

MEDICAL PROTECTION SOCIETY
PROFESSIONAL SUPPORT AND EXPERT ADVICE



Online medical records and the doctor–patient partnership

MPS research report



Contents

Introduction	3
Healthcare in the digital world	4
Medical records and the doctor–patient partnership	5
Getting medical records online: unanswered questions	9
Making online records a success	17
References	22
Methodology	23





Introduction

Patient access to online health records has the potential to transform patient care. Greater access to information for patients can increase knowledge and understanding, promote autonomy and informed choice and enhance the doctor–patient partnership.

In order to realise these advantages, great care needs to be taken to manage the associated risks. MPS is acutely aware of the importance of keeping sensitive information confidential and has significant experience of the risks facing patients if their information is not protected. We have contributed to the RCGP’s implementation plan for GP practices – *Patient Online: The Road Map*¹ – and support the principle of their pragmatic phased approach. We have also contributed to the *Information Governance Review*² led by Dame Fiona Caldicott, which will play an important role in informing safeguards for patient information.

But success will require the engagement and participation of individual doctors and patients across the country. This report sets out MPS’s research into what the public and doctors think.³

Our research shows it is not enough to just equip patients with the ability to access their medical records online and inform them of their rights; patients also need to be supported and informed about how to understand and use their information safely, appropriately and effectively. We are concerned that the need for this support has not been given adequate consideration and think it should be an essential component of implementation plans from the outset.

The current rhetoric around the new services patients will have does not reflect the emerging implementation plans, or what is practical. This could mean that the promise of online medical records will merely serve to widen the gap between what patients expect from their healthcare and the reality of what can be delivered.



Healthcare in the digital world

People today use the internet to manage many aspects of their lives: to shop, learn, socialise and manage finances. This digital revolution has huge potential to reshape healthcare in the UK, not just for clinicians through the advantages of digitising records and test results, but also for patients through changing behaviours.

One of the most dramatic innovations will be patient access and control of their medical records

As is already the case in some other countries, patients in the UK will increasingly start to use health apps, social media and web portals to access information about their health. They will be able to check their medical records, book appointments and order prescriptions online, and ultimately will be able to have virtual consultations with their doctor.

All this has enormous scope to fundamentally change the dynamics between doctors and patients. This is to be welcomed: better informed and empowered patients working in partnership with clinicians will improve healthcare in this country.

One of the most dramatic innovations will be patient access and control of their medical records and the benefits as well as the potential problems of this change will also apply to other digital innovations.

For the advantages of online medical records to be realised, and to ensure the NHS stays on track towards the other digital health innovations which lie beyond, both doctors and patients will need to see these innovations as a collaborative enterprise.

AN INFORMATION REVOLUTION – THE GOVERNMENT'S VISION⁴

- Online access for patients to their own health records held by their GP
- Online appointment booking
- Order repeat prescriptions online
- Secure electronic communication for patients with their GP practice
- Electronic health records to follow patients to any part of the NHS or social care
- Telehealth and telemedicine more widely available
- Paperless NHS.⁵

Medical records and the doctor–patient partnership



"I have always felt that patients should be able to own their records and hence would feel more responsible for their own health...and more able to be involved in management."

MPS member

How do patients access records now?

Contrary to the common public perception that medical records belong to an individual, legal ownership of health records resides with the NHS trust or organisation that owns the paper or database on which the record is stored.⁶

This means that, ultimately, NHS medical records are the property of the Secretary of State, from whom the NHS trust or organisation derives their authority.⁷ Arguably, this includes limited property rights to the information contained within records, especially as it is NHS employees, or doctors contracted by the NHS, that generate the content.

However, patients have had the formal right to request access to their records since 1984, and it is perhaps this right to access and control the use of their data which is more important to patients.⁸ The right to access is currently provided for by the Data Protection Act (1998).⁹ This Act also provides legal safeguards which

reflect the ethical and professional responsibilities of doctors towards their patients: doctors must not release confidential information about third parties without consent or unless it is reasonable to do so, nor can they release information that could be harmful to the patient or any third party.¹⁰

Despite the long-standing right to access their records, MPS research shows that 72% of people never have and one in ten GPs have never received a request from a patient to see a copy of their records. In fact, more than one in five people (22%) are not aware that they can request access to their records. Such results may be because people simply do not feel the need to look at their medical records.

Alternatively, these results may suggest that patients are not yet familiar with the concept and advantages of managing their health collaboratively with healthcare professionals, rather than passively consenting to suggested care or treatment.

Shared decision-making

Informed patient consent to treatment has often been seen as a core component of doctor-patient interactions. However, this narrow legal principle is now subsumed into a much broader relationship-based concept where effective two-way doctor-patient communication is the ideal with common access to detailed, accurate information key to achieving this.

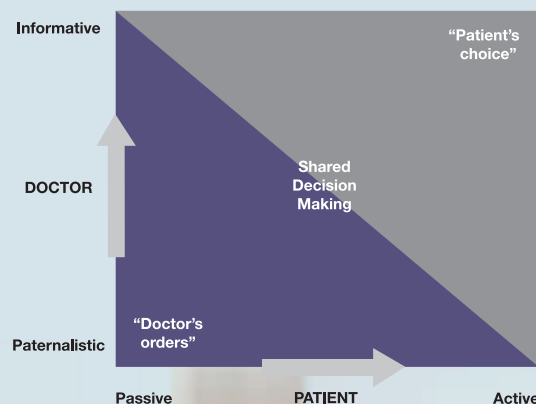
As can be seen in the diagram above, genuine shared decision-making lies between the extremes of the 'doctor knows best' and 'patient-directed' care. Patients should be actively involved in their care, but also need professional advice.

81% of doctors agree the public need more support in understanding how to make properly informed choices about their care

Doctors need to give information to their patients, but also help them to understand their options so both can reach an agreed course of action.

To make this a reality, patients will need to access and share the background information contained in their medical records in order for them to understand and reflect on the management of their conditions. There is already a clear need to make the sharing of records easier – our research shows that 42% of patients who had already accessed their records in the past did so to share them with another healthcare professional.

Reproduced from MPS Mastering Shared Decision Making workshop



"Information without good communication is of little value."

NHS Future Forum report



Online access

Ensuring that patient medical records are available online, including letters between healthcare providers, summaries of hospital visits and results of investigations, is a simple and effective way to improve patient access to information and facilitate shared decision-making. There is a clear appetite amongst the public for this: 59% agree that they would be interested in accessing their medical records online.

Despite these advantages, unanswered questions remain around how online records access will be implemented, and how the potential risks will be managed.

- Will the access be read-only, or will patients be able to amend or annotate their record?
- Will patients be able to access everything, or just a summary?
- Will patients be able to control who can access their records, or will they only be able to review who has seen them?
- Will there be safeguards to prevent access to third party or harmful information similar to those provided for by the Data Protection Act? If so, how will these be incorporated?
- Will access be retrospective, and if so, how will this comply with data protection principles and the safeguards above? Or will access be from a defined date onwards and will this be what patients expect?

Initially, practical considerations will dictate the services offered to patients, but in the long-term these questions will need to be answered. The UK could learn from international experience and needs to carefully consider what doctors and patients think and expect.

CASE STUDY

Getting access right in Australia

Australia introduced an opt-in summary care record which patients can access online. Access is controlled by patients and can be set up to allow relatives or carers access if necessary. There are two settings: basic default access – which allows any healthcare professional who is treating a patient within a registered organisation to view their eHealth record, and advanced access – where only healthcare organisations that patients authorise can have access. In an emergency, this can be overridden.¹¹

However, the Australian Medical Association has been critical of this set up:

[The shared electronic health summary] has the potential to give doctors and patients an accurate up-to-date list of ailments, treatments, tests, and medications. But [it] cannot currently deliver these core services. Under the current design ... patients might not sign up and might not give access to their treating GP, or they could omit or remove important medical information without consultation with their doctor.¹²

Dr Steve Hambleton, President, Australian Medical Association

What about those patients who may have problems getting online?

7.5 million people in the UK have never used the internet, and 5.2 million households do not have internet access.¹³ This may affect certain groups more than others – for example, the very elderly, unemployed, chronically sick and those on low incomes. Some of these groups are those most likely to benefit from online access to their records.

Our research shows that 76% of doctors agree that some members of the public may not have the technology to access their records, and 83% of doctors agree that vulnerable groups of people will be disadvantaged by the proposed changes. Steps need to be taken to ensure that vulnerable individuals and groups have their interests protected and that information available online will always be available in other formats where necessary. Patients need to understand that online engagement may be suitable in certain circumstances, but it is no substitute for face-to-face consultations with their doctor.

"I am concerned that this may transfer emphasis and resources to the well-resourced and articulate at the expense of the...vulnerable."

MPS member

Getting medical records online: unanswered questions



What are medical records for?

The purpose of medical records may depend on your perspective. The patient-centred view is that medical records are there to provide accessible information for the patient about their care. The professional-centred view is that the record exists to support specialist communication between healthcare professionals.

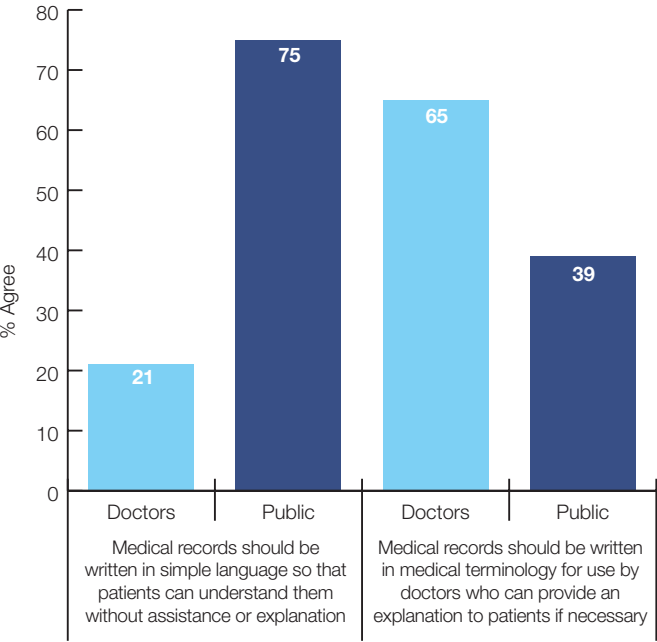
MPS's research shows that, in fact, there is a common understanding about the purpose of medical records with 68% of doctors and 63% of the public agreeing that the main purpose of the medical record is to give doctors an overview of all the medical treatments a patient has received to help doctors manage their healthcare.

This common understanding should serve as the basis for how online records should be written, accessed and shared. However, our research shows that work still needs to be done to reach an agreement on how records should be written.





Graph 1: How should medical records be written?




As Graph 1 shows, patients agree records should be written in simple language they can understand, while doctors agree they should be written in medical terminology. Shared decision-making requires that patients can understand their records, but there are risks in requiring doctors to write medical records using patient-friendly language. Doctors might need to consider omitting entries that may cause distress or anxiety and could be deterred from fully documenting diagnostic thought processes. For example, will a clinician still put a differential diagnosis in the record in case the patient sees it and is unnecessarily concerned? If doctors omit parts of, or limit, records in this way it would potentially breach their professional and contractual obligations.¹⁴

Doctors and patients will need to reach a common understanding that doctors will have to continue to use some medical terminology in order for medical records to achieve their agreed purpose of effective communication between professionals to ensure continuity of care. Doctors should use their judgment as to the appropriateness of what they write and be prepared to explain the record to their patients, but steps need to be taken to ensure this does not adversely impact on consultation time.

Patients and their doctors will need support in achieving this collaborative approach to the content of records and tools to help patients make sense of their records would be useful.

PATIENT SUPPORT TOOLS

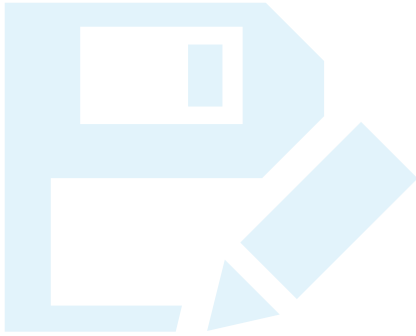
Denmark's online health portal allows patients to view their medical records, but alongside the record there is also a patient medical handbook with 3,000 articles and 2,000 illustrations. There are also online patient forums to facilitate patient-to-patient knowledge sharing.¹⁵



84% of doctors agree that online access would mean more time spent explaining the contents of records to patients who do not understand clinical language.

"As professionals we should use appropriate technical language AND always be ready to explain or translate."

MPS member



26% of the public think they should be able to request that their entire medical record is deleted

Who can amend medical records?

One of the suggested advantages of online access is that patients will be more involved in their care and able to identify mistakes in their records.¹⁶ This already happens to a certain extent with paper records; a quarter of those patients who already access their paper records do so to check their accuracy and three quarters of GPs (and half of all doctors) have been asked by a patient to amend or remove something from their record.¹⁷

However, this suggestion may set the false expectation that patients will be able to readily change things in their records that they do not like, whereas, in reality, the doctor is responsible for the accuracy of the record.¹⁸

Graph 2 (right) shows that most of the public would like some level of involvement in making changes to their medical record – of those, 90% agree this should be in collaboration with their GP. Doctors similarly agree that amendments should be made in collaboration with them, with few agreeing patients should be able to make changes without them.

There are, however, extreme positions on both sides. A third of doctors do not think that medical records should ever be amended, 40% of the public who would like to be involved in amending their records do not believe they should need their GP's approval,

and a sizable minority of the public think they should be able to delete their entire medical record.

There is already a disparity between what patients expect to be able to do with their records and what doctors think the appropriate level of control by patients should be. Greater online access may alter the perception of who should control the content and widen this disparity.

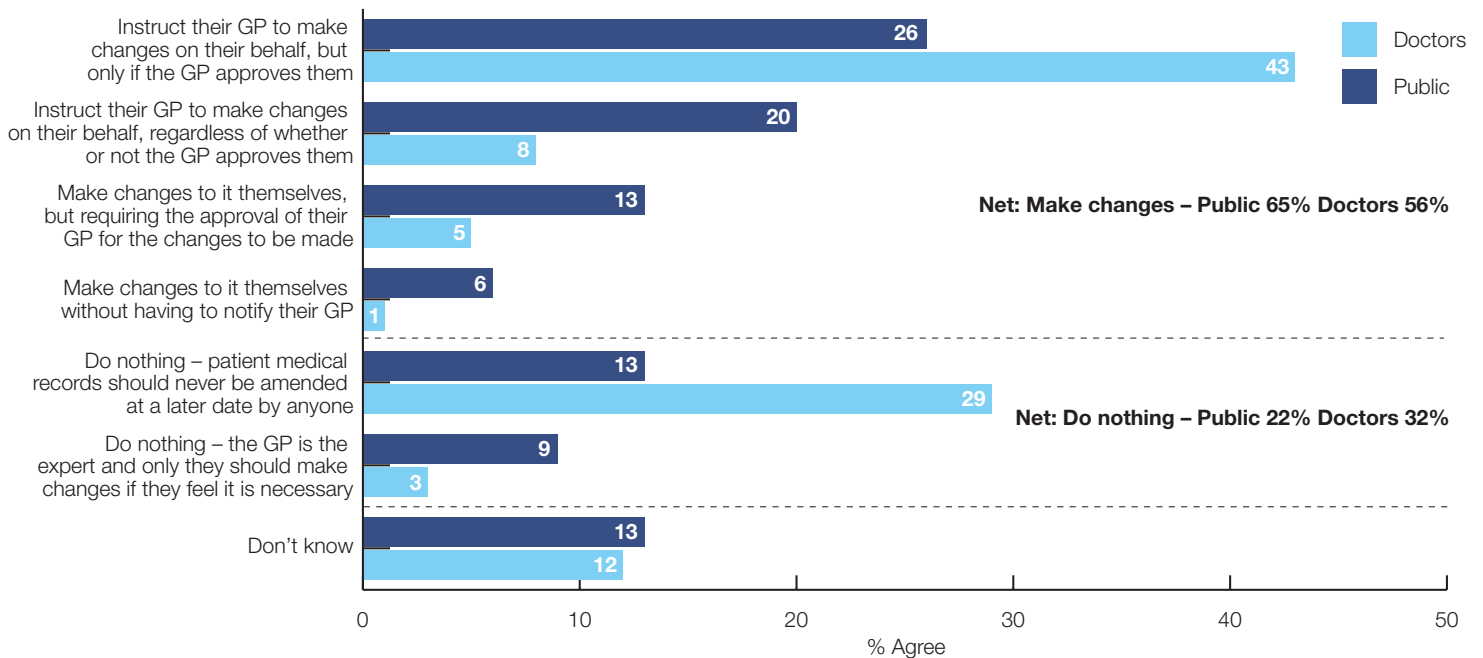
However, the picture is not entirely clear. When asked directly whether patients should be able to amend their medical records online, 59% of the public and 93% of doctors disagreed – although this may be more due to security concerns rather than a lack of desire to make amendments.

We need to build on the partial consensus revealed by our research that GPs should play a central role in controlling and amending medical records and acknowledge that there is a desire for individual patients to be involved in their medical records, albeit, short of complete control. As with building a common understanding of the purpose of the medical records, patients and their doctors will need to develop a collaborative approach to amending medical records, as many clinicians already have. There will need to be support for both to do so.

DIFFERENT AUTHORS OF THE MEDICAL RECORD

In Australia, only identified healthcare professionals can enter information in the clinical section of the record, but patients have their own section in the e-Health record where they can enter basic health information and keep (private) notes for their own use.¹⁹

Graph 2: If patients wanted something changing in their medical records, they should be able to:



Particularly sensitive information, such as mental health, sexual health, child protection and counselling, could be restricted by default on an online record



How do we keep records secure?

Online records might increase the risk of large-scale data loss or instances when individual records are seen because of a lack of awareness of how to protect them. Naturally, both doctors and the public are very concerned about this (see Graph 3). It appears these concerns are justified, with over half of doctors aware of records being lost in their practice and one in eight members of the public claiming their records have been lost in the past.

Perhaps it is because of these concerns that the public, whilst clearly interested in being able to see their medical records online, show some ambivalence as to whether this is a good idea. Opinion is evenly divided as to whether the potential benefits outweigh the potential negatives. However, the public is very clear that they consider doctors to be the key to protecting their medical information, with trust for GPs to keep records safe very high. Doctors trust GPs the most too, but also have high levels of trust for other medical professionals (see Graph 4).

Both doctors and the public were considerably less trusting of care homes and social care providers when it comes to keeping medical records safe. This raises serious concerns about the possible consequences of patients being able to share their

records with who they like. Even more worryingly, three quarters of doctors stated they did not trust patients' relatives to keep records secure. Greater patient awareness about how they can protect their own data will be key to dealing with these concerns.

In addition, the contracts of unregulated personnel should impose the same standards of confidentiality, data protection and information governance required for regulated professionals. This way, the public would be reassured that standards of data control are uniform across, and within, organisations.

There is also a case for special restrictions to be placed on parts of a person's medical record, or on certain categories of information for all patients. For example, particularly sensitive information, such as mental health, sexual health, child protection and counselling, could be restricted by default on an online record. Our research suggests there would be support for sensitive information not being online. As well as giving patients peace of mind, these protections could be a way of extending to online records the safeguards currently provided under the Data Protection Act that aim to prevent harmful information being released.²⁰



"I think it is inevitable that online access to medical records will happen, but security is going to be a real problem."

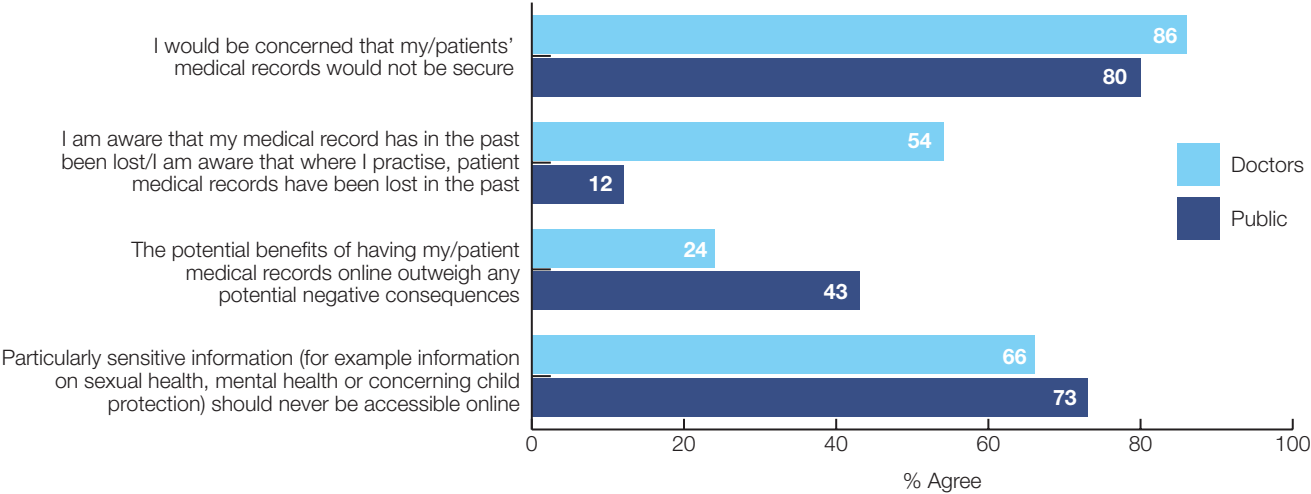
MPS member

Protecting privacy – International examples

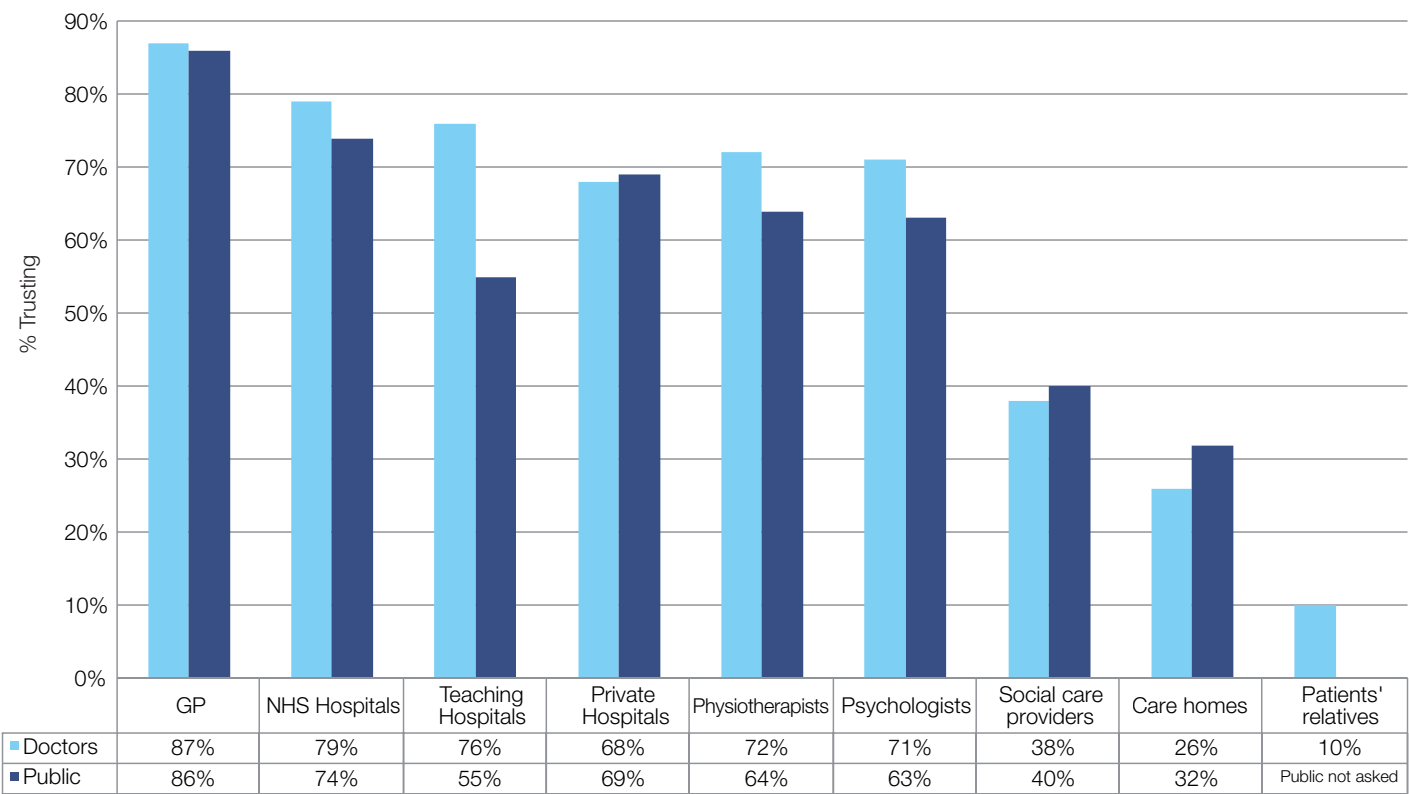
When Australia introduced online medical records for patients, they created new legislation specifically to protect the security and privacy of the patient's eHealth record. Records are protected by audit trails, technology and data management control, and security measures such as encryption, secure logins and passwords.²¹

In Denmark, the online health portal has a log, so that patients can easily see which health professionals have accessed their personal data, allowing them to monitor who has seen their records.²²

Graph 3: Views on online medical records



Graph 4: Trust in different groups to keep medical records secure and confidential



Making online records a success

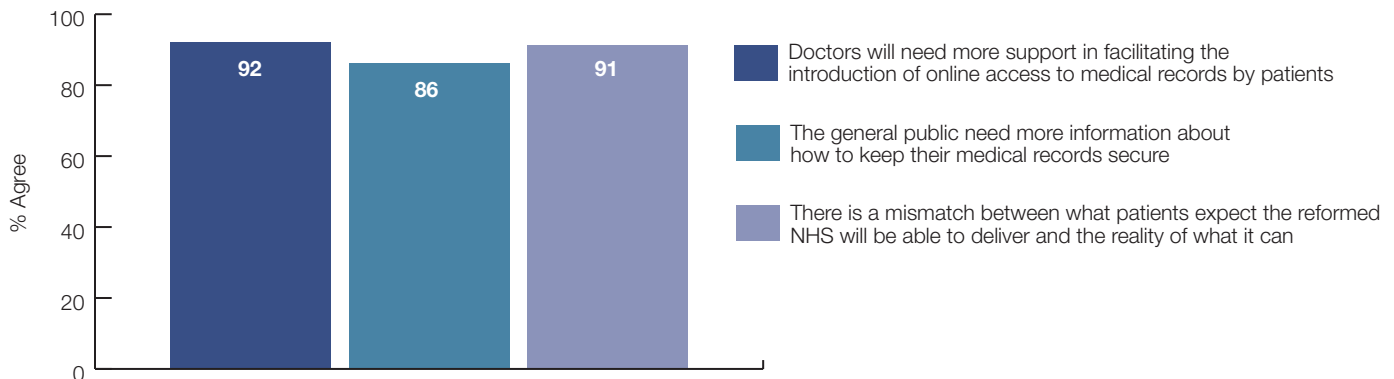


Support for patients and doctors

Doctors and patients alike are only just starting to find out about the prospect of having online medical records. Doctors are aware that they will need more support (see Graph 5).

But doctors also say that patients will need much more information about how to use their records and keep them secure – 71% of doctors agree that the information and education programmes that will be necessary to support online medical records should be provided by central government. As there is a nationally mandated target for delivering these changes, the support required to make them a success should also be nationally co-ordinated (see overleaf).

Graph 5: Doctors' views on making online records a success





*"Expectations will be influenced
by the way in which the access
is introduced to the public."*

MPS member

Managing expectations

Our research shows the various issues that will need thinking through, but it also shows a disparity between the services that patients expect they will have through online access to their records and what the professionals who provide their healthcare think is realistic in the immediate term. Doctors are critically aware of the gap in expectations that these new digital services may create (see Graph 5 and *Diverging Expectations?* overleaf).

The RCGP's *Patient Online: The Road Map* sets out a realistic and practical approach to implementation but the results may well fall short of government commitments made so far. There needs to be a careful attempt to avoid inflating public expectations beyond what can realistically be delivered and creating public disenchantment with what will be a valuable innovation.

A more collaborative approach, listening to the concerns of both doctor and patient, could realign patient expectations with reality.

CENTRALLY PROVIDED SUPPORT IN AUSTRALIA

In Australia, support and education programmes for both healthcare professionals and patients are a key part of the implementation of the system. Communication methods include:

- Written materials such as brochures, eNewsletters and leaflets that target consumers and providers in general and specific cohorts: healthcare providers, older Australians, chronic conditions, mothers and newborns
- Key messages and FAQs
- An online eHealth Learning Centre – this plays a vital role in distributing educational material and resources to each of the various stakeholder groups. Patients can register to receive regular information and updates
- eHealth champions who help to explain the benefits of the eHealth record through case studies
- A dedicated telephone helpline.²³



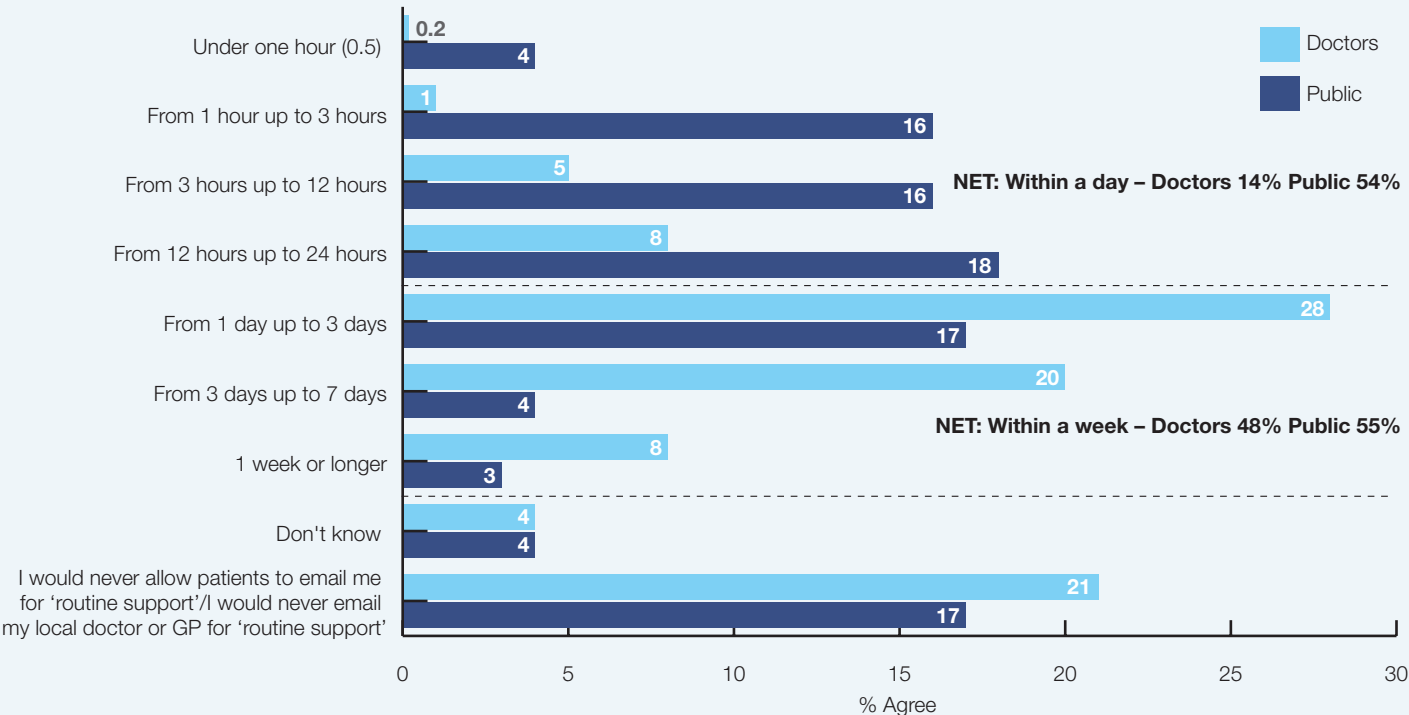
DIVERGING EXPECTATIONS?

Doctors are concerned that electronic communication with patients will have consequences on their time – 87% believe that it will increase patient expectations of ‘real time responses’ from doctors and practices.

Graph 6 shows this stark difference in expectations with more than half of the public expecting a response to an email within just one day, which only 14% of doctors think is realistic.

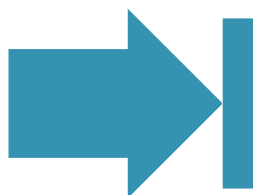
We need to ensure that patients are aware of realistic timeframes for a response and that patients with urgent problems do not use these routine communication channels.

Graph 6: Expectations of response times to emails for ‘routine support’



“Patients will expect instant access and answers to all queries immediately. The relative anonymity of posing questions and complaints online rather than face-to-face will inevitably lead to greater expectation and complaints.”

MPS member



Conclusion

Healthcare professionals should be encouraged to acknowledge the advantages that can be gained from the introduction of digital innovations such as online medical records. They will also need help introducing these innovations to patients and demonstrating how they can improve their care.

There also needs to be a change in the culture and mindset of patients, who must be supported in the critical role they will play in their own healthcare and helped to understand how they can use their own information safely and appropriately. Disadvantaged groups will need a particular focus.

Information and support needs to be at the heart of the implementation plans. There would only need to be a small number of controversial disclosures or data losses to fundamentally damage the trust between the medical profession, patients and the public and undermine the whole endeavour. It is crucial that both doctors and patients see access to online records, and the other technological innovations that will follow it, as an extension of the valuable doctor–patient relationship, rather than a replacement or a threat to it.



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Methodology

Survey results are based on two surveys:

ComRes interviewed 1,766 English adults online between 2 and 4 November 2012, on behalf of the Medical Protection Society. Data were weighted by the figures in the National Readership Survey to be demographically representative of all English adults.

MPS conducted the survey of UK MPS members. The survey was initially sent out to approx 15,000 MPS members in November 2012. The survey received 650 completed responses (4%), with GPs having the highest representation with 48%.

Full survey results can be found on the MPS website – www.mps.org.uk

How to contact us

The Medical Protection Society

33 Cavendish Square
London, W1G 0PS
United Kingdom

www.mps.org.uk
www.dentalprotection.org

General enquiries (UK)

Tel 0845 605 4000
Fax 0113 241 0500
Email info@mps.org.uk

Please direct all comments, questions or suggestions about MPS service, policy and operations to:

Chief Executive
Medical Protection Society
33 Cavendish Square
London W1G 0PS
United Kingdom

chief.executive@mps.org.uk

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We are a mutual, not-for-profit organisation offering more than 280,000 members help with legal and ethical problems that arise from their professional practice. This includes clinical negligence claims, complaints, medical council inquiries, legal and ethical dilemmas, disciplinary procedures, inquests and fatal-accident inquiries.

Fairness is at the heart of how we conduct our business. We believe that patients who have experienced an adverse event are entitled to, and should receive, a full and open explanation. We also believe that patients who have been harmed through a member's negligence should receive fair compensation.

We actively protect and promote the interests of members and the wider profession. We promote safer practice by running risk management and education programmes to reduce avoidable harm.

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