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My healthy future: young people 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 young people, and the impact this may have on citizens, health systems and wider society.

Potential of new technology

In 20 years technologies will be enabling us to predict disease, prompt behaviour change, prevent disease and intervene in management of health problems. There would be new opportunities to:

- Understand health and its determinants

- Promote engagement with health

- Increase access to health and healthcare

- Provide better quality and more acceptable care

In the future there will be an increased range of interventions to support those with health problems. These would broadly be designed for young people and underpinned by changes in infrastructure including:

- Common and accepted use of standardised electronic health records accessible by the individual and flowing freely between health service providers

- AI driven diagnostics trained to behave appropriately for the individual

- Data driven understanding of young people as a group on which individualisation can be built

What is the potential of new technologies to inform and improve young peoples healthcare?

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Tools to understand individual health

- **Understanding individual drivers for lifestyles and better ability to change these** – driven by more research and big datasets, it may be possible to understand drivers, concerns, and motivations of young people as a group and individuals,and enable them to optimise lifestyles for health (even though this might not be their primary concern)

- **Understanding biological risk** – a range of biomedical and digital biomarkers that would help individuals learn about risk. Specifically there would be much greater use of genome sequencing and a range of other biomedical and digital biomarkers

- **Identifying and responding to an individual's risky behaviours** – technologies including wearables and environmental sensors would enable prediction and detection of risky behaviours in individuals and prompt with increasingly personalised advice (e.g. provision of information, motivational prompts or helpful interventions such as booking appointments)

- **Understanding and identifying early an individual's possible health problems** – machine learning driven analytics may be able to engage with an individual's dataset, that would include health service derived and more personal data obtained through apps to extract information relevant to particular health problems (for example, evidence of early disease) and provide information or signpost to relevant advice

- **Understanding maturity and capacity** - better understanding of competence, maturity and capacity from digital data which could be used to judge capacity and impulsiveness (through brain scans) for use in healthcare settings

- **Normalisation of health** – digital tools may encourage normalisation of health conditions and social inclusiveness

Tools to promote health engagement

Tools to promote health engagement for young people would become increasingly sophisticated. They would provide information, respond to health needs and link individuals to care. They would respond to different needs in ways that are adapted for different individuals and that focus on the whole pathway.

Tools for young people might utilise the status and influence of the peer or use social media networks, some of which may be focused on those with specific needs, such as disability.

Technology may also enable young people to articulate their health needs as a group. Adolescents occupy a unique space in society. Their needs tend not to be voiced at political or national levels, except through campaigns and lobbying. In the future technology could enable young people to voice their concerns and needs directly, without mediation, improving the landscape of young people's health.

Tools to widen access

The development of tools that promote access to services was also discussed. Examples included:

- ◾ 'Artificial experts' e.g. consultations with dieticians, personalised counsellors or GPs

- ◾ Advice and signposting access to care – e.g. mental health support

- ◾ Telehealth – e.g. for those who may not have easy access to healthcare due to geographical location

- ◾ Digital hubs within social networks and peer support for people with similar conditions

- ◾ Engaging different demographics and utilising new tools for societal engagement and healthcare access

- ◾ Online tools to link individuals to testing and treatment e.g. in sexually transmitted disease

Increased quality, range and number of health interventions

This will particularly be the case for care of young people with long term conditions, to enable them to live as normal a life as possible (e.g. the use of insulin pumps which provide continuous monitoring and insulin infusions, thereby enable better control, whilst also being more discrete and thus empowering the individual and reducing stigma).

'Most digital tech will not be provided by state funded healthcare. Using tech will rely upon the individuals themselves and incur costs to these individuals, which may increase health inequalities'.
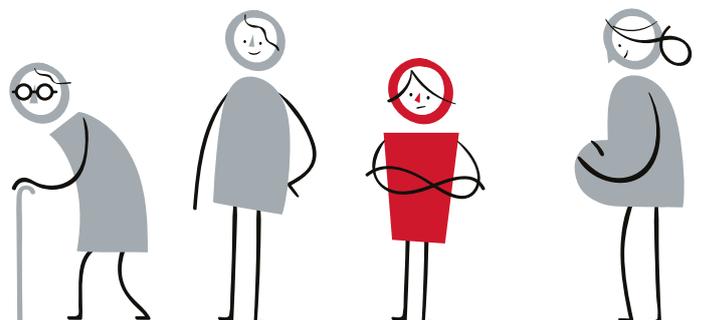
Issues and opportunities

For society

- New personalised prevention technologies would largely influence health by altering the role of the individual

- Technologies may enhance the ability of the individual to contribute but also raise the potential for them to be isolated

- It will become the norm that things are done through data sharing

- Technology developments raise the idea that there are solutions to every problem. Increased expectation may lead to disillusionment with healthcare, confusion and wasted resources

- There is potential for links with health insurance and the possibility that black box data might be used to stratify individuals

- There was concern that nudging through technology becomes coercion

- There is potential for malicious applications

- There might be an anti-technology and anti-data pushback which would have consequences for healthcare

- There is a major risk that the social determinants of health would begin to be overlooked

- There is a risk that increased use of technologies for personalised prevention and health improvement, with an emphasis on individual risk and behaviours, will widen health inequalities and lead to adverse consequences

- The changing emphasis of responsibility would mean that people may be more likely to blame themselves (or others) for individual health problems and that society could conclude that 'poor health is the fault of individual behaviours'. Even within the context of personal apps it was noted that these are 'dissociated from the realities of individual circumstances e.g. a lack of open space ito walk in, or insufficient money to buy healthy food'

What issues will arise as these technologies are brought into play?

Implications for individuals

- New technologies, with their focus on the central role of the individual may give rise to additional pressures or harms to those individuals

- Potential for increased social pressure. Adolescents can be particularly sensitive to rejection and exclusion. Existing apps can contribute to poor mental wellbeing and it is known that there are negative impacts of social media on mental health

- Personal reminders and health alerts may become intrusive

- Constant monitoring and reminders may lead to obsessive behaviours – for example in the context of dieting or exercise

- Managing the emotional impact of health information. We need some way of helping people to manage their reaction to information and diagnoses

- An increase in sharing information may increase the potential for stigmatisation – particularly in the areas of mental health or sexual problems

- Potential for stigmatisation or discrimination in later life arising from inability or great difficulty in erasing information that has been collected as a young person

Implications for health systems

The health system needs to consider how best to integrate and use these new technologies (whether provided by the health system or through the commercial sector) and use them most effectively and efficiently with individuals and for wide population benefit. It is likely there will be increased numbers of players in healthcare – it will become increasingly commercialised and the control of technology within the NHS will be lost.

Evaluation

We do not currently know how to evaluate the success of technologies, including positive and negative unexpected outcomes and confounding factors. It will be necessary to develop new parameters for evaluation of these technologies that can accommodate the unforeseen consequences that arise from complex interventions; some of these will be detrimental. It will also be necessary to take account of the fact that technologies are developing very rapidly; using current methods technologies are often out of date before they have been evaluated.

'If digital health is such a big thing, people need to realise the influence of school and social networks on how adolescents share information and use digital media'
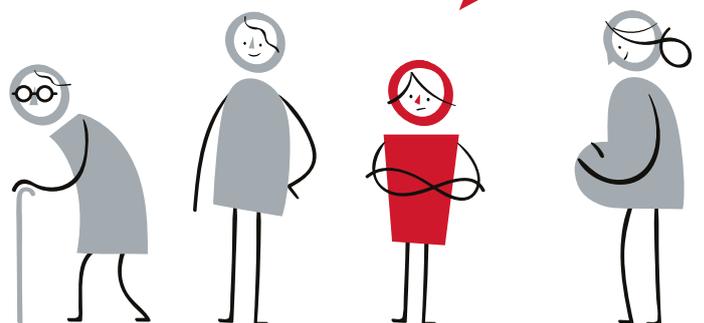
Robust information

Ensuring that the information that people access is robust and knowing who and which apps (or technologies) to trust amidst a wealth of information is increasingly problematic. However, people do need reassurance that the apps they access are providing reliable information and advice and using data safely. This was not an issue solely for commercially available technologies.

The human factor

What level of human support will be required in addition to technology? It was assumed that some therapists and clinician will provide support but it was doubtful whether there would be sufficient capacity to deal with the increase in data produced by adolescents. This means that there will need to be a balance of digital and 'in person' support, which must adapt to different circumstances. In particular, although teenagers are thought to like to be self-reliant it is not certain where, and how, this might apply to managing their own health issues.

The impact of commercialisation

Commercialisation could cause a shift away from centralised provision of healthcare, and a push towards privatisation and the US model of self-funded healthcare (and the decline of the NHS). The role of the NHS in controlling quality and effectiveness of medical technologies will be significantly weakened when there is an expanded commercially driven sector.

Legal consequences for younger people

Gillick competence

Increased data may make decisions increasingly complex, which could drive up the bar for 'Gillick' competence and increase reliance on parents for decision making. In instances where an adolescent does not have capacity to refuse life-sustaining treatment, some information might go directly to parents (as they have maintained their parental rights), and therefore data will be shared without consent. This leads to loss of autonomy for the adolescent, and may feed into avoidance of accessing health services. It was thought that competence should be decision specific. In this arena we might lose that because it starts when they are eleven, and is reviewed maybe once a year but is not reconsidered with every individual decision.

- There are issues around being able to prove consent and ensuring that it has been given. We have no way of proving that consent is provided

- Inadequacy of parental locks e.g. online streaming services

- Difficulty in ensuring that parental consent has been provided where required

'**What use is NHS assessment of technology if they are not able to do anything about it?'**
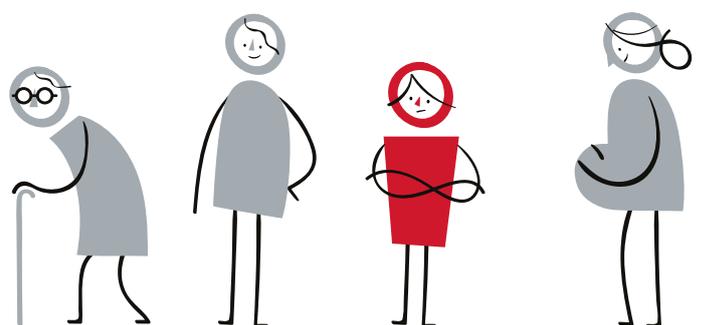
The data challenge

Healthcare in the future will involve a vast quantity of data that is collected by individuals and healthcare systems and transferred between them.

Legal implications

Possessing data creates duties to monitor information and there is potential for legal action where data is not appropriately monitored and negative consequences occur.

Wider concerns

Concerns included the following:

- Data collected by and about young people creates a significant digital footprint which is potentially sensitive both at the time and for the future

- Highly sensitive data is being collected in cloud storage devices but there are safety and security concerns. What if security isn't maintained?

- Data is so prevalent that, even without an individual's personal information, it is possible to make predictions about them using information gathered from others

- The capacity of healthcare professionals to deal with the information in a responsible and legally appropriate way

- The need to monitor information that is sent to health professionals in real-time

- Whether the collection of healthcare data sustainable?

- The loss of data between electronic health record systems with upgrades, changes of location, etc

- Significant interoperability challenges with electronic health records

- Transparency in digital manipulation: e.g. gamified apps are digitally manipulating individuals to get more exercise, which may be benign (e.g. for health promotion) but there could be less wholesome motivations (e.g. targeted advertising)

- Cyber crime and cyber security

- Concerns about genomics and blockchain because genomics provide a unique identifier

- Consideration of opt-in and opt out schemes and whether those who choose to opt out are disadvantaged
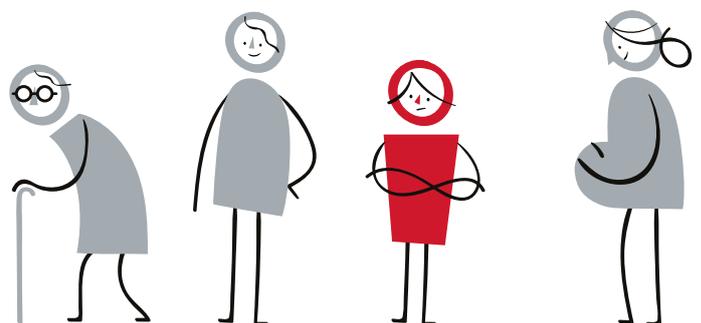
Solutions and suggestions

In small groups to workshop participants discussed the issues in more detail and suggested ways to address them.

Information safe-guarding and protection

- Need for a long-term information governance strategy

- Contractual provisions and transparency

- Privacy by design and data protection by design

- Well-resourced regulators

Evaluation

- Need for independent evaluation of apps or software for diagnostics with streamlined processes

- New methods will be required to reduce cost and time required for evaluation

- Consider alternatives to evaluation – for example, education

Ethical and legal implications

- Revisit Gillick competence in the context of technologies for personalised prevention in young people

- Ensure that data safeguards apply including privacy by design, parental involvement in consent, dynamic processes for consent and the right to be forgotten

Risk of increasing inequalities

- Acknowledge that technology will not solve the problem of inequalities in health

- Since current drivers are largely profitability there should be system overview with equality monitoring and the possibility of development of regulations concerning inequality

- Ensuring resolution of infrastructure issues that preclude access to technology e.g.: data connectivity, broadband speed, availability of technology devices to the individual

- NHS App Store – Apps should undergo an equality impact assessment before they are made available

What will be the desirable objectives and priorities for the future?
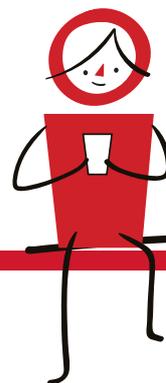
- Explore parallels for protecting equality in other domains e.g: pharma, teen pregnancy, where Government initiatives have made progress.

- Develop technology impact statements on particular population groups

- Improve digital and health literacy among children and young people to ensure that they are able to read and understand health information

- Reducing cost barriers to information; reduce pay walls; open access

- Stimulate communities to consider improvements to their own health and how most appropriately to deliver them. Avoid emphasis on individual responsibility

- Monitor the use of and benefit from technologies with respect to different population groups and reduce differences in outcome by working with groups who are not benefitting

Information provision

- Co-creation of tech between young people and developers is key

- The involvement of other stakeholders (schools, professionals, parents, policy-makers) will be necessary

My healthy future young people workshop participants

Alison Hall – Head of Humanities, PHG Foundation, Ann Hagell - Research Lead, Association for Young People's Health, Anna Moore - Implementation Lead for the THRIVE partnership and trainee psychiatrist at the University of Cambridge Department of Psychiatry, Bethan Davies - Research Fellow, Nottingham University, Eloise Norbury – Events and Engagement Manager, PHG Foundation, Emma Cave - Professor of Healthcare Law, Director of Research and Deputy Dean of the Law School, Durham University, Eustace De Sousa - National Lead for Children, Young People and Families, Public Health England, Hilary Burton – Consultant in Public Health, PHG Foundation, Jo Gibbs - Senior Lecturer in Infectious Disease, University College London, Johan Ordish – Senior Policy Analyst, PHG Foundation, Karen McCullagh - Course Director for the LLM in Media Law, Policy and Practice, University of East Anglia, Liz Cairncross - Research Manager, The Health Foundation, Louise Gaynor - Policy Analyst, PHG Foundation, Miranda Mathieson - Digital Champion, Brook, Priscilla Alderson - Emeritus Professor, University College London, Rebecca Bazeley - Marketing and Communications Manager, PHG Foundation, Ron Zimmern - Chairman, PHG Foundation Sobia Raza - Head of Science, PHG Foundation, Sofia Strommer - Psychologist and Research Fellow in Behavioural Science at the MRC Lifecourse Epidemiology Unit, University of Southampton, Sonny Coduri-Fulford - Clinical Champion, Brook, Susanne Schweizer - Sir Henry Wellcome Fellow, University College London, Tanya Brigden – Policy Analyst, PHG Foundation

Contact: intelligence@phgfoundation.org

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