# NIHR 'Health Futures' 20 year forward view

**RESPONSE FROM THE ASSOCIATION OF MEDICAL RESEARCH CHARITIES**

**JUNE 2017**

The Association of Medical Research Charities (AMRC) is a membership organisation of the leading medical and health charities funding research in the UK. We represent 140 medical research charities including the Wellcome Trust, Cancer Research UK and the British Heart Foundation. In 2015, AMRC member charities:

- invested over **£1.6 billion of research funding in the UK** - more than either the Medical Research Council or National Institute for Health Research;
- made **capital investments of £86 million** in the UK;
- contributed to the knowledge economy by funding the **salaries of over 17,000 researchers** in the UK; and
- recruited **170,000 people to charity-funded clinical trials**.

**Question 1: In relation to your area of interest (discipline or geography), what differences do you foresee in the state of health and provision of healthcare in England in 20-30 years' time? In your answer, please consider if/how these changes might affect some populations (within England) differently to others, i.e. socioeconomic, ethnic groups and/or geographic groups.**

As a membership organisation, we represent many different diseases and long term conditions. Inevitably, each specific AMRC member charity has its own views and priorities over health and provision of healthcare in 20-30 years' time. We have however procured some sector-wide views that may be helpful to consider:

Key differences anticipated by AMRC:

1. A shift in the healthcare needs towards chronic rather than acute care

   Advances in research will result in better treatments and therapies, and ultimately better care. Consequently, individuals are likely to live with conditions for longer: diseases affecting all age groups which are currently terminal may no longer be in the future. Cancer Research UK is funding research with the aim that within the next twenty years, 75% of people diagnosed with cancer will survive[1]. Only a quarter did in 1970 and 50% do today. Breast Cancer Now has a similarly bold ambition that by 2050 everyone with breast cancer will survive[2]. Ambitions such as these are the driving force behind many charities representing a myriad of diseases and conditions ranging from diabetes[3] to stroke[4], from cardiovascular disease[5] to Parkinson's disease[6,7]. As we step closer to meeting these aims, healthcare demographics will change and many more people will live with, and beyond, a condition they are diagnosed with.

   Healthcare services will need to adapt to these changes to support an ever increasing population of 'survivors' allowing them to live healthy independent lives. While a 'cure' may be still far out of reach for many diseases within the 20-30 year timeframe of this report, we do perceive a shift towards chronic disease management.

[1] http://www.cancerresearchuk.org/sites/default/files/cruk_strategy_highlights.pdf
[2] http://breastcancernow.org/breast-cancer-research
[3] https://www.diabetes.org.uk/Research/Our-approach-to-research/
[4] https://www.stroke.org.uk/what-we-do/about-us/our-vision-mission-and-values
[5] https://www.bhf.org.uk/about-us/bhf-strategy
[6] https://www.parkinsons.org.uk/content/our-vision-and-values
[7] https://www.cureparkinsons.org.uk/research-vision

2. A greater focus on healthy ageing

A consequence of overcoming diseases that have traditionally have been terminal will clearly mean that people live longer. Subsequently, efforts will need to be focused on the importance of healthy ageing so that people can live independent, healthy lives with as fewer healthcare needs as possible for as long as possible. Lifestyle factors – mainly nutrition and exercise – have long since been a key message in healthcare education but as we understand more about a wide range of factors that support healthy ageing, so will the need for trusted, good quality, accurate information.

However, it would be naive to assume that this offers a total solution. Despite our best intentions, diseases and conditions will still occur and it is conceivable that the patient of the future is more likely to accrue several chronic but treatable health conditions and live with them simultaneously. This will have a number of repercussions on healthcare provision – including an increase in healthcare requirements and a potential increase in pharmaceutical (and non-pharmaceutical) needs, both of which will contribute to increasingly complex healthcare provision. This could represent challenges in terms of meeting these requirements – both in terms of resource and the expertise required to provide such complex care.

From a research perspective, this also opens up new challenges in terms of developing new treatments and therapies that complement other medicines, and those which are kinder to patients, thereby reducing the potential for negative side effects. Research into the systems of healthcare to best meet the ongoing needs of patients with multi-morbidity will also be needed – the traditional model of single disease specialities may soon be no longer fit for purpose. Research areas such as inflammation, mental health (as discussed below), cardiovascular conditions, neurodegeneration and obesity represent themes that cross several pathological boundaries and will require new approaches. This signifies an important culture change that, to some extent has already begun – to understand the patient need and to treat the individual rather than the disease.

3. Mental health

Traditionally, mental health has been an area of low research investment and healthcare provision compared with other diseases and long term conditions. Mental health conditions – such as anxiety disorders, attention deficit hyperactivity disorder, bipolar disorder, depression, eating disorders, obsessive compulsive disorders, post-traumatic stress disorder and schizophrenia[8] affect 1 in 4 people in the UK each year. The costs to the economy are significant – with estimates ranging from £70-100bn each year[9]. However, AMRC's recent spotlight report on mental health indicates that just 5.5% of all medical research funding is in mental health[10].

Over the next 20 – 30 years, we envisage that mental health is likely to gain more traction with the research community and greater awareness and understanding from the general public. Research funding is likely to increase and re-balance previous inequalities and this may lead to enhanced stratification relating to diagnostics and treatment options. Studies are already demonstrating that mental health can be the subject of a 'secondary effect' in many conditions such as cancer[11] and heart disease[12]. This represents a significant challenge that our health service of the future must be ready to tackle. We would encourage health service providers to engage with charities leading on this work at the earliest opportunity.

4. Greater stratification of disease

As we understand more about the biology of diseases, stratification will increase allowing more tailored approaches to diagnostics and treatments. We anticipate this will increase across many disease areas facilitated

[8] https://www.mqmentalhealth.org/articles/mental-health-conditions
[9] http://www.oecd.org/els/emp/MentalHealthWork-UnitedKingdom-AssessmentRecommendations.pdf
[10] http://www.amrc.org.uk/sites/default/files/doc_lib/Mental%20Health%20Spotlight%20Report.pdf
[11] http://www.macmillan.org.uk/documents/aboutus/newsroom/consequences_of_treatment_june2013.pdf
[12] https://www.bhf.org.uk/heart-matters-magazine/wellbeing/mental-health/mental-health-survey

by functional genomics linked with phenotypic data. Ensuring that these data are linked and that patients are able and empowered to collect their own data may help to fuel this shift towards targeted disease diagnosis and treatment.

Charities are playing an increasing role in this space. For instance, Arthritis Research UK co-funded research to examine tests and techniques to improve diagnostics and investigate whether certain subsets of patients respond better to treatments[13]. Similarly, initiatives such as the 100,000 Genomes project[14] are likely to be catalysts for such change. Our healthcare environment must be receptive to these changes and sufficiently agile to be able to handle the way in which diseases are diagnosed, managed and treated in the future.

5. Changing the way that care is provided – moving away from primary care towards self-management and secondary care in the community.

As our demographics change, it seems sensible to assume that so will our healthcare environment. We anticipate an evolving picture whereby the primary care model moves towards community providers driven by the need for patients to be able to access local care and support. This integration between health and social care is already beginning with GP Confederations[15] paving the way for secondary care business competing for contracts to run services. While there may be pros and cons to this approach, community care will become particularly important, particularly in older populations where disease management is key. For instance, in Alzheimer's disease, patients feel happier if they can remain independent and in their own homes for as long as possible[16]. As such delivering in-home care services would bring significant patient benefit.

As well as changing how healthcare is delivered, so will the methods by which we undertake medical and healthcare research. New clinical trial designs may be required as patients travel less often to a hospital setting. New end points may also need to be considered driven by what patient groups deem relevant and feasible to measure in a home setting. Understanding the patient voice is vital to ensuring that healthcare is provided in the best possible way. A key issue will also be cost effectiveness, and for research, a return on investments. Health economic research will be paramount to this, but more experts are needed to fully understand the impact of treatments and healthcare systems in real life settings – now and in the future. Charities can play a role here – for instance the National Osteoporosis Society developed a cost-benefit calculator for NHS organisations reviewing the economic case for intervention of fracture liaison services[17]. Similar tools will need to be developed to allow commissioners to make informed decisions about future healthcare needs – and crucially, what investments can be made now that lead to savings in the future.

6. Effects on populations

With the potential for such large scale changes to the way in which healthcare is provided, there is a danger that our health service becomes fragmented – both within certain strands of the health service itself, and geographical distribution of services provided. Planning for the health service of 2050 will be paramount in achieving better care for patients. We would encourage full dialogue with charities and patient groups to ensure that services have the best chance of meeting patient need. Initial attempts to do this are already underway – such as 'Devo health' in Greater Manchester[18] which may offer insights into how future healthcare budgets could be operated.

[13] http://www.arthritisresearchuk.org/news/press-releases/2015/may/matura.aspx
[14] https://www.genomicsengland.co.uk/the-100000-genomes-project/
[15] http://www.cityandhackneygpconfederation.org.uk/
[16] https://www.alzheimers.org.uk/info/20030/staying_independent
[17] https://nos.org.uk/for-health-professionals/service-development/fracture-liaison-services/fls-implementation-toolkit/
[18] http://www.gmhsc.org.uk/

Charities tend to operate locally or nationally and have a breadth of understanding of how local needs may vary compared with the national average. For instance, Yorkshire Cancer Research recently revised their strategy based on insights of cancer patients throughout Yorkshire[19]. Following research led by the charity, they discovered that people in Yorkshire are more likely to get cancer, and more likely to die from it, than most other counties in England. The reasons behind this include social deprivation, post-industrialisation and life style choices. Additionally, there are clear disparities in the availability of healthcare services and inequalities in accessing early diagnostics, clinical trials and treatments. The charity is aiming to become one of the leading authorities on regional cancer related issues by 2025. Similarly, Guy's & St Thomas' Charity focuses specifically on the health needs of people living in the London boroughs of Lambeth and Southwark, with work focussing specifically on the urban environment, diversity and deprivation[20]. Such insights from a local level are paramount in planning for a future healthcare service.

Finally, there is a potential that certain sections of society could be left behind 20 to 30 years from now. Differing levels of education and literacy, socio-economic factors, ethnicity and religion may all play a role in delivering a healthcare service for everyone. These factors must be considered in future planning.

7. New and emerging conditions

Finally, the potential for newly emerging and unforeseen diseases that have not traditionally been associated with UK healthcare should not be overlooked. The recent outbreak of Ebola and the UK's readiness to react and handle such pressures is a key consideration in planning for a healthcare system of 2050. As global climate change influences our environment, it is perceivable that disease pathogens may move to new host areas and change disease distributions. This is likely to be exacerbated by an increasingly mobile population with worldwide travel already commonplace. Clearly planning for such scenarios is beyond the scope of this report, but the potential impact of new and emerging conditions on UK healthcare should not be overlooked.

**Question 2: What do you think will be the key drivers of the changes you have described?**

There are many disease-specific drivers that could influence the changes described in question 1, however below, we outline several overarching factors that are likely to act as catalysts for change:

1. Technology and digital

Arguably we have already seen huge advances in digital technology that have changed the healthcare landscape. This is likely to accelerate throughout the coming decades. AMRC's recent 'Delving into digital' conference[21] highlighted the many ways that digital advances are changing the environment and we anticipate that digital will be one of the fastest growing areas, offering the largest potential impact on health and research by 2050. The huge array of digital products currently available – such as healthcare apps, wearable devices and assistive technologies are already informing patients about their conditions and transforming lifestyles. For instance, technologies such as those developed by Nightscout[22] provide a mechanism of remote monitoring of glucose for type 1 diabetes. Another seemingly common sense solution offers a new way to overcome practical challenges associated with ostomy pouches[23]. These advances are likely to grow in number and complexity, and are forming the foundations for future digital advancement into healthcare.

[19] http://yorkshirecancerresearch.org.uk/strategy-and-objectives/
[20] https://www.gsttcharity.org.uk/get-involved/knowledge-hub/personal-perspectives-urban-health
[21] https://www.youtube.com/playlist?list=PLdKoIvG0zK3P71IX_u-JFKSa7euyGBrGt
[22] http://www.nightscout.info/
[23] http://www.11health.com/solutions/patients

Technology is also becoming increasingly integrated. Everyday objects such as a mobile phone can now be turned into a medical device with the application of new technology[24]. This pace of this change is likely to accelerate – and technologies entering our homes such as Amazon's Echo are thought to be future platforms to host healthcare apps[25]. By 2050, it's not difficult to perceive interactive social robots providing personal healthcare companions[26]. These, combined with wifi-connected wearable sensors and other medical devices will allow health and environmental information to be incorporated into healthcare discussions between a patient and clinician. They also offer opportunities to change the way in which healthcare is delivered and monitored[27], how we undertake research in the future [28] and how we train healthcare professionals[29,30].

The scale of the pace of change is tremendous and our regulatory frameworks must be agile if we are to adapt to such change. Without this, we may stifle innovation resulting in patients ultimately missing out on unrealised potential of digital technology.

2. Routine use and sharing of data

The use of data will be critical for delivering healthcare by 2050. All the issues raised in Question 1 assume an environment that supports the collection, storage, use and sharing of data. As such, the infrastructure and regulatory environment must be supportive in these respects. Efforts are also being made to increase broader understanding of patient data and their potential benefits to society[31] but this needs to be supported by the healthcare and research communities.

Data in the future will also be generated from a huge range of sources – genomics, phenotypic and environmental. As mentioned earlier, the use of wearables and connected health devices may result in a healthcare system that becomes quickly overwhelmed with data resulting in the potential benefit being lost. Solutions that integrate data with healthcare pathways are crucial. Technology giants such as Google (e.g. Google Fit[32]) and Apple (e.g. Apple HealthKit[33]) are attempting to connect health data exchanges but this needs meaningful engagement and planning as early as possible.

3. Finance

Finance is one of the main drivers currently influencing healthcare provision. This is unlikely to change going forwards as our health service continues to balance delivery of care with financial pressures. The mechanism of reimbursing new medicines needs careful consideration. Development of medicines is becoming more expensive as treatments become more advanced, targeted and specific. Drugs of the future will involve new mechanisms of action. As such the costs of R&D will increase, as will the price of new treatments and therapies. Finance models need to explored that allow the NHS to afford such treatments. Recent changes to way in which NICE and NHS England undertake technology appraisals with the introduction of a budget impact threshold offer a short sighted and impractical way of doing this. Instead, a more nuanced and informed reimbursement strategy should be explored.

[24] http://www.peekvision.org/
[25] http://www.healthcareitnews.com/news/boston-childrens-hospital-launches-amazon-alexa-app-kidsmd
[26] http://www.cataliahealth.com/
[27] https://singularityhub.com/2015/11/11/exponential-medicine-this-virtual-assistant-tells-you-when-to-put-down-the-bacon/
[28] http://www.seaheroquest.com/en
[29] http://www.medicalrealities.com/medical-realities-announce-the-virtual-surgeon/
[30] https://www.statnews.com/2017/04/13/virtual-reality-stanford/
[31] https://understandingpatientdata.org.uk/
[32] https://www.google.com/fit/
[33] https://www.apple.com/ios/health/

Additionally, repurposing of medicines must also be explored if we are to deliver cost effective medicines for the future. The advantages of using repurposed drugs mean that the costs of R&D are potentially much lower and the speed in which they can be delivered is vastly increased. But finance models are required to support repurposing to enable the benefit of these drugs to be realised.

4. Societal

One of the largest drivers behind the changes described in question 1 is the power of the patient. Patients are no longer an out of touch bystander where healthcare is done to them. Instead, they are becoming much more informed over their conditions and increasingly involved in research. This is likely to be a significant factor driving what healthcare will look like by 2050. The science behind patient involvement is also gathering pace, driven by the fact that listening to patients and understanding their needs leads to better research and better care. By 2050, we anticipate that the barriers preventing patients from sharing their views will no longer be acceptable and patients will be front and centre in driving healthcare and research.

**Question 3: In your view, what will be the major trends in health and healthcare in England over the next 20-30 years? (Going beyond your immediate area and expertise).**

These answers are broadly given in answer to Question 1 and 2 but generally:

- An ageing population with an increase in prevalence of associated healthcare conditions such as cancer, bone disease (e.g. osteoarthristis), Alzheimer's disease, eye disease (e.g. age related macular degeneration, glaucoma), diabetes, cardiovascular disease (including hypertension, hypercholesterolaemia and atherosclerosis, cerebrovascular disease (e.g. stroke), type 2 diabetes and Parkinson's disease. This is also likely to be associated with an increase in procedures such as joint replacements, treatment of breaks and fractures after falls, and minor operations such as hernia repair and cataract operation[34].

- Greater availability of services for patients with mental health problems and an increase in treatment options including cognitive behavioural therapy, medication and psychotherapy – individually and in combination.

- Routine use of genomics in healthcare settings so that diseases can be more easily stratified, diagnosed and treated with specific and tailored options. This will require the health service to become more genomically educated so that the benefits of such technology can be maximised.

- Delivery of more care in the community away from primarily care settings and integration between health and social care. This may also mean greater provision of healthcare remotely using routes such as telehealth.

- A digitally driven healthcare service incorporating personal technology, artificial intelligence, machine learning and virtual reality with healthcare.

- Greater recognition of the importance of data and how this can benefit healthcare and research.

- A health service built by and with patients, and considering potential globalisation of health services and interactions between the NHS and health service providers around the world.

- A far greater understanding of environmental factors associated with disease and healthcare.

[34] https://data.gov.uk/dataset/hospital_admissions_-_by_age_and_gender/resource/8dd5928f-1d0d-4f05-8f2a-92ab6a7f20b3

**Question 4: Are there any commonly discussed issues related to the future of health and healthcare in England which you believe to be overstated? If so, why do you believe them to be overstated?**

We are unable to offer comment on this question.

**Question 5: Are there any issues that are underrepresented in the debates around the future of health and healthcare in England? If so, please describe them and explain why you think they merit greater attention.**

As discussed in answer to question 2, the way in which technology and treatments move from research into routine practice should be explored in detail. Efforts should be focussed on removing barriers to adoption so that new technologies can reach patients as quickly as possible. Our health service should also be one that embraces innovation and welcomes new technologies that will bring benefit to patients. Clarity over the mechanisms of doing this is key, particularly at a time when the UK should be encouraging companies to invest in the UK research and healthcare sectors[35].

As pertinent to recent events, data security and cyber protection will also be the subject of continued public interest. Efforts should be placed on providers to be digitally secure and mechanisms of data protection and accessibility need to be explored. While patients are generally happy for their data to be used for research, better guidance and governance structures will be required to ensure data are collected, stored, accessed and used appropriately and maintaining safeguards.

A further area which can often go underrepresented is the need for increased multidisciplinary work. If we are to deliver on the health challenges of the future, we need experts to come together and research new and improved treatments and therapies. This type of work has already begun in some fields[36] but could be extended to other areas should there be encouragement to do so.

Additionally, under-reported issues around the culture healthcare research should also be considered. For instance, the way in which we conduct high peer review is an ongoing concern amongst many funders due to an ever increasing burden on peer reviewer's time and a lack of recognition of the importance of such activity. Peer review is however vital for funding high quality, evidence based research and all AMRC members work to the highest standards of peer review in their research funding operations. Other concerns around research integrity have also surfaced more recently and this likely to continue to concern researchers, funders, healthcare providers and patients. Efforts must be focussed on unpicking the culture of academic competitiveness, pressure to publish and bad practices concerning how research is undertaken. This is vital to build a research landscape of the future that rewards research quality, accuracy, need and impact.

**For further information, please contact Dr Andy Clempson, Senior Research Policy Manager, Association of Medical Research Charities, a.clempson@amrc.org.uk**

[35] http://www.amrc.org.uk/publications/amrc-response-to-nice-and-nhs-e-consultation-on-health-technology-appraisal
[36] http://www.cancerresearchuk.org/funding-for-researchers/our-funding-schemes/multidisciplinary-project-award