My healthy future: healthy adults workshop

In 2018, the PHG Foundation held four life stage workshops to inform *My healthy future*, focusing on the future of healthcare in 20 years’ time. At this workshop, experts met to discuss how new technologies are shaping the health of adults, and the impact this may have on citizens, health systems and wider society.

Potential of technology

The discussion centred on the following main areas:

- Collecting data on individuals
- Behavioural interventions/modifications
- Helping individual choices
- Education and knowledge
- Shaping and informing policy
- Enhancement

Collecting data on individuals

There will be a multitude of different ways in which data will be collected on individuals. This may include biomedical and digital technologies, often working together. The following examples and possibilities were raised:

Genomics/biomedical

*Germline sequencing available from birth* - quick, cheap germline whole genome sequencing might be undertaken in newborns and could be combined with other ‘omics data including gene expression, and epigenetics data. It would be available from the beginning of life, although it is likely that parents would choose what information to receive. Information would be integrated into delivery of healthcare across the life course as appropriate (e.g. immediate health risks at birth or reproductive risks for those planning a family). Overall it was felt that the information will lead to insights about risk of disease, enabling the delivery of psychosocial support, tailored medications and interventions.
Near-person and portable sequencing - there may be further miniaturisation of DNA sequencing instruments with developments in quantum graphene, and nanopore-based devices. This may enable near-person or near-specimen sequencing and analysis of personal and environmental DNA. These could be synchronised with a mobile phone. Since the device is capable of doing the sequencing and analysis itself, there would be no need to send data to the cloud. Molecular diagnostics have been developed and await IVD regulatory approval. Such devices are transportable and so could be used at any time for a variety of purposes, from clinic to community (e.g. pathogen sequencing of meals to prevent the spread of foodborne diseases).

Monitoring and managing the stomach microbiome - this could use real-time sequencing to encourage the diversity of the microbiome, which has been associated with mental health and is thought to influence many physiological processes.

Other ‘omics’ - e.g. cell free tumour DNA and circulating tumour DNA (ctDNA) as novel biomarkers in early cancer detection.

Sensors

Network of 50 personal sensors and digital twin - it was suggested that there could be a ‘body network’ of up to 50 different body sensors implanted, adhered or connected externally. They would together become an internet communications network which would form a ‘digital twin,’ which could be interrogated by the individual to provide insight into the consequences of health-related behaviours. An element of gamification or links to social media could be added to provide motivation and reward healthy behaviours.

Bio-sensors to understand the exposome - environmental exposure matters but their effect can be complicated and difficult to measure. Metabolomic data may help in characterising the exposome. This could use non-invasive measures, such as respiratory gases and bodily fluids, and would be integrated with other environmental factors.

What will be the desirable objectives or priorities for the future?
Environment sensors to help individuals improve their health - the example was given of a personal sensor, such as a mask, to monitor the quality of air being breathed and prompt a move to a fresher environment.

Sensors available around the home via the ‘Internet of Things’ - for example a lavatory that takes automatic samples of urine or stool to check for cancer, pregnancy or other biomarkers.

Discrete biosensors embedded into clothing - smart tattoos or discrete and streamlined worn sensors could provide continuous monitoring of factors such as temperature, stress or heart rate, which can be harmonised and interpreted to provide a meaningful profile of an individual.

Explicit real time food intake monitoring - for example, a corneal implant and stomach biosensors which would provide the individual with information about the calorific value of their food and its nutritional value, in order to inform eating behaviour.

Home sensors connected to individual - smart home (fridge, cupboards, floor etc.) and ‘omics’ technologies (the microenvironment) could communicate with the individual, providing more information to help identify options for preventing future disease. An example was of a smart home for preventive care in the elderly with sensors in the floor to detect gait changes, voice tracking to detect early Parkinson’s disease, and use of the toilet to detect possible urinary tract infection.

Enablers

Smartphone apps that could facilitate effective lifestyle modification for all (improving diet, avoidance of smoking), adapting to various levels of sophistication in the users.

Information will lead to insights about risk of disease, and enable delivery of psychosocial support, tailored medications and interventions.
**Adult health**

**Apps for clinicians** to aid integration and interpretation of mass data. Platforms may be available that enable mass data integration, and allow clinicians to consider this alongside phenotypic characteristics of their patient, perhaps in the form on an app.

**Behavioural interventions/modifications**
Technologies may be employed to help promote behavioural modifications. A very futuristic vision was suggested where individuals may have a personal prevention plan at age 18, based on genomics, information from electronic health records, baseline lifestyle measurements and social data, which may then enable personalised ‘contextualised nudges’ on behaviours.

Examples of technologies to assist the promotion of behaviour change included:

**Smart behaviour change** - using behavioural psychology to understand and tailor approaches to improving lifestyle.

**New range of physical activity interventions** - technologies to encourage a new range of exercise that may be particularly suitable and/or preferred by the individual.

**Intelligent robotic pets** - to counter loneliness and promote exercise.

**Devices for social and community connectedness**: Loneliness across the life course is a major public health challenge, which may be combatted with devices that link to people with similar interests or in the immediate environment, assisting in developing social connectivity and helping to build community cohesion.

**Assisting individual decision-making**
A number of technologies will enable individuals to make health choices, either on their own or through interaction with a healthcare or other professional. These might include:

**Technologies to help doctors communicate complex risk to individuals** - and enable them to then integrate this with the individual’s views and values, to inform their lifestyle choices.

**Technologies to help individuals visualise the impact of health choices** - these would be directly relevant to the individual and might, for example include a virtual reality mirror to show likely appearance at a future date if smoking is continued.
**Adult health**

**Technologies for individuals to communicate their values** - such technologies would help people think about, articulate and communicate their values and what matters to them in life. This could assist them in making lifestyle choices and exercising autonomy in decision-making.

**Devices for all round life planning** - devices could integrate relevant datasets relating to an individual to assist in career, employment and consumer choices.

**Education and knowledge** - technologies can also be used to inform the education of children. For example, virtual or augmented reality may be developed for individuals based on health projections to simulate the physical sensations and experiences of future health conditions with a view to enabling them to better manage those conditions.

**Shaping and informing policy**

Technologies that collect data from individuals could also be used at a population level to shape approaches to health promotion and healthcare. Examples that were suggested included:

**Technologies for capturing complexity in health** - current technologies to collect information about individuals do not currently capture the bio-psycho-social (holistic) dimensions of health. This may be possible with future technologies.

**Device based standardised systems for surveillance of health** - health behaviour by using more objective and device-based measures, pooling and standardising data.

**Regulation to optimise health** - regulation may be introduced as a form of technology to optimise health and reduce risk. This might include fine tuning of regulations regarding commercial goods; for example minimal alcohol cost, taxing sugary food, enforcing plain packaging of cigarettes to minimise their attractiveness.

**Future vision of enhancement**

It was noted that, although currently we use technologies as a means of preventing, monitoring or mitigating disease, in the future they may be used to augment already good health, for example with brain chips or performance enhancing bionic limbs.
Issues

In the second session issues were introduced individually, following which they were discussed by all participants and grouped into the following main themes:

1. Aims and values
2. Social and public health considerations
3. Psychosocial outcomes
4. Control and choice
5. Professionalism
6. Data
7. Providing reassurance and trust in the age of the rise of the machine
8. Financial
9. Implementation problems and solutions

This section provides an account of issues raised and discussed during the session. During this session, debate on the individual issues was limited, although the workshop was broadly in agreement over the main themes and the relevance of issues within them.

Aims and values

The group was concerned that the further development and use of technologies for personalised prevention as well as the adoption of lifestyles and interventions aimed at improving health may lead to a 'reductionist view of health'. It was vital to retain and develop a view of 'being human' rather than 'being healthy'. A sense of purpose is necessary, being associated with reduction in social isolation, a sense of empowerment and feeling valued. Concepts of freedom, liberty and joy are also central, although these may change over years. It was important to acknowledge that human beings have characteristics which may seem to be flaws but without these 'flaws' there would be much less creativity and art. People sometimes want and need to take risks and it is not always appropriate to follow the 'nudges' that may be pushing them towards healthier choices.

Social and public health considerations

Participants expressed concern that an emphasis on technologies focusing on an individualistic approach to health through personalised prevention may lead to neglect of the wider dimension that addresses public health issues. This was described as an 'eclipse of public health strategies'. There are major political and social challenges that must be met if we are to reduce inequalities as well as other structural issues that are important determinants of health within the population. These determinants could be addressed without adopting new technologies.
Indeed, health inequalities could rise as a result of new technologies for personalised prevention, if, under the ‘inverse care law’, those that need the new technology most would be the least likely to get access to it. Even those who were able to access new technologies to provide information about risk or possible early disease may not be able to benefit from it if they lack the resources to follow up the suggested changes. Providing access to technologies might be necessary but not sufficient to promote better public health.

Within health services, the increasing dependency on artificial intelligence (AI) may mean that a ‘two-tier’ service could gradually emerge. In the future the majority of individuals would perhaps consult an AI advisor in the first instance, before a long wait to see a human clinician. More wealthy individuals would likely be able to by-pass this stage and benefit from greater access to earlier human clinician interaction. On the other hand, greater use of AI technologies may increase the capacity of health systems to review and triage larger numbers of patients quicker.

Finally, the view was expressed that these technologies are being ‘sold as providing greater autonomy’ over health, but this is only a narrow sense of autonomy. They might provide people with information to decide, yet not the ability to enact the required personal changes.

**Psychosocial outcomes**

A number of psychosocial harms may arise from increased use of technologies aimed at personalised prevention. Even though these are meant to have positive effects in improving health, there might be ‘unintended negative consequences’. Delegates mentioned the following:

- **Feelings of inadequacy that may be triggered by failing to meet targets:** this may lead to increased guilt, psychological effects, anxiety and negative effects on mental health

- **Increased anxiety and isolation:** it was suggested that individuals may become too preoccupied with their own wellbeing. On a wider level there may be failure to see population level effects

- **Self-stigma:** there may be a potential for psychological harm and ‘self-stigma’ arising from test predictions

- **Potential for digital addiction:** there may be vulnerability to the addictive effects of nudges. Constant connectedness may have adverse effects on mental health
Overall participants thought that it was vital that, alongside all these technologies, the sense of connectedness to a community is retained: a meaning for life; a sense of belonging; a function; and a feeling of value and importance to society.

Control and choice
Discussion centred around the apparent paradox that technologies aimed at increasing personal control and choice might, in reality, end up reducing it. Overall, the perception was that those developing personalised prevention are, themselves, defining what is normal, what is important and what responsive behaviours are expected. At the very least, this is paternalistic but it may be more problematic. Society is making ‘cultural assumptions about what is normal, what we are aiming for and what is the right way to be and to live’. The question of ‘who decides when to nudge you and in what way’ is an important one for society.

More troubling still are the ways in which individuals may be controlled, restricted or even discriminated against on the basis of their health data. This may be important in areas such as employment, health insurance or access to healthcare.

Professionalism
Two main themes ran through the discussions about the role of health professionals in technology enabled personalised prevention:

The changes in practice that health professionals must make to implement this effectively
Although there is awareness of new technologies, there are concerns about recognising and understanding the complexity and uncertainty inherent in this data, as well as about communicating and explaining this to patients. Technologies will only be implemented once professionals are satisfied with changes in practice and outcomes.

There is further ‘fear of the unknown’ amongst healthcare professionals trying to deal with a ‘data tsunami’. Challenges include:
- How the data is integrated
- How far data generated outside the health system can be trusted and how professionals will use this in clinical care
- Products outside the health system are often focused on early detection and may lead to more overdiagnosis
Fear of the unknown related to digital data

Fear that greater availability of data will lead to increased demand, which professionals will be unable to manage.

**Good professional practice**

Lastly, concern was expressed surrounding maintaining good medical practice. Good medical care is built on wisdom, experience and understanding. The reduction in direct human interaction between doctor and patient could mean losing sight of what is in the best interests of the patient.

**Data**

The data, and who is responsible for it formed a recurring theme in the workshop. Large quantities of data from disparate sources are being created and there are challenges in developing appropriate means of collecting, analysing and integrating it.

The development of detailed databases of personal information related to the health of individuals raises concerns about data security and vulnerability. At a system level there were concerns about the potential fragility of data systems and the possibility of commercial or malicious attacks. Around individuals, participants identified problems arising from criminal activity, such as blackmailing or data manipulation to mask personal information.

With citizen generated data, challenges include trustworthiness when the data is generated outside the health system.

Overall, there were concerns about who controls the data and its quality. Standards would be required around interoperability between electronic health records and health data, the reduction of silos for data between different elements of healthcare, privacy for trackables (ensuring data is safeguarded) and creating the necessary infrastructure for data linkages between different sources.

**Providing reassurance and trust in the age of the rise of the machine**

There are an increasing number of applications of AI to promote better individual health. For the foreseeable future, AI will be used to support human decisions rather than make them independently, but increasingly 'machines will know more than the doctor about an individual' and the doctor will 'become useless' without AI technologies.
Ethics must be built into the design and development of AI. It is known that decision making on the basis of algorithms can lead to adverse outcomes for some, so there should be opportunities for human intervention, and opportunities to contest AI-determined decision making so that it is not solely automated. Whether ‘[the] clinician [is] assisting the algorithm’ or vice versa, with increased use of AI in healthcare there will be a need to clarify clinical liability when adverse outcomes occur.

It will also be important to regulate algorithmic decision-making (which was described as ‘black box’ medicine) ‘without human input’. There was a perception that currently major organisations are ‘unwilling to accept responsibility of regulating AI’. However, there was also a plea that regulation should be ‘good and proportionate’.

Financial
It was thought that personalised prevention and its related innovative technologies are currently largely driven by the commercial sector and would continue to be so in the future, with the NHS ‘reacting to what is happening’. The group questioned who is paying for personalised technologies and concluded that the cost is being passed on to the end user.

Recommendations
In the final session, participants worked in small groups to develop and suggest ways in which some of the workshop’s main identified issues could be addressed.

Data
Role of government
- The UK government should incentivise technology development, which should be international
- Leaders should be fostered within government and the health service
- The government should consider the need for a long term vision for data and security
- The government should continue to play an active role in the development of governance for AI
Standards

- There should be international and cross-sector cooperation to develop open, global standards for technology development, which should include the health sector and wider engagement stakeholders.

Security

- Cybersecurity should be embedded into health infrastructures with laws and rules for detecting the falsification or tampering with data and methods to detect when this happens.

Citizen generated data

- There should be recognition of the key role for patient groups, both in collecting high quality data and especially in representing the patient perspective. Citizen led research should be supported.

Psychosocial outcomes

Behaviour change apps and disease risk information were identified as two clear areas with potential for psychosocial outcomes. There was a need for:

- Patient /consumer/citizen-centred research
- Evidence on outcomes, which could inform the development of policy
- Standards (possibly self-regulation), which should form part of upstream design of technologies
- Consideration of potential for an NHS ‘seal of approval’ to assert that it meets certain standards, rather than imposing regulation as such
- Consideration of how and to what extent people (‘human support’) should be involved in the delivery of the technology

Professionalism

Changes would be required in the understanding, attitudes and roles of health professionals. The following main actions were suggested:

- Professional autonomy and power. Professionals should be involved and consulted at an early stage and throughout development to ensure shared ownership of developments in policy
- There would need to be a cultural change for health services and these changes should be ‘appropriately marketed’, for example using case studies and involving innovators as exemplars of specific changes.
Recognising and communicating complexity and uncertainty will be important. Apps should be developed for clinicians to illustrate a range of possible results and risks using different graphics and methods.

Some retraining of professionals will be necessary to develop skills, understand and deal with the massive increase in data, provide empowerment and ensure access support.

The use of technologies may free professional time, where possible this should be used to enable professionals to focus additional time and resources on more complex patients.

**Implementation**

It was generally agreed that uptake and implementation of new technologies was not keeping pace with their development. Potential ways of facilitating and promoting implementation were suggested as follows:

- **Resolving cross functional benefits**: interested groups should work together to ensure that adoption of new technologies was mutually beneficial to all parties and not just driven by self-interest.

- **Creating the right tariff structures for apps**: realistic pricing will facilitate earlier adoption.

- **Recognising issues before technologies become entrenched**: it is often difficult or impossible to determine the impact of a technology before it is in place; once it is in place it can be hard to change.

**Social and public inequalities**

Those designing and developing new technologies should always be conscious of the potential for exacerbation of social and public inequalities in health that may arise. Methods of development should therefore incorporate certain features:

- Technologies should be designed with collaboration in mind, especially for public health goals.

- New voices should be invited into the design and development of behaviour change apps. Although often led by the commercial sector, development should include citizens, community groups, social scientists and the public health community.
Technologies should be developed to support bottom up, democratic & collaborative approaches to health and not solely in support of business or commercial goals.

**Providing reassurance and trust in the age of the rise of the machine**

**Regulation**

AI and machine learning (ML) applications straddle several different regulatory frameworks. Depending on the context, the Care Quality Commission (CQC), or the Medicines and Healthcare Products Regulatory Agency (MHRA) may have regulatory oversight over algorithm development and accreditation. The CQC regulates medical services (delivered by humans); the MHRA regulates medical devices (including algorithms and software) pursuant to the EU Medical Devices Directive. Given that AI will, in the future, deliver healthcare without human intervention, there is an increasing need for clarity about what regulations should apply and whether a new institution might be required in the future to have oversight of this area.

**Public understanding of risk**

There is a need for rationalising the public’s perception of risk with respect to AI. Developers and health systems must be conscious of the emphasis on safety in the assessment of apps.

**Removing systemic bias from AI/ML.**

Using ML on existing data may replicate the biases that were inherent in the design of the tools and the data used to develop it. It will be necessary to:

- Find ways of examining existing bias in AI
- Find ways to remove systematic bias so that machines are as unbiased as possible
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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.