end of life care. If euthanasia is funded, there must be more money for palliative care.
10. Learn lessons from industry in how to manage money. (See **Integration and Partnerships**)
11. Use slots from the private sector but mandate prices for the NHS so that private companies can't overcharge.
12. Allow gainshare models, where companies are paid a proportion of savings after implementation rather than an upfront price, to enable agreed services to still be funded while governments decide budget. Pay for medicines through an outcome-based payment scheme too. (See **Commissioning and Referrals**)
13. Have someone oversighting spending on cancer care so that trusts don't get stuck behind anxiety about what to spend.
14. Reduce the need to make business cases for funding work that is clearly being heavily used. This will give people hope.
15. Make sure the willingness to pay threshold is the same as other departments and remove the disease modifier for funding decisions, which was considered to be ageist. (See **Health Inequalities**)
16. Incorporate employability into prioritisation of the waiting list.

What will happen if no action is taken

Healthcare is vital economically. An increasing number of people are out of work as cancer is becoming a long-term condition. Without improving healthcare and thereby productivity, how will the UK have a large enough economy for taxes to fund healthcare?

There are things that the NHS cannot provide at the moment and people are now starting to provide for their own health care through private providers because the NHS doesn't offer the things they want.

[10] https://www.who.int/health-topics/universal-health-coverage.

Participants suggested that this might mean we need a new model that is not necessarily a fully tax funded healthcare service.

The high level of bureaucracy around one-year budgets disincentivises innovation.

Possible objections and barriers

Some worried about how to protect people who can't pay for healthcare if a capped contributions model was introduced (Intervention 2). They argued that the cost of managing co-payment schemes was prohibitive. Others warned that if general practice goes the same way as dentistry this will destroy trust. Nevertheless, other participants argued that in the triangle of affordability, accessibility and quality you can't have all three. They suggested that when the NHS was founded, healthcare was simple, cheap, and ineffective.

Some wondered whether the social care budget should come under the Department of Health and Social Care rather than local authorities (Intervention 2).

Some participants were concerned that any tax increases aimed to tackle products that cause poor health would hit the poorest hardest (Intervention 3). (See **Health Inequalities**)

Participants wondered how to manage expectations about treatment while funding the transformation of the healthcare service, including funding the workforce (Intervention 8). Some felt that the NHS will never be able to do everything it does at the moment while investing for the future. Others agreed that the population is aging and it would not be possible to do all these things with the current level of public spending. They wondered if the NHS should stop spending on some things. Some even felt that the NHS cannot afford cancer care. However, others pointed out that the UK spends more on cosmetics and tobacco than cancer care. Nevertheless, they agreed that in the current system we are not affording it, but that this is a choice. Still others argued that Denmark managed to transform cancer care with a flat budget. In Denmark, if a region overspends they will get less budget next time. In the UK, if a region overspends it will get more budget. Money that doesn't get used has to be scraped back from the government.

Others felt that money just flows away through the old NHS systems (Intervention 10).

Others wondered how to bring coalitions together and prove cost-effectiveness of gainshare payment schemes (Intervention 12).

Some participants argued that there is a disconnect between the strategy and where the money is (Intervention 13). Currently the budget for hospital care and the budget for medicines that could reduce hospital care are separate and disconnected. (See **Integration and Partnership**)

Some participants complained that the NHS has a rigid payment system with no one empowered to make decisions (Intervention 13). (See **Leadership**)

Some suggested that incorporating employability into prioritisation of the waiting list would be a scandal, especially if automated (Intervention 16).

14. Research, Clinical trials, implementation

Suggested interventions

1. Incentivise and embed research as part of routine care. GPs should suggest clinical trials as part of normal practice. Prepare patients for a clinical trial pathway and use plain language to get informed consent.
2. Centralise protocols and make sure all off-protocol drugs are given through a clinical trial.
3. Take advantage of Brexit to disrupt the drug development paradigm and run more UK-based clinical trials. Reduce development costs through a UK development arm. Give UK patients faster access to innovations.

4. Plan ahead for testing new drugs.
5. Use clinicaltrials.gov to identify patients for research.
6. Use algorithms to screen data to increase the pool for randomised control trials. These can screen out acuity and comorbidity.
7. Some suggested getting rid of the whole concept of randomised control trials and replacing them with models conducted using NHS data. This will enable treatments to be used earlier.
8. Speed up introduction of new treatments.
9. Allow outcome-based payment schemes. (See **Commissioning and Referrals**)
10. Test things in living labs and ongoing pilots which are reiterated until the innovation is right. However, the NHS must also design for scale and use the knowledge and evidence base around scale and change.
11. Use community-based researchers to find out what communities need.

What will happen if no action is taken

The UK is very good at research and innovation, but it is good at breakthrough, not follow through. Participants suggested that if the UK were to develop a cure for cancer, they would not be able to roll it out across the NHS. Cancer is the vanguard of precision medicine. Research is powerful in the UK but currently our citizens may not benefit from it as research is not translated into options offered to them. Spend on medicines is low in the UK compared to other countries due to the slowness of getting them approved through NICE.

Biosciences are disincentivised through the difficulties of clinical trials and slow adoption of innovation. If reimbursement for innovation is not improved there will be less research in the UK and some companies may not approach NICE with new medicines and innovations.

Innovation does not get passed to other trusts when approved in one. (See **Integration and Partnership**)

Some research that is being done could lead to savings, but only if implemented in the next few years. It is important to have evidence-based not opinion-based change.

Research active hospitals have better outcomes, meaning research is an essential, not a luxury.

Possible objections and barriers

Some participants pointed out that the border in Northern Ireland is a problem for conducting clinical trials without regard to EU mandates (Intervention 3).

The NHS Secure Data Environment (SDE) was suggested to be insufficient for companies who want to use NHS data to develop algorithms (Intervention 7). The processing power in an SDE limits research uses. Pseudonymised data use, where researchers are legally liable for misuse of data, was considered a better solution. However, others were worried about the waste of abolishing SDEs when they have only just been allocated. (See **Data sharing**)

Participants worried that risk aversion is a problem and people aren't making the decisions that allow deployment of things that will make a difference (Intervention 8). Trusts are often more concerned about information governance than how quickly they could get new interventions to patients. Decisions keep being referred upwards and it was suggested that in the NHS there are a lot of people who can say no but very few who can say yes. People need to move from no to yes. (See **Commissioning and Referrals**)

Some participants wondered how to move from pilots to implementation. They suggested that the NHS has chronic pilot-it is and what is needed is large-scale change, not pilot and spread (Intervention 10).

15. Data sharing

Suggested interventions

1. Empower patients to hold their health records themselves. Embed data into the NHS app so that patients can control it. Get patients involved in data collection. (See **Coproduction**)
2. Use one central system. Independent national oversight could be important to reassure people. All records should go to one government-held source and be pseudonymised. This was considered feasible in cancer due to the small population.
3. Identify who controls who can use data in the NHS. People need a figure they can trust.
4. Ensure all stakeholders get fair value from data, without skewing towards one in particular. Access to data should not just be for research. Decision makers also need access.
5. Introduce an independent unit to consider policy and provide data to the health secretary.
6. Reconcile electronic patient data with clinical trial inclusion criteria. Harmonise methods of data collection.
7. Link up primary and secondary care data, as well as palliative care and social care. Remove siloing of data which makes it inaccessible (See **Integration and Partnership**)
8. Use data to accelerate adoption of treatments. Cancer patients definitely want this. (See **Research, Clinical Trials, Implementation**)
9. Change the deal with the population to ask for more tax and more data in exchange for healthcare. There is a balance between individual freedoms and collective good.
10. Be transparent about why data will be useful to the health service. Provide good information to help the patient understand. Have this conversation at the start. Give people confidence that their data will have proper oversight and make the case that you will have a better survival rate if you do get a disease.
11. Outcomes must be underpinned by data.
12. Revive the idea of a cybersecurity research institute.
13. Employ better managers who can support staff with the complexities of data management.

What will happen if no action is taken

Health relevant data can help improve health and wellbeing for all society. Participants stressed that the UK has very good data. However, at the moment data is not given back to people: it disappears into a black hole. It is also not shared. At the moment the health secretary could not access patient data to help inform decision making.

Data is needed to understand what works. Data about what goes on in patients' lives outside of interventions could be even more important.

It is important to have data available to make the UK an attractive environment for clinical trials. This is more important than earning money from it locally. (See **Research, Clinical Trials, Implementation**)

During COVID, the secretary of state made data available through a notice. There were no data breaches and the UK led the world in research. Some participants argued that the UK is still in a COVID moment, as the NHS will not survive if it does not adjust. Therefore, the secretary of state should give another notice allowing use of data. Currently, people are fabricating COVID angles for research so that they can use the data.

Possible objections and barriers

Participants worried that not everybody trusts institutions with data (Intervention 2). They suggested that people are more able to share data with supermarkets than with the health service. Others pointed out the people are also shocked that data is not shared between people responsible for their health. They suggested that patients want better treatment and are willing to accept risks over data to get treatment. They want their data to be used for good things, such as health. The idea that data isn't already being manipulated is not possible anymore, so it is better that the data could be used for good. This story is not told enough.

Some participants were worried about the impact of the Electronic Patient Record (EPR) (Intervention 6). It is mandated by NHS England but best practice is now moving to patient-held records. However, trusts are still chasing EPR. This is taking money out of what is really needed. IT department staff are overloaded. (See **Implementation of Technology**)

Some participants were worried about the many different companies being used by trusts to collect data such as Patient Reported Outcome Measures (PROMs) (Intervention 6). Information governance was thought to cause this problem by constantly suggesting changes of system. Instead a central decision on which system to use is needed. There was also concern that some companies used by NHS providers to collect data are holding that data to ransom and won't allow the NHS to use it.

Participants were concerned that data is localised into silos that are not shareable (Intervention 7). They emphasised that sharing data within the health service is moral not just practical as it helps avoid a dying child having to tell their story again and again. (See **Integration and Partnership**)

Some suggested that people do not want to be data points. They worried that data makes clinicians lose sight of the patient (Intervention 9).

Some emphasised that people are worried about losing data, misuse of data, and the quality of NHS cybersecurity (Intervention 12). They worried that misinformation is spread about data misuse to privatise the NHS, but also that NHS Digital actually still thinks of the data as 'theirs' even though it is the patient's data. There was concern about how to ensure data users are genuinely doing good.

Participants worried about people on the frontline who will struggle to work with these ideas that are beyond their education (Intervention 13). Some suggested that the defensive attitude to data was caused by the 'sticky middle' low-level managers. (See **Workforce**)

Appendix 2: Summary of previous December 2023 consultation

Previous consultation December 2023

This follows on from a St George's House consultation in December 2023[11]: its context being the concerns around the:

- ability to diagnose and treat the increasing incidence of cancer (with a 30% increase expected by 2040)
- increasing variability in the quality of cancer care across the UK
- unsustainable rising cost of cancer care

This 2023 consultation identified problems in the NHS and defined needs for;

- long-term planning
- clear responsibility and accountability
- reliable, relevant DATA on which to support delivery
- collaborative working across the boundaries of care
- leadership development and enablement
- improved public engagement, perception of services, and transparency
- improved primary care relationships and reconnection between health and social care services
- public-private partnerships
- improved value of clinical and health services research
- a clearly defined MedTech strategy

The consultation was aligned with other commissions reporting around that time on the state of the NHS such as the Times and BMJ. Since that time, UK clinical cancer experts supported by Lancet Oncology have published proposals for a new National Cancer Control Plan[12] [13] [14].

A new administration was elected in July 2024, swiftly commissioning The Darzi report which reported on an independent investigation of the NHS in England (September 2024)[15]. It acknowledged that the NHS was in serious trouble and was "broken". Within the report the DHSC and NHSE published 330 data analyses on the state of NHS care. It was recognised that the NHS had now reached crisis point and urgent action was needed.

[11] St George's House, Health Care UK – A Radical Rethink A St George's House Consultation in partnership with Cancer Research UK. Monday, 11th – Tuesday, 12th December 2023, https://www.stgeorgeshouse.org/wp-content/uploads/2023/12/Final-Consultation-Report.pdf, accessed 9 Jan 2025.

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[15] Department of Health and Social Care. Independent report. Independent investigation of the NHS in England
Lord Darzi's report on the state of the National Health Service in England.
https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england accessed 9 Jan 2025.

Appendix 3: List of Participants 2024

Chair: Rt. Hon. Professor Lord Kakkar KG House of Lords

Dr Amar Ahmed GP Partner and Trainer Wilmslow Health Centre

Miss Jenny Chigwende Chair & Health Lead W12 Together

Ms Nuala Close Former VP of Cancer HCA UK Jefferson Close Consulting – Coaching and Consultancy for Senior Leaders

Professor Martin Curley Director, Digital Health Ecosystem Innovation Value Institute, Maynooth University

Professor Dame Lesley Fallowfield Professor of Psycho-oncology Sussex Health Outcomes Research and Education in Cancer (SHORE-C)

Baroness Ilora Finlay of Llandaff Chair Bevan Commission

Dr Susan Galbraith Executive Vice President, Oncology R&D AstraZeneca

Dr Clare Hague Managing Director Oncology Access Solutions Ltd

Mr Stephen Hammond Consultant and previous Health Minister 2018

Sir David Haslam, CBE Chair of Trustee Board Young Lives vs Cancer

Mr Richard Jones President and Chief Strategy Officer C2 – AI

Professor James Kingsland, OBE Clinical Professor - Primary Care University of Central Lancashire. Healthworks UK

Professor Mark Lawler Associate Pro-Vice Chancellor Queen's University Belfast

Mrs Angela McFarlane Vice President, Strategic Planning Northern Europe IQVIA Limited

Mr Will Morrison Cancer Performance Lead Department of Health and Social Care

Dr James Mountford Editor-in-Chief, BMJ Leader BMJ Group

Sir John Oldham Adj Prof Global Health Innovation

Professor David Pendleton Professor of Leadership Henley Business School

Professor Pat Price Visiting Professor Imperial College London

Ms Sarah Quinlan, MBE Director Radiotherapy UK

Dr John Sheehan Consultant Radiologist Blackrock Health Clinic

Professor Gordon Wishart Chief Medical Officer at Check4Cancer Check4Cancer / Anglia Ruskin University

Mr Richard Wyatt-Haines Director Health and Care Innovations Limited (HCI)

Professor Rob Yates Visiting Professor in Practice London School of Economics and Political Science

Pre-reading material: A Blueprint for the NHS - Fixing the Problems - St George's House

Document prepared by: Ms Siobhan McShane Rapporteur, Ms Nuala Close, Dr Clare Hague and Prof Pat Price

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