PHG
FOUNDATION

making science
work for health

The 10 year health plan for England

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NHS England

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Q1. What does your organisation want to see included in the 10-Year Health Plan and why?

Context

The PHG Foundation is a health policy think tank with the mission to make science work for health. We support the responsible development and adoption of technologies based on knowledge of the human genome, other biomarkers and health information.

We seek to ensure these technologies are implemented to ensure genuine public benefit, while guarding against unethical or undesirable consequences. This mission is driven by our vision for a world in which the application of science and technology leads to better health outcomes for people and populations. Our proposals for the 10-Year Health Plan are guided by this vision and arrived at through our interdisciplinary approach, drawing on our teams' expertise in science and the humanities. Our submission is informed by an online discussion event we held in late November to gather input from a range of stakeholders with an interest in genomics and health data.

As an organisation we closely monitor developments in science and technology to identify opportunities to shape health systems and identify risks. We recognise the huge progress in the field of genomics over the past 25 years, resulting in the development of genomics services within the NHS. Building on this we expect the range and effectiveness of technologies that generate, process and apply genomic, other 'omic and biomarker data will grow in this time period. Increasingly powerful, AI-supported systems and approaches will drive advances in research, trials, diagnostic workflows, clinical decision making and health system management. The 10-Year Health Plan should exploit the benefits these innovations can deliver, whilst addressing the challenges such technologies pose, as well as their downstream impact on professional roles and responsibilities.

Data must be at the core of the 10-Year Health Plan. Combining data from biomarkers, biometrics and other sources offers a compelling vision for better population health, of more effective health care, with better diagnosis, earlier detection and treatment of disease, and reduction of unnecessary treatment. However, the ability of the NHS to realise any of these benefits is currently

undermined by a failure to collate, share and gain insight systematically from the routine data already collected.

There remain fundamental issues with the data and digital infrastructure within the NHS, and concerns associated with the culture of data sharing and information governance. We outline the key opportunities and challenges this will present in response to the third question.

We also believe the 10-Year Health Plan will benefit from taking an approach that recognises the interconnectedness of the three policy shifts that frame this consultation. The use of technologies could either help or hinder the movement of care from hospitals to communities, and some technologies will suit such a move whilst others will not. Close examination of specific technologies and the contexts in which they are applied will be necessary to ensure high standards of care are maintained.

Likewise, a sustainable shift towards prevention will depend heavily on the effective functioning of community services in health care and beyond. The scope and scale of prevention efforts will need to reflect the capacity and willingness of organisations beyond the NHS and beyond health, as we describe further in our response to question four.

With this in mind, the 10-Year Health Plan should seek to develop a joined-up approach to the future of health care to overcome existing silos in policy development and implementation. The merits of such an approach are relevant not just for policy making but also for making sense of data and improving digital infrastructure, tackling the causes of ill-health, and fostering the relationships that can make or break any health system. Our proposals can be condensed into four essential aims, through which we believe achievable and transformative improvements to the NHS and the nation's health can then be achieved. These are:

◆ Centrality of data: we believe that the secure and effective generation, processing and use of data across services is fundamental to the future of healthcare, including more convenient, community based and personalised care.

◆ Systems approach: we believe that preventative health care must recognise the interaction and interdependence of biological, environmental and behavioural factors. This means that, from government departments down, we must overcome siloed thinking and take a more systematic approach to health.

◆ Openness to innovation: we believe that advances in biomarker and genome-based technologies have significant potential, if introduced and used responsibly. Services need support, capacity and time to ensure implementation is successful.

◆ Human-centredness: while adoption of new technologies and systems will enable more effective and tailored treatments, improvements in health care will depend on the quality of human relationships through which they are achieved. In particular there needs to be recognition that people cannot be considered in isolation, but that the context of their community, whether professional or personal, is essential to understand and respect.

These aims should be drawn together under the vision of a dynamic, learning and innovative health system, shifted towards prevention, and which explicitly seeks to achieve greater equity in outcomes across the population. Both will be essential to reduce the overall burden of disease, improve health outcomes and promote social justice and a flourishing society.

Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

Broadening the scope of community health services and data In the coming years, we anticipate that people's interactions with health services will take an increasing variety of forms, beyond traditional clinical settings, with a greater emphasis on prevention and early intervention. At the same time, growing consumer interest in lifestyle interventions is likely to further blur the boundaries between lifestyle and health, which may raise expectations around personal responsibility and create new opportunities for commercial actors. These trends could align with the shift towards greater care in community settings, however they also point towards important challenges associated with such a transition, particularly in relation to equity of access and outcomes.

Direct-to-consumer health, fitness and lifestyle tools and devices for use outside of the health system may serve to further engage citizens in their health, including those with long-term health conditions. In the right circumstances some may also offer valuable insight and additional data for the greater personalisation of an individual's care. However they could exacerbate health inequalities if not accessible and useful for everyone. The 10-Year Health Plan should consider a strategy for ensuring health services function equitably in the context of the citizen-generated data, the integration with health system-generated data, and the opportunity to better engage citizens as partners in their health, for example the Our Future Health initiative. Consideration will also need to be given to the variation in capacity and willingness of a wide range of patients and members of the public to engage with and use information resources and other tools to support their own health.

The success of moving more care from hospitals to communities must not bemeasured by reductions in hospital-based care but by the evaluation of the care being delivered in communities: what it consists of, who it is reaching, and how it is helping to improve the health of individuals and populations.

Recommendation: Articulate metrics of success for the shift of healthcare into the community that measure health outcomes not location of activity.

Cultural implications of shifting towards the community

The 10-Year Health Plan should prepare for the impact of movement of care into the community on professional roles and responsibilities. The nature of patient-clinician conversations and interactions will evolve, with more taking place in a virtual environment and new sources of patient data becoming available. Further development of effective patient communication and health

coaching skills will be needed. Similarly, as technologies may enable the movement of some forms of monitoring and care from secondary to primary care and primary care to the community, both systems and workforce will need adaptation and training support to ensure this delivers better and more cost-effective care.

Ultimately, it will be about finding the right place for the right intervention. This requires understanding what is achievable in practice, factoring in both how health care can be further guided by scientific and technological advances, and the extent to which this can align with organisational, professional and personal norms.

Recommendation: The cultural implications of shifting care towards the community are recognised and supported.

The role for devolution

A key lever that the 10 Year Plan for the NHS can utilise is around devolution. Many elements of the NHS are currently too centralised, resulting in stifled and disempowered services. There is a need for strategy at a national level that articulates aims and standards, with support and flexibility for local innovation and implementation that reflects the often unique configuration of services and skills.

Recommendation: Utilise devolution to support local innovation and decision making to improve health outcomes.

Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

Optimisation and strategic implementation of technology requires both investment in data and digital infrastructure and a commitment to engaging with and addressing cultural expectations and concerns from NHS staff, patients and citizens. Much of our response aligns with the recommendations of the recent Sudlow Review.

Improving the NHS data and digital infrastructure

A unified data and digital infrastructure is fundamental. For data to play an improved and expanded role, enabling better use of technology in the NHS, several steps are in need of addressing in the 10-Year Plan.

Recommendations:

◆ Address basic data and digital infrastructure needs. All services within the NHS need to have fully implemented electronic patient record systems.

◆ Create an interoperable system. Support is needed for interoperable electronic health records systems and laboratory reporting infrastructures, particularly infrastructures to flag future screening or surveillance needs in individual patient records. The implementation of the NHS Federated Data Platform offers potential to improve interoperability but Trusts need

time and support to engage with the initiative.

◆ Ensure information governance supports, not hinders, innovation. The complex and fragmented bureaucracy associated with accessing sensitive health data for research, validation and clinical implementation is a huge barrier within the NHS. Currently the risk of sharing data does not seem to be balanced by any consideration of the risk of not sharing data. The NHS should signpost and facilitate mechanisms for data access more effectively.

Developing centralised data sharing infrastructures will facilitate and streamline data sharing and analysis.

◆ Embed data collection in test pathways. More consistent data recording by health care professionals/patient facing systems and better alignment of data recorded, as well as consistency in prompts and alerts flagged by electronic health records. Aligning AI-driven thresholds for clinical interventions/clinical support systems (e.g. referral for different interventions or providers) will help to resolve inconsistencies and maintain quality.

◆ Standardise data across the NHS digital infrastructure. A consistent taxonomy within and between clinical specialties and different professional groups providing patient care is a requirement for an effective and interoperable data infrastructure. There is an urgent need for consensus about which phenotypic/clinical symptoms could be used as prompts for AI-driven decision support systems.

◆ Secure data storage and access The National Data Guardian Review of Data Security, Consent and Opt-Outs noted that 'Most people do not feel the need to know what is happening with their data, and people want to be able to trust the system and know that everything is okay'[1]. Whilst the public recognise that data is never completely safe, storing data in secure data environments that can only be accessed by trusted actors could promote public confidence in data sharing. One way to do this is through the use of Secure Data Environments (SDEs) - secure computing platforms that store large amounts of data and provide remote, secure access for data analysis at scale - the majority of which are currently focused on access for research. There also needs to be ransparency about the potential uses to which the data will be put and the collaborations involved.

Improvements in the structuring, integration and interoperability of data sources, as well as streamlining regulation and governance, will be crucial enablers for making better use of existing technologies. Furthermore, given the data-driven nature of many emerging technologies, national implementation of any new technology needs to consider wider infrastructure

1. National Data Guardian for Health and Care. Review of Data Security, Consent and Opt-Outs. June 2016. Citing an Interview with representative from national patient representative charity National Voices. 1 December 2015.

and workplace culture for adoption to be successful.

Engagement

Studies have found that the public is broadly supportive of their health data being shared, if several conditions are met. First, the primary goal of data sharing must be to promote the public interest. Second, there must be sufficient safeguards in place to protect the privacy of data subjects and prevent the misuse of data. And finally, there must be trust in the organisations collecting and using data, and transparency around

expected use. Staff will need to engage with how patient data is mobilised across the NHS so that they can act as a competent interface between patients, members of the public and technological developments. They need the support and capacity to develop their skills and competencies, both to maximise the potential of innovations and to ensure they can engage and communicate change with patients and citizens.

The prospect of more intensive data collection, for example to guide prevention and early diagnosis, does also raise challenges for the governance of electronic health records. Unanswered questions relate to where these records are held, who can access them and the extent of data security measures. Enabling patients to update their own records with details of lifestyle or environmental risk factors offers additional opportunities for granularity and data integration. However it also risks compromising data quality and increasing existing inequalities where these opportunities are more difficult for some groups to take up.

We propose that a key action is to embed feedback from ongoing public engagement to both inform the general public on the risks and opportunities arising from data sharing, and gather feedback around values, acceptable uses and red lines relating to use of data for healthcare and research, to support policy development. One challenge will be addressing how to cater for the inevitable diversity in what is acceptable to the different groups that make up the public.

Recommendation: Embed feedback from ongoing public engagement around data sharing.

Building a learning health system

A key component of creating a successful data and digital infrastructure will be the shift of the NHS towards becoming a learning health system. Currently innovations and service improvements are implemented without ensuring there is evaluation and consideration of whether the technology has had the intended impact. Simply introducing a technology is unlikely to add value or improve health outcomes. Without feedback to R&D, new innovations are less likely to meet remaining gaps or address new healthcare challenges. Any technology needs to be surrounded by systems and infrastructure which will facilitate its use. Beyond data, it is essential for NHS resources to prioritise adoption of technologies which both solve an existing problem or unmet need and to facilitate the decommissioning of obsolete or less effective services as technologies progress.

As part of this, it will be important to pay close attention to the impact of innovation on health care pathways and ensure integration with workflow happens smoothly. Digital twin technologies, which operate as a virtual replica of physical entities, systems or processes, offer a promising novel approach to doing this. Whilst they have been developed to model individual patient care, digital twins can also be used by health services to simulate real clinical scenarios to support training of staff or predict how changes in a test pathway could lead to improved clinical services. For example, digital twin technology is already being implemented to help reduce NHS backlogs by optimising patient flows and improving hospital processes at Guys and St Thomas NHS Foundation Trust, with subsequent reductions in waiting times and costs.

Recommendation: Feedback mechanisms should be built into future innovation so that the health system becomes a continuous source of learning, research and development.

Aligning an innovation ecosystem with the clinical need

In general, there is not enough clarity about unmet clinical need and the evidence base required for novel technologies to be translated from research into the NHS. We need to find better ways to innovate and evaluate technologies rather than simply undertaking studies of interest which never get implemented because they cannot meet regulatory and value expectations. This is particularly important in fields where there is rapid research progress resulting in innovative technologies that may not align with current regulatory or value methodologies such as Advanced Therapy Medicinal Products. The 10-Year Health Plan should set out clear expectations for clinical priorities to ensure that proposed applications of technology benefit patients, have clinical utility and are cost effective.

Implementation of a novel test or technology needs to consider how the pathway allows for continuous monitoring as this equips the NHS with the data needed to make strategic decisions and support equitable service delivery. This is demonstrated by the EXPRESS study, evaluating the implementation of the national prenatal exome sequencing service in England to determine the optimal pathway for service delivery.

Differences in service implementation across England were identified. However, in this case, the ability to make comparisons and draw conclusions between different models of delivery were limited because of gaps in the data collected and a lack of interoperable databases.

Recommendation: Ensure clarity on clinical priorities, how they will be regulated andvalued within the NHS.

Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Advancing early detection and prevention has the potential to enable people to live healthier lives for longer. This will require harnessing technological innovation, and new models of healthcare that maximise the benefits for individuals while ensuring equity across the wider population. It will

represent a fundamental shift as health care professionals and patients will need to reorientate from a demand-led service to one which embraces health promotion and disease prevention.

Key innovations enabling improved disease detection, prognosis, risk assessment and prevention include:

◆ Genomic sequencing for the identification of disease causing and redisposing genetic variants including for rare diseases and cancer.

◆ Multiomic sequencing and analysis of other biomarkers of disease risk and progression, such as RNA and proteins.

◆ Non-invasive cell-free DNA testing ('liquid biopsy') for the detection and haracterisation of pre- symptomatic, early stage and less accessible cancers.

◆ AI-based tools for the analysis of clinical and biomedical 'big data' which can be used to refine existing screening and improve early diagnosis for specified conditions (e.g. cancer imaging, cardiac arrhythmias and retinal disease). AI based tools can also be used to integrate multiple sources of data in order to triage waiting lists across the health system to reduce waiting times.

Risk prediction, stratification and screening

Over the next 10 years there is an opportunity to adopt increasingly sophisticated ways of predicting individual disease risk to improve prevention and early detection of disease. Advances in technology mean it is now possible to aggregate a greater range of factors to estimate overall risk of disease at an individual level. This approach holds promise as a means to grapple with the interaction of biological, environmental and behavioural factors in the causes of ill-health. The challenge is to create processes and systems that can distinguish between the technologies that can provide effective prevention and those that cannot. And then to ensure that tools for prevention can be appropriately assessed in the NHS context in which they will be delivered - including those that may bring together a wide range of different information sources.

At a population level, this could inform population stratification and enable interventions such as screening and surveillance to be targeted towards those who are more likely to benefit from them. This is important, both in terms of reducing costs and reducing unnecessary concerns and interventions for patients. At an individual level, the success of these information technologies remains less obvious and will depend on the extent to which findings can be made meaningful within the context of clinical care and individuals' own lives.

Polygenic scores have garnered recent attention as a tool to refine and improve risk stratification, particularly when combined with conventional risk factors. Integrated risk prediction models, like CanRisk, are already being used to personalise screening and prevention for breast cancer. The CanRisk tool was created to provide a user-friendly, web-based interface for healthcare professionals, integrating genetic, familial and lifestyle factors to inform risk assessment. CanRisk, and the underlying model, has been extensively validated in clinical practice, demonstrating accuracy and

reliability in predicting breast cancer risk. However, although polygenic scores may offer improved risk prediction for some common diseases, this may not be the case for all conditions and robust evidence for each indication will be needed.

Recommendation: Deploy risk stratification technologies where there is clear clinical benefit.

Representative datasets and risks to health inequalities

An additional, significant barrier to the use of genomic technologies for risk prediction is that they are more accurate in some populations than others. The lack of representative datasets is a well-documented challenge not only in genomics and biomedical research, but across healthcare research in general. This means that genomic tests, and other medical technologies such as AI tools, are predominantly developed using data from European ancestry populations, despite being intended for use in diverse populations with mixed ancestry groups. This underrepresentation limits the generalisability of research findings, exacerbating health inequalities. The potential for these technologies to embed, compound and scale existing health inequalities means that caution is needed and efforts must be made to ensure that models are trained on data that reflect the diversity of the population to which they will later be applied. Initiatives such as Our Future Health, which is looking to recruit 5 million volunteers reflecting the UK's diverse population, may help to build representative datasets through which more accurate polygenic risk score models can be developed.

Recommendation: Improve representation of diverse populations within health datasets.

Prevention: the wider context

A health system focussed on prevention will need to be mindful of the significant role that social determinants of health play in driving both overall health outcomes and exacerbating health inequalities. Although many of these determinants, such as income, education and housing, lie outside the scope of DHSC/NHSE decision making, they have a significant impact on health outcomes. Evidence shows that disadvantaged groups are more likely to engage in higher risk health behaviours, experience discrimination and are less likely to access health services. They might also have systematically different experiences within the services that they do use, including in terms of the quality of care they receive, perpetuating a cycle of distrust. For example, a review commissioned by the NHS Race and Health Observatory found evidence of women from ethnic minority backgrounds experiencing 'stereotyping, disrespect, discrimination and cultural insensitivity' when using maternal and neonatal healthcare services. The Core50PLUS5 programme is informing action to reduce healthcare inequalities at both national and system level and has identified five clinical areas of focus. However mitigating these inequities will require efforts to improve equitable access across all services to ensure that they are timely, appropriate, easy to get to and use, sensitive to user choice and need, and culturally competent. Ultimately, a move towards prevention will require addressing inequities caused by social determinants of health through working in partnership

across services, sectors and communities, at local, regional and national level. For example the government could take action to address the challenges facing the food system as identified in the 2021 National Food Strategy.

Recommendation: Address the wider determinants of health and health inequalities through cross-governmental collaboration.

Q5. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example:

Quick to do, that is in the next year or so

◆ Commit to developing the 10 Year Plan using the principles of centrality of data, a systems approach, openness to innovation and human-centredness.

◆ Develop and implement an ongoing public engagement strategy, which includes a national citizens panel, aligned to the data and digital infrastructure commitments, designed to support greater understanding and awareness of the purpose of this infrastructure.

◆ Address barriers to the sharing of health data by reforming information governance and culture. Support a balanced approach to the risks of data sharing that considers the effects of both sharing and not sharing data on patient outcomes.

◆ Ensure that services, researchers and technology developers are signposted to a single front door for access to NHS data. This will minimise duplication of effort, save time and improve consistency in the terms for data sharing.

◆ Explore and assess the potential for digital twins to be used in NHS systems and pathways to inform service delivery improvements.

◆ Articulate clinical priorities, how they will be regulated and valued within the NHS.

◆ Ensure that implementation of new technologies is based on clinical priorities that address unmet need or will result in clinically meaningful changes in care.

In the middle, that is in the next 2 to 5 years

◆ Ensure there is devolution of health decision making, to empower local services to innovate and implement new technologies that meet their community's needs.

◆ Articulate metrics of success for the shift of healthcare into the community that measure health outcomes not location of activity.

◆ Ensure the cultural implications of shifting care towards the community

are recognised and supported.

◆ Develop mechanisms to evaluate preventative interventions.

◆ Improve data standardisation of diagnostic codes to improve clinical relevance and sufficient phenotypic granularity would facilitate health care professionals to be able to order and interpret tests more efficiently and effectively.

◆ Health benefits of screening and early diagnostic interventions must be robustly demonstrated before implementation, either by trials or extensive modelling, to ensure that screening is beneficial for patients.

Long term change, that will take more than 5 years

◆ There is an urgent need to improve data and digital infrastructure due to the sheer scale of investment required, and the impact on health and quality of care. This should include addressing basic data and digital infrastructure needs and creating an interoperable health data system

◆ Create a learning health system culture within the NHS with feedback mechanisms built into future innovation so that the health system becomes a continuous source of learning, research and development