

NHS Information Strategy:

Using online NHS and care services to improve care

Summary

Carers UK has championed the role of technology of many different kinds to improve the lives of carers. The development of digital services has the potential to continue to improve carers' experience of arranging, managing and co-ordinating care, their ability to care for others (linking directly to the self-care programme) and to look after their own health and well-being.

How technology fits in with carers' lives and changing demography

There are 5.4 million carers in England and the number is growing. With a rising ageing population and a rising pension age, increasingly carers will have to juggle work and care.¹ By 2037, we will need 40% more carers, which will mean in England the number of carers will go up to just over 7 million.²

Many carers do not live with the person for whom they care.³ The time spent by carers in arranging, managing and co-ordinating care can be significant.

In terms of what they do:

- 47% help the person they care for deal with care services and benefits
- 38% help with aspects of personal care such as washing and bathing, dressing, feeding, etc.

¹ Taken from the Census 2011, all published in Facts About Carers 2015, Carers UK

² Carers UK, 2010, It Could be you?

³ NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10
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- 82% provide a range of practical help and some of this will include taking them to appointments, etc.
- 38% provide physical help with moving/lifting.⁴

The impact of caring can be significant:

- Carers providing 50 hours or more care a week are twice as likely to suffer ill-health⁵
- Around 2 million people have given up work to care.⁶
- Almost 1 in 3 (30%) carers had seen a drop of £20,000 or more a year in their household income as a result of caring.⁷
- 61% of carers said that they were worried about the impact of caring on their relationships with friends and family⁸

Digital and online services have the potential to improve carers' lives and those of the people they care for.

How does this fit with strategic work?

The NHS England's Strategy for the next 5 years, the Five Year Forward View sets out the clear challenge for the NHS over the next few years., Spending pressures come at a time when an ageing population means more people are requiring care and a there is growing desire to improve outcomes for patients and carers.

The current drive to integrate health and social care planning through Sustainability and Transformation Plans, due to be delivered by April 2016, sets ambitious and challenging targets to improve care, reduce costs and integrate services through to 2020. A digital strategy is critical to this being successful and underpins all the plans going forward. The right interventions within this plan could help carers to care for others better, reduce the amount of time they spend compensating for a fragmented system and improve access for them to services at a time more convenient to them.

⁴ HSCIC data from 2010, excerpts published in Facts About Carers 2015

⁵ Census 2011 data, published in Facts About Carers 2015, but also new corroborative evidence from: Thomas, GP, Saunders, CL, Roland, MO and Paddison CA. [Informal carers' health-related quality of life and patient experience in primary care: evidence from 195,364 carers in England responding to a national survey](#). *BMC Family Practice*; 15 May 2015; DOI: 10.1186/s12875-015-0277-y

⁶ Carers UK and YouGov (2013) as part of Caring & Family Finances Inquiry UK Report (2014) Carers UK

⁷ Carers UK (2014) Caring & Family Finances Inquiry UK Report

⁸ Carers UK, State of Caring 2015

What do carers want?

Evidence directly supplied from carers shows the following are things that matter to them. Meeting all these needs can make the difference between poor and good health, between not coping and managing well, to having free time or being stretched to the limit, to being able to juggle work or giving up work to care.

Carers want:

- To be identified, recognised and supported
- Information about the condition/s
- Information shared by pros (carers not repeating info)
- Care to be well co-ordinated
- To be able to access services easily

How could digital make a difference?

Digital platforms cannot solve every problem but they have the ability to provide information and advice round the clock, to tailor information, to allow access when people want it..

What do carers currently use that the NHS and social care offers digitally?

Carers were asked which of the following services they used. Of the 1,150 carers in England who responded to the question:

Finding and booking services online	13%
Emailing a GP/repeat prescriptions	84%
Choosing and booking appointments online	54%
Accessing my patient record online	13%
Health consultations e.g. skype or other video conferencing solutions (1.64%)	2%

Source: State of Caring 2016 (3,232 responses indicated from England)

Areas of potential for growth

Finding and booking care services online: There is potential for growth in finding and booking care services online. Lists provided by the Care Quality Commission which rate regulated services are a logical place to start in terms of regulated services. There are other services that provide support through independent care workers which use digital platforms and these are becoming more popular.

Emailing GPs: Emailing a GP and repeat prescriptions are clearly the most used services. Over half of those responding are choosing and booking appointments.

Online patient record: This is also sometimes referred to as the Personal Health Record online (PHR). The results demonstrate very clearly that awareness about the patient record online is very low and this was clear from the comments too, some of which also suggested that some GP practices were not clear that this existed or said did it not exist. Theoretically the service should exist in every GP practice.

Carers' views about the online patient record show the potential for some growth, but also caution about the need to maintain a variety of approaches that are tailored - keeping telephone contact, face to face contact and the ability to email as well when a more individualised response is required.

"It all helps, aids and speeds up caring services."

"Local pharmacy has a repeat prescription service so I do not need to go to GP and this saves me at least one trip."

"My surgery has just introduced these online services but I have not used them as yet."

"I did not know anything about these services."

"I don't use them but would."

"I am not confident when using a computer."

"I would prefer to discuss these options with my GP and his receptionist rather than speak to a machine."

The evidence from the USA, particularly from Kaiser Permanente, shows that patients who used online patient records were more likely to adhere to medication regimes and less likely to visit the GP (dropping from 83% to 53% in one study). In

clinical settings, independent research has also shown decreases visits to A&E and hospitalisation for people with diabetes. Similar to the results of our survey, the functions most used were repeat prescriptions, booking appointments, viewing test results online.⁹

The Patient's Information Forum describes the Personal Health Record in the following way; *"Why is the shared Personal Health Record so important? PHRs are the greatest innovation in the field of health information for generations. As such, they herald an enormous cultural change for all of us. By understanding the power of PHRs and supporting their implementation and use, organisations that produce and provide health information are ideally placed to help make patients and the public more confident, empowered and informed."*¹⁰

Skype health consultations: Currently only a fraction, at 1.6%, of all those people who use online NHS and care services – suggesting this has potential for growth in the future.

Dependencies for growth in online NHS and care services

Quotes from carers show the diversity of views regarding online NHS and care services. Many like to have a tailored conversation. For others it is the usability of online services which can be time-consuming and not customer friendly. Others do not feel confident using technology. Finally, there is the issue of not having good connectivity in certain parts of the country making access much more difficult.

Carers knowing about these services is as important as reliability. When email systems go wrong and a prescription is not correctly delivered, it can have very serious consequences.

What is the online patient record?

Every GP practice now has online patient records and every patient has the right to get access to them. There are three different operating systems being used, and EMIS is the

⁹ Personal Health Records Putting patients in control? John Cruickshank Carl Packman Jon Paxman September 2012, 2020health and latterly publication in Medical Care, 2014, by University of California San Francisco Medical School, Assistant Professor Dr Urmimala Sarkar, et al.

¹⁰ Patient Information Forum, Guide to Health Records Access, 2013

most frequently used digital platform. GP practices have different ways of signing people up.

In practice

St Johns Medical Practice in Lewisham is pro-active, has banners advertising the online patient records and services in the practice. Practice staff answering the telephone regularly ask patients booking appointments to do it online through their online patient portal and encourage sign-up. In order to get a unique logon, a patient must bring photo ID.

Can carers access the patient record of the person they care for?

Yes, but confidentiality is important. Some systems have proxy access functionality available and can give access to the carer. GP practices may ask for some assurances e.g. that the carer can demonstrate that they have lasting power of attorney over health and care decisions, or has a third party agreement with them showing clear permissions from the patient. In other words, these are the same types of safeguards that are needed to ensure that information remains confidential.

What can CCGs, local authorities, NHS Foundation Trusts and Mental Health Trusts do?

CCGs and local authorities could roll out simple awareness measures through local voluntary organisations, particularly carers' organisations, to the carers they support about the online patient record and functionality and how it might help.

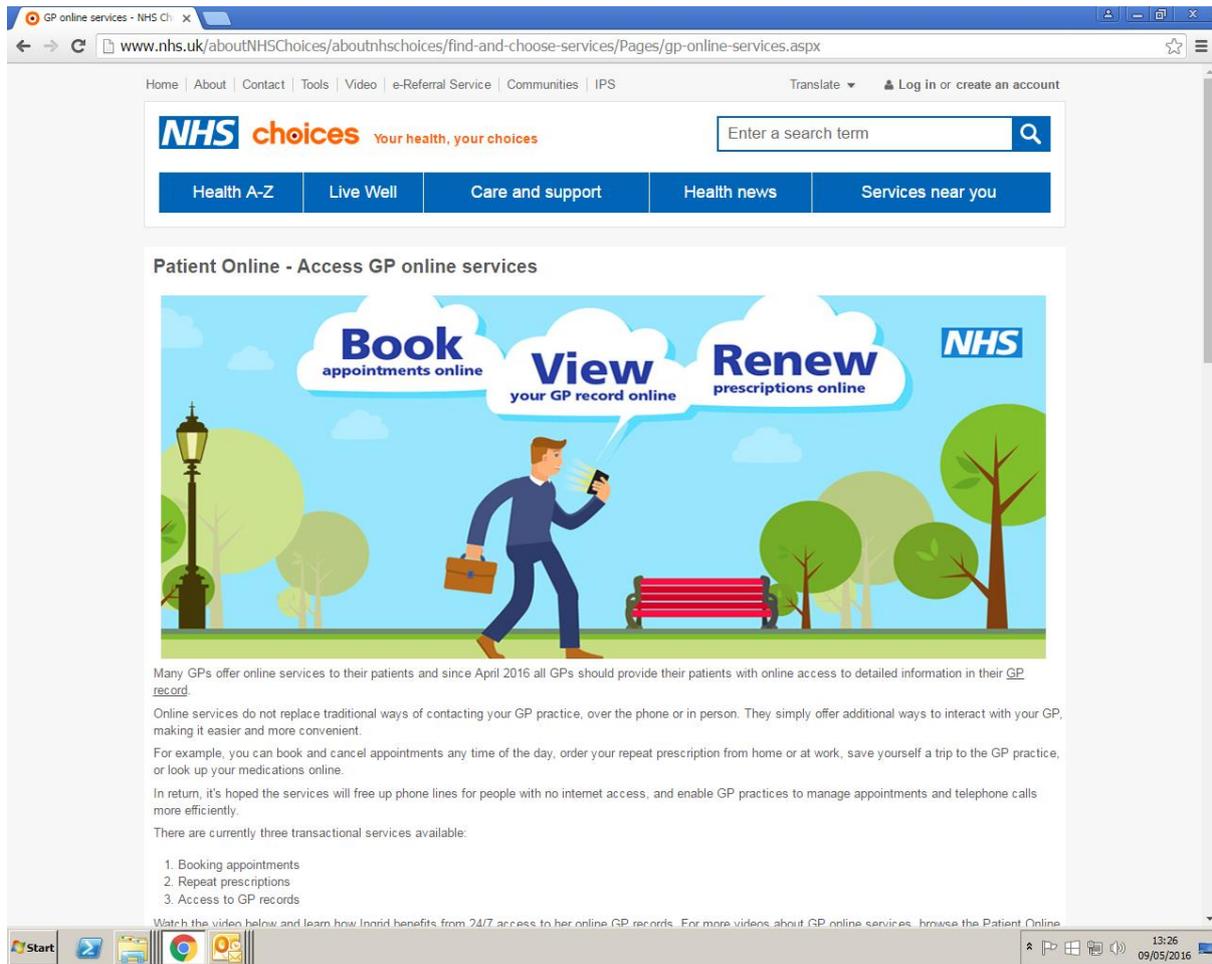
CCGs and local authorities, along with NHS Foundation Trusts and Mental Health Trusts need to ensure that carers are part of any digital roadmap that is being developed. The care provided by carers needs to be considered an integral part of these plans.

Carers need to be a visible and considered part of the Sustainability and Transformation Plans being developed in order to meet the goals set for this process and success delivery.

Areas that have important developments using carers' registers in GP practices and online registrations for services for carers need to look in the future how these might fit with the technological developments in care services.

What will Carers UK be doing?

We will be telling carers that they can see their records online and making them aware of the changes coming through via digital technology. We will continue to work with others to see how carers' journey throughout health and social care could be improved with the use of digital platforms whilst ensuring that those not digitally connected still have the means for contact, interaction, information and advice.



The screenshot shows the NHS Choices website page titled "Patient Online - Access GP online services". The page features a navigation bar with "NHS choices Your health, your choices" and a search bar. Below the navigation bar are buttons for "Health A-Z", "Live Well", "Care and support", "Health news", and "Services near you". The main content area includes an illustration of a man walking with a briefcase and a smartphone, with speech bubbles indicating services: "Book appointments online", "View your GP record online", and "Renew prescriptions online". The NHS logo is also present. Below the illustration, there is text explaining that many GPs offer online services and that since April 2016, all GPs should provide online access to detailed information in their GP record. It lists three transactional services available: 1. Booking appointments, 2. Repeat prescriptions, and 3. Access to GP records. The page also includes a footer with the date 09/05/2016 and time 13:26.

Simple summary:

Electronic patient records – have you got yours?

Looking after someone can take up a lot of time, so anything that makes life easier, can make a difference. Getting signed up to your GP online services could help with that too. In England, every person can get access to online services – as this should be offered by every GP practice since March 2015.

What does it do?

There are different systems and some trials going on. Essentially you should be able to:

- See test results
- See your list of medication
- See your allergies listed
- Order repeat prescriptions
- Book GP appointments online.

In time, the online patient record will build extra functions, like seeing a summary of consultations and even allowing you to add notes. The idea is that core information can be shared between different professionals so that if you end up in A&E, they know what medication you are taking, and other really important information.

Can I see the electronic patient record for the person I care for?

This depends on whether you have clear permission from the person you care for if they are an adult or if you have lasting power of attorney for health and care decisions or some other legal reason.

How do I get onto the electronic patient record?

Contact your GP practice to find out how to sign up. Some will ask you to come in personally and bring photo ID. They then give you a unique login code which is personal to you.

More information is available at:

www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/what_to_do.aspx

www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Documents/2016/01589-02-NHS-Patient-FAQs.pdf

Contact us

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