

Consultation response: Developing the long term plan for the NHS

Submitted to

NHS England

Submitted by

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Life stage programmes: Ageing well

What more could be done to encourage and enable patients with long-term health issues to play a fuller role in managing their health?

There are considerable opportunities for new and emerging technologies to support more effective patient engagement with personalised self-management, an area under current exploration by the PHG Foundation My Healthy Future project. These could range from relatively simple digital health tools such as apps for information and support (including from relevant patient communities) to more accurate and responsive biomedical sensors and medication delivery systems, such as the MedicSen system for diabetic patients (currently being trialled in Spain) that incorporates a continuous glucose monitor; an app to calculate insulin requirement; a needle free patch that administers the insulin; and personalised meal plans for up to one month ahead.

However, whilst making the most of tools to offer more personalised and relevant support to patients, recognition will need to be given to the relative capacity of different individuals to use them. Co-development alongside patients and clinicians is likely to maximise utility.

Proliferation in the number and range of direct to consumer health/fitness/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, and some may offer valuable insight and additional data for the greater personalisation of an individual's care. The health system should consider a strategy for these tools/devices and the 'citizen generated data' they create, its integration with health-system generated data, and the opportunity to leverage this data to better engage citizens as partners in their health.

Developments in digital pathology will have a significant impact on the delivery of pathology services... and also lay the foundations for computer analysis of images, including any future tools that use machine learning approaches to facilitate and speed up diagnosis

Clinical priorities: cancer

What should the top priority for improving cancer outcomes and care over the next five and ten years be?

There is a golden opportunity to make the most of current molecular diagnostic testing and ensure that every eligible patient receives testing most relevant to their cancer. Work by Cancer Research UK (Molecular Diagnostic Provision in England, 2015) and the Cellular Molecular Pathology Initiative (Overcoming Barriers to Molecular Diagnostics and Digital Pathology Uptake, 2016) have previously highlighted challenges facing uptake of cancer molecular diagnostic tests.

In particular the pathology staff gap, recently also reported by the Royal College of Pathologists (Meeting pathology demand, 2018) is of particular concern. Investment in training the current workforce and the pathologists of the future should therefore be a priority, as should ensuring that clinicians are made aware of the diagnostic opportunities and have access to appropriate funding mechanisms to utilise them.

Developments in digital pathology will have a significant impact on the delivery of pathology services, by enabling a more flexible mode of image storage and retrieval (digital image vs. a physical slide), allow remote analysis of slides by experts and also lay the foundations for computer analysis of images, including any future tools that use machine learning approaches to facilitate and speed up diagnosis.

What more can be done to ensure that:

- a. More cancers are prevented?
- b. More cancers are diagnosed early and quickly?
- c. People can maintain a good quality of life during and after treatment?
- d. People with cancer have a good experience of care?

In terms of cancer prevention, there is considerable scope to harness 'big data' to better understand the epidemiology and the pathophysiology of different cancers and their subtypes, and to understand and better predict risk. This will require consensus not only about which data should be collected, but also on interoperability of systems and formats for data collection across different NHS sites. Findings from analysis of these data should inform policy around screening, diagnosis, and prevention.

Of note, greater use of increasingly diverse technologies for screening could result in over-diagnosis and this should be taken into account when evaluating new screening tools and planning policies for their use.

Drawing on wider data sources to inform scientific understanding, and on additional information from individuals, may make it possible to refine screening programmes and more accurately stratify populations into low, moderate and high risk sub-groups. Since investing in prevention is strongly desirable, all groups should receive effective communications to explain their risk and NHS support to take relevant steps to reduce it where possible.

The health system should make the most of new technologies to identify cancer earlier, less invasively and more precisely

As the number and range of highly-personalised cancer therapeutics... rises, challenges around equity of access on the basis of costs will inevitably also increase

However, this support should avoid a 'one size fits all' approach and focus primarily on those at highest risk.

The health system should make the most of new technologies to identify cancer earlier, less invasively and more precisely, and also that allow more precise stratification of patients - for example, to determine prognosis or to target therapies appropriately.

Examples include: circulating tumour DNA ('liquid biopsy') tests that are currently available as a molecular diagnostic test for non-small cell lung cancer, but are also being investigated in clinical trials as a monitoring tool for tumour response to treatment and progression; breath biopsy technology that is being investigated as a non-invasive method of facilitating diagnosis of lung and other cancers; image analysis, particularly machine learning approaches facilitated by digital pathology; and testing for non-DNA biomarkers, such as CA125 in ovarian cancer.

Increasing knowledge of and engagement with new technologies within the health system will facilitate not only the optimal use of current tests, but also allow the health system to make the most of new technologies as they become available. There is a valuable opportunity to achieve this engagement within the health system via the multi-disciplinary team (MDT). For example, clinical champions who are knowledgeable about a technology or other innovative approach can be the point of contact on the MDT – this person could be a clinical scientist, a clinician or a pathologist.

Of note, participation in MDTs to support personalised medicine for cancer patients is already placing significant and growing time demands on some health professionals. With moves to embed genomic medicine across the NHS, which will have a particularly profound impact on cancer services, consideration will need to be given to the time requirements for MDTs.

With the increasing variety of tests and technologies available a joined-up approach to diagnostics is also required that links pathology, imaging, genetics and other approaches.

Of note, whilst genomics and other science and technology offer unprecedented opportunities for earlier and more precise diagnosis and more targeted and effective treatments, there are complexities. One issue is that as the number and range of highly-personalised cancer therapeutics such as CAR-T therapies rises, challenges around equity of access on the basis of costs will inevitably also increase.

Another is that ensuring that cancer patients maintain a good quality of life and have a good experience of care relies on so much more than technological tools. Patient-centred care and shared decision-making are vital to ensure that the best choices are made for the patient's preferred outcomes. This could mean streamlining access to innovative treatments or participation in clinical trials for promising new treatments, but actions may also be needed to minimise the risk of inappropriate use of valuable and limited health resources on interventions lacking sufficient evidence of clinical utility.

Experience shows that a major barrier to patient access arises when busy health professionals are simply not aware of the availability of innovations

Providing optimal care and quality of life will undoubtedly also mean maintaining and improving life-planning and decision-making support for newly diagnosed cancer patients; services for those living with cancer as a chronic condition (a group that may expand as the capacity for prompt diagnosis and long-term management options increase); and end-of-life and palliative care.

How can we address variation and inequality to ensure everyone has access to cancer diagnostic services, treatment and care?

Equity of access to innovative technologies and treatments across the NHS is an important principle which should guide implementation of these technologies. Timely and comprehensive 'diffusion' of uptake cannot be assumed, and further steps to accelerate effective access are strongly indicated.

Experience shows that a major barrier to patient access arises when busy health professionals are simply not aware of the availability of innovations, or of how to access them for their own patients. The appropriate training of current and new staff about new technologies should therefore be developed through all feasible channels and at different levels of seniority.

Whilst professional development has always been necessary, the pace of technological change is now such that even more frequent learning may be necessary to keep abreast with emerging opportunities (this includes but is certainly not limited to developments in genomics).

The single most effective means of achieving this is to ensure that innovations are supported by easily accessible and appropriately targeted information (ideally in multiple formats) for health professionals, commissioners and funders and patients, as well as appropriate policy and guidance to support their use.

Academic Health Science Networks and/or other bodies charged with supporting uptake of innovations should be required to provide evidence that they are routinely providing additional support to all NHS institutions, centres and services within their geographic region to adopt and use innovations for patient benefits, following successful initial pilots and trials at selected sites.

Of note, some digital technologies such as telemedicine or augmented reality (for specialist surgery) could in themselves be utilised to directly widen access and merit careful consideration in this light. Trials of technologies to provide increased access to cutting edge care for particularly geographically remote patients could inform wider measures to improve access to some (though not all) forms of specialist care.

Future technological developments may provide opportunities to reshape the NHS to some degree to help accommodate increasing demand and limitations on the availability of specialist staff

Enablers of improvement: workforce

What is the size and shape of the workforce that we need over the next ten years to help deliver the improvements in services that we would like to see?

The current Topol Review of the healthcare workforce is providing a thorough overview of the implications of developments in genomic medicine and digital technologies, to which we have provided detailed input. Digitisation of health data, an essential prerequisite for many potential improvements, will require baseline levels of digital competency; and levels of genomic literacy and skills relevant to different professional roles will also be needed.

It is important to note that these and other innovative tools should be used to underpin person-centred healthcare, shared decision-making that respects and integrates data generated by the patient (citizen generated data); and different ways of accessing care.

Thought should be given how to enhance attributes such as compassion and dignity within the new interactions, and to keep in mind the various dimensions of a whole person rather than reducing them to a dataset. Moreover, as the nature of patient-clinician conversations and interactions evolves (for example, with more taking place in a virtual environment) and new sources of patient data become available, further development of effective patient communication and health coaching skills (focusing on potential interventions for disease prevention and health promotion) 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 to ensure this delivers better and cost-effective care.

Future technological developments may provide opportunities to reshape the NHS to some degree to help accommodate increasing demand and limitations on the availability of specialist staff. The increasing use of multi-disciplinary teams (MDTs) to triage resources appropriately across existing clinical boundaries is likely to be effective, and the development of new forms of allied health professional (for example, specialists in bioinformatics and AI or in patient health coaching) may also be useful.

How should we support staff to deliver the changes and ensure the NHS can attract and retain the staff we need?

Artificial intelligence (AI) and other technologies offer opportunities to boost NHS capacity, improve patient care and redirect the NHS workforce somewhat into those areas and activities where they can most benefit patients. However, successful development, deployment and integration of technologies will require engagement from healthcare professionals, and so suitable investment of their time in these endeavours will pay dividends.

AI-driven tools to support diagnosis and clinical decision-making will not work if staff do not have the time to enter patient data properly

To help staff implement the changes needed and ensure they deliver rapid benefits, actions should include:

- Ensuring that additional learning is highly focused and practical – health professionals already have challenging training and CPD requirements and curricular are already extensive
- Working with Royal Colleges and other professional groups to provide consistent, tailored learning at all stages of professional education and development
- Allowing extra time for staff professional development – the pace of technological change increasingly requires this, and it will pay off when it comes to implementation of useful technologies
- Ensuring that all changes (such as digitisation) are supported by robust infrastructure with standardised formats and interoperability
- Building into staffing rotas the time genuinely needed to use technology to best effect; for example, AI-driven tools to support diagnosis and clinical decision-making will not work if staff do not have the time to enter patient data properly. In some cases this will necessitate a conscious change to clinical pathways or practices and supporting infrastructure that facilitate standardised, high-quality data capture by design

Enablers of improvement: primary care

How can the NHS help and support patients to stay healthy and manage their own minor, short term illnesses and long-term health conditions?

Digital health, apps, wearables and self-monitoring all offer new opportunities – patients are increasingly keen to utilise approaches that can save both their own time and that of health professionals. Clinical provision can be cost-effective in the right circumstances, and may offer new opportunities for constructive engagement in care with some demographic groups, such as younger patients. However, consideration will need to be given to the variation in capacity and willingness of different patient sub-groups to engage with and use information resources and other tools to support their own health and self-management.

Tools of this kind need to be properly designed and assessed with real patients to establish their true clinical utility and learn lessons about how they can be most appropriately used from real-world pilots and trials. There is a particular need for more consistent regulation and accreditation of apps; NHS Digital's use of organisations such as ORCHA to provide systematic quality assurance may encourage greater trust and confidence in the infrastructure for evaluation and ultimately encourage uptake. The regulatory framework established by EU Medical Devices Regulation might also provide greater clarity about safety and effectiveness.

Primary care could play a greater role in promoting health, preventing disease and supporting self management for patients

What other kinds of professionals could play a role in primary care, what services might they be able to deliver which are currently delivered elsewhere and how might they be supported to do so?

There is scope to offer a wider range of services for patients that could support self-management and disease prevention via other professionals such as counsellors, clinical psychologists, dieticians, physiotherapists and exercise instructors and coaches.

How could prevention and pro-active strategies of population health management be built more strongly into primary care?

Personalised prevention could form a highly effective approach, recognising that populations are composed of individuals and that population-level information and interventions, whilst valuable, have their limitations. Primary care is well-placed if sufficiently resourced to better support individuals to understand their own risks and prioritise actions to maintain and improve their own health.

Coupled with adoption of useful new technological interventions as discussed above, primary care could play a greater role in promoting health, preventing disease, and supporting self-management for patients through personalised prevention and person-centred care. This would require offering information, advice and more holistic support tailored to the individual, working closely with social care.

Digital innovation and technology

How can digital technology help the NHS to:

- a. Improve patient care and experience?
- b. Enable people and patients to manage their own health and care?
- c. Improve the efficiency of delivering care?

If implemented and integrated effectively, digital technology has enormous potential to help the NHS across all of these three aspects.

Improving patient care and experience

Broadly, digital systems such as electronic health records (EHRs) are needed for safer, more efficient and more effective healthcare to facilitate the capture of and allow timely access to patient health records. The ability to connect different health datasets can also help in personalising medicine and care for each patient's unique needs.

Interoperable EHRs and digital records could support safer care by allowing clinicians prompt access to relevant medical information about the patients in their care (including medications or contraindications), and by facilitating the timely return of medical test results. Digitally-enabled point-of-care or near-patient testing can improve care through more rapid return of test results thereby facilitating faster-decision making about a patient's care. Reducing the need for patients to wait for results and to schedule additional appointments to discuss test results would improve their experience.

The adoption of underpinning digital infrastructure is a prerequisite to harnessing the full potential it [AI] may offer

Digital technology and infrastructure are fundamental to the delivery of and ongoing improvements in some domains – genomic medicine being one example where digital approaches to store, analyse and manage large volumes of data are essential.

Moving forward, digitisation of health data will more generally provide the foundations upon which new innovations or knowledge to improve care or patient experience can be formed. Artificial intelligence in healthcare is a case in point - there is much excitement around its potential, but the adoption of underpinning digital infrastructure is a prerequisite to harnessing the full potential it may offer.

Enabling people and patients to manage their own health and care

Given the potentially pervasive nature of digital technology (as evidenced by smartphones and m-health), it could be used effectively to better engage and inform users about their own health and potentially encourage a more proactive approach to health and wellbeing.

Some digital solutions may support people to better manage long-term chronic conditions e.g. portable digital devices to monitor health. Digital access to high-quality and accurate health information may also help people self-manage minor ailments, whilst telemedicine and m-health can support the delivery of care outside of the traditional healthcare setting and in people's own homes.

Potentially, digital access to their own patient records could also, by enabling people to recall and understand their medical history, help them to recognise patterns that could be indicative of declining health and encourage them to seek medical advice more promptly.

Improving the efficiency of delivering care

Digital records and technologies could facilitate more seamless and integrated care by ensuring that healthcare professionals have access to the most up-to-date information at the right time and are able to share this as necessary with other professionals involved in the patient's care. They can also support the analysis of health and care data, including outcomes, which in turn could provide evidence to help inform changes in practice or new policies.

Some digital tools can ease the burden of administrative tasks, such as scheduling appointments or ordering repeat prescriptions. Certain digital innovations including developments in machine learning have the potential to expedite repetitive tasks such as analysing medical images. As well as introducing efficiencies (and potentially improving precision), this could also potentially free-up doctors' time for more patient-facing activities.

Industries that have excelled at applying digital technologies have also invested in understanding what their users' needs are

What can the health and care system usefully learn from other industries who use digital technology well?

Digital technology has infiltrated many, if not most, other aspects of modern life, including banking, retail, travel, hospitality, and education to name just a few examples. Statistics suggest that digitisation within these sectors is increasingly being embraced by a significant proportion of the population (e.g. 69% of adults aged 16 or over used online banking in 2018, compared to 35% in 2008, according to the Office of National Statistics]). These trends could be attributed to the greater flexibility, control, and choice that digital technologies may provide.

Key lessons that the health and care system could learn from these sectors are to:

- Focus on user-experience and user-friendly design of digital system. Added convenience and improvements over existing non-digital experience is key to encouraging adoption of digital solutions. This applies to health professionals as well as to patients.
- Cater to different needs and preferences. Not all people will be inclined or able to adopt digital technologies. Use of internet services varies depending on age group and is lower in over 65's compared to younger age groups (Office of National Statistics). To cater for different user-groups, many sectors accommodate both digital and non-digital preferences. For example customers can bank online or visit a physical branch; many airlines have options for customers to either download an e-ticket to their smart-phone or to print or collect a paper ticket at the airport.
- Understand user needs. Industries that have excelled at applying digital technologies have also invested in understanding what their users' needs are, where/what the pinch-points are in existing services, and how digital services can improve and enhance existing experiences. In health and care, user needs may range from greater convenience to schedule appointments and the ability to view personal health records, to better or completely new ways to access health information or services. Some degree of user-consultation and co-development is critical to designing and effectively deploying digital technologies. As digital capabilities develop over time, many sectors adapt or change their digital services and typically seek feedback from users to improve their experience.
- Prioritise data and cyber security and communicating with users on how they can also help safeguard data. Any provider of a digital service must contend with the increasing sophistication of internet malware and cyber-attacks. Maintaining and upgrading data security is a constant requirement with digital systems and like other sectors health and care will need to radically upgrade these capabilities and continue to innovate around security and risk management.
- Be receptive to new ways of working. Many of the sectors that have implemented digital technologies and services successfully at scale have also needed to transform their workflows, operations and retrain staff and/or access new skills-sets. Arguably many of these industries have approached their digital transformation as an integral and interconnected - rather than adjunct - component of their services.

How do we encourage people to use digital tools and services? (What are the issues and considerations that people may have?)

Issues and considerations that people may have around the use of digital services include:

- Trust and confidence in how their data and confidential information are used and managed. A 2016 Wellcome Trust commissioned survey by IPSOS Mori (The one way mirror) on public attitudes towards commercial access to health data, found that drivers for acceptability centred around why (purpose), with whom, and what data are shared. Data breaches and scandals across the wider digital economy (e.g. Facebook and Cambridge Analytica) may also impact on levels of trust and confidence, as do public concerns around the use of their data (and by extension digital services that use their data) by third parties and in ways that may disadvantage them.
- Variable levels of digital competency and engagement. Data from the Office of National Statistics indicate different demographic trends in the levels of interaction with the internet. This is significant because the vast majority of digital tools/services are internet-enabled. 20% of disabled adults had never used the internet in 2018, and older adults were less likely to use the internet than their younger counterparts. Experience, preferences, and digital competency may all influence the uptake of digital tools.

People could be encouraged to use digital tools and services by:

- Design of user-friendly digital tools and services that are convenient to use and meet a need and/or help enhance and improve existing user-experience
- Raising awareness and understanding of the importance of health data for care delivery – since many of digital health tools/services are data driven or data generating. Previous reports of the National Data Guardian for Health and Care have indicated low awareness of how data are used not only by the public, but also by healthcare professionals within the NHS. Understanding Patient Data is one initiative to help address this issue. An ongoing drive to raise awareness at all levels of the NHS and across the wider public will be vital
- Promoting visibility of the digital tools or services that are available and endorsed by the NHS; this is needed to make people aware of the existence of these tools and to demonstrate how they might aid, improve or enhance a service or experience
- Prioritising data security to give people the confidence that their personal and sensitive health data will be safeguarded when they interact with tools which collect or handle this data
- Fostering a culture of transparency around data use and the safeguards and security measures in place, and the reasonable steps users are expected to take to protect their personal data

Actively working with patient groups, carers, charities and the wider public to encourage them to get involved in trialling innovations is highly desirable

How do we ensure we don't widen inequalities through digital services and technology?

Robust evaluation when technologies are implemented will be essential, as will understanding and planning for different preferences and different levels of digital competency. This would include proactive identification of subgroups of patients who may have limited or no access to diagnosis, treatment or management as a result of limited use of digital services or technologies. This could include aspects relating to individual behaviours (e.g. age, poverty) or infrastructure/geography (lack of access of those living in rural communities to internet).

There will be a need to proactively plan alternative patient pathways for those who have limited access to digital technologies for reasons described above, and also to explore opportunities for digital services and technologies to actively help to reduce inequalities (e.g. facilitating remote access to specialist services in rural or isolated communities).

3. Enablers of improvement: research and innovation

How can we increase opportunities for patients and carers to collaborate with the NHS to inform research and also encourage and support the use of proven innovations (for example new approaches to providing care, new medical technologies, use of genomics in healthcare and new medicines)?

Actively working with patient groups, carers, charities and the wider public to encourage them to get involved in trialling innovations is highly desirable. Efforts to engage with these groups may be more successful if there is some degree of involvement from the earliest possible stage of development, and the utility of tools developed in this way is also likely to be greater.

Encouraging and supporting the use of proven innovations within the NHS necessitates ensuring that relevant staff are made fully aware of the utility and availability of these tools and the standards and pathways in which they should be utilised.

In addition, commissioners and funders should be made aware of their benefits, consider these for commissioning and provide reimbursement mechanisms for them to be used appropriately if specific innovations are commissioned for NHS care. This will require devoting dedicated resources to ensure that implementation plans to support the uptake of proven innovations can be developed in a timely fashion and in partnership with relevant clinicians and patient groups; and that active communications are undertaken to ensure relevant stakeholders are made fully aware of both the innovation and the supporting information and structures.

Monitoring and understanding the impact of the opt-out on research datasets will be essential, as will better understanding the social, cultural, and structural barriers and facilitators to research participation

Without such efforts, the intended benefits from this investment in developing and approving the innovation will not be realised. Of note, participation of frontline clinical staff in the evaluation of innovations and in the development of national or local implementation plans and communications to support should be actively incentivised to ensure that they gain both protected time away from clinical duties and professional recognition of their efforts.

This cannot be left solely to the innovators or early adopters and enthusiasts, or widespread adoption and equitable access across the country will not be achieved.

What transformative actions could we take to enable innovations to be developed and to support their use by staff in the NHS?

Allocate and enforce a fixed proportion of time for training to understand and engage with useful innovations, and incentivise those who actively engage with the development and trial of innovations and/or supporting policy, patient engagement and communications with appropriate professional recognition and additional time aside from clinical duties.

How can we encourage more people to participate in research in the NHS and do so in a way that reflects the diversity of our population and differing health and care needs?

Initiatives such as the National Patient Opt-out might play a role in increasing the numbers of people participating in research through providing a one-off consent to the use of their personal data for secondary uses including research.

It could also negatively impact the participation of minority or disadvantaged groups and other demographic groups if they choose to opt-out of sharing for purposes beyond their direct care.

This could make certain health research datasets less representative of the diversity of the population. Monitoring and understanding the impact of the opt-out on research datasets will be essential, as will better understanding the social, cultural, and structural barriers and facilitators to research participation by different population sub-groups e.g. socio-economic groups, ethnic minorities, the elderly etc.

What should our priorities be to ensure that we continue to lead the world in genomic medicine?

Personalisation and stratification of medical care in the coming years will unquestionably be built on genomics, although it will probably also encompass a host of other technologies for precise disease prediction, diagnosis, prognosis and management.

Implementation of genomics across mainstream clinical specialties will proceed most effectively by building on the new National Genomic Medicine Service. In addition to the system of laboratory testing, analysis and reporting offered, it will be essential to include a shared digital infrastructure (and corresponding standards for data entry) to enable sharing and aggregation of all genomic and clinical data within the NHS to optimise patient care.

It will be essential to maintain suitable security of the central data repositories and platforms with proportionate safeguards for patient privacy

These facilities must be supported by ongoing investment in order to ensure that they develop and evolve in line with computational innovation, and remain fully intra-operable with other essential NHS digital systems.

The implementation of genomics and its equitable mainstream use will also require support for clinicians and other healthcare professionals across different specialities, many of whom have currently a limited understanding of genomics and practical experience of how they should use it.

This may include support to identify which patients will benefit from genetic testing; to select the most appropriate test for their patient; to supply the contextual phenotypic and clinical information to inform the referral process; and interpret test reports and know how to act upon them appropriately.

Actions the NHS could take to address these aspects include:

- Working with the medical colleges and other professional bodies to develop the evidence base and clinical care pathways for the implementation of new genomic diagnostics, and to establish standards for genomic medicine practice. This will directly support uptake and change in practice in the various clinical disciplines. These will also inform the education and training needs of clinical staff, and mitigate against the risk of variable and potentially ineffective implementation across different disciplines, regions and institutions
- Building on Health Education England's genomics programme to develop and comprehensively deliver highly focused and easily accessible core training for clinicians in genomics
- Supporting the development of new ways of working across specialities for example through the multidisciplinary team meetings (MDTs) approach to support testing and interpretation. This will address the expected increase in the volume, complexity and scope of genomics testing
- Supporting changes in professional roles so that a wider range of health professionals (such as nurses and healthcare scientists) become involved in genomics
- Continued improvement of the essential digital infrastructure to underpin the capture and sharing of the important contextual clinical and phenotypic information
- Development of reliable and easily accessible clinical information systems relating to genomics for NHS staff, and of an appropriate externally accessible resource for patient information about genomics and health should be considered

It will be essential to maintain suitable security of the central data repositories and platforms, with proportionate safeguards for patient privacy. However, the capacity to reanalyse data in the light of growing data holdings and new scientific knowledge should be retained, along with the capacity to easily alert clinicians and allow them to recontact patients where new information of clinical significance is identified. National standards and processes for data submission, analysis and reporting will need to be put in place and regularly reviewed in the expectation of regular revision, alongside additions and amendments to diagnostic criteria and algorithms.

Trust is the essential element for future success, so open dialogue and discussion in the public arena are strongly indicated

Sufficient resources will be required to meet the need for laboratories to process the expected increasing number of test requests. Consideration should also be given to the need to integrate the collection of valuable data for ongoing research alongside clinical practice. This could range from the submission of accurate phenotypic data, through to systems to ensure that test results are linked with clinical actions and outcomes.

Successful delivery of world-class genomic medicine in the NHS requires many different elements, including an ongoing programme of evaluation and evidence collation, and also the prospective evaluation of potential future opportunities for genomics to improve health. This could include screening and risk evaluation to inform disease prevention, whether in the form of population, cascade or ultimately individual screening. Infrastructure and systems for genomics should permit sufficient versatility to be utilised for infectious disease services and other forms of disease prediction and prevention as may become feasible over time, based on emerging evidence. The question of the interface with public health systems, primary and community care is therefore worth careful consideration from the earliest stages.

The health system could better enable systematic adoption and access to cutting-edge genomic services through support for active engagement efforts to (i) inform key stakeholders within the health system of the effectiveness and benefits of relevant genomic testing within cancer, rare diseases, common diseases (ii) to facilitate the diffusion of knowledge, best-practice, and experience across the network of genomic laboratory and clinical services that are being established as part of the National Genomic Medicine Service.

Public understanding of the critical importance of sharing clinical and genomic data within (and arguably beyond) the NHS to inform better care and to support ongoing research and service improvement will be crucial in ensuring that the NHS continues to lead the world in genomics. Trust is the essential element for future success, so open dialogue and discussion in the public arena are strongly indicated. This should include clear messaging about how the NHS plans to use such data to improve the care of current and future patients alongside clarity about the extent and limitations of privacy protection and consent mechanisms within the NHS.

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PHG Foundation is a health policy think tank with a special focus on how genomics and other emerging health technologies can provide more effective, personalised healthcare