Developing the long-term plan for the NHS

Life stage programmes: Staying healthy

Questions

1.5 What is the top prevention activity that should be prioritised for further support over the next five and ten years

We welcome prevention as a priority in the long-term plan for the NHS. Prevention offers one of the most cost effective and potentially impactful approaches to addressing many of the challenges currently faced by the NHS.

- Any approach to prevention must ensure join up with the wider public health community including Public Health England and local authorities
- Up to a third of dementia cases may be avoidable through lifestyle and health factors, many of which are the same as those for cardiovascular disease.
- However, just 34% of UK adults think it’s possible to reduce the risk of dementia, compared to over three quarters (77%) who recognise that the risk of heart disease can be reduced.
- We need to increase public and health professional awareness of the potential to reduce the risk of developing dementia, starting with the simple message that what is good for your heart is good for your brain.
- Prioritisation of dedicated dementia risk reduction and wider brain health campaigns for both the public and health and social care professionals has the potential to make a major impact on the prevalence and burden of dementia in our society.

1.6 What are the main actions that the NHS and other bodies could take to:
   a) Reduce the burden of preventable disease in England?

   - With an aging population in England it is essential that the NHS and other bodies promote messages that, maintaining a healthy lifestyle throughout your life, and in particular mid-life is important for helping to lower your risk of dementia.
   - Building on progress to extend the dementia awareness raising component of the NHS Health Check to include 40-64 year olds, NHS England should develop specific public and health practitioner awareness campaigns that will raise awareness across the country to all age groups.
Life stage programmes: Ageing well

Questions

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

- According to the 2014 report, *New Perspectives and Approaches to Understanding Dementia and Stigma*, the social stigma surrounding dementia is impeding early diagnosis, care and research into the disease. It is essential the NHS works with charities to understand the views of people living with dementia and their carers, to better understand how they want to manage their health.
- Utilising opportunities that new technologies offer, to integrate the monitoring and tracking of people’s health, empowering them to take a fuller role in managing their health.

1.16 What are the main challenges to improving post-diagnostic support for people living with dementia and their carers, and what do you think the NHS can do to overcome them?

At present, having a timely and accurate diagnosis is a critical challenge for people living with dementia. Once diagnosed people living with dementia need clear treatment options and care pathways across the NHS in England.

- We welcome the development of a nationally agreed template (published in February 2017) to support services to move towards delivery of personalised and integrated care across the Well Pathway.
- However, the transferring of information between healthcare professionals remains complicated and time-consuming. The interoperability of systems within and between the NHS and social care needs to be addressed, using where appropriate new approaches and technology to achieve the full integration of care for people living with dementia.
- There is growing recognition that dementia is often present with other co-morbidities. People with co-morbidities often require a high level of health service assistance, consequently it is vital that dementia care is not considered in isolation from the other diseases that often coincide, like diabetes, stroke or visual impairment.
- The development of integrated, place-based services that consider needs in more holistic ways should ultimately result in better quality care for people with dementia. Such approaches must be supported, nurtured and encouraged consistently across the country.
- A timely/early diagnosis can also open up opportunities for people to participate in research which in turn provide individuals with support, education and a feeling of control which has the potential to enhance quality of life.
- The lack of an affective disease modifying treatment means people living with dementia face a steady decline in their health. It is critical to invest in dementia research to ensure we discover new treatments as soon as possible for people living with dementia.

Enablers of improvement: Workforce

Questions

3.1 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?

- With 209,600 new cases of dementia a year in the UK, it is critical the plan considers ways of alleviating current pressures on healthcare professionals right across the dementia patient pathway, to deliver the best possible treatment and care for people living with dementia.
- Over the course of the 10-year plan, and likely in the next five years, we will see the first disease-modifying treatments for dementia. This will have a significant impact on the workforce, with a greater involvement from specialities such as neurology, radiology and nuclear medicine expertise for the interpretation of data. Consequently we believe there needs to be urgent consideration given to preparing the NHS workforce for the first disease modifying disease treatment for dementia.
- The NHS workforce should be supported in the uptake and adoption of new technologies that streamline and improve service delivery, especially in growth areas, alongside new technologies that improve patient care from diagnosis to treatment and support.

Enablers of improvement: Digital Innovation and Technology

Questions

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

- Many new technologies are being developed to support people with dementia to live independently for longer, but there is also a desperate need for new treatments, preventions and better diagnostic tools. Investment in research must continue if we are to defeat dementia.
- For people living with dementia to benefit from scientific advances being made, it’s important that our healthcare system is able to keep pace and adopt cost-effective new treatments and technologies quickly.
- The public and patients need to be aware of the benefits of new technologies in terms of making their healthcare experiences easier, or by freeing up clinical time to focus on what will have most impact.
- Digital tools should not replace health practitioners but should support and enhance clinical practice.
- To build the public and patient’s trust of new technologies there needs to be clear and concise stewardship of patient data by the NHS, with transparency at every stage of the patient data life cycle.

Enablers of improvement: Research and Innovation

Questions

3.11 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)?

- We need a commitment to embed dementia research within the NHS, to make the UK a world leader in delivering clinical research.
• As part of standard clinical practice, every patient should be advised of research opportunities including Join Dementia Research. We want an NHS that can empower patients to make informed choices to take part in research.
• We are advocating for linked, accessible longitudinal patient health records. Integrated patient records across the healthcare system offers researchers an invaluable resource for research, driving improvements in treatments and care.
• To comprehensively embed research within the NHS there needs to be a supportive culture across the whole NHS, not just for those clinicians directly involved in research. Support needs to be given to those clinicians who are identifying patients or talking more generally about the positive impact of research.
• Clinicians who are directly involved in research need their time protected, this includes protection within clinician’s NHS contracts.
• At present there is a lack of flexibility in clinical contracts for ringfenced and protected time, and questions remain over the availability of funding, as well as a lack of research being promoted to junior clinicians.
• We would encourage NHS England to continue efforts to emphasise the legal duty of commissioners to promote the conduct of research, and to encourage the recognition that research offers value across different clinical disciplines.
• In some areas time limited research opportunities compared to open-ended NHS contracts need to be addressed if we are to comprehensively embed research within the NHS.
• A lack of awareness of the available research opportunities for clinicians in some disciplines, as well as a lack of role models in senior positions needs to also be addressed.
• Currently there is a perverse incentive in the system in the recruitment of dementia patients for clinical trials. If a site is running a clinical trial, then they accrue data and receive payment for this. However, if a site identifies patients and signpost them to a trial being led by another centre, they do not receive any payment. Join Dementia Research overcomes this challenge by being patient led, with data centrally collected.
• Recognition needs to be given to education and training on the importance of clinical trials, the positive impact for future treatments as well as patients today. This is particularly important for allied health professionals and nursing staff who have regular and sustained contact with patients who may wish to participate in clinical trials.

3.13 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?

The NHS has always sought to be at the forefront of scientific development. If we are to improve the lives of people with dementia by 2025, we need to double the number of researchers and people participating in dementia research.

• According to NIHR more than 30,000 people were recruited for dementia and neurodegeneration studies in 2017/18. At present, we do not know how many people were recruited through the Join Dementia Research initiative, or the proportion of newly diagnosed patients and carers being told about Join Dementia Research. Without this vital data we do not have a clear picture of how people are being recruited or the challenges they may face in accessing information and research including vital clinical trials.
• NHS England should work with NIHR to specifically encourage public and patient involvement (PPI) at an early stage of trial design to identify the outcomes that patients want.
• The NHS should ringfence time for clinicians and support staff to undertake research. The AMRC (2013) states that 62% of almost 400 health professionals they polled said they did not have sufficient time to participate in medical research.
• Integrating research as a priority for the NHS workforce should be a crucial part of the 10-year NHS plan.

3.14 How can we increase research in topics that have traditionally been under-examined?

We believe in the power of research to change the future and we’re funding groundbreaking dementia research projects across the UK and beyond to help us reach that goal sooner. But urgent progress is needed, for every 1 dementia researcher there are 4 cancer researchers. The research base is therefore still small, especially in relation to the scale and impact of dementia and compared with other major diseases. To encourage efficient and effective research into dementia, we need an NHS that can:

• Facilitate changes within NHS structures to support dementia research, this includes engaging with NHS staff at all levels, whilst offering leadership that values the importance of research, especially in areas of unmet need, such as dementia.
• Embed a research culture by ensuring that time to undertake research is protected, included within clinician’s NHS contracts.
• Provide new opportunities, such as developing an 'unmet need' stream within the NIHR Advanced Fellowships – clinical academic option to encourage the continuing development of a research culture in dementia.

Enablers of improvement: Engagement

Questions

3.16 How can the NHS encourage more people to share their experiences in order to provide an evidence base for checks on whether changes introduced under the long-term plan are driving the changes people want and need?

• NHS England should make use of the unique bridging role of charities to better align patient care, research, and innovation, and ensure that research is seen as integral to care.
• NHS England should increase transparency by championing and explaining how patients and charities have informed priorities, and the adoption and spread of innovation.

3.17 How can the NHS improve the way it feeds back to people about how their input is shaping decisions and demonstrate that the NHS is the world’s largest learning organisation?

• The NHS needs to use patient data both quantitative and qualitative to measure and demonstrate the impact of patient feedback. Improving the mechanism between data collection and service change/improvement and then demonstrating it is essential.
• We need leadership and ownership at all levels, as well as protected time and resource within the NHS to encourage a culture which values patient experience data. This data can shape decisions and showcase the NHS as a learning organisation. Shared learning could be taken from the Cancer Patient Experience Survey and expended to patients with different conditions across the NHS in England.