NATIONAL INFORMATION BOARD
Personalised Health and Care 2020

Patient Carers and Service User Vision
Patient, Carers and Service User Vision

What this document is for
This Patient, Carers and Service User Vision aims to say briefly, in plain English, what the Government’s and national health and care organisations’ current portfolio of programmes will enable health and social care services to deliver for people in England through improved use of information technology. It describes what will be different as the national health and care organisations support local services to introduce the changes planned by the National Information Board.

People will be able to use this vision document to understand why and how changes are being introduced locally and to see whether the planned improvements are really happening. The organisations in charge of ensuring these improvements take place will also use it to check whether people are receiving what they have been promised. Health and care professionals have a similar document (the Clinical Vision: http://www.aomrc.org.uk/publications/reports-guidance/information-digital-technologies-clinical-requirements-2020/ ) to help them understand what will be different about how they can deliver services.

Different local services will introduce some of these changes at different speeds.

Sometimes they will deliver things in different ways. Some plans are about doing things better, some are about doing new things, and some are about doing both. Work has already started to deliver many of these changes, so some people have seen new benefits already in the way their services are organised and delivered.

However these plans are put into practice locally, it’s important that services work with people and communities to make sure they meet local needs in the right way. Working closely with patients, carers and citizens will help ensure that digital technologies are accessible and meet their needs, and will help make services better. Local decision-
makers also need to make sure that people know about how things are changing and what new opportunities are available.

**What will be different across a wide range of services**
Patients, carers and service users should experience improvements to how health services use digital technology.

These changes will:

- Give patients, carers and service users more information about, and control over, services that will work around their needs.
- Give people better support to take more control of, and responsibility for, their own health and wellbeing.
- Reduce or get rid of many of the things that people can find frustrating or inefficient about using health and care services.
- Give people confidence that whichever services they use, the right people have access to the right information.
- Help different services to work better together so people can move more quickly and easily between services without noticing the joins, whether services are delivered by the NHS, care homes, home care services, local councils or other providers.
- Give people more information about how services use their data to understand how their treatments have worked.
- Help people know how to decide which information they are happy for researchers and planners to use, to develop new and improved treatments and services.
- Make it much easier for people who are blind or partially sighted to use electronic information than previous systems based on paper records and letters and help people with other communication needs.

**How this will affect what matters most to people**

If you're generally healthy and want to stay that way, you will be able to find online information and advice that you can trust and that will help
you to maintain your fitness and wellbeing and prevent problems developing in the future. If you think you might need to see or speak to someone about a concern, online support through NHS 111 will help you to work out if you do, and how to get the right help. It will be easier to find information online at nhs.uk, which will also mean that getting access to services when you need them will be simpler.

As more people use mobile apps and wearable devices to keep healthy, the NHS will help you understand which you can safely trust and let you link information from devices and apps into your health records. This will make it easier for you to monitor your own health and alert you to changes that mean you might need attention from a health professional. Free WiFi in all NHS premises will mean that if you need help to know how to use these sources of information and support, health professionals will be able to show you.

**When you need help from your GP or other primary and community services**, you will be able to book and change appointments online as well as seeing and tracking your test results and other information about your health. That will enable you to have better, more informed conversations with people providing your care. Increasingly, you'll be able to talk to doctors and other health professionals by phone or video call if that’s better for you. It will also be quicker and easier for your GP to take advice from specialist colleagues where needed using remote consultation.

Joining up systems across GP practices and hospitals will also make it easier for doctors and other health professionals to co-ordinate your care, to refer you (or enable you to refer yourself) to other services, and to share the information you need them all to have. For example, your GP will automatically know if you are admitted to or discharged from hospital. The red book, familiar to parents of children under 5, will become an electronic red book, giving parents and professionals easy online access to child health records.
When you need medicines, you’ll have choice about where, when and how they are delivered to you. The accuracy of prescriptions will also be improved.

**When you or someone you care for need emergency care or planned care in a hospital,** the results of diagnostic tests, X-rays and scans will be available quickly and easily to everyone who needs to use them to care for you. If you need help from more than one team, it will be quicker and simpler for them to work together to meet your care needs. If the hospital changes your usual medicines, your GP will automatically be informed.

When you're ready to leave hospital, if you need continuing support, the same information will be readily available to everyone who needs to plan and provide this for you in the hospital, at your GP surgery and, if you need them, in your local council's social care team. If your hospital specialist has prescribed new medicines for you, your GP will be able to monitor how they are working and make adjustments when you need them, without you having to go back to the hospital.

**If you or someone you care for have a long-term mental or physical health condition, or need help from social care services,** you'll be more able to take charge of the things that support improved health and wellbeing, preventing further problems arising and enabling you to get on with the other things in your life. You'll be able to connect with, to be supported by and to support others with similar experiences.

Information and advice on different types of treatment and support will be available to help you and your health and care professionals discuss and decide what will work best for you and develop your individualised care plan. If you're dealing with a number of medical conditions or have a range of social care needs, you'll have more information to help you to help yourself and you'll find it easier to use online information that will help you. This will include information about the social care support you are eligible for and how to get access to it. Carers will also find it easier to get hold of the information and support they need and are entitled to.
People who currently don't have access to or find it hard to use online information and support will get help so they don't miss out.

**Developing treatments and services that will work for each individual**

Data from gene testing will be drawn together with other health information and analysed in new research hubs. As a result, we will develop an advanced understanding of how particular combinations of conditions and characteristics are likely to affect people’s health and risk of disease.

This will enable health professionals to tailor care to individual patients by choosing treatments and services that are proven to be effective for each unique person. It will also lead to the development of new ‘precision’ medicines which will improve people’s health more quickly and effectively.

**Work that will help you to be able to trust that your personal information is held securely and used as you want**

All of the work to deliver the improvements described in this document depends on reliable and secure systems. Over the lifetime of these plans, health and care services will gain the most joined-up, robust and secure computer systems and networks they have ever had. But security also depends upon how people use systems. The Government has consulted the public on the recommendations of a major review of the rules that should apply to data security and explains how it intends to achieve the necessary security in its response to that consultation: [https://www.gov.uk/government/news/government-responds-on-cyber-security-and-data](https://www.gov.uk/government/news/government-responds-on-cyber-security-and-data).

There is also huge potential to join up information to understand the outcomes of treatments and so researchers can find out more about the conditions that are not yet well understood. This also provides an opportunity for people planning services to find out more about the types of service that will best meet the health and care needs of their local communities. The Government has consulted on the best way for people
to be able to decide who can use confidential, personal information about them for these reasons. Again, the Government explains how this will work in its response to the consultation: 