



Royal College of  
General Practitioners

# Patient Online: The Road Map



# Foreword



The College agreed to lead this important programme as we were confident that we could provide the professional leadership, training and support that GP practices and their patients would need to create what is a significant culture change in patient access.

With over 46,000 members, the College is the largest body representing GPs in the UK. We were also ideally placed to bring together the numerous professional and patient groups, including the RCGP's own Patient Participation Group, to make it happen.

Patient online access to records and services presents us with great opportunities. As well as having secure communication channels, patients will be able to book appointments, request repeat prescriptions and view their test results. However, there will also be major implications as patients gain access to their own records – not only for GPs, but also for patients themselves and their carers.

From the outset, our focus has been on the practical steps needed for GP practices to deliver patient online access by 2015. Over the past six months, we have worked in partnership with a broad cross-section of patients' groups and professional organisations. Critical issues such as information governance and safeguarding have been carefully considered, as have the implications for health inequalities and the protection of vulnerable individuals and groups.

This could not have been achieved without the hard work, commitment and tenacity of the many organisations and individuals involved. I am indebted to Dr Imran Rafi, Chair of the RCGP Clinical, Innovation and Research Centre, whose leadership of the programme has been simply outstanding. My thanks also to the members of the Patient Online Stakeholder Group and to the Chairs and members of the seven working groups who helped to get us to this stage, despite the challenging timescales.

In the Road Map that you see before you, we believe we have produced an appropriate, workable and realistic way forward – for all parties. I hope it will become an invaluable resource for GPs and their teams over the coming months and years.

A handwritten signature in black ink, appearing to read 'Clare Gerada'.

**Professor Clare Gerada** RCGP MBE MOM FRC Psych FRC GP FRCP  
Chair of Council  
Royal College of General Practitioners

# Executive summary

Patient Online describes access by patients to online services (booking and cancelling of appointments, ordering of repeat prescriptions), online communication with the practice and online records.

Following on from the recommendations of the Department of Health (DH) information technology (IT) strategy paper 'The Power of Information', by 2015 the NHS Commissioning Board (NHS CB) expects all general practices in England to offer Patient Online. Online access is another means whereby patients can share relevant information with their practitioner to help the patient make informed decisions about their health care.

The Government asked the RCGP, working in partnership with patient groups and professional organisations, to lead on development of guidance, particularly for general practices, to support online patient access and engagement with their online general practice records. A scope of the key principles and messages relevant to Patient Online has been produced through consensus methodologies within working groups and through wider stakeholder engagement.

The information technology (IT) to provide Patient Online will need to be mandated through the GP Systems of Choice (GPSoC) and local service providers (LSP) contract processes. The report titled *Innovation, Health and Wealth: accelerating adoption and diffusion in the NHS* (Department of Health, 2011) makes direct reference to patients having access to personal general practice records by 2015, and states that 'this will help drive service improvement and also enable competition and innovation among supporting data and digital service providers.'<sup>1</sup>

Between 2013 and 2015 there is both a need and an opportunity to evaluate, support, train and educate the workforce in primary care to rise to the challenges posed by patient access to transactional services and their own records. The NHS CB expectation is that, over this period, there will be a steady and progressive rise in the number of practices offering online services and access to records.

Promotion of patient and public eHealth literacy remains paramount, and is particularly important for disadvantaged groups. Failure to address this could result in a widening of the digital divide. It is necessary to adopt a socio-technical approach to implementation, which addresses the needs of staff, their working practices, job roles, culture and goals, and a technical system (which refers to the tools and technologies that support and enable work processes) is also reflected in this Road Map.

The programme of work described in the Road Map has established what could realistically be offered now and what might be offered in the future. The opportunities exist to improve patients' involvement in care and enhance their experience of general practice through using Patient Online. This document should be cited as:

Rafi I, Morris L, Short P, Hassey A, Gower S, de Lusignan S on behalf of the Patient Online Working Groups (2013) *Patient Online: The Road Map*. London: Royal College of General Practitioners (Clinical Innovation and Research Centre).

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<sup>1</sup> Department of Health. *Innovation, Health and Wealth: accelerating adoption and diffusion in the NHS*. London: DH; 2011. p. 18. [www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_134597.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_134597.pdf) [Accessed 12/12/12]

# Preface

Patient Online describes access by patients to online services (booking and cancelling of appointments, and ordering of repeat prescriptions), online communication with the practice, and access to online records. By 2015, the NHS Commissioning Board (NHS CB) expects all general practices in England to offer Patient Online.

Patient Online should be seen within the context of improving patients' involvement in care and enhancing their experience of and engagement with their practices. This work complements other initiatives that relate to innovation of care and shared decision making, including, from the Future Forum, 3 Million Lives<sup>2</sup> and Delivering Assisted Living Lifestyles at Scale (DALLAS)<sup>3</sup>, as well as health and social care integration.

The aim of the work, which is described and summarised in the Road Map, together with the role of the Royal College of Practitioners (RCGP), is to offer appropriate support and guidance to practices and patients. The Road Map has synthesised input from key individuals and groups, patients and professionals.

The use of information technology to improve the care of patients is a laudable objective. The challenge for each general practice is to consider what impact Patient Online is likely to have on the delivery of their services.

With that in mind, the three main objectives of the Road Map are to provide:

1. guidance on the implications of implementing Patient Online in general practice
2. guidance on what is needed to implement Patient Online in general practice
3. a plan for the next steps (during 2013–2015) in delivery of the 2015 commitments.

Patient Online offers practices an enhancement to current working practices. It is anticipated that Patient Online will act as a stimulus for commissioning groups to consider how they could best support their practices and/or groups of federated practices. The Patient Online Road Map should assist patient participation groups (PPG) in supporting their practices, and help patient organisations to tailor their provision and delivery of health information.

The RCGP considers it important that the uptake of Patient Online is not perceived as a performance management tool, but rather that it is taken up willingly in order to benefit patients and practices.

This document has therefore been produced by the RCGP to support and inform GPs and their practices during this time of change by evaluating the important relevant themes that highlight key messages and principles.

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<sup>2</sup> <http://3millionlives.co.uk>

<sup>3</sup> [www.innovateuk.org/\\_assets/0511/sbri\\_comp\\_dallas.pdf](http://www.innovateuk.org/_assets/0511/sbri_comp_dallas.pdf)

# Endorsements

Endorsements have been sought from stakeholders and supporting organisations for agreement on the principles within the Road Map and support for patients, GPs and practice staff. The following endorsements have been received.



**Royal College  
of Physicians**

## **Royal College of Physicians**

The Royal College of Physicians welcomes the opportunity to be involved with Patient Online. Helping patients to make decisions about their healthcare through increased access to information will have a positive effect on their experience both in primary and secondary care. Patient Online has potential to improve the interface between primary and secondary care. Better access for patients leads to improved patient involvement in their care, which facilitates better shared decision making between a patient and their doctor. We fully support the need for collaborative working between GPs, secondary care physicians, patient groups and the NCB in order to make Patient Online a success.



Royal College of  
**Paediatrics and Child Health**  
*Leading the way in Children's Health*

## **Royal College of Paediatrics and Child Health**

Dr David Low, Chair of RCPCH Informatics for Quality Committee welcomes on behalf of RCPCH the patient online road map led by the RCGP. Children are very frequent users of primary care services. This when implemented will enable these services to be more parent centred, with transactions and interactions being more accessible, efficient and effective. The ability to access health records should also encourage young people to become more actively involved in their own health and healthcare as well as parents for their children.



ROYAL  
PHARMACEUTICAL  
SOCIETY

## **Royal Pharmaceutical Society**

We welcome the RCGP's work supporting their members to enable patients to have access to their records. We anticipate that patients will want to share their records with other healthcare professionals involved in their care, including pharmacists. One of the benefits for GPs when records are shared with pharmacists is that they will be able to see what additional medicines patients are buying over the counter as well as which medicines have actually been dispensed. Patient safety will be greatly enhanced if healthcare professionals can communicate via the patient's record.



*The Royal College of*  
**Midwives**

## **Royal College of Midwives**

The Royal College of Midwives welcomes the Road Map for Patient Online access. The RCM believes that enabling women to access their health records will promote a collaborative approach to care during their pregnancy. Patient Online access will extend cooperation and aid better communication between midwives, the women they care for and members of the woman's care team.



Royal College  
of Nursing

## **Royal College of Nursing**

This practical Roadmap is an essential first step towards more people understanding their health needs and managing their own care and treatment, where they wish to do so. The development of the roadmap has been an excellent example of collaboration among patient, professional, service and supplier organisations. The RCN is looking forward to continuing to work in this partnership to ensure that nursing staff are informed and supported to make patient online access a reality.



### Royal College of Psychiatrists

The Patient Online Road Map is encouraging and opens up exciting new possibilities which will help patients to take ownership of their health information, to foster innovation and to facilitate communication of essential health information. The College endorses the current Road Map. However the College would draw attention to the needs of patients with mental illness in all settings and appreciates that the roadmap would need further revision in order to fully meet these needs. Patients who are detained under the Mental Health Act (1983), who lack capacity to make decisions about accessing their health records, prisoners or homeless people with mental illness, children and long-term inpatients are groups who would benefit from clarification of the many issues around access in future revisions of the roadmap. Finally supporting patients to transfer relevant online record information to mental health services could enhance practice in areas ranging from medicine reconciliation to seasonal vaccination.



### National Children's Bureau

Children and young people who are given the opportunity to be actively involved in their care will be better equipped to manage their own health and access health services independently, as they grow in confidence. With the right support, online access to their health records and to health information can play a central role in helping children and young people to make the most of local health services and be as healthy as they can be through adolescence and into adulthood. This is a real opportunity for GPs, as the primary providers of healthcare to children and young people, to consider how they and their practices can be best prepared to work with children, young people and parents to provide online services so that all their young patients benefit.



### Association of Directors of Adult Social Services

ADASS welcomes the work that the RCGP has done to start to make information from their GP patient records available to the citizen. This is consistent with the increasing citizen involvement that has already been implemented (although not online) in social care through personalisation and personal budgets. There is reference in the material to care planning models and the need for systems to support this. We would agree that care planning based on the individual's goals is at the heart of care for people with major needs and work is required so that it can be achieved collaboratively across all care systems, including those operated by the citizen (and their carers) themselves. We would like to flag up the need for this work. We will also find this document and the work undertaken helpful in defining service user access for adults to their social care records.



### Intellect

Providing patients with online access to records and services is a natural step in improving patient engagement and service delivery in the NHS. Intellect, on behalf of the information technology industry, is delighted to have provided industry advice to this excellent road map and we will continue providing support to the development of a market that can deliver intuitive solutions that benefit GPs and patients.



### Medical Defence Union

The policy of providing electronic access to patient records is likely to have a substantial impact on the MDU's GP members and to become a major part of their clinical work over the next few years. It is important that the medico-legal aspects of this project are properly considered and we are grateful for the opportunity to contribute medico-legal comments on our members' behalf to the stakeholder group responsible for developing the Road Map.

# Stakeholder Acknowledgements

The following stakeholders have expressed their acknowledgement for the Road Map.

## **Medical Protection Society**

The work led by the RCGP in Patient Online – The Road Map provides useful, practical advice to GP practices in giving their patients access to their medical records online. MPS thinks patient access to online health records has the potential to improve patient care. Greater access to information for patients can increase knowledge and understanding, promote 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 and avoid unintended consequences. We think this document provides useful support for doctors but there will also need to be information, education and support from central government for patients. It will also be important to ensure that public expectations are not inflated beyond what can be realistically delivered in the immediate term. Consideration will need to be given to the views and expectations of both patients and doctors and MPS will be publishing our own research into this in April 2013.

## **NHS Commissioning Board**

The NHS Commissioning Board would like to thank the RCGP for accepting the invitation from the Department of Health to lead a genuinely collaborative approach in taking forward this important work on primary care online patient access. It would particularly like to express its thanks to Dr Clare Gerada for her support of this important agenda; Dr Imran Rafi for his excellent leadership; and other colleagues in the RCGP and stakeholder organisations for their expertise, hard work and carefully judged contributions. The relationship of trust and mutual respect forged in developing this document will be important in delivering on the commitment to make a reality of patient online access in primary care. While there remain genuine issues to be resolved as we move forward with delivery, there are also progressively greater benefits for both patients and general practices to be realised. This Road Map document is the start of that journey. The thorough and robust work that has gone into it can now be built upon to ensure that practical support for patients and practices alike is developed to make a reality of this important innovation in patient participation.

## **National Voices**

There is a growing body of evidence that having online access to their health records promotes a more engaged, informed, grown-up relationship between patients and the NHS, which can have positive impacts on health outcomes and the efficient use of limited resources. The NHS has been a long way behind other sectors in its use of modern communications technologies, but this is changing, and there is now a strong policy drive to ensure that people who want it should be able to transact electronically with services and have access to their records. The barriers to progress are not so much technical as cultural. We need to make this agenda mainstream and to clearly sell the benefits: to doctors, practice managers and patients. As part of that, practices need practical help and support to get there. That is the purpose of this road map, which clearly and thoroughly sets out the issues that need to be addressed. National Voices hopes that it will be widely used as part of a broader movement to give patients a stronger and more informed voice in care.



# Acknowledgements

This project has been made possible through the hard work of the project core team, the working group chairs and vice-chairs, the working group members and support members, and the stakeholder group. As the project developed it became clear that there was a readiness to engage with this work, and many people offered their expertise, support and guidance to develop the work described in this document.

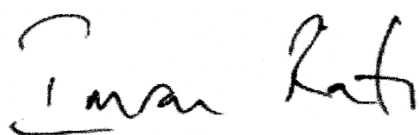
The timescales have been challenging, and Arwen Wilcock, Richard Haigh, Richard Ives, Bruce Elliot, Lucy Wood and Jana Dale deserve special praise for their dedication to ensuring that we remained on track, while Chris Gush (RCGP Clinical Innovation and Research Centre) and Henry Pares (Department of Health) have supported the project with their leadership and guidance.

Special thanks must go to the excellent and hardworking RCGP Health Informatics Group, led by Libby Morris, Alan Hassey and Marcus Baw. Thanks are also due to Peter Short, Sandy Gower, Simon de Lusignan and Beverly Ellis, who have worked hard as leaders of their respective groups, and to the RCGP Health Inequalities Standing Group, led by Una Macleod.

We are particularly grateful to all of the groups and organisations, both within and outside the RCGP, that have provided constructive advice and feedback, especially our colleagues from the British Medical Association General Practitioners Committee.

Gillian Watson (RCGP) and Eileen Phillips (NHS CB) have guided us ably on the communications and publicity arm of the work, and we are particularly grateful to Toto Gronlund, Antony Chuter, Patricia Wilkie, Howard Leicester and Zoe Renton, among many others, who have represented the patients' perspective.

Finally, we wish to thank the college officers, led by Clare Gerada and Amanda Howe, and our recent Chair of Clinical Innovation and Research, Helen Lester, all of whom have provided positive support and advice for this project, particularly at the most challenging times.



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Chair of the Stakeholder Group  
Chair of the Clinical Innovation and Research Centre (CIRC)  
Royal College of General Practitioners



# Table of contents

<b>Foreword</b>	<b>I</b>
<b>Executive summary</b>	<b>II</b>
<b>Preface</b>	<b>III</b>
<b>Endorsements</b>	<b>IV</b>
<b>Stakeholder acknowledgments</b>	<b>VI</b>
<b>Acknowledgements</b>	<b>VII</b>
<b>Table of contents</b>	<b>VIII</b>
<b>Abbreviations</b>	<b>X</b>
<b>1.0 Introduction</b>	<b>1</b>
1.1 The aim of this document: guidance and next steps	2
1.2 The principles of access to records	4
1.3 The baseline: current provision of electronic access	5
<b>2.0 First steps to offering Patient Online</b>	<b>7</b>
2.1 Introduction	7
2.2 Defining the offer: What would the practice offer?	8
2.3 Access to online records	12
2.4 Secure communication with the practice	15
2.5 What could be done now: consider the information governance and security risks	18
2.6 The functionality of GP IT systems: the present and the future, market liaison	23
2.7 Risks cited by the supplier community	25
2.8 Patient-centric system design principles	26
2.9 Current or future data standards	27
<b>3.0 What needs to be developed?</b>	<b>28</b>
3.1 Training, education and development support for general practices, primary healthcare teams, patients, carers and advocates	28
3.2 Issues relating to health inequalities	31
<b>4.0 Evidence and evaluation</b>	<b>33</b>
<b>5.0 Phase 3 (2013–2015)</b>	<b>36</b>
5.1 Background and wider context	36
<b>6.0 Summary</b>	<b>40</b>

<i>Box 1: NHS Operating Framework data</i>	5
<i>Box 2: A general practice offering online access to specific patient groups – case study</i>	9
<i>Box 3A: The different items that could be offered within Patient Online (taking into account differences in practices' capabilities)</i>	9
<i>Box 3B: More detailed consideration of the different elements within a clinical record</i>	10
<i>Box 4: NHS CB mandated commitment and the Patient Online proposed categories</i>	12
<i>Box 5: Case study from Diabetes UK – Patient Online and care</i>	14
<i>Box 6: Case study from Cancer Research UK – breast cancer</i>	15
<i>Box 7: Medical Protection Society factsheet, 2012</i>	17
<i>Box 8: Summary of high-risk issues from the Information Governance Risk Register</i>	18
<i>Box 9: Important principles relating to domestic violence</i>	20
<i>Box 10: Important principles from the Medical Protection Society (abridged letter)</i>	21
<i>Box 11: Letter from the Medical Defence Union – principles</i>	22
<i>Box 12: Exemplar functionality to support online access</i>	24
<i>Box 13: Specific exemplar themes and educational topics</i>	30
<i>Box 14: Looking ahead. Exemplar: how IT may support collaborative care planning (Sue Roberts, RCGP Care Planning Steering Group; Chair, Year of Care Partnerships)</i>	38
<b>Appendices</b>	<b>41</b>
Appendix 1: Programme plan and methodology	41
Appendix 2: Patient Online access – defining the offer	43
Appendix 3: Information Governance Risk Register	52
Appendix 4: Stakeholder Group and Working Group membership	57
Appendix 5: Key messages from this document	61
<i>Key messages to the NHS CB</i>	61
<i>Key messages to practices</i>	61
<i>Key messages for system delivery</i>	62
<i>Key messages relating to support, training and education</i>	63
<i>Key messages relating to health inequalities</i>	63

# Abbreviations

API	application programming interface
BMA	British Medical Association
CCG	clinical commissioning group
CFH	Connecting for Health
CPD	continuing professional development
DH	Department of Health
DPA	Data Protection Act
EHR	electronic health record
GMC	General Medical Council
GP	general practitioner
GPC	General Practitioners Committee
GPSoc	GP Systems of Choice
ICO	Information Commissioner's Office
ICT	information and communications technology
IT	information technology
LSP	local service provider
LTC	long-term condition
NAPP	National Association for Patient Participation
NHS	National Health Service
NHS CB	NHS Commissioning Board
OOH	out of hours
PPG	patient participation group
QOF	Quality and Outcomes Framework
RA	registration authority
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RNIB	Royal National Institute of Blind People
SCR	summary care record
SSM	support for self-management
YOC	Year of Care (programme)

# 1.0 Introduction

The NHS Future Forum was set up by the Government in 2011 to consult broadly on the future of the NHS. As part of their review, the NHS Future Forum examined the Government's information strategy and made several key recommendations which have been accepted in the Department of Health (DH) information strategy report.<sup>4</sup> The commitment made by the DH on general practice is that by 2015:

- All NHS patients will have secure online access, where they wish it, to their personal general practice records.
- All general practices will be expected to make available electronic booking and cancelling of appointments, ordering of repeat prescriptions, and communication with the practice.

A central action followed this, whereby the Government asked the RCGP, working in partnership with patient groups and professional organisations, to lead on the development of guidance to support patients' access to and engagement with their general practice records.

The RCGP agreed to take forward this work, and the Patient Online Road Map is a key part of this, through its scoping of the work to consider the important principles.

The DH information strategy report stated that *'practices that can already provide their patients with online access to their records are encouraged to do so as soon as possible. Practices are encouraged to extend the range of transactions that people can deal with online, for example: electronic booking and cancellation of GP/nurse consultations, repeat prescriptions, access to test results and online secure communication between GPs and patients.'*

The recently announced NHS CB mandate<sup>5</sup> confirms this aspiration:

*'The Board's objective is to achieve a significant increase in the use of technology to help people manage their health and care. In particular, the Government expects that by March 2015:*

- *Everyone who wishes will be able to get online access to their own health records held by their GP. The Board should promote the implementation of electronic records in all health and care settings and should work with relevant organisations to set national information standards to support integration.*
- *Everyone will be able to book GP appointments and order repeat prescriptions online.*
- *Everyone will be able to have secure electronic communication with their GP practice, with the option of e-consultations becoming much more widely available.'*

<sup>4</sup> Department of Health. *The Power of Information: putting all of us in control of the health and care information we need*. London: DH; 2012. [www.informationstrategy.dh.gov.uk](http://www.informationstrategy.dh.gov.uk) [Accessed 12/12/12]

<sup>5</sup> Department of Health. *A Mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015*. London: DH; 2012. [www.wp.dh.gov.uk/publications/files/2012/11/mandate.pdf](http://www.wp.dh.gov.uk/publications/files/2012/11/mandate.pdf) [Accessed 12/12/12]

## 1.1 The aim of this document: guidance and next steps

The aim of the work described in the Road Map and the role of the Royal College of Practitioners (RCGP) is to offer appropriate support and guidance to practices and patients.

The three main objectives of the Road Map are to provide:

1. guidance on the implications of implementing Patient Online in general practice
2. guidance on what is needed to implement Patient Online in general practice
3. a plan for the next steps (during 2013–2015) in delivery of the 2015 commitments.

The work presented in this document aims to summarise expert opinion and feedback on what online access involves, and to provide a series of key messages. However, in view of the separate and unique challenges presented by e-consultation (consultation can either be in real time through a live messaging/chat function or videoconferencing facility such as Skype, or via an asynchronous chain of emails between a patient and a doctor about a clinical topic), this will not be considered in this document, whereas what will be evaluated is online communication, which is administrative messaging between practice staff and patients that does not require a doctor's clinical expertise.

Electronic personal health records (ePHRs) are also beyond the scope of this document when they refer to health information being managed by the individual, as opposed to an electronic healthcare record that is managed by the clinician or institution.<sup>6,7</sup> These two specific areas are deemed to be beyond the remit of the project (see Appendix 1) at this point.

### Key message to the NHS CB

- There is a need for further exploration, funding and commissioning of studies on e-consultation, particularly in the setting of online diagnosis and treatment. Before any implementation is considered, the risks and benefits to practices and patients need to be defined.

This document focuses on the various challenging areas, providing guidelines on good practice, expert views and guidance to support consideration of implementation and/or enhancement of Patient Online. For each key message an approximate timeline will be provided.

The programme plan is summarised in Appendix 1. The programme has been divided into three phases:

- **Phase 1:** initiation and defining of the scope of the work (June to September 2012)
- **Phase 2:** specification development and initial delivery (October to December 2012)
- **Phase 3:** the RCGP working with partners to have roles relating to support, training and education, with an evaluation of implementation and roll-out by 2015.

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<sup>6</sup> [www.ncbi.nlm.nih.gov/pmc/articles/PMC1447551/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1447551/)

<sup>7</sup> [www.pifonline.org.uk/products-page/product-category/guide-to-health-records-access](http://www.pifonline.org.uk/products-page/product-category/guide-to-health-records-access)

Seven working groups were established, and each has considered the following key themes in exploring the implications of Patient Online:

1. defining the offer
2. communicating the (balanced) benefits to practitioners, patients, carers and advocates
3. information governance and safeguarding
4. support, training and education
5. supplier and market liaison
6. the Road Map
7. evidence and evaluation.

We anticipate a further update of the Road Map document as more evidence and experience accrue. In particular, a systematic review by the Evidence and Evaluation Working Group of the evidence of how quality of care may be linked to online access is currently under way, and key messages from this will be published in spring 2013.

The importance of emerging evidence and evaluation will grow over the next 2 years in order to inform practices and patients, as well as policy makers. This is exemplified by the DH impact assessment document, *The Power of Information*,<sup>8</sup> which extrapolates and models the impact of online access from a small cohort of available data.

The UK is a leader in primary care services. General practice, as a specialty, is a leader in the use of IT systems<sup>9</sup> to support quality electronic healthcare records. However, many different uses of IT exist to enable innovative daily practice. For example, current mobile technology, such as medical smartphone applications, offers a range of activities such as literature search applications and evidenced-based information tools.<sup>10</sup> The recent publication of the *Social Media Highway Code*<sup>11</sup> by the RCGP illustrates, and provides guidance on, the different types of interactions that healthcare professionals might have with the public through the use of social media outlets.

The use of IT to drive service improvement is laudable. If we can use IT to deliver quality accessible care that addresses health inequalities, to reduce fragmentation of care and provide coordinated care for people with multiple morbidity, and to involve patients and carers more in decisions about their health, then we will succeed in meeting the challenges facing general practice to sustain services.<sup>12</sup>

When considering the value of IT, we must also take into account the unintended consequences of the use of health information technology. This includes the likelihood that there will be an increase in the number of communications between patients and their practices which deal with questions and queries particularly relating to patient records. As this may exacerbate the digital divide among disadvantaged social groups, the effect on eHealth literacy (defined as the ability of people to use IT to improve or enable health and social care) and on the quality of communication between healthcare professionals and patients will need to be considered. Some of these issues have been addressed by members of the RCGP Health Inequalities Group and RCGP Learning Disability Group, and have been incorporated in this and supporting documents.

<sup>8</sup> Department of Health. *The Power of Information: putting all of us in control of the health and care information we need*. London: DH; 2012. [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_134181](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_134181) [Accessed 12/12/12]

<sup>9</sup> NHS Commissioning Board. *Securing Excellence in GP IT Services*. London: DH; 2012. [www.commissioningboard.nhs.uk/files/2012/12/gp-it-op-model.pdf](http://www.commissioningboard.nhs.uk/files/2012/12/gp-it-op-model.pdf) [Accessed 12/12/12]

<sup>10</sup> Mosa A, Yoo I and Sheets L. A systematic review of healthcare applications for Smartphones. *BMC Medical Informatics and Decision Making* 2012; 12: 67. [www.biomedcentral.com/content/pdf/1472-6947-12-67.pdf](http://www.biomedcentral.com/content/pdf/1472-6947-12-67.pdf) [Accessed 12/12/12]

<sup>11</sup> Royal College of General Practitioners. *The Social Media Highway Code*. London: RCGP; 2012. [www.rcgp.org.uk/policy/rcgp-policy-areas/social-media-highway-code.aspx](http://www.rcgp.org.uk/policy/rcgp-policy-areas/social-media-highway-code.aspx) [Accessed 12/12/12]

<sup>12</sup> Royal College of General Practitioners. *RCGP Consultation – Better Care for Patients: defining the role of general practice in 2022 – a call for action*. [www.rcgp.org.uk/policy/rcgp-policy-areas/~media/Files/Policy/2022%20Consultation%20Document.ashx](http://www.rcgp.org.uk/policy/rcgp-policy-areas/~media/Files/Policy/2022%20Consultation%20Document.ashx) [Accessed 12/12/12]

## 1.2 The principles of access to records

The *NHS Constitution* (2010)<sup>13</sup> and the *NHS Care Record Guarantee* (2011)<sup>14</sup> enshrine the principles of access to records by patients. These are highlighted in the RCGP guidance on enabling access to records.<sup>15</sup> The principles set out in these documents can be summarised as follows:

- In the UK, under the Data Protection Act (DPA) 1998 and Access to Medical Reports Act 1988, patients (including 'Fraser/Gillick-competent' children), or anyone authorised by the patient, are entitled to access their records, including reports supplied by a medical practitioner for employment, insurance or other purposes.
- Patients should be given appropriate information and opportunities to exercise control over the healthcare decisions that affect them.
- Giving patients direct electronic access to their health records is one method of sharing relevant information to help them to make informed decisions about their health care.
- If online access is being provided under the NHS, this should be at no cost to either the patient or the practice.
- Health organisations should strive to provide a secure mechanism for enabling Patient Online, and when it is available they should inform patients of the facility and how to use it.
- Health records are used by health professionals as a tool for providing care. Patient access or input must not have an adverse impact on the effectiveness or quality of that tool.
- Health professionals should withhold confidential third-party information from patients before enabling access to records.
- Parents, or those who have parental responsibility for children who are not deemed to be 'Fraser/Gillick competent', are entitled to access a child's medical records in the child's best interests.
- There are provisions under the Mental Capacity Act 2005 for England and Wales for access to the records of patients who lack capacity.
- Access to online records does not replace formal rights of access under the DPA, and patients can still make subject access requests in the usual way, unless:
  - such access is likely to cause serious harm to the physical or mental health, or condition, of the patient or any other person
  - it may relate to or be provided by a third person who can be identified from the information and who has not consented to the disclosure.

<sup>13</sup> [www.dh.gov.uk/health/category/policy-areas/nhs/constitution/](http://www.dh.gov.uk/health/category/policy-areas/nhs/constitution/) [Accessed 12/12/12]

<sup>14</sup> [www.nigb.nhs.uk/pubs/nhscrg.pdf](http://www.nigb.nhs.uk/pubs/nhscrg.pdf) [Accessed 12/12/12]

<sup>15</sup> Royal College of General Practitioners. *Enabling Patients to Access Electronic Health Records. Guidance for health professionals*. London: RCGP; 2010.  
[www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/-/media/Files/CIRC/Health%20Informatics%20Report.ashx](http://www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/-/media/Files/CIRC/Health%20Informatics%20Report.ashx) [Accessed 12/12/12]



## 1.3 The baseline: current provision of electronic access

It is likely that some practices may not have contemplated offering online access, or do not have the functionality in their IT systems to enable it. However, many practices do have such functionality, and Box 1 shows recent data on practices that offer online access.

### Box 1: NHS Operating Framework data

The NHS Operating Framework for 2012–2013 has provided provisional data regarding the 8121 general practices in England. As of September 2012, practices have the following capabilities:<sup>16</sup>

- Access to a list of current medications/ordering medication; 98% of general practices now have the functionality and, encouragingly, almost 40% of practices have willingly explored and enabled these services. Other practices that currently do not have functionality may be willing to consider offering this type of access in the future, once their systems are enabled, and where they feel able to do so.

#### Online records

- Around 75% of practices have the capability to provide electronic access to medical records. Less than 1% of practices have supported and enabled access to these data.
- Around 570,000 patients (1% of the total in England) registered with 63 general practices may currently, if they wish to do so, have electronic access to their own medical record. Only a small number of these patients have so far sought such access or used it.
- Approximately 42 million patients (75%) are registered with 6111 general practices (75%) which have the functionality to allow patients to view their own medical records electronically, but where that functionality has yet to be enabled for patient use.

#### Online services

- Around 98% of general practices now have the functionality for patients to book and cancel appointments, and 37% of practices have enabled these services.

#### Online communication

- This refers to secure online communication between clinicians and patients facilitated by and recorded within the electronic GP record (i.e. secure electronic messaging between patients and the GP practice, a named doctor or deputy). No data are currently available.

<sup>16</sup> Data provided by the DH and subject to change.

Having established a baseline, the question then arises as to what would be deemed a success by 2015 if practices were supported and offered training in Patient Online, moving from innovation to mainstream. This depends on the perspective from which one is judging this.

- From the perspective of **patients** it would be something tangible, namely that there is efficient access to their individual records, while at the same time they are not disadvantaged. The majority of general practices involve patients in decision making about their own health care. One measure of success of Patient Online would be the evidence that it promotes these attributes of quality care.
- From the viewpoint of **individual practices**, successful implementation would be an IT service that supports and assists them with their workload and administration, while at the same time enabling patients to access services efficiently and effectively, and assisting with the needs of patients who have complex medical conditions.
- From the perspective of **GP contract negotiators** and **NHS employers** (and **practices**), successful implementation would be the offer of Patient Online that is resourced, and which demonstrates not only that patients and practices benefit, but also that the workforce is able to manage demand without unintended consequences.
- The **RCGP** would want general practices that offer Patient Online to be supported using educational and training tools in partnership with their patients.
- The **Government** would want every practice in England to offer Patient Online.

It is recognised that there are challenges in ensuring that practices can offer Patient Online access safely and securely. These have been addressed through this programme of work and have been highlighted in this document. They include important issues such as the following:

- security and confidentiality
- helping patients to understand how to use their records
- issues relating to consent and protection of sensitive data, such as third-party data
- equality issues (i.e. identifying vulnerable or disadvantaged patients, and those who are at risk of coercion)
- adequate resourcing.

The key driver is the NHS CB mandate. There are factors to be considered that will influence the capability of practices to meet this expectation. In particular, the NHS CB will set the overall direction in the procurement of IT system requirements and standards, and presumably the monitoring. The GP Systems of Choice (GPSoC) and local service provider (LSP) contracts are the two methods through which the NHS funds the provision of GP clinical IT systems in England. GPSoC includes all of the leading GP clinical IT systems in use in England.

Between 2013 and 2015 we anticipate a steady rise from the current baseline of achievable online services. This will require a focus on support, training and funding relating to online services, online records and the use of asynchronous online communication (asynchronous tools enable communication between users). It will be important to capture both quantitative and qualitative measures of success, and in particular to identify whether there is promotion of the attributes of quality care as identified and/or defined by patients. Evaluation will be an important aspect, especially leading up to 2015. Having reliable data (both quantitative and qualitative) will help to enrich the field. The NHS Operating Framework offers a mechanism for capturing quantitative data across England.

### Key message for the NHS CB

Funding streams are made available through the NHS CB to enable the study and evaluation of e-consultation before implementation is considered for mainstream general practice. The funding should be part of the necessary and important broader evaluation of the impact of Patient Online.

# 2.0 First steps to offering Patient Online

## 2.1 Introduction

Progress towards meeting the NHS CB mandate by 2015 does not have to be an all-or-nothing step. Practices can consider adopting a phased introduction of items relating to Patient Online, based on their local circumstances. As these practices gain experience and learning, this could aid the building of confidence and trialling of additional aspects of online provision. This does depend on the functionality of the IT system in use, which may vary from the ability to log on and view appointment options and repeat medication, to full access to the entire medical record.

- Some online services (e.g. online prescriptions) can be offered relatively easily, and there may be natural matches which lead practices to implement online services. For example, Patient Online could suit and benefit a practice that has a high proportion of commuters, allowing them ease of access to appointment booking.
- Proponents of full access (i.e. both retrospective and prospective access) point out the benefits in terms of sharing clinical decision making and care planning, while at the same time being mindful of the implications of opening the record in terms of third-party information.

The guidance in this Road Map applies to either new practices which would like to offer Patient Online, or those that currently offer some aspect of Patient Online and want to expand what they can offer.

### Practices that are new to Patient Online

What could be done now?

- Agree the principle of offering or expanding Patient Online, ideally in discussion or in partnership with the practice patient participation group.
- Consider the information governance and security issues that might be relevant, and how risks may be mitigated. Which patient groups need to be considered?
- Ascertain the functionality of your IT system. What can it do for you? What may be possible in the future?

What needs to be developed?

- Assess and grow the ongoing support, training and education needs of staff, patients, carers and advocates.
- Consider issues relating to health inequalities. Which groups of patients need special attention? How will patients be informed of the offer? What information should be made available?

## Practices that are already offering some aspects of Patient Online

Consider whether the practice wants to expand what they can offer.

- Consider the information governance and security issues.
- Ascertain the functionality of your IT system.
- What additional education needs are there for the practice staff?
- Consider issues relating to health inequalities. Are there further groups of patients who need to be considered who have not been able to access services?

## 2.2 Defining the offer: What would the practice offer?

This section describes the work from the Defining the Offer Working Group (see Appendix 2).

The first step is to be clear about the initial stages involved in what the practice would want to offer. This will be dictated by many practice factors, including staff and resources, IT systems, patient demand and patient demographics, as well as the principles of patient enablement, shared decision making and care planning. It would be important that practices are not seen to be making these decisions in isolation, as dialogue with patient representative groups and NHS colleagues and team members is essential. Involvement of other disease-specific organisations who already deliver a patient portal would be desirable, perhaps at clinical commissioning group (CCG) level.

The key issues can be summarised as follows:

- What mixture of services and items does the practice want?
- How does the practice want to tackle e-communication?
- How far towards full Patient Online does the practice want to go?
- Consideration of the information governance and security approach.
- What is the IT functionality of the practice IT systems?
- What training and education are required for practice staff and patients?

The Defining the Offer Working Group considered features or elements of access to services and to the patient record in the following way.

Key discussion items were described under the following grouped headings to provide a summary of the suggested offering that practices might want to consider. This includes the following:

- the feature (e.g. online prescriptions)
- clarification or expansion of the feature being offered (e.g. print or cancel prescription)
- the potential benefit
- the potential risks
- mitigation that could address the potential risks.

The Defining the Offer Working Group has taken a pragmatic approach and highlighted the benefits and potential risks, as well as mitigating against risk in both the Defining the Offer document (see Appendix 2) and the Information Governance Risk Register (see Appendix 3).

The RCGP 2010 guidance on enabling access advised that record access be considered a staged process with a *'gradual introduction to test results, clinic letters ... gradually extended to the complete record.'* Box 2 presents an example of what one practice offers, while Box 3A summarises different items that could be offered by practices with the dependencies specified. Box 3B provides further details of what is covered by the range of offers for online access, while Appendix 2 provides more details about the potential benefits and risks.

## Box 2: A general practice offering online access to specific patient groups – case study

Dr Tim Walter, a GP from Newbury, Berkshire, has led his practice, which looks after 14,500 patients, in offering Patient Online access to services such as online appointment booking and ordering of prescriptions for many years, as well as offering full access to the patient record over the last 6 months. His practice proactively sought out patients with diabetes and rheumatological conditions, as these patients in particular benefit from ready access to their test results. He has found that by offering access to these results, his service has become more efficient as the patients are able to see their test results before they attend the clinics, and thus have better ownership of their condition. He is mindful to ensure that the administrative staff check that letters and updates to records are correctly entered in the patient records. During a 1-month period, 833 patients logged in a total of 2218 times, 386 appointments were made and 116 appointments were cancelled, medical records were viewed 32 times, and 423 medication requests were made.

## Box 3A: The different items that could be offered within Patient Online (taking into account differences in practices' capabilities)

The range of items developed by the Patient Online group has been classified as follows:

### **Ash (A)**

Items specified include functionality that is already present in current systems and that many practices are already using or considering implementing as a first step in offering online access. Resources will need to be identified to enable practices to take on these new work processes, such as password management.

### **Birch (B)**

Many practices will have standard functionality to be able to offer these items for patients. These items bring additional workload, and therefore any implementation will require negotiations with the profession.

### **Cedar (C)**

Items specified will present practices with ethical and/or implementation challenges, with potential risks to confidentiality and/or patient safety or with significant workload implications, and would be seen as an enhanced practice offering. They are only likely to be provided by general practices with a strong interest in access to records, and after the risks have been mitigated.

### **Date (D)**

These items may be desirable, but should only be considered once the preliminary items (e.g. the Ash and Birch items) have been achieved, again subject to negotiation.

Box 3B highlights these levels and provides further details about what is covered by the range of offers for online access. Appendix 2 provides more detail, together with the potential benefits and risks at each level of offering.

**Box 3B: More detailed consideration of the different elements within a clinical record**

This section aims to identify the different (but not mutually exclusive) elements within a clinical record that **could** be made available for access, and to provide some assessment of the potential benefits and risks of making these elements accessible. In addition, it addresses the distinction between online services (e.g. appointment booking) and online records.

Ash (A)	Birch (B)	Cedar (C)	Date (D)
<b>Account management</b>	<b>Online test results (after GP has viewed them)</b>	<b>Prospective access to medical record</b>	<b>Summary care record (SCR) information</b>
Set and reset username and password, resourced  View online help and tutorials when using system  View demographic details  View carer details (where already recorded in GP clinical system)  View disability needs and personal requirements	View test results <b>after</b> they have been reviewed by GP and labelled with an action and/or message (e.g. 'normal', etc.)  Download/print test results	View all coded data, including their associated free text  Print/download data  <b>See Date items for past records access</b>	Summary information from the patient record in a view that is convenient for patients, which includes: <ul style="list-style-type: none"> <li>■ medications</li> <li>■ allergies and adverse reactions</li> <li>■ immunisations</li> <li>■ contact and carer details (where already recorded in GP clinical system)</li> </ul> Print/download summary information
<b>Online prescription management</b>	<b>Core information</b>	<b>Test results (before GP has viewed them)</b>	<b>Past records</b>
Prescription requests  Cancel prescription requests  Print prescription requests	Information from the patient record in a view that is convenient for patients, which includes retrospective access to: <ul style="list-style-type: none"> <li>■ medications</li> <li>■ allergies and adverse reactions</li> <li>■ immunisations</li> </ul> Print/download core information	Selected patients can view test results <b>before</b> they have been reviewed by GP	Online access to records prior to the date of the patient requesting online access

**Box 3B: Consideration of the different elements within a clinical record** continued

Ash (A)	Birch (B)	Cedar (C)	Date (D)
<p><b>Online appointment management</b></p> <p>Request or book appointment with GP, practice nurse or other health professional</p> <p>Cancel appointments</p> <p>Print details of appointment booking</p>	<p><b>Scanned or attached documents (after GP has viewed them)</b></p> <p>Letters in</p> <p>Letters out</p> <p>Other documents that may be scanned in (e.g. investigation results, such as radiology)</p>	<p><b>Scanned or attached documents (before GP has viewed them)</b></p> <p>Clinic letters and discharge summaries</p> <p>Other documents that may be scanned in (e.g. investigation results, such as radiology)</p> <p>Download/print scanned or attached content</p>	<p><b>Patient additions to records</b></p> <p>Enable patient to add (i.e. append) information to clinical record</p>
<p><b>Online advice and information</b></p> <p>Access, download and print 'information prescriptions' and patient information leaflets</p>	<p><b>Audit trail</b></p> <p>Audit trail to show who has accessed every online record is mandatory</p>	<p><b>Online access for carers and advocates (as nominated by the patient)</b></p> <p>Nominate others who can access records. These others should have their own login account with permissions set by the patient</p> <p>This should allow for more than one carer, and also for different access for each carer</p>	<p><b>'Edit my details'</b></p> <p>Patients will want to be able to update their demographic details, but any changes will need to be authorised by the practice first</p>
			<p><b>Complete/update online health assessment</b></p>
			<p><b>Exposure of secure standardised API for:</b></p> <ol style="list-style-type: none"> <li>1. online prescription and appointment management</li> <li>2. records access.</li> </ol> <p>Systems suppliers would provide an application programming interface (API) to allow interaction with clinical records, enabling external applications to access and utilise these data</p>



Box 4 shows the proposed NHS CB mandated online access in relation to the RCGP Patient Online items classification.

#### Box 4: NHS CB mandated commitment and the Patient Online proposed categories

<b>NHS Commissioning Board mandated commitment</b>	<b>Patient Online items classification</b>
Electronic booking and cancelling of appointments	Ash
Ordering of repeat prescriptions online	Ash
Viewing test results after GP has viewed them	Birch
All NHS patients to have secure online access to their personal GP records	Cedar (for prospective and not retrospective access; however, practices may exercise their own judgement)
Online communication with the practice (asynchronous)	Not yet assigned

There will be some practices that are in a stronger position to embrace change. Patient Online may well be very challenging for others. Ultimately, any practice with the relevant IT functionality can offer whichever items are most appropriate for them. Ash Practices may gain some potential administrative advantages by enabling online services such as electronic booking and cancelling of appointments and ordering of repeat prescriptions online. This offer also states that patient account management, which includes patient demographic data, could be included. The offering document highlights the potential benefits and risks, but there will be a need for resources to fund the items that are being offered.

## 2.3 Access to online records

This could be defined as either full retrospective access or prospective access from a date that the practice sets. Both offer the patient much more information about their health status. With regard to offering Patient Online, the benefits and risks are outlined in the Defining the Offer document (see Appendix 2) and the Information Governance Risk Register (see Appendix 3).

- Prospective access would require IT systems to be able to set access from a date defined by the practice, with the offer of core medical information.
- Retrospective access has the potential to cause a significant increase in workload for practices (as records would need to be checked for third-party data, which would either need to be redacted, or consent for release sought from that third party). All care-based governmental and NHS information provided officially should not be in the third-party bracket, as it should be a principle of all care organisations to ensure that such information is cleared with the patient or service user before being passed on.
- Both types of access are associated with significant information governance risks (see the section on the functionality of GP IT systems later in this document).

### Key message to practices

One possible strategy that practices might use to gain confidence when considering Patient Online is to offer progressively more elements of access to records over the next 2 years, while monitoring workflow in practices and also, if possible, capturing patients' experiences. These include patients being offered (depending on IT functionality):

- viewing of demographic details (Ash)
- viewing of online test results after the GP has viewed them (Birch)
- core information, such as allergy status and immunisations (Birch)
- scanned or attached documents (Birch)
- viewing of information about referral letters (Birch)
- an audit trail to show who has accessed the record (Birch)
- access to all coded data with prospective free-text data (Cedar and Date).

### Key messages to the NHS CB

- The Defining the Offer Working Group is of the opinion that the component of Patient Online that refers to online records access must be prospective. This is because of the practicalities of what can be disclosed in the context of Patient Online, given the necessary checks and ensuring that the process is appropriately managed. However, ultimately this is at the discretion and judgement of the individual practice. Patients still have the legal right to view their records as stated in the Introduction.
- The professions' representatives should have the opportunity to negotiate any contract changes that refer to online access, prior to commencing implementation and delivery over 2013.

### Key messages to practices

- Learning from early adopters is important. However, the very early adopters of online access to full records may not be representative of most in general practice, but do offer considerable experience and knowledge. The Patient Online Evidence and Evaluation Group has a website (University of Surrey: [www.clininf.eu/projects/patient-access/case-study-form.html](http://www.clininf.eu/projects/patient-access/case-study-form.html)) where case studies are being collected, and this type of portal will continue to collect evidence and evaluate practices' experiences over the next 2 years.
- Exemplars of practice or practice groups should be collected through an easily identifiable portal to serve as case studies of why Patient Online may reap benefits, and to learn from practices who have offered Patient Online during 2012–2015.
- Retrospective access to patient records will require management of the information governance risks and will have workload implications for practices. Retrospective access to records should be considered in due course after practices have considered the necessary practicalities and implications. GPs may consider offering retrospective access on a case-by-case basis for patients who are likely to benefit most because of their complex case histories and/or long-term conditions. There would need to be a short delay while records are checked for third-party information.
- Over the next 2 years (2013–2015), practices could consider progressively extending the elements of the record which might be offered, in partnership with their patients.
- Evaluation of the experiences of practices over the next 2 years (2012–2014) will be important for updating practitioners and patients about the challenges and benefits of opening up access to partial or full records.

There will need to be technical capability for all functionality described to support practices.

The potential benefits of Patient Online in the management of two common long-term conditions, namely diabetes and cancer, are highlighted in Boxes 5 and 6, respectively.

**Box 5: Case study from Diabetes UK – Patient Online and care**

Without careful, continued management of their condition, a person with diabetes faces a reduction in life expectancy of between 6 and 20 years. Online access to their health records has considerable potential benefit for people with diabetes, who spend 8757 hours a year self-managing their diabetes and around 3 hours of contact time with health and social services.

Self-management means that people have to make choices and decisions about how to manage their life and their diabetes. Good self-management can improve the quality of life of people with diabetes and reduce their risk of developing complications. It can also help to prevent hospital admissions, or make those times when they do need to go into hospital, for whatever reason, a better experience, with a reduced length of stay. Access to accurate, personalised information about their condition, including test results, HBA1C status, blood pressure, cholesterol level, and risk status for foot problems, contributes to a person's ability to self-manage their condition.

Online access to health records is also likely to support shared decision making between the person with diabetes and their healthcare providers (e.g. when preparing care plans). People with diabetes report that online access provides a sense of control and empowerment, enabling them to influence their own health and make 'informed choices.' Electronic records access has the potential to increase people's feelings of trust towards their GP and, more widely, towards the health service. It stops them feeling as if they are being 'kept in the dark', 'puts them on an equal footing' with healthcare professionals, and makes them feel more included in decision making about their own health.

Online records access can act as an 'incentive' to improve one's health management. It enables people to track trends, to 'see the whole picture' and to set clear goals. Similarly, people with diabetes are reassured by the fact that the system 'holds the information that they forget', and provides clarification once they have had time to reflect on a discussion with their GP. Some people find that it adds value to the time they spend at their practice. It enables them to prepare for appointments in advance, thereby making these more productive and more valuable. Overall, the largest reported benefit of records access is its ability to save people time and to improve efficiency. People with diabetes link this to a reduction in the stress associated with communicating with their GP surgeries, and emphasise that it saves both 'effort' and 'energy', providing an 'instant fix.'

However, although people with diabetes view online records access as a big step in the right direction, many feel that current difficulties are preventing the system from reaching its full potential. On the whole, people do not think that access to records has greatly increased the quality of care that they receive. They report frustration due to the administrative and technical difficulties that they have encountered. In addition, two key areas generate anxiety, namely the misinterpretation of information, and security. People describe the 'needless worry' caused by the misunderstanding or misinterpretation of information on a record. Some have genuine concerns about security breaches, including hacking and information from their record getting into the hands of the wrong individuals (especially future employers and insurance companies). However, others report that issues relating to security do not cause them anxiety and they trust the system.

**Box 6: Case study from Cancer Research UK – breast cancer**

Consider a woman aged 42 years with known hypertension which is controlled on treatment. She has been diagnosed with left-sided breast cancer, treated by mastectomy and adjuvant chemotherapy, and completed treatment with Herceptin. She is now being treated with hormonal agents, and it is important that she retains the ability to keep a diary of adherence with and any possible side effects of endocrine and/or other therapies. She could use online access in combination with internet search engines to:

- link to lifestyle advice and information about her risks of osteoporosis
- link to information on warning signs for Herceptin-induced cardiotoxicity
- directly link to information about how to cope using online forums and local support groups (particularly in dealing with depression and anxiety related to the psychological effects of her diagnosis).

## 2.4 Secure communication with the practice

A working definition of secure asynchronous (i.e. non-live) online e-communication as stated by the Supplier and Market Liaison Group is as follows:

*The unilaterally independent process of secure online communication between clinicians and patients, facilitated by and recorded within the electronic GP record. This is the electronic messaging between the patient and the practice, the named doctor or deputy.*

It offers the patient another route for contacting the practice, and can help patients to prepare for consultations. From the patient's perspective, the benefits include saving time, and avoiding the need for travel and inappropriate visits. There will need to be a mechanism for incoming emails from any email address to secure NHS addresses, with outgoing emails from a secure NHS address.

However, there is the potential for high workload and dependences. There need to be clear guidelines on use and information governance issues, such as duty of confidentiality in accordance with the Data Protection Act 1998 and General Medical Council (GMC) guidelines. There also needs to be a clear awareness of the risk of coercion, and the need to ensure informed consent and correct patient identification – these are all paramount when dealing with inappropriate asynchronous communication.

Practices need to set up systems to send automatic messages to patients (e.g. 'message received'). They also need to consider how to enter the patient notes, and this will have workflow implications.

Automatic messages need to be displayed to warn patients that their messages cannot be answered in real time, and that urgent messages should be communicated by other routes. The Road Map group had concerns about patient safety, as some patients may not understand the distinction between asynchronous and synchronous communication, and expect a reply to a message about a medical problem that needs urgent attention. There is a need for public information about the appropriate use of e-communication. Also, there is evidence from sociological studies of older people's use of the internet<sup>17</sup> that lack of trust in this form of communication is central to the

<sup>17</sup> Sarkar U et al. Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. *Journal of the American Medical Informatics Association* 2011; 18: 318–21.

limited levels of take-up in this group; face-to-face communication engenders trust, not greater access per se, and it is the quality of communication access to a professional that is important.

- The Medical Protection Society has issued practical guidance on how to deal with emails, which serves as a useful guide for managing secure e-communication<sup>18</sup> (see Box 7).
- The recent publication of the *Social Media Highway Code* by the RCGP<sup>19</sup> illustrates and provides generic guidance on how healthcare professionals might interact with the public through the use of social media outlets, and contains helpful pointers to consider when using e-communication. Principles from the Royal College of Nursing document on text messaging can also be used.

### Key messages for practices

- Although e-communication offers the potential for convenience in terms of patient access, practice systems and procedures need to be in place to mitigate against information governance risks.
- There are concerns about capacity in practices with regard to managing asynchronous communication.

### Key messages for the NHS CB

- There needs to be negotiation around any possible contract changes between the professions' representatives and the NHS Commissioning Board before implementation in 2013, and before the delivery arm of training and support.
- There needs to be evidence and evaluation of practices with regard to the use of asynchronous secure e-communication during 2013–2015.
- Studies of e-communication and patient safety are recommended.

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<sup>18</sup> Medical Protection Society. *Communicating with Patients by Fax and Email*. Leeds: MPS; 2012. [www.medicalprotection.org/uk/england-factsheets/communicating-with-patients-by-fax-and-email](http://www.medicalprotection.org/uk/england-factsheets/communicating-with-patients-by-fax-and-email) [Accessed 12/12/12]

<sup>19</sup> Royal College of General Practitioners. *The Social Media Highway Code*. London: RCGP; 2012. [www.rcgp.org.uk/policy/rcgp-policy-areas/social-media-highway-code.aspx](http://www.rcgp.org.uk/policy/rcgp-policy-areas/social-media-highway-code.aspx) [Accessed 12/12/12]

**Box 7: Medical Protection Society factsheet, 2012****Use of email**

Email is an attractive way for patients to communicate with the practice, and the demand for such a service will undoubtedly increase over time. Safeguards are required in order to preserve patient confidentiality. Unless messages are encrypted, patients should be aware that their messages could potentially be read by a third party.

Only appropriate matters should be dealt with via email exchanges, e.g. appointment scheduling, ordering repeat prescriptions and obtaining test results. A standard protocol for email exchanges could prevent emails from patients asking for more complex information about medical symptoms or their proposed treatment, which would be difficult for the practice to respond to quickly and appropriately. It is important to ensure that all emails to and from the patient are included as part of the patient's medical record.

**It is a good idea to:**

- ensure that there are appropriate levels of encryption
- liaise with your IT provider to ensure that appropriate safeguards are in place and information on the clinical system remains secure
- have an automated response indicating that the email has been received, when the patient should expect to receive a reply, and a recommendation that they should contact the practice directly if the matter is urgent
- monitor email enquiries at regular intervals and ensure that they are promptly brought to the attention of the relevant person
- respond in a professional manner and, in particular, avoid 'text speak'
- ensure that there is a mechanism in place to deal with enquiries that arrive while you are on leave or away from the practice
- check that any email communication is from a secure NHS email address and not from a private email service provider.

**It is important not to:**

- forget that email exchanges are an important part of a patient's medical records
- underestimate the amount of work that is likely to be involved in both setting up and maintaining such a system
- forget that many of the subtleties of communication, including non-verbal cues, are lost when communicating by email
- use email to respond to complicated or difficult problems
- forget to set aside some time in the working day to respond to email enquiries
- forget to have robust procedures in place to follow up any matters that arise from an email exchange.

## 2.5 What could be done now: consider the information governance and security risks

This section should be read in conjunction with the Information Governance Risk Register (see Appendix 3), which provides a comprehensive account of the important issues faced by practices that might affect their patients. Provided that the 'on/off switch' for online access lies with the practice, many risks can be mitigated.

This section is also intrinsically linked with definition of the offering, and with the support, training and education needs of practices which are discussed in more detail in Section 3. Practices are encouraged to review the Information Governance Risk Register. It may be useful to recommend that practices also review aspects of this with their practice patient participation groups, in order to develop an accurate view of what patients perceive the main risks to be.

There are five predominant risk titles that are considered within the Information Governance Risk Register, each of which has a vulnerability defined, mitigation explored with notes, and an inherent risk score calculated (based on the product of likelihood and impact), together with mitigating controls.

The guidance in the risk register covers, in particular, the high-risk issues identified under each of the five risk titles, together with an attempt to provide mitigating control. The mitigations have been produced in liaison with the Caldicott Information Governance Review. These issues are summarised in Box 8.

### Box 8: Summary of high-risk issues from the Information Governance Risk Register

Risk title	High-risk issue	Mitigating control
Identity management	Need for education and training within practices on identifying management and defining processes	An education and training strategy (2013 onwards)
Third-party data <sup>21</sup>	The need to define solutions for entries that contain third-party data	Offering coded entries, marking third-party data and filtering defined extracts (by September 2013). Liaison with the Caldicott Information Governance Review
Consent management	Risks to patient records in sharing access with others	Mandate system requirements through GPSoC to allow monitoring (2013 onwards)
System and data security	Clinicians may not know who has online access	A requirement for GP systems to specify which records have Patient Online enabled (2013 onwards)
Safe record-keeping guidance	Inconsistent guidance on access by health or social care services when sharing records	Coordinated and authoritative guidance through the Caldicott Review (2012–2013)

<sup>21</sup> Department of Health, Caldicott Review. *Information: to share or not to share? Information Governance Review*. London: DH; 2012. [www.caldicott2.dh.gov.uk](http://www.caldicott2.dh.gov.uk) [Accessed 12/12/12]



Clearly some practices have taken a pragmatic approach, and instead of waiting for a national IT solution for identity management they use standard methods of verifying identification (e.g. passport photo, utility bill with full name and address) before issuing a password to enable online access. Other solutions may need to be developed, such as filtering of third-party data.<sup>22</sup>

Dependencies also include awaiting guidance on sharing of records from the current Caldicott Information Governance Review, and the development of new system functional requirements. Finally, even when mitigating against risk, it must be made clear that some high risks remain, as in the case of coercion, particularly in the setting of domestic abuse (see Box 9).

The British Computer Society and the DH have produced guidance on safe record keeping by patients. Their document *Keeping Your Health and Social Care Records Safe and Secure*<sup>23</sup> will be of value to patients when handling the information they may receive.

### Key messages to practices

- Practices should read the Information Governance Risk Register and review within practice meetings what risks may be pertinent or relevant to their practice population and IT system (2012 onwards).
- The RCGP 2010 guidance on enabling access (which covers children, relatives, carers, advocates, people who lack mental capacity, and situations where there are family disputes) is useful and very relevant.<sup>24</sup>
- Both the definition of the offering and in particular the Information Governance Risk Register consider risks to children, patients who have carers and those who are victims of coercion.
- Mitigation against coercion may not have a clear solution. Domestic violence and cyberstalking by the abuser are particularly prevalent issues, and communications with Professor Gene Feder, RCGP Clinical Champion for Domestic Violence, have highlighted such issues (see Box 9).

<sup>22</sup> Care-based governmental and NHS information provided officially may not be in the third-party bracket, as it should be a principle of all care organisations to ensure that such information is cleared with the patient or service user before it is passed on.

<sup>23</sup> Department of Health and British Computer Society. *Keeping your Health and Social Care Records Safe and Secure*, London: DH and BCS Health; 2013. [www.bcs.org/upload/pdf/social-care-records.pdf](http://www.bcs.org/upload/pdf/social-care-records.pdf) [Accessed 12/12/12]

<sup>24</sup> Royal College of General Practitioners. *Enabling Patients to Access Electronic Health Records: guidance for health professionals*. London: RCGP; 2010. [www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/~media/Files/CIRC/Health%20Informatics%20Report.ashx](http://www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/~media/Files/CIRC/Health%20Informatics%20Report.ashx) [Accessed 12/12/12]

### Box 9: Important principles relating to domestic violence

The British Crime Survey (BCS) findings of stalking prevalence (highest estimate: 22% lifetime, 7% in the past year) give a 5.5% lifetime risk of interference with online medical records by a partner, and a 1.75% annual risk.

Ask every patient if there might be someone else accessing their record if they are offered online access. If this is the case, do not grant access, and switch off access if it has already been granted.

Consider the potential for abusive family members to gain access via coercion or deception, thereby increasing their control over the patient's health.

There is a need for clinicians to be aware of digital stalking, harassment and coercion as tools of domestic abuse. Practices should have systems and named individuals in place that support staff when coercion is suspected.

There is a need to disguise domestic violence codes, as in the Identification and Referral to Improve Safety (IRIS) programme.<sup>25</sup>

Domestic violence training that highlights the need for communication between domestic violence agencies is needed. Multi-agency risk assessment conferences and general practice will lead to sensitive letters on records.

Excluding any records of domestic abuse and/or violence from the accessible record is a partial solution when victims disclose such behaviour. However, this would have to be automatic, otherwise the clinician might fail to remember. Moreover, such an approach cannot address that risk when the clinician is ignorant of the abuse because it has not been disclosed.

Further guidance can be found at:  
[www.caada.org.uk/dvservices/CAADA\\_GP\\_guidance\\_manual\\_FINAL.pdf](http://www.caada.org.uk/dvservices/CAADA_GP_guidance_manual_FINAL.pdf)

The RCGP Health Inequalities Group has commented and provided feedback on the definition of the offering, and the Information Governance Risk Register products, and these have been incorporated within the relevant documents and in this Road Map. Similarly, members of the RCGP Ethics Committee have provided comments, and these have been considered from the ethical perspective of online access, alongside the pragmatic considerations. The Medical Protection Society (see Boxes 10 and 11) and the Medical Defence Union have provided some useful principles.

<sup>25</sup> Feder G, Davies RA, Baird K et al. Identification and Referral to Improve Safety (IRIS) of women experiencing domestic violence with a primary care training and support programme: a cluster randomised controlled trial. *Lancet* 2011; 378(9805): 1788–95.

### Box 10: Important principles from the Medical Protection Society (abridged letter)

Information can be used to support communication, improve knowledge and promote shared decision making/support informed choice.

1. Are patients sufficiently aware of the risks to their confidentiality that they themselves might pose? There is a need for understanding and skills.
2. The implications of patients being able to routinely add to their medical records should be carefully considered. How should this be recorded in the records and responded to?
3. Patients may also wish to routinely correspond electronically with their doctor. We need to ensure patients realise that such communications do not happen in 'real time' and can be subject to unpredictable delay, and that they are aware of realistic timeframes for a response. There should be safeguards in place to ensure that patients with urgent problems do not use these routine communication channels.
4. There are particular patient groups and types of information which may necessitate restrictions on access by default. There are issues in mental health, sexual health, child protection and counselling which may require a data controller to consider proactively whether information should be accessible by the patient.
5. Greater patient access to medical records will also have an impact on how those records are generated, and possibly how useful they are. It will be a significant cultural change for clinicians to use patient-appropriate language in records. Medical records will essentially be written for a different audience, as clinicians will have to consider the need to inform and reassure patients, otherwise greater patient use of their records may lead to an increase in consultations to explain records to worried patients. The utility of records may also be adversely affected. Accommodating patients' legitimate desire for routine access to their records should not divert attention from this primary purpose.
6. There is an appropriate expectation that patients will be able to identify mistakes in their records, but this may raise unrealistic expectations about the nature and extent of changes to the records available to patients. This could also lead to conflict between patient and doctor.
7. There should be greater clarity about what third-party information in medical records actually is, as well as how it should be stored and when it should be redacted or disclosed.

**Box 11: Letter from the Medical Defence Union – principles****Possible medico-legal advantages: prescription errors, test results and follow-up**

Online access allows a check that the drug name, dosage and instructions on the record are consistent with the drug prescribed. Patient electronic records may help with identifying problems such as drug allergies or interactions. Problems can also arise if test results are not noted in the records, or if a patient follow-up is missed and it may help to prevent some problems of this nature arising if patients are able to check their own records, but this will always remain the responsibility of the doctor.

**Clear communication**

It is suggested that patient-held records may aid clear communication. However, for them to have the most benefit, patients would need to be able to understand the contents.

**Will access be read-only?**

If patients have read-only access, this is less likely to present medico-legal difficulties that might arise if the records were amended by someone other than the treating doctor(s)/healthcare professional. Patients would still need a facility to comment on any factual inaccuracies or to question the content of the records and to seek amendment (as is their right under DPA legislation) but any corrections/amendments would need agreement from and remain the responsibility of the doctors who created the records. This is preferable (medico-legally) because the records may be required at a later date for evidential purposes, for example, if litigation or complaints arise. They must be a complete and accurate record and only the doctor should be able to alter/correct or amend the records.

**Will records be portable?**

If it is intended that records are portable (either electronically or paper records) this can give rise to medico-legal problems in ensuring that the version the patient has is up-to-date and has not been amended, changed or updated since it was provided to the patient.

**Will access be only prospective or retrospective?**

Retrospective access has the potential to create a number of difficulties medico-legally and especially in terms of third party data. At present, when a subject access request is made under the Data Protection Act 1998 (DPA), the records are scrutinised to ensure third party data is not improperly disclosed. This is a time-consuming process for GPs, even at present, but we think it would become all-consuming if there was a plan to grant retrospective access to records. We do not think it would be possible for GPs to undertake the necessary level of scrutiny on all past records before they were made available.

In respect of third-party and sensitive personal data that may be excluded from records under the DPA, if access were given prospectively, it would be necessary to consider how this could be done most effectively. One option may be to use a 'sealed-envelope' system for certain types of records, for example, mental health records or child protection records, so that it is clear in advance that additional scrutiny of this information may be required before routine patient access.

**How reliable are the records?**

The question of the reliability of the records arises in a number of the scenarios above. It is also seen in the context of information (information about third parties or correspondence with other clinicians for example) that is withheld from the records, but which may be material to any other clinician who may be asked to rely on the record handed to them by a patient. There will need to be a way of indicating that information has been withheld (properly under the DPA) so that any other treating clinician is aware the record is incomplete and, if he, or she, needed to see it, would have to access from the GP responsible for the record.

## 2.6 The functionality of GP IT systems: the present and the future, market liaison

Individual practices are currently able to utilise a GP system of their own choice through GPsOC or LSP contracting mechanisms. The current systems that provide Patient Online are not directly specified within existing contracting requirements.

For the purposes of consistency, a Patient Online general practice systems supplier is defined as *current or future suppliers of GP systems that can or will need to make patient data securely available online*.

Each of the systems varies with regard to what it offers as or under online access. Future work will include market liaison, through industry representatives such as Intellect, to monitor progress in market development. The Information Governance Working Group has highlighted the need to mandate Patient Online through GPsOC, or its equivalent, to allow patients to move between practices in the knowledge that what they are offered will be comparable but not automatically set, so that a discussion should ensue on its appropriateness. Therefore, for safety reasons, passwords should not be transferred automatically when a patient moves practice, but must be re-established so that a dialogue and discussion take place between the patient and the new practice.

### Key message to the NHS CB

- There must be commonality between systems and services when patients move practices, which require mandating through GPsOC or other mechanisms, from 2013 onwards.

GP systems suppliers would need to provide many functional options that will give practices flexibility in what they can offer. Some of these are listed in Box 12. The Supplier and Market Liaison Group is mapping out which functional requirements are available now and which need to be developed.

**Box 12: Exemplar functionality to support online access****What should be available through all current systems:**

- Patient Online disabled by default, set and reset username and password
- Appointment booking, cancelling, repeat medication ordering
- Access to test results
- Messaging to the practice and back to the patient
- Access to the record, partial records access, prospectively and retrospectively

**What could be developed (between 2013 and 2014):****Key message for GPSoC/LSP/IT commissioners:**

These requirements should be mandated through contractual mechanisms, which include monitoring, specifically in areas that are required to be consistent across suppliers, and there should be review of such requirements as they are generated.

- Identity management and patient authentication
- Setting of functionality on offer
- Facility for monitoring by clinicians of who has shared access to records
- A sensitive data exclusion facility that enables the practice to restrict patient access to certain data
- A sensitive data exclusion facility that enables the patient to restrict the availability of certain information to others when sharing the record
- An exclusion facility for information prior to a defined date
- The availability of an audit trail showing who has viewed the record
- A facility that enables the patient to annotate and/or add comments to the record
- A system that can incorporate 'help pages' and guidance from practice or other sources
- Security questions set up for password resets

In order to support practices, Intellect has stated that it will encourage GP suppliers to offer guidance to practices. This will allow practices to consider what functionality their IT system currently possesses to match against any offering.

The Supplier and Market Liaison Working Group will continue its evaluation and review of current and future planned or provisional capacity over 2013, and this will help to inform practices.

The NHS CB should encourage innovation, diversity and development by all current and future suppliers of products in order to offer expanding choice, value and convenience to patients and carers from online services linked to general practice from 2013 onwards.

To enable this transition, there need to be mechanisms in place through the NHS procurement process that will incentivise market developers to produce business plans which lead to innovative and usable products. Engagement with GPSoC, the current scheme through which the NHS funds the provision of GP clinical IT systems in England (or its equivalent), is of paramount importance to prevent inherent delays in translation and implementation.

## Key message to the NHS CB

- In order to expedite innovation and translation, NHS procurement of GP IT systems needs to be responsive and agile, to encourage market development (from 2012 onwards).

## Key messages for system delivery

- Functionality to set and reset username and password is needed, through an administrative process that provides a secure authentication procedure (from 2013 onwards).
- Features that support all of the offerings are required (from 2013 onwards).
- The facility is needed for an audit trail that both allows the patient to see who has accessed the record, and enables the practice to audit its own system (e.g. how many patients are registered, how many patients are registered and users, how many patients are registered and non-users) (from 2013 onwards).
- The ability to set different levels of access rights is needed (from 2013 onwards).
- To prevent exacerbation of health inequalities, it is recommended that national standards and legal requirements for online accessibility should be adhered to, both with regard to the design of Patient Online Access websites and for the process of obtaining authentication and login materials from the practice (from 2013 onwards).
- System designs, developed and supported through funding mechanisms, that allow secure communication between patients and their practice should be in place (from 2013 onwards).

The opening of the market may lead to innovative products, which might include mobile applications and portals that could be integrated with other facilities, such as support for a long-term condition (e.g. diabetes or cancer). These could be supported by the development of sustainable modular and generic programming interfaces. With the discussions around the new contract for GPSoC, and the link with the IT strategy paper, it is likely that 2013 will see more and better products being developed.

The Supplier and Market Liaison Working Group considered three topic-specific areas that will directly affect both practices and patients. These are:

- risks cited by the supplier community
- patient-centric system design principles
- current or future data standards.

## 2.7 Risks cited by the supplier community

Making the assumption that general practices could meet the targets set around Patient Online means that there is a dependency on IT support, and particularly on the general practice suppliers.

General practices need to have an awareness of the potential risks that suppliers face. In discussions with the Supplier and Market Liaison Working Group, three types of risks have been cited by the suppliers, namely general risks and risks specifically to current suppliers and future suppliers.

The signal by the Government that by 2015 all practices should offer Patient Online should be a stimulus to encourage innovation, diversity and development, with a provision for meeting practice requirements. There are mass market opportunities that could open up, depending on the national decisions that are taken. For example, stimulation of an 'apps' market may develop with commissioning or pump prime open-source development, or through innovation awards.

Whatever systems are in place, they will require support services for practices as well as local and national leadership. The importance of data standards and platforms that enable innovation, as well



as reliability and security, remains paramount. The NHS will not work without structured records. Professions need to use the language that is meaningful to them while supporting the health record data structures.

## 2.8 Patient-centric system design principles

The message here for practices is that there is an opportunity for both current and future suppliers to design products not only with the clinician perspective at the heart of design, but also with the involvement of the user in the design as well as the implementation phase. This includes individuals or populations who might be disadvantaged by new technology, such as older, disabled patients, or those who do not speak English. This benefit would be a key pointer and measure of successful delivery for many patient groups. This was highlighted in particular by patient representatives in the Supplier and Market Liaison Working Group.

It is important to take into account patients with disabilities (e.g. visual impairment). The key messages for designers that emerged from these groups include the following:

- involving the end user at every stage, from product design, through implementation and testing, to post-launch maintenance
- knowing the range of alternative formats typically required, and the basic principles for their production
- exploring the free assistive technologies both as a test of basic system accessibility, and as an indicator of what disabled people may be experiencing in real life
- One Voice and Intellect having the opportunity to work together if accessibility is to be delivered for all groups across all platforms. One Voice Coalition for Accessible ICT (One Voice) is a consortium of charities and major IT companies. One Voice can provide advice on accessibility across multiple disabilities and technologies
- knowing that the Office for Disability Issues has advice on document accessibility, venues and language<sup>26</sup>
- HM Revenue & Customs also provides a model for alternative format production, which is available on request to any customer<sup>27</sup>
- knowing about the Cabinet Office and cross-government access for citizens.<sup>28</sup>

### Key message for system delivery

General practice computer systems suppliers should work with new entrants in 2013 when making the user interfaces for patients generic and transferable between systems, and able to cater for disabled groups.

### Key message for the NHS CB

- The NHS CB, when it commissions new products, should sponsor or advocate patient-centric design.

<sup>26</sup> Office for Disability Issues. *Alternative Formats: making your communications more accessible*. [odi.dwp.gov.uk/inclusive-communications/alternative-formats.php](http://odi.dwp.gov.uk/inclusive-communications/alternative-formats.php) [Accessed 12/12/12]

<sup>27</sup> HM Revenue & Customs. *HMRC Services for Customers with Particular Needs*. [www.hmrc.gov.uk/contactus/particular-needs.htm](http://www.hmrc.gov.uk/contactus/particular-needs.htm) [Accessed 12/12/12]

<sup>28</sup> Cabinet Office. *Government ICT Strategy*. [www.cabinetoffice.gov.uk/content/government-ict-strategy](http://www.cabinetoffice.gov.uk/content/government-ict-strategy) [Accessed 12/12/12]

## 2.9 Current or future data standards

It is important to ensure that Patient Online implementation supports good security and information governance practice. Also of prime importance to practices will be the utilisation of meaningful language through structured records and less use of narrative.

The Supplier and Market Liaison Group highlighted the need for data standards to facilitate an innovative approach to the process of Patient Online. Standards described by the group were concerned either with allowing user functionality or with content/professional standards.

### Allowing user functionality

This concerns the way in which information is represented and how particular functions are executed. For example, it includes ensuring that the patient experience of Patient Online is similar, irrespective of the underlying system providing the services. This makes the transition from one system to another easier when a patient moves practice, or when a practice switches systems. GPSoC will turn functional requirements into a specification, and the supplier then decides how to implement this. Another example is the development of standards and interface mechanisms so that third parties can integrate online access into apps, portals and other products and services with ease of navigation. Data standards that support direct care must be used.

### Content/professional standards

This concerns the actual information content and which functions are supported and are likely to be domain specific. A good example is the work of the Royal College of Physicians in standardising medical records.<sup>29</sup> Having a common extract of records for patients, which is easy to understand, will be of value, but not at the expense of lowering the quality of the medical record.

To achieve the understanding of healthcare records by patients will require time and investment. The British Computer Society and the DH have produced guidance on safe record keeping by patients.<sup>30</sup> London Connect has also produced guidance for patients entitled 'It's your record: a guide to accessing health records online.'<sup>31</sup>

It is also important to learn from other exemplars of online portals:

- The South London and Maudsley Foundation NHS Trust (SLAM) provides a service called 'MyHealthLocker', which uses patient-controlled records to promote self-management.<sup>32</sup>
- Renal PatientView, which is facilitated through NHS Kidney Care, serves to empower renal patients through online access to their test results.<sup>33</sup>
- My Diabetes My Way uses a shared record scheme (primary and secondary care) for patients with diabetes in Scotland.<sup>34</sup> Ensuring that record access implementations support good security and information governance practice and the use of meaningful language through structured records, with less use of narrative, is likely to be of prime importance to practices.
- Cancer Research UK has plans to create a portal to offer cancer patients supported, secure online access to their cancer records across the patient pathway.

<sup>29</sup> Royal College of Physicians. *Generic Medical Record Keeping Standards*. London: RCP; 2007. [www.rcplondon.ac.uk/resources/generic-medical-record-keeping-standards](http://www.rcplondon.ac.uk/resources/generic-medical-record-keeping-standards) [Accessed 12/12/12]

<sup>30</sup> British Computer Society and the Department of Health. *Guidance on Safe Record Keeping by Patients*. London: BCS and DH. [www.bcs.org/content/conWebDoc/43313](http://www.bcs.org/content/conWebDoc/43313) [Accessed 12/12/12]

<sup>31</sup> [www.myhealth.london.nhs.uk/sites/default/files/u3246/ItsYourRecord.pdf](http://www.myhealth.london.nhs.uk/sites/default/files/u3246/ItsYourRecord.pdf)

<sup>32</sup> [www.ehi.co.uk/news/ehi/8168/myhealthlocker-works-to-engage-patients](http://www.ehi.co.uk/news/ehi/8168/myhealthlocker-works-to-engage-patients) [Accessed 12/12/12]

<sup>33</sup> [www.kidneycare.nhs.uk/our\\_work\\_programmes/empowering\\_patients/renal\\_patient\\_view](http://www.kidneycare.nhs.uk/our_work_programmes/empowering_patients/renal_patient_view) [Accessed 12/12/12]

<sup>34</sup> [www.mydiabetesmyway.scot.nhs.uk/diabetes/MDMW\\_Year\\_1\\_Evaluation\\_v1\\_1.pdf](http://www.mydiabetesmyway.scot.nhs.uk/diabetes/MDMW_Year_1_Evaluation_v1_1.pdf) [Accessed 12/12/12]

## 3.0 What needs to be developed?

The input and recommendations from the Support, Training and Education Working Group highlight the importance of, and evidence for, adopting a socio-technical approach. Practices, in partnership with their patients, will need to focus first and foremost on planning for the appropriate organisational changes that will support Patient Online and bring most benefit. Patient Online cannot just be switched on without due consideration of the necessary organisational changes. The key principles that have emerged from the Definition of the Offer Working Group and the Information Governance Risk Register will form the platform on which the needs of practices will be identified and addressed.

### 3.1 Training, education and development support for general practices, primary healthcare teams, patients, carers and advocates

The primary aims of the Support, Training and Education Working Group were as follows:

- to identify existing sources of training and support that can assist and support general practices, patients, carers and advocates in utilising online access most effectively
- to recommend what and how future resources should be developed to ensure the successful implementation of Patient Online access to records and services by 2015.

Their focus was to ensure that the following criteria were met.

#### **Practices and primary healthcare team members have access to:**

- practical guidance to help them best identify, target and interest patients who are likely to benefit most from Patient Online access
- RCGP-approved guidance to address all of the key challenges, supported by toolkits and any necessary CPD learning modules and other training that is relevant to GPs, practice managers, practice nurses, receptionists and all members of the primary healthcare team
- appropriate IT training and additional support from GP systems suppliers
- accessible standards to ensure that information in patients' primary health records is recorded and shared in an open but safe manner
- appropriate training, education and development support that can be commissioned, delivered and maintained in all practices during implementation, and sustained beyond this.

#### **Patients, carers and advocates have access to:**

- practical, relevant and accessible information and other supporting materials tailored to specific needs and conditions to enable them to make best use of online access to records and services
- sources of technical support if they have a problem accessing the services that they need online
- support that meets the needs of potentially disadvantaged groups and overcomes challenges such as, for example, not having home internet access, not having English as their first language, etc.
- advice and information that help them to look after any copies of their records that they keep for themselves, and to share these safely with trusted third parties.

The group's recommendations also identified the levels of support, types of training and range of resources that could be offered by the RCGP (from 2013 onwards) and other suppliers, and how these could be commissioned in partnership with other bodies, including Health Education England

and the NHS Commissioning Board (from 2013 onwards). The expertise of the British Computer Society (health) will be sought.

The group also recommended guidance for patients, carers and advocates, with a focus on ensuring practical support materials that are resourced and designed, developed and delivered in partnership with key patient and carer groups, both within the RCGP (e.g. the RCGP Patient Partnership Group), and with key partners such as the National Association for Patient Participation (NAPP), the BMA's Patient Representation Group, the Royal National Institute of Blind People (RNIB), Cancer Research UK, Diabetes UK and Age UK. The aim is to ensure that the needs of disadvantaged groups and of patients with long-term conditions are given the highest priority (from 2013 onwards).

The working group cited seven key principles in their recommendations that underpin the necessary training, education and support needed.

1. Usability is the key goal.
2. Practices and patients should be provided with a range of choices, resources (including e-learning) and approaches that they can adapt to their local circumstances.
3. Proposals should, wherever possible, build on what already exists rather than starting from a blank sheet.
4. Recommendations should build on the lessons that have been learned from similar initiatives within primary care, such as Access and Responsiveness, Choose and Book, and the Directed Enhanced Service (DES) to facilitate information management and technology (IM&T) adoption to support the delivery of the National IT agenda to support health and social care..
5. Peer-to-peer learning is an integral part of any learning approach, and protected time for such learning must be factored into any future roll-out.
6. Products should have a systematic process to ensure that they are reviewed and updated in line with developments in policy and practice.
7. Patient Online needs to be carefully implemented in the light of resource and clinical priorities. It must be funded and not be prioritised over a patient's clinical care and safety.

As is evident from the baseline figures in the Introduction, there are challenges ahead in terms of providing time for practices and representative patient groups to plan how best to implement Patient Online, and to develop and deliver the necessary underpinning training and educational support.<sup>35</sup> It is also important to ensure that there are adequate resources to support training in transactional services, as there is significant variation with regard to how these services are used. Also of importance are the lessons learned from previous IT projects, such as the Summary Care Record and HealthSpace programmes.<sup>36</sup>

However, if undertaken according to the socio-technical principles outlined above, it will hopefully yield benefits for both patients and practices. The needs of different professional groups should be considered, and there will be a wide range of competence in the use of IT. Provision of protected time for training is very important. In the Royal College of Nursing eHealth 2012 survey,<sup>37</sup> 77% of the respondents stated that lack of protected time for IT training was a barrier, and 62% said that they would need extra training in order to help a patient to use a personal health record, computer, or other information and communications technology (ICT). The target population for training and education needs to explicitly include community staff.

As Phase 3 of this project develops, a web portal will be set up that will collate the resources identified and highlight initiatives around Patient Online.

<sup>35</sup> *Learning to Manage Health Information: a theme for clinical education 2012. Making a difference.* [www.cln.nhs.uk/eice/images/learningtomanage\\_12.pdf](http://www.cln.nhs.uk/eice/images/learningtomanage_12.pdf)

<sup>36</sup> Greenhalgh T, Stramer K, Bratan T et al. *The Devil's in the Detail: final report of the independent evaluation of the Summary Care Record and HealthSpace programmes.* London: University College London; 2010. [www.ucl.ac.uk/news/scriefullreport.pdf](http://www.ucl.ac.uk/news/scriefullreport.pdf)

<sup>37</sup> [www.rcn.org.uk/\\_data/assets/pdf\\_file/0005/391109/004115.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0005/391109/004115.pdf) [Accessed 12/12/12]

## Key messages relating to support, training and education

- The RCGP should work with patient partnership groups and other stakeholders (e.g. the Royal College of Nursing) to support the development and hosting of a range of relevant learning and communication materials. Suggested topics for exploration are listed in Box 13.
- Bodies such as the National Association for Patient Participation (NAPP), the RCGP's Patient Partnership Group and Standing Commission on Carers, and the BMA's Patient Liaison Group are recommended as the key umbrella partners for this support, in addition to the condition-specific support from patient and carer representative groups such as Cancer Research UK, Diabetes UK, Age UK and the RNIB, during 2013–2014.

The online systems of general practice systems suppliers must be as intuitive as possible for patients. In addition to the planning and delivery of effective systems of support, along with systems training, the advice and guidance of the relevant user groups is key during 2013–2014. Those practices that are addressing some of the main issues relating to Patient Online are likely to be considering some of the following key points and clinical and educational themes (described in Box 13):

- issues relating to security and confidentiality
- enabling patients to understand how to use their records, data and information<sup>38</sup>
- issues relating to consent and protection of sensitive data, such as third-party data
- equality issues – that is, identifying vulnerable or disadvantaged patients, particularly those who are at risk of coercion.

### Box 13: Specific exemplar themes and educational topics

- **Child protection:** how to record cause for concern<sup>39</sup> and the basis of any decision making, as well as recording of interactions with health visitors, social care and hospital colleagues.
- **Adult safeguarding:** early recognition of coercion, and what to do if coercion is suspected.<sup>40, 41</sup>
- **Access and consent:** access by adolescents to their records, denying parents access to their children's records, and issues relating to Fraser competency and consent.
- **Disagreements:** how to manage disagreements about the record entry and diagnosis with the patient.
- **Requests for access:** how to advise patients on requests for access from insurance companies, solicitors, the police and employers.<sup>42</sup>
- **Special groups:** recording of information around managing special groups, such as medical records of adopted children, and the disclosure or restriction of information about individuals where the Human Fertilisation and Embryology (Disclosure of Information) Act 1992 applies.

<sup>38</sup> Royal College of General Practitioners. *Enabling Patients to Access Electronic Health Records: guidance for health professionals*. London: RCGP; 2010. [www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/~media/Files/CIRC/Health%20Informatics%20Report.aspx](http://www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/~media/Files/CIRC/Health%20Informatics%20Report.aspx) [Accessed 12/12/12]

<sup>39</sup> Woodman J, Allister J, Rafi I et al. A simple approach to improve recording of concerns about child maltreatment in primary care records: developing a quality improvement intervention. *British Journal of General Practice* 2012; 62: e478–86.

<sup>40</sup> [www.rcgp.org.uk/clinical-and-research/clinical-resources/domestic-violence.aspx](http://www.rcgp.org.uk/clinical-and-research/clinical-resources/domestic-violence.aspx) [Accessed 12/12/12]

<sup>41</sup> Womens Aid. *Keeping Yourself Safe*. [www.womensaid.org.uk/page.asp?section=00010001000800010001](http://www.womensaid.org.uk/page.asp?section=00010001000800010001)

<sup>42</sup> British Computer Society and the Department of Health. *Guidance on Safe Record Keeping by Patients*. London: BCIS and DH. [www.bcs.org/content/conWebDoc/43313](http://www.bcs.org/content/conWebDoc/43313) [Accessed 12/12/12]

## 3.2 Issues relating to health inequalities

The RCGP Health Inequalities Group has highlighted key health inequalities issues which may arise as a result of Patient Online, and which therefore need to be considered. This will be particularly relevant over the next 2 years, when there is an opportunity to study the impact of offering Patient Online to specific groups of potentially disadvantaged patients.

### The key principles for consideration

1. Certain groups of individuals are likely to be relatively disadvantaged by Patient Online.
2. Certain groups may need to be protected and specific arrangements made for them.
3. There may be opportunities for Patient Online to help to address health inequalities.
4. There may be unintended consequences of using Patient Online.

### Certain groups of individuals are likely to be relatively disadvantaged by Patient Online

It is recognised that there is a digital divide in terms of access to internet services and ownership of technology. Affected individuals and disadvantaged social groups<sup>43</sup> are at risk of being marginalised unless efforts are made to identify them and intervene. This includes people who are visually impaired and those who do not have easy access to the internet, including older people, those lacking mental capacity, those living in care homes or nursing homes, those living in areas where the internet connection is slow, people who are homeless and those living in poverty. Individuals who need to access public IT (e.g. in libraries) must ensure that health information is kept confidential, and a reliance on family or friends again raises the issue of confidentiality.

eHealth literacy (defined as the ability of people to use information technologies to improve or enable health and health care) is relevant to people with poor literacy skills, who currently rely on administrative staff to navigate information on their behalf. This also includes people who are not fluent in English.<sup>44</sup> However, the level of health literacy in the general population is low, with 43% of people aged between 16 and 65 years unable to effectively understand and use everyday health information, as shown by research and data from the Government's 2011 national skills survey.<sup>45</sup>

### Certain groups may need to be protected and specific arrangements made for them

There has already been discussion in the Information Governance Risk Register and the Definition of the Offer about setting different layers of access if carers are involved, and this is reiterated for people lacking mental capacity. How should their guardians gain access? How can mechanisms be put in place to ensure that access to records is not being given to surrogates inappropriately? Agreement to access and monitoring of access layers will need to remain a dynamic process and be agreed for people who normally rely on the support of family members or other carers (including paid professionals, such as accommodation support workers) to access services.

<sup>43</sup> Neter E and Brainin E. eHealth literacy: extending the digital divide to the realm of health information. *Journal of Medical Internet Research* 2012; 14: e19.

<sup>44</sup> [www.healthliteracy.org.uk/seminar-presentations-to-download](http://www.healthliteracy.org.uk/seminar-presentations-to-download) [Accessed 12/12/12]

<sup>45</sup> London South Bank University. *New research by LSBU academic reveals health information is too complicated*. Online news article posted 6 December 2012. [www.lsbu.ac.uk/news-php/news.php?newsid=772](http://www.lsbu.ac.uk/news-php/news.php?newsid=772) [Accessed 12/12/12]



However, there must be an acceptance that some individuals and families with multiple problems, whose level of engagement with scheduled care is poor and who currently struggle to forward-plan appointments, will engage more effectively with drop-in services or assertive outreach contacts. It is important that this health service resource remains prioritised for these patients' families and for the practices that require it.

### **There may be opportunities for Patient Online to help to address health inequalities**

Patient Online could potentially free up phone-line and administrative resources to target support for patients who need additional support to gain access. The challenge for primary care and the wider NHS is to ensure that a two-tier and potentially stigmatising system is not established, or at the very least that the risk of this is minimised. Paradoxically, Patient Online may lead to claims of inequity of access if there is a perception that it is given priority. There will be an important need for the provision of wide public engagement, including public information leaflets. Information provided in alternative formats, such as Braille, or the use of software designed to aid the visually impaired, will be important. Patients who do not speak English may be able to understand their care better by using translation software on their record, or by having a friend or relative interpret their record for them.

### **There may be unintended consequences of using Patient Online**

Practices that look after people who have difficulty accessing records, or those in deprived areas, could be further disadvantaged. Although Patient Online may free up administrative time, it is possible that routine tasks, such as making an appointment or ordering prescriptions, may become more difficult, especially for these groups. Thus the engagement of patients who could be considered 'hard to reach' might become even harder. Practices would need to mitigate this through recognition, education and training of staff and monitoring of workflow processes.

### **Key messages relating to health inequalities**

- The use of IT to improve or enable health and health care must be viewed alongside the effect of a digital divide and lack of eHealth literacy in disadvantaged social groups, which could lead to a widening of social inequalities. Tools, studies and research findings relating to health and eHealth literacy should be gathered during 2013–2015 to inform this issue.
- Evaluation of the impact of Patient Online must include an assessment of socially disadvantaged groups and involve the RCGP Health Inequalities Group and the RCGP Learning Disabilities Group, in collaboration and partnership with patient groups during 2013–2015.
- Public information about what Patient Online may involve and its implications will be of paramount importance, and will need to involve the voluntary sector as well as links between commissioning groups and their local population, ideally in association with local patient groups.

## 4.0 Evidence and evaluation

The Evidence and Evaluation Working Group is currently conducting a systematic review of the impact of online access on workload and quality of care and has been collecting case studies that will help to inform this work.

The working group has explored the evidence for benefit or harm for patients having online access to their records – i.e. to view and comment on their medical records and also from the provision of transactional services. Transactional services include the provision of online facilities to order repeat prescriptions, book appointments, and view test results.

The group will be publishing its findings in mid 2013. The protocol for the review is in press.<sup>46</sup>

### Progress with the current review

This protocol has been submitted for publication and has been registered with PROSPERO (International Prospective Register of Systematic Reviews).<sup>47</sup> Reviewers with appropriate training and expertise have volunteered to conduct the review. The review team has completed around 50% of the papers requiring review.

### Scope of the evidence identified

Searches of eleven bibliographic databases have been conducted to identify evidence in response to four key questions:

**Key Question 1:** What is the association between online patient access to their electronic health record (EHR) and utilisation of health care, health outcomes (including patient safety), patient experience and satisfaction, and adherence, equity and efficiency?

To date there is only limited evidence in terms of benefits, and no evidence in terms of harm.

Much of the evidence has looked at patients' attitudes prior to the implementation of online access, envisaging how records might be used, what benefits they might have, and the potential downsides in terms of workflow, workload and risks to privacy. Apart from small case studies by advocates of patient access, there have been few studies showing unequivocal benefit. There is evidence that a minority of patients make use of records access when this is provided, with modest implications for the workload of physicians. Perhaps unsurprisingly, there may be inequity with regard to taking up online access.

**Key Question 2:** What is the association between online patient access to transactional services provided as part of their ambulatory care EHR and utilisation of health care, health outcomes (including patient safety), patient experience and satisfaction, and adherence, equity and efficiency?

<sup>46</sup> Mold F, Ellis B, de Lusignan S, Sheikh A, Wyatt JC, et al.. The provision and impact of online patient access to their electronic health records (EHR) and transactional services on the quality and safety of health care: systematic review protocol. *Accepted for publication Informatics in Primary Care*. 2013.

<sup>47</sup> PROSPERO Registration Number: CRD42012003091



Here most of the evidence relates to the use of specific technologies, or programmes such as prevention and immunisation, or looking for medication errors. Email and short messaging services (SMS) are examples of technologies that have been used effectively. There are some trials, but generally the evidence is relatively scarce. However, use of health information is not without its problems in terms of navigation, semantics (the meaning of terms) and restricted use of email.

**Key Question 3:** What is the association between the practitioner and healthcare team being provided with education and staff training, making workload and workflow changes, achieving regulatory compliance and business process changes for ambulatory care, and patient uptake of online access and transactional services as part of their ambulatory care?

There appears to be growing use of telephone as well as email and other electronic communications. The complex relationship between face-to-face, telephone and email contacts with patients has been well documented, and is an area that we are carefully reviewing.

**Key Question 4:** What is the association between IT developments that provide records access, systems for enhancing privacy and security, usability and accessibility of transactional services, and the business process for technical development of EHR systems, including lead time for their development and patient uptake of online access and transactional services as part of their ambulatory care?

There are many concerns about harm, and about the importance of putting in place the right business model to ensure clinician collaboration (e.g. uptake improved once online visits became a billable item in an insurance funded health system). There are also concerns about coercing people to provide records access to others.

## Summary

Providing online access to records is acknowledged to be potentially empowering for patients and a shared goal for the consumers and funders of health care. However, the review so far suggests that there is no immediate major benefit to be gained from online access to records. Indeed attempts are still being made to articulate how and where it will best fit in.

The situation appears to be different for transactional services. Different types of technology and services appear to provide demonstrable benefit, although this is generally described in a narrow clinical area. Fitting this all together, and in particular teasing out what reduces the workload and what adds to it, and how to incorporate these technologies into workflow, is a challenge for reviewers and health service managers alike. There may be a place for developing learning objectives, curricula and training materials on how best to deploy these technologies in primary care; and understanding how the implementation of online access might change the nature of medical records and the time needed to make records more patient friendly.

There appears to be a complex relationship between the number of face-to-face, telephone and email or other electronic communications with physicians, and overall workload. Facilitating more electronic communications may reduce the number of contacts via other means, but their interplay has yet to be established and a greater number of methods of communication may also increase overall workload.

Implementation of technology in health care is often a mutually transformation process. Provision of access may lead to changes in the way that information is recorded, on clinical workflow, and how patients interact with clinicians. Similarly the technology will change as systems are used in earnest.

Getting the business model right, and seeing an IT opportunity for organisational development is a prerequisite for adoption. There is, quite rightly, concern about privacy and confidentiality even though reports of actual harm are rare. Failure to engage professions in this process may lead them to retreat into defensive practice.

## Conclusion

Online access to records is a potential enabler of clinician–patient communication, but there is only limited evidence of benefit, although none of significant harm. An implementation of this sort is likely to be mutually transformational. The nature of the medical record may have to change if it is to be used for a new shared purpose, and business process models will have to incorporate any extra time needed to transact in this way. Health systems appear to have put systems in place to maintain privacy and confidentiality, although little appears to be in place for training the workforce for these technological developments. Transactional services and broadening of electronic communication appear much more promising, and have the potential to be incorporated into a wide range of clinical workflows and business processes. Well designed and developed transactional services have the greatest potential for providing immediate benefits for patients and efficiency gains for healthcare providers.

## 5.0 Phase 3 (2013–2015)

It is hoped that the Road Map will prompt individual practices to think about their current position and how they can get to where they need to be by 2015. Phase 3 is about helping each of them to reach their desired state by 2015. The aspiration is that all practices feel supported and enabled to offer Patient Online.

However, it is important that the offer is taken up willingly and without practices suffering penalties or being performance managed. It also needs to be delivered and evaluated in the setting of current challenges within general practice, which includes the importance of access, continuity and coordination of care, managing multiple morbidities, and enabling greater patient involvement in decision making about service improvement, improving communication between patients and the profession, and also improving the quality and coordination of patient care and efficiencies.

This section summarises the next steps of the work, which will involve the RCGP working through a collaborative partnership with the focus on support, training and education, with an evaluation of the implementation of online access by 2015. In the call for evidence and ideas as part of the Department of Health's consultation paper on Innovation in the NHS, the RCGP stated that it plays 'a strong role in supporting and fostering the development, diffusion, and adoption of new ideas and practice in the NHS.'

The aim of Phase 3 is to further develop and implement the recommendations of Phases 1 and 2 of this project. This phase will run from early 2013 to April 2015, and is divided into the following two primary stages:

1. development (up to September 2013)
2. delivery (from September 2013 to December 2014).

The RCGP workstreams for this phase will mirror the working groups from Phase 2 and will include a strategy and oversight group, which will provide detailed definition and use the experience and insights recorded in the Road Map. As it is likely that GP systems of choice (GPSoC) will continue to be available in the future, and because of commercial relationships and sensitivities, the RCGP will not lead on the supplier and market liaison arm, but may provide clinical input.

### 5.1 Background and wider context

We anticipate that Patient Online:

- could be a stimulus for commissioning groups to consider how they could best support their practices, and federated practices
- will lead to patient participation groups supporting their practices and patient organisations being able to tailor their provision and delivery of health information<sup>48</sup>
- will lead to the development of resources and training modules to meet the educational needs of practice staff.

<sup>48</sup> Royal College of General Practitioners. *Medical Generalism: why expertise in whole person medicine matters*. London: RCGP; 2012. [www.rcgp.org.uk/~media/Files/Policy/A-Z%20policy/Medical-Generalism-Why\\_expertise\\_in\\_whole\\_person\\_medicine\\_matters.ashx](http://www.rcgp.org.uk/~media/Files/Policy/A-Z%20policy/Medical-Generalism-Why_expertise_in_whole_person_medicine_matters.ashx) [Accessed 12/12/12]

## Development

Each practice should consider the framework of support, training and educational material that they need to enable the level of offer that they are currently providing or will be providing.

There is recognition that materials will need to be varied, using a mix of resources (e.g. e-learning) which should be piloted and updated. The case studies that are being collected by the current Evidence and Evaluation Working Group will provide a source of learning material that may be of benefit to patients and practices (see Box 13 for exemplar topics and sources for case studies).

There are dependencies or external factors, as outlined within the Road Map, which may influence and inform the work through Phase 3. These include the following:

- RCGP governance processes (early 2013)
- national GP contract negotiations, outside the remit of the RCGP, will need to be ongoing. How the negotiations progress and their ultimate impact on this work will be considered at the appropriate time (during 2013)
- development of the commercial framework that supports online services (which may not occur until late 2013)
- the completion of the systematic review of online access (in April 2013). This will highlight areas of work that might benefit from further evidence and evaluation. During 2013–2015, the accumulating evidence base for Patient Online will develop and increase in terms of the workload implications, issues relating to information governance and safeguarding, the perceived benefits of online access and the link with quality of care
- working with the recommendations of the Caldicott Information Governance Review (due for publication in spring 2013).

## Delivery

Phase 3 offers the possibility of trialling Patient Online, particularly in practices that have not considered online access before and within specific patient groups.

It is possible for practices to consider the merits of Patient Online, assess what their training needs are, receive the appropriate support they require, and get easy wins by starting to provide transactional services. Learning from adopters about the merits of Patient Online, both from within their clinical commissioning groups and from practices distributed around England, is of value.

The delivery arm of Phase 3 will require collaboration, shared learning with qualitative indicators of success monitored and captured through survey, and also relationship building, particularly with clinical commissioning groups that have a key role in terms of guidance and support with their constituent practices. The programme of delivery should reflect organisational capabilities. Training support could consist of regional-based face-to-face training days, with joint delivery with patient groups and contributions from the general practice systems suppliers.

Practices may decide to offer online access to specific patient groups, such as those with multiple morbidity (frequent attenders) and specific conditions such as cancer and diabetes, particularly where care planning may have a role (see Box 14). This would require those patients that have the opportunity to consider the benefits and disadvantages of online access and to receive appropriate support.

- The need for communication with patients and practices will be of prime importance.
- This will require strong engagement with patient groups and professional networks, as the Support, Training and Education Working Group has identified.
- The communications arm of the project will be of prime importance over the next 2 years.
- Administration staff will need to be trained to assist patients who have complex needs that require active management of information availability (e.g. child protection-related records when a carer may be under investigation).

**Box 14: Looking ahead. Exemplar: how IT may support collaborative care planning (Sue Roberts, RCGP Care Planning Steering Group; Chair, Year of Care Partnerships)**

The NHS Mandate contains three related items:

- access to electronic medical records<sup>49</sup>
- personalised care planning: so far, more people with long-term conditions (LTCs) will have developed the knowledge, skills and confidence to manage their own health and live life to the full,<sup>50</sup> referred to as support for self-management (SSM)
- care that feels more joined up.<sup>51</sup>

The terminology relating to care plans and care planning has for some time been a barrier to delivering better patient care. The presence of a physical ‘care plan’ has been the focus of much of the policy direction of the last two administrations. This is important for coordination of care, especially between different parts of the health service, social care, and staff within integrated multidisciplinary teams. In this context, the ‘care plan’ usually refers to one or more ‘treatment plans’ developed by different members of the team, with or without the involvement of the patient. Inter-operability of the various systems to enable record sharing has been the focus for digital developments.

The RCGP policy document, *Care Planning: improving the lives of people with LTCs*, emphasises care planning as a collaborative process that brings together the traditional clinical perspective with SSM, helping the individual to identify their own goals for living with their LTC, their personal action plan and the need for future support. This involves a new way of thinking about people with LTCs, building on traditional consultation skills, and an infrastructure to support the process, such as sending test results or prompts for reflection to the individual before the consultation. This requires changes to the clinical record, to include goals and action plans, the administrative process, and the production of personalised documents. In this situation it is the structure and content of the clinical record itself that need to be the focus of digital developments.

The RCGP approach to care planning is based on the learning from the Year of Care (YOC) Programme. This programme worked with local IT facilitators and others to find ‘work arounds’ for the common GP systems to enable the core elements of collaborative care planning to take place. The YOC Programme has developed Customer Requirements for collaborative care planning, and matching Read Codes have now been released. However, they have been unable to influence the DH-directed developments in Connecting for Health (CFH). The RCGP work on access to electronic records could support the RCGP work on care planning, and provide stimuli to develop an electronic record which is fit for purpose. If this was incorporated as standard on GPSoC, it would be available to new communities of care planning practice immediately after training, enabling them to get up to speed faster, as well as ensuring that patients have access to records that reflect their personalised care planning process.

<sup>49</sup> Department of Health. *A Mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015*. Paragraph 2.6. London: DH; 2012. [www.wp.dh.gov.uk/publications/files/2012/11/mandate.pdf](http://www.wp.dh.gov.uk/publications/files/2012/11/mandate.pdf) [Accessed 12/12/12]

<sup>50</sup> NHS Mandate paragraph 2.5.

<sup>51</sup> NHS Mandate paragraph 2.8.

Evidence and evaluation would be important in terms of assessing whether there is greater patient satisfaction and patient enablement, as well as efficiency gains for the practices. Measuring improved health outcomes and linking them to patient empowerment offers the possibility of formal research evaluation, ideally in the form of randomised controlled trials, although this would be beyond the scope of this phase of the work. However, reviewing specific patient groups, the use of survey instruments and considerations relating to further systematic reviews will help to build on the evidence base, identify gaps in knowledge and test new ideas.

Measures and success criteria for the implementation of Patient Online will need to be developed to be used in an evaluation framework in the prospective evaluation going forward, as it is rolled out. This should allow for the clear definition of success criteria, tangible and intangible (i.e. narrative-based) metrics, and use an iterative and responsive feedback into the programme development.

This evaluation should include the impact not only on patients, but also on health professionals and on cost in terms of time and other resources. This may not be the responsibility of the RCGP, but it will need to be addressed.

Provisional timelines will need to be set to evaluate the work during Phase 3 (dependencies allowing):

Stage 1: Planning	November 2012 to January 2013
Stage 2: Project set-up	January 2013 to March 2013
Stage 3: Development (This covers development of training, education and support materials.)	January 2013 to August 2013
Stage 4: Delivery (This covers training, education and support delivery, together with a strong communications strand.)	September 2013 to December 2014

## 6.0 Summary

The programme of work described in the Road Map has established what could realistically be offered now and what might be offered in the future. The opportunities exist to improve patients' involvement in care and enhance their experience of using online services.

The history of national-level implementation of new systems in primary care is widely regarded as a success. It is generally acknowledged that systems that have not received grassroots GP support have not succeeded. The nature of the contractual arrangements between the NHS and GPs is such that new systems may be taken up with minimal resourcing if they are of obvious business benefit and/or have little impact on the workplace.<sup>52</sup> For Patient Online to succeed, there needs to be collaborative working, partnerships and negotiation between the NHS CB, professional representative bodies, patient organisations, training bodies and commissioning groups, to name but a few, as all of these have an interest in highlighting general practice at the forefront of innovation and service development.

Practices that want to offer Patient Online can do so, if they have the relevant functionality, and the intention of this guidance is not to hinder innovation or IT-enabled change to practice. Their experiences will be invaluable to the wider NHS community and would help to support uptake. For the practices that have not considered offering Patient Online and for those who want to expand their services, options are available. It is advised that early adopters consider some of the key identified information governance issues and that they set up practice processes that mitigate against risk.

Practices could use a menu approach to select what might be applicable, relevant or useful to them or their patients. Online services offer practices a way of enhancing their administrative functions and meeting the needs of different patient groups (e.g. those living in rural areas where public transport is scarce, or in commuting communities). Between 2013 and 2015 one might anticipate a steady increase in the number of practices offering such services to meet the NHS CB commitment. Current figures suggest that a significant proportion of practices with the relevant functionality offer online transactional services already, with little guidance, support or funding needed.

Practices could consider testing ideas and online innovations. Some patient groups may be ideally suited through the support of their practices to access their own results (e.g. patients with diabetes, or with renal disorders or rheumatological diseases). Many of these patients already receive or carry their own paper results, and enabling access may improve patient appreciation and satisfaction. Offering access to test results is a subset of offering access to the patient's record.

We anticipate a steady rise in the use of online functionality over the next 2 years. This IT-enabled change management programme, like all large-scale programmes, will bring with it tensions and challenges that are best managed through collaboration, exchange of ideas and constructive negotiations.

The Road Map aims to look ahead. The DH information strategy paper 'The Power of Information' has many aspirations, including the sharing of records and integration between health and social records. This document may highlight the differences between information-sharing practices in health and social care organisations, when in fact there is a lot of commonality in information governance, with similar toolkits. The Caldicott information Governance Review will provide information on the principles of shared records, and this will apply in principle to the impact on users of community modules of GP systems.

However, the focus, with 2015 in mind, remains on supporting general practices and their patients.

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<sup>52</sup> Dr Paul Cundy, Support, Training and Education Working Group.

# Appendices

## Appendix 1: Programme plan and methodology

The Future Forum recommended that:

- the RCGP should be approached to lead the project, with support from the DH, and form partnerships with the British Medical Association (BMA) and the NHS Commissioning Board, along with relevant patient organisations and stakeholders
- support structures are put in place to enable patients to understand how to use their records data and information
- issues relating to consent and protection of sensitive data are to be explored, evaluated and acted upon, including strategies to protect the most vulnerable patients
- common standards and guidelines are developed for patient data governance across England
- corresponding training and support are developed and implemented for GPs and other healthcare professionals, for appropriate use and governance of patient data.

### Convening of the stakeholder and working groups

The programme has been divided into three phases.

- **Phase 1** – initiation and defining of the scope of the work (June to September 2012):
  - setting up of a stakeholder group for quality assurance
  - defining the themes and potential products
  - setting up of seven working groups and identifying chairs, working group members and defining the outputs from the groups
  - agreement on working group outputs by the stakeholder group.
- **Phase 2** – specification development and initial delivery (October to December 2012):
  - working group (WG) meetings
  - development of the outputs
  - patient and clinical representation.
- **Phase 3** – the RCGP working with partners to have roles relating to support, training and education, with an evaluation of implementation and roll-out by 2015.

The roles of the stakeholder group and the members and the terms of reference of the group were set out for two main reasons – first, to provide important professional and patient representation, and secondly, to provide quality assurance to the project. The following seven working group themes arose through discussion with the stakeholders and through a pragmatic iterative process:

1. defining the offer
2. communicating the (balanced) benefits to practitioners, patients, carers and advocates
3. information governance and safeguarding
4. support, training and education
5. supplier and market liaison
6. the Road Map
7. evidence and evaluation.



There was an agreement that professionals, patients and patient groups would be represented through each of the working groups and on the stakeholder group. It was fundamental to the notion of the provision of online access by practices that all of the groups would be discussing issues relating to vulnerable groups and the socially excluded. Therefore it was important that the RCGP Health Inequalities Group was involved, so that they could provide comments on any relevant products developed by the working groups.

## Appendix 2: Patient Online access – defining the offer

### Introduction

There are many different definitions of Patient Online, depending on the IT system in use, and varying from the ability to log on and view appointment options and repeat medication, to full access to the entire record, both current and past. Proponents of ‘full records access’ (usually meaning access to all parts of the medical records, both current and past, and without prior checking of the record by the clinician) point out the benefits in terms of sharing clinical decision making and responsibility with patients, possibly improved medication concordance, and a reduced need for certain types of consultation. Other groups have wide-ranging concerns about the difficulties, risks and potential legal implications of record access, including leakage of third-party information, and the additional clinical workload that would be generated by records access.

This section aims to identify the different elements within a clinical record that could be made available for access, and to provide some assessment of the potential benefits and risks of making these elements accessible. In addition, it addresses the distinction between transactional functionality (e.g. appointment booking) and access to information in the record. Explanation of other acronyms and abbreviations used can be found at the foot of this document.

*It should be noted that systems for Patient Online are already available at the present time to GPs who wish to initiate records access, both prospectively and retrospectively. The framework laid out in this document need not in any way prevent ‘early adopters’ from using online records access, which will sow the seeds for greater use and acceptance of records access in clinical care in the future.*

### Security

Security has been a major concern of many people involved in the development of the guideline, and a recurring theme during the consultation process. All of the features and items described below would need to be protected by a robust and secure authentication procedure, yet one which does not deter the end user. A minimum standard for security is described in the WG3 risk register. A number of security-related points have been discussed in relation to the features described below, and since many of these are generally applicable to the whole system rather than a single feature, they have also been repeated here:

- **Patient Online must be disabled by default and the patient must opt into the system. If the patient is concerned about security, third-party data, coercion or indeed any other aspect of Patient Online, they should be advised that the safest course of action is not to enable it.**
- Where the patient chooses to download, print or otherwise extract personal data from their record, they should understand that the data are no longer protected by the system’s security measures.
- Patients must have very clear guidance on the use of their records upon registering, and understand that the responsibility for security lies ultimately with the patient.

### Health inequalities and accessibility issues

As a service that is delivered using the internet and computers, Patient Online has the potential to further exacerbate existing social and health inequalities, as it requires access to the internet and at least basic computer skills. However, there are positive advantages for people who have particular communication difficulties, as technology can offer improved ways of presenting and displaying information.

Information should be presented in a machine-readable format so that systems and assistive technologies can manipulate and display content in the most appropriate format for end users. National standards and legal requirements for accessibility should be adhered to, both for the design of Patient Online websites, and for the process of obtaining authentication and login materials from the practice.

### Information governance

**Information governance issues relating to Patient Online are considered in detail through the work of the Information Governance Working Group.**

### Notes on implementation

There is considerable concern that records access may increase GP workload. In addition, the level of password management support required could be significant in terms of workload.

The systems suppliers will take some time to develop the functionality to support Patient Online, and this may delay implementation.

Many of the proposed features described below are as yet untested in large-scale use, and therefore it is advisable that consideration is given to the use of existing records-access GP sites as pilot sites, and expanding this

**Due to the complexities involved in retrospective access to records, the default across the items should be to prospective access only from the date a GP practice decides to go live.**

However, individual practices may exercise their own judgement in this matter, and may choose to offer retrospective access as well.

### Access utilities

The tables below list the different utilities that are available in current systems, as well as ideas for future development of online access. The main advantages and potential risks of each utility are listed. In view of the risks, potential mitigatory approaches are suggested.

#### Ash

Defined Items specify functionality that is generally already present in current systems and that many practices are already using, or considering implementing.

#### Birch

Many practices will have functionality to be able to offer these items for patients. These items generate an additional workload, and therefore any implementation will require negotiations with the profession.

#### Cedar

These items present particular ethical and implementation challenges, and potential risks to confidentiality or patient safety. These items have significant workload implications. They are only likely to be provided by GP practices with a strong interest in Patient Online, and after the risks have been mitigated.

#### Date

These items have been suggested and may be desirable, but should be considered only after the above utilities have been achieved. They are currently out of scope.

## Ash (A)

These items specify functionality that is generally already present in current systems and that many practices are already using. Practices that are implementing these features will need to consider the business process change required.

Feature	Expansion	Potential benefits	Potential risks	Mitigation
<b>Account management</b>	Set and reset username and password resourced.	This functionality is necessary for administration of the system.	Data leakage may disclose identity information that could be used for identity theft.	Advice about password strength must be mandatory and password strength should be 'moderate' or 'good.' Accounts cannot have a weak or absent password.
	View online help and tutorials when using system.	Provides a portal for delivering online training to patients in using the system at higher access levels.	This level of data is very basic and does not constitute records access. It is however a prerequisite for accessing higher levels.	Password administration/password reset should be handled by the system and should not normally be a workload burden for the practice.
	View demographic details.	Some data are viewable and the records access software and infrastructure are present, creating a starting point on which further records access might be enabled.	There is a risk of coercion even with this minimum level of data (e.g. coercion to set username/password known to abusive partner).	
	View carer details (where already recorded in GP clinical system)			
	View disability needs and personal requirements.			
<b>Online prescription management</b>	Prescription requests.	May reduce administrative burden and telephone calls associated with management of repeat ordering.	Generally, the risk of leaking damaging information is low.	Online prescription management is already widely available in current systems and should be regarded as a minimum starting point for practices. It should be carried out through the system so that there is a level of authentication.
	Cancel prescription requests.	Advantages for patients in being able to order at a time that is convenient to them.	Disclosure of a prescription request to family members could potentially breach the confidentiality of Fraser-competent young people, or of those with mental health problems.	Risks are addressed in WG3 guidance (e.g. how to manage the transition from child to Fraser competence to adult, in terms of access permission).
	Print prescription requests.	Likely to benefit patients who find it difficult to attend the practice or phone the practice (e.g. commuters, patients with disabilities).	Risk of coercion.	
<b>Online appointment management</b>	Request or book appointment with GP, practice nurse or other health professional.	May reduce the practice's administrative burden and telephone calls associated with booking and cancelling appointments.	Generally, the risk of leaking damaging information is low.	Enabling online appointments should be regarded as a minimum starting point for practices unsure of record access, and allow development of provision of more record elements.
	Cancel appointments.	Transparency with regard to timing and availability of appointments may help to manage patients' expectations.	Disclosure of a consultation booking to family members could potentially breach the confidentiality of Fraser-competent young people.	It must be carried out through the system so that there is a level of authentication.
	Print details of appointment booking or cancellation.	Patients are likely to see an early practical benefit from online appointments; feedback from patient groups is very positive.	Risk of coercion.	Guidance for management of the transition from child to Fraser competence to adult in terms of access permission is discussed in WG3.
		Likely to benefit patients who find it difficult to attend the practice or phone the practice (e.g. commuters, patients with disabilities).	Management of appointments is more visible.	
<b>Online advice and information</b>	Access, download and print 'information prescriptions' and patient information leaflets.	Improves access to targeted, patient-specific medical information.	Patients in the lowest socio-economic groups, and therefore potentially in the highest clinical risk groups, might have least access to this information, depending on their access to the Internet.	Existing automated systems for providing such information should be used where possible.
		Provides a new medium for health professionals to provide targeted information.	Those who do not speak English as their first language may find access more difficult – information should be available in different formats and languages and should be centrally available.	
		Some patient groups with specific communication needs could benefit from information presented in electronic formats.		

## Birch (B)

Many practices will have functionality to be able to offer these items for patients. These items generate an additional workload and therefore any implementation will require negotiations with the profession.

Feature	Expansion	Potential benefits	Potential risks	Mitigation
<b>Online test results (after GP has viewed them)</b>	<p>View test results after they have been reviewed by GP and labelled with an action and/or message (e.g. 'normal', etc.).</p> <p>Download/print test results.</p>	<p>Patient is presented with a result that has been clinically reviewed, and the 'action' label added by the GP could include advice to the patient or further information, representing added value to the patient.</p> <p>Any 'wrong patient's test in wrong record' error is likely to be picked up by the GP before the patient can view it.</p>	<p>Practices need to be aware that results and comments would not necessarily be viewed by the patient.</p> <p>It may not be appropriate for all test results to be communicated in this way. We suggest that this should be used for 'selected' test results, based on clinical judgement.</p> <p>The option 'contact the practice' must also be available, rather than displaying a result.</p>	<p>System design could alert if the patient has not viewed/been informed of test results.</p> <p>Urgent results must continue to be communicated to the patient where appropriate.</p>
<b>Core information</b>	<p>Information from the patient record in a view that is convenient for patients, which includes retrospective access to:</p> <ul style="list-style-type: none"> <li>■ medications.</li> <li>■ allergies and adverse reactions</li> <li>■ immunisations.</li> </ul> <p>Print/download core information.</p>	<p>Allergies and adverse reaction information are potentially life-saving.</p> <p>Access will enable patients to check that information is accurate.</p>	<p>Risk of coercion, primarily due to presence of medication history.</p>	
<b>Scanned or attached documents (after GP has viewed them)</b>	<p>Letters in.</p> <p>Letters out.</p> <p>Other documents that may be scanned in (e.g. investigation results, such as radiology).</p>	<p>Provides the patient with a more complete picture of their care, enabling improved sharing of medical care and decision making.</p> <p>Would help the patient to track their referrals.</p>	<p>Significant risk of identifiable third-party data leakage</p> <p>Significant risk of patient's data being accessed by unauthorised person (password/authentication obtained by hacking, coercion or other means).</p>	<p>If the patient is concerned about data leakage, they should be advised that the safest course of action is not to enable records access.</p> <p>Records access must be disabled by default and the patient must opt into the system.</p>
<b>Audit trail</b>	<p>Audit trail to show who has accessed every online record is mandatory.</p>	<p>Would allow the patient to see who has accessed their record using the online system. This could be useful for detecting unauthorised access. The audit trail should be patient-visible, and the system should display the date and time of the last login on the initial page.</p>		

## Cedar (C)

These items present particular ethical and implementation challenges, with potential risks to confidentiality or patient safety, and they also have significant workload implications. They are only likely to be provided by GP practices with a strong interest in records access, and after the risks have been mitigated.

Feature	Expansion	Potential benefits	Potential risks	Mitigation
<b>Prospective access to medical record</b>	<p>View all coded data, including their associated free text.</p> <p>Print/download data.</p> <p><b>See 'Date level', below, for past records access.</b></p>	<p>Adds value to the record access. For example, it allows the patient to review a recent consultation to remind them of the course of action that they agreed with their health professional.</p>	<p>All coded data would include QOF codes, business codes and administration codes, which will 'dilute' the clinical information that the patient wants to access. The patient might find it difficult to find the information they want within the large amount of data.</p> <p>Alerts (e.g. about a violent patient) and other critical internal information may be visible, and there is a risk that this may lead to such information not being recorded out of concern that the patient may react adversely.</p> <p>Risk of compromising the quality of the record, as GPs may be reluctant to record subjective or unsubstantiated data (e.g. differential diagnoses, including cancer). This would detract from the medical record's primary purpose, which is to facilitate information sharing among health professionals.</p> <p>Concern among clinicians about the potential for disputes, complaints, and legal and GMC proceedings resulting from entries made in the clinical notes.</p>	<p>The system design should allow the practice to apply an automated filter to the record, to determine what is visible.</p> <p>There is ICO guidance on recording alerts in the records of violent patients: <a href="http://www.scimp.scot.nhs.uk/wp-content/uploads/documents/use_of_violent_warning_markers.pdf">www.scimp.scot.nhs.uk/wp-content/uploads/documents/use_of_violent_warning_markers.pdf</a></p> <p>The system design should allow the patient to filter information by category (i.e. it can filter out non-clinical codes).</p> <p>Codes could be automatically linked to relevant patient information documents; these would provide explanations of difficult, worrying or ambiguous terms and would not incur additional workload for the practice.</p>
<b>Test results (before the GP views them)</b>	<p>Selected patients can view test results before they have been reviewed by the GP.</p>	<p>Offers more rapid access to the test result, as there is no need to wait for the GP to review it.</p> <p>This is of most benefit to 'expert patients' (e.g. renal patients who know their parameters and can interpret them).</p>	<p>Potential for causing harm or concern to the patient if there is a misunderstanding about a result. Interpretation of test results is not an exact science, and can be difficult even for clinicians. High risk of causing alarm, possibly unnecessarily, to a wide range of patient groups.</p> <p>A 'wrong patient's test in wrong record' error is not likely to be picked up by the GP before the patient can view it.</p>	<p>Practices are likely to want to enable this feature only for specific patients and/or for specific test results. The system design should provide sufficient granularity to allow this.</p>

## Cedar (C)

*continued*

Feature	Expansion	Potential benefits	Potential risks	Mitigation
<b>Scanned or attached documents (before the GP views them)</b>	<p>Clinic letters, discharge summaries and other documents that can be scanned in (e.g. investigation results, such as radiology).</p> <p>Download/print scanned or attached content.</p>	<p>Offers more rapid access to the result, as there is no need to wait for the GP to review it.</p> <p>This is of most benefit to 'expert patients' (e.g. renal patients who know their parameters and can interpret them).</p>	<p>As with test results, some results would be better communicated in person to the patient. Therefore allowing access to the results before the GP has viewed them incurs greater risks.</p> <p>There are some documents, such as child safeguarding reports, which are explicitly marked 'NOT for further sharing beyond the distribution list in the letter.' If these are shared with the patient via the records access system before the GP has been able to view them, this might cause harm.</p>	<p>At present it is not technically possible to automate the process of identifying letters that are suitable for immediate patient viewing and those that would need to be reviewed by the GP first. For this reason, allowing the patient access to attached documents before the GP has viewed them is not recommended.</p>
<b>Online access for carers and advocates (as nominated by the patient)</b>	<p>Nominate others who can access records. These others should have their own login account with permissions set by the patient.</p> <p>This should allow for more than one carer, and also different layers of access for each carer.</p>	<p>Would allow patients to share and discuss their records with others.</p> <p>Would improve access to the healthcare records of those who wished to nominate an advocate, carer, guardian or similar individual.</p> <p>The patient could elect to show elements of their record to clinicians caring for them in other care environments (e.g. Accident and Emergency, hospice, internationally).</p>	<p>Sharing under coercion is a risk that has been highlighted, and which is more fully discussed in the output of WG3.</p> <p>The implications for children's records are considered in the output of WG3.</p>	<p>The level of access rights could be mitigated by allowing the patient to nominate one or more specific individuals and create an access account for them.</p> <p>If patients believe themselves to be at risk of coercion, they should not register for record access, or they should de-register if they are already registered.</p> <p>Patients should be advised that they must take full responsibility if there is any subsequent misuse of the confidential information by friends or family after they have shared the username and/or password.</p>

## Date (D)

These items have been suggested, and may be desirable, but should only be considered once standard and enhanced levels have been achieved. They are currently out of scope.

Feature	Expansion	Potential benefits	Potential risks	Mitigation
<b>Summary care record (SCR) information</b>	<p>Summary information from the patient record in a view that is convenient for patients, which includes:</p> <ul style="list-style-type: none"> <li>■ medications</li> <li>■ allergies and adverse reactions</li> <li>■ immunisations.</li> <li>■ contact and carer details (where already recorded in GP clinical system).</li> </ul> <p>Print/download summary information.</p>	<p>Different systems present summaries in different ways. Basing this on the summary care record (SCR) additional information agreement helps to standardise these core data. Work on agreeing a standard SCR data set is already under way.</p> <p>Very useful for patients.</p> <p>Information about allergies and adverse reactions is potentially life-saving.</p> <p>Will enable patients to check that information is accurate.</p>	<p>Past medical history is normally recorded in coded form in the primary care record. Coded data items are often linked with free text which could contain contentious information and needs to be screened to prevent inadvertent access to third-party information or outdated terminology.</p> <p>Coded data may contain free-text negation which would be misleading or dangerous if left out. Prospective access may help to mitigate this risk.</p> <p>Risk of coercion.</p>	<p>Guidance must warn practices to review outdated codes and either remove them or replace them with more appropriate codes.</p> <p>Basing this on SCR additional information may help to mitigate third-party risks.</p>
<b>Past records</b>	<p>Online access to records prior to the date of the patient requesting online access.</p>	<p>Potential to provide the patient with much more information, which in some cases could have added utility.</p>	<p>Potential to jeopardise the doctor–patient relationship through disclosure of past episodes of care.</p> <p>The workload involved in checking the record for third-party data before allowing retrospective access to the full record will potentially inhibit the majority of practices.</p> <p>Risks of access to third-party information, etc.</p>	<p>This area will be examined more carefully in the risk register of WG3.</p> <p>It is likely that the workload issues and potential risks outweigh the potential benefits of retrospective access.</p> <p>The default across all items MUST be prospective access only. The ability to set an 'access-from' date is essential.</p>
<b>Patient additions to records</b>	<p>Enable the patient to add (i.e. append) information to the clinical record.</p>	<p>Enable patients to have greater involvement in their care and medical record.</p> <p>Chronic disease monitoring could be done remotely (e.g. remote blood pressure monitoring in patients with hypertension).</p> <p>Apps and other software could be used to make entries in the clinical record utilising API.</p>	<p>Potentially harmful if used inappropriately</p> <p>Monitoring of clinical record changes would generate an unmanageable workload for the practice.</p> <p>Risk of vandalism or deliberate addition of incorrect data.</p> <p>Practices will need guidance on the medico-legal liability implications of acting on information added to the record by the patient.</p>	<p>The system design would need to clearly identify patient entries and allow the clinician to filter these out for clarity.</p> <p>The system design would need to allow 'include/exclude patient entries' in the QOF.</p>
<b>'Edit my details'</b>	<p>Patients will want to be able to update their demographic details, but any changes will need to be authorised by the practice first.</p>	<p>Practices and patients may benefit from an additional mechanism for the patient to maintain up-to-date contact details.</p>	<p>Patients may move outside the practice boundary but amend their record so as to appear to be still residing within the practice boundary.</p> <p>Potential security risk if the patient's mobile phone number is used as a way to support recovery of a lost password.</p>	<p>Validation required by system and confirmatory message to patient and practice.</p>



## Date (D)

*continued*

Feature	Expansion	Potential benefits	Potential risks	Mitigation
<b>Complete/update online health assessment</b>		Opportunistic data collection.	Data may be of poor quality.  There is a risk that the data may be entered by someone other than the patient.	There must be a robust mechanism for patient-entered data to be identifiable and verifiable.
<b>Exposure of secure standardised API for:</b>	Systems suppliers would provide an application programming interface (API) to allow interaction with clinical records, enabling external applications to access and utilise these data.	This would allow third-party developers to produce software that could allow patients to extract their data and use it in creative and as yet unconsidered ways.  Examples include Medical Alert apps, repeat prescriptions apps and appointment booking apps.	The API must have the same level of security as ordinary online access.  A closed API would allow some development, but would be restrictive, by increasing the difficulty of development for that platform, or imposing an upfront cost.  A series of non-standardised (system-specific) APIs would allow some development. However, developers would have to either concentrate on developing for a single system supplier's platform, or develop an application that can interact using a variety of APIs.	Suppliers who choose to make their API open, free and (where possible) standardised would be more likely to attract freelance development, which would in turn enhance the functionality of their platform.
<b>1. Online prescription and appointment management</b>				
<b>2. Records access</b>		An <b>open</b> API would allow a wide range of developers to produce apps; this increases innovation.  A <b>standardised</b> (between systems) API would make it easier to develop apps that work on more than one platform, and this would make app development in this area more attractive to investors and innovators. However, this does require significant cooperation from the systems suppliers.		

## Two-way asynchronous communication online

Feature	Expansion	Potential benefits	Potential risks	Mitigation
<b>Two-way asynchronous communication online</b>	The unilaterally independent process of secure online communications between clinicians and patients facilitated by and recorded within the electronic GP record (i.e. secure electronic messaging between patient and GP practice, named doctor or deputy).	<p>Enables the patient to have another route by which to contact their GP practice. May help the patient to prepare for the consultation.</p> <p>Audit trail to show that messages (outgoing and incoming) have been appropriately viewed and actioned.</p> <p>Opportunity to develop one to many online communications, allowing clinicians to efficiently inform, support or educate targeted groups of patients.</p> <p>Utilises technology to make some existing processes (letters and phone calls) quicker, targeted and significantly more efficient. Potential reduction in the number of telephone calls and unnecessary appointments.</p> <p>Potential improvement in patient satisfaction. Benefits include patient savings in time and travel, combined with fuller information to support independence and self-care.</p> <p>Substitution for some face-to-face consultation, freeing net saved time for those who need face-to-face consultations.</p>	<p>Huge workload and business change implications for practices.</p> <p>Liability issues (e.g. not acting promptly in response to an email because it is received during consultation time or OOH)</p> <p>Risk of harm to patients if it is expected that the practice will deal with the message in real time.</p>	<p>The system design needs to send an automatic message to the patient (e.g. message read).</p> <p>The system design needs to flag and enter it in the clinical record for medico-legal purposes.</p> <p>Automatic messages should be displayed to warn the patient that messages will not be answered in real time, and that urgent messages should be communicated by other routes.</p> <p>Clear professional and patient-focused guidance on 'ground rules' for practices and for patients to whom this service may be offered. These are vital to ensure that expectations are managed safely, that patients accept the 'terms and conditions' involved explicitly, and that practices manage the introduction of this service within a bounded framework which substitutes it for other time, in a manageable way (and therefore do not fear a 'deluge of email' intruding on personal or otherwise planned work time).</p> <p>Must only be 'turned on' for patients who request it, rather than for the whole registered population.</p> <p>Explicitly exclude the use of 'open' email which is not integrated into practice workflow and patient records.</p>

## Appendix 4: Stakeholder Group and Working Group membership

### Stakeholder Group membership (including Working Group membership)

Organisation and name	
RCGP (Chair of CIRC & Patient Online Stakeholder Group): <b>Dr Imran Rafi</b>	<b>WG6</b>
NHS Commissioning Board (NHS CB): <b>Giles Wilmore</b>	<b>WG1, 6</b>
NHS Commissioning Board: <b>Kathy Mason</b>	
Royal College of Physicians (RCP): <b>Professor Iain Carpenter</b>	<b>WG1S, 2S</b>
Royal College of Paediatrics and Child Health (RCPCH): <b>Dr David Low</b>	<b>WG3</b>
Royal College of Nursing (RCN): <b>Alison Wallis, Anne Casey</b>	<b>WG1S, 2</b>
Royal College of Midwives (RCM): <b>Jeanne Tarrant</b>	<b>WG1S, 3S, 5</b>
British Medical Association (GPC): <b>Dr Chaand Nagpaul, Dr Tom Black</b>	<b>WG6 (rep1–6)</b>
Women's Health and Equality Consortium (WHEC): <b>Zoe Palmer</b>	<b>WG2S, 3S</b>
RCGP Professional Development Board (PDB): <b>Professor Nigel Sparrow</b>	<b>WG4</b>
RCGP Patient Partnership Group (PPG): <b>Antony Chuter, Harvey Ward</b>	<b>WG6</b>
RCGP Health Informatics Group (HIG): <b>Dr Libby Morris</b>	<b>WG1, 3, 6</b>
National Clinical Lead: <b>Dr Peter Short</b>	<b>WG2, 5, 6</b>
Royal College of Psychiatrists (RCPsych): <b>Dr Hashim Reza, Dr Justin Marley</b>	
Association of Directors of Adult Social Services: <b>Ian Swanson</b> (supported by <b>Keith Strahan</b> )	<b>WG3S</b>
RCGP General Practice Foundation (GPF): <b>Sandy Gower</b>	<b>WG4, 6</b>
University of Surrey: <b>Professor Simon de Lusignan</b>	<b>WG6, 7</b>
National Children's Bureau: <b>Zoe Renton</b>	<b>WG7</b>

### Working Group membership

#### Working Group 1: Defining the Offer

Working Group	Working Group Subgroup
<b>Chair: Dr Libby Morris</b> (RCGP HIG) <b>SH, WG3</b>	Professor Iain Carpenter (RCP) <b>SH, WG2S</b>
Vice Chair: Dr Marcus Baw (RCGP HIG) <b>WG3</b>	Dr Brian Fisher (GP, PAERS) <b>WG4</b>
Dr Alan Hassey (RCGP HIG) <b>WG3</b> , Caldicott Review Panel	Jeanne Tarrant (RCM) <b>SH, WG3S, WG5</b>
Dr Joanne Bailey (BMA GPC) <b>WG3</b>	Anne Casey (RCN) <b>SH</b>
Giles Wilmore (NHS CB) <b>SH, WG6</b>	Dr Nick Booth (RCGP HIG)
Henry Pares (DHID) <b>WG6</b>	Howard Leicester (Patient Representative) <b>WG3, 5</b>
Dr Matt Hoghton (RCGP Learning Disability Champion/CIRC Medical Director)	Michelle Hodson-Curran (Patient Representative Thalidomide Trust) <b>WG3S</b>
	Dr Arjun Dhillon (RCGP HIG)

## Working Group 2: Evidencing and Communicating the Benefits

Working Group	Working Group Subgroup
<b>Chair: Dr Peter Short SH, WG5</b>	Dr Paul Maddy (Vice Chair iSoft User Group) <b>WG5</b>
Scott Cunningham (My Diabetes My Way Patient Advocate)	Dr Chris Frith (GP Pan User Group)
Barbara Smith (North West Change and Benefits Lead)	Kathie Applebee (RCGP GPF Practice Management Group); Chair National Vision User Group (NVUG) <b>WG4</b>
Dr Richard Fitton (GP expert)	Zoe Palmer (WHEC) <b>SH, WG3S</b>
Dr David Wrigley (BMA GPC) <b>WG5</b>	Professor Iain Carpenter (RCP) <b>SH, WG1S</b>
Alison Wallis (RCN) <b>SH</b>	Toto Gronlund (DHID, Patient Representative) <b>WG4S, WG7</b>
Dr Erik Wilkinson (GP)	Eileen Phillips (DH Head of Media Relations) <b>WG6</b> Gillian Watson (RCGP, Public Relations Manager) <b>WG6</b>

## Working Group 3: Information Governance and Safeguarding

Working Group	Working Group Subgroup
<b>Chair: Dr Libby Morris (RCGP HIG) SH, WG1</b>	Dr John Williams (RCGP HIG)
Vice Chair: Dr Alan Hassey (RCGP HIG, Caldicott Review Panel) <b>WG1</b>	Michelle Hodson-Curran (Patient Representative Thalidomide Trust) <b>WG1S</b>
Dr Marcus Baw (RCGP HIG) <b>WG1</b>	Ninjeri Pandit (London Connect)
Dr Joanne Bailey (BMA GPC) <b>WG1</b>	Jeanne Tarrant (RCM) <b>SH, WG1S, WG5</b>
Dr David Low (RCPCH) <b>SH</b>	Zoe Palmer (WHEC) <b>SH, WG2S</b>
Dr Leo Fogarty (RCGP HIG)	Ian Swanson (ADASS) <b>SH</b>
Rachel Merrett (BMA GPC)	Professor Gene Feder, Dr Alex Sohal (RCGP, Domestic Violence Clinical Champions) Alastair Kent, Melissa Hillier (Genetic Alliance UK) Howard Leicester (Patient Representative) <b>WG1, 5</b>

### Working Group 4: Education, Support and Training

Working Group	Working Group Subgroup
<b>Chair: Sandy Gower</b> (RCGP GPF Practice Management Group Co-Lead) <b>SH</b>	Anita Lightstone, Hugh Huddy (RNIB)
Vice Chair: Professor Nigel Sparrow (Chair RCGP Professional Development Board; GPF Board) <b>SH</b>	Russell Vine (Chair, Practice Management Network)
Kathie Applebee (RCGP GPF Practice Management Group; Chair NVUG) <b>WG2S</b>	Di Millen (DHID)
Fiona Dalziel (RCGP GPF Practice Management Group Co-Lead)	Toto Gronlund (DHID, Patient Representative) <b>WG2S, WG7</b>
Dr Patricia Wilkie (Chair, National Association for Patient Participation)	
Jenny Aston (Chair, RCGP GPF Nursing Group)	
Dr Brian Fisher (GP Representative, PAERS) <b>WG1S</b>	
Dr Beth McCarron-Nash (BMA GPC)	

### Working Group 5: Supplier Liaison/System Development

Working Group	Working Group Subgroup
<b>Chair: Dr Peter Short SH, WG2</b>	Dr Chris Frith (GP Pan User Group)
Vice Chair: Dr Paul Maddy (Vice Chair iSoft User Group) <b>WG2S</b>	Geraldine Mynors (Mynors Suppiah, Patient Representative)
Lynne Jones (Practice Manager)	Kemi Adenubi (GPSoC)
Howard Leicester (Patient Representative) <b>WG1, 3</b>	Phil Molyneux (Yorkshire and the Humber Programme for IT)
Dr David Wrigley (BMA GPC) <b>WG2</b>	Dr Filson Ali (GP Associate in training, Honorary member Renal Support Group)
Jeanne Tarrant (RCM) <b>SH, WG1S, WG3S</b>	
Jon Lindberg (Intellect) <b>WG6S</b>	
Ewan Davis (HandiHealth)	

## Working Group 6: Road Map

Working Group	
<b>Chair: Dr Imran Rafi SH</b>	Carol Sheppard (Academy of Medical Royal Colleges)
All Working Group Chairs: <b>SH</b>	Gillian Watson (RCGP, Public Relations Manager,) <b>WG2</b>
Dr Chaand Nagpaul (BMA GPC) <b>SH</b>	Jon Lindberg (Intellect) <b>WG5</b>
Dr Paul Cundy (BMA GPC)	Dr Caroline Fryar (Medical Defence Union)
Holly Trotman (BMA)	Sara Hiom (Cancer Research UK)
Una McCleod (RCGP Health Inequalities), supported by Jonathan Hamston	Harvey Ward (Patient Representative and Chair RCGP PPG) <b>SH</b>
Giles Wilmore (NHS CB) <b>SH, WG1</b>	Samantha Meikle (London Connect)
Antony Chuter (Patient Representative and RCGP PPG) <b>SH</b>	David Jones, Kerriane O'Rourke (Diabetes UK)
Henry Pares (DHID) <b>WG1</b>	Dr Iain Crinson (Sociologist, St George's University of London)
Vanita Patel (RCGP Policy)	Eileen Phillips (DH Head of Media Relations) <b>WG2</b>

## Working Group 7: Evidence and Evaluation

Working Group	Working Group Subgroup
<b>Chair: Professor Simon de Lusignan SH</b>	Georgios Michalakidis (University of Surrey)
Vice Chair: Beverley Ellis (University of Central Lancashire)	Dr Freda Mold (University of Surrey)
Toto Gronlund (DHID, Patient Representative) <b>WG2S, WG4S</b>	Mary Cavill (RCGP)
Professor Jeremy Wyatt (University of Leeds)	
Dr Theodoros Arvanitis (University of Birmingham)	
Christina Franco (University of Dundee)	
Professor Frank Sullivan (University of Dundee)	
Professor Aziz Sheikh (University of Edinburgh)	
Professor Azeem Majeed (Imperial College)	
Professor Simon Jones (University of Surrey)	
Dr Hannah Blakey (St George's University of London)	
Dr Phil Koczan (UCL Partners; RCGP HIG)	
Dr Mary McCarthy (GP)	
Zoe Renton (National Children's Bureau) <b>SH</b>	
Fiona Barker (University of Surrey)	
Professor Tom Quinn (University of Surrey)	
Dr Neha Kataria (Princess Alexandra Hospital)	
Dr Umesh Chauhan (RCGP)	

We would like to thank the following RCGP groups who have provided excellent constructive feedback:

- RCGP Health Inequalities Group
- RCGP Ethics Group
- RCGP Safeguarding Forum.

## Appendix 5: Key messages from this document

### Key messages to the NHS CB

- There is a need for further exploration, funding and commissioning of studies on e-consultation. This particularly applies in the setting of online diagnosis and treatment. The risks and benefits to practices and patients need to be defined before any implementation is considered.
- Funding streams are made available through the NHS CB to enable the study and evaluation of e-consultation before implementation is considered for mainstream general practice. The funding should be part of the necessary and important broader evaluation of the impact of Patient Online. The Defining the Offer Working Group feels that the component of Patient Online that refers to online records access must be prospective. This is because of the practicalities of what can be disclosed in the context of Patient Online, given the necessary checks and ensuring that the process is appropriately managed. However, this is ultimately a matter for the discretion and judgement of the individual practices. Patients still have the legal right to view their records as stated in the Introduction.
- The professions' representatives should have the opportunity to negotiate any contract changes that refer to online access, prior to commencing implementation and delivery during 2013.
- There is a need for negotiations concerning any possible contract changes between the professions' representatives and the NHS CB before implementation in 2013, and before the delivery arm of training and support.
- There is a need for evidence and evaluation of practices with regard to the use of asynchronous secure e-communication during 2013–2015.
- Studies around e-communication and patient safety are recommended.
- There must be commonality between systems and services when patients move practices, which requires mandating through GPSoC or other mechanisms, from 2013 onwards.
- To expedite innovation and translation, NHS procurement of GP IT system needs to be responsive and agile to encourage market development (from 2012 onwards).
- The NHS CB, when it commissions new products, should sponsor or advocate patient-centric design.

### Key messages to practices

- One possible strategy that practices might use for gaining confidence when considering Patient Online is to offer progressively more elements of access to records over the next 2 years while monitoring workflow in practices and also, if possible, capturing patients' experiences.
- Learning from early adopters is important. However, the very early adopters of online access to full records may not be representative of most in general practice, although they do offer considerable experience and knowledge. The Patient Online Evidence and Evaluation Group has a website (University of Surrey):

[www.clininf.eu/projects/patient-access/case-study-form.html](http://www.clininf.eu/projects/patient-access/case-study-form.html)

It is here that case studies are being collected, and this type of portal will continue to collect evidence and evaluate practices' experiences over the next 2 years.

- Exemplars of practice or practice groups should be collected through an easily identifiable portal to serve as case studies that demonstrate why Patient Online may reap benefits, and to learn from practices who have offered Patient Online during 2012–2015.
- Retrospective access to patient records will require management of the information governance risks, and will have workload implications for practices. Retrospective access to records should be considered in due course after practices have considered the necessary practicalities and implications. GPs may consider offering retrospective access on a case-by-case basis for patients who are likely to benefit most because of their complex case histories and/or long-term conditions. There would need to be a short delay while records are checked for third-party information.

- Over the next 2 years (2013–2015), practices could consider progressively extending the elements of the record which might be offered, in partnership with their patients.
- Evaluation of the experiences of practices over the next 2 years (2012–2014) will be important in terms of updating practitioners and patients about the specific challenges and benefits of opening up access to partial or full records.
- Although e-communication offers the potential advantage of convenience in terms of patient access, practice systems and procedures need to be in place to mitigate against information governance risks.
- There are concerns about capacity in practices with regard to the management of asynchronous communication.
- Practices must read the Information Governance Risk Register and review within practice meetings what risks may be pertinent and/or relevant to their practice population and IT system (from 2012 onwards).
- The RCGP 2010 guidance on enabling access (which covers children, relatives, carers and advocates, and people who lack mental capacity, as well as family disputes) is useful and very relevant.<sup>53</sup>
- Both the definition of the offer and, in particular, the Information Governance Risk Register consider risks to children, patients who have carers and those who are victims of coercion.
- Mitigation against coercion may not have a clear solution. Domestic violence and cyberstalking by the abuser are particularly prevalent issues, and communications with Professor Gene Feder, RCGP Clinical Champion for Domestic Violence, have highlighted such issues.

### Key messages for system delivery

- There is a need for functionality to set and reset username and password, through an administrative process that provides a secure authentication procedure (from 2013 onwards).
- There is a need for features that support all of the offers (2013 onwards).
- The facility is needed for an audit trail that must both allow patients to see who has accessed the record, and allow the practice to audit its own system (e.g. how many patients are registered, how many patients are registered and users, and how many patients are registered and non-users) (from 2013 onwards).
- The ability to set different levels of access rights is needed (from 2013 onwards).
- To prevent exacerbation of health inequalities, it is recommended that national standards and legal requirements for online accessibility should be adhered to, both for the design of Patient Online Access websites and for the process of obtaining authentication and login materials from the practice (from 2013 onwards).
- System designs, developed and supported through funding mechanisms, that allow secure communication between patients and their practice should be in place (from 2013 onwards).
- General practice computer systems suppliers should work with new entrants in 2013 when making the user interfaces for patients generic and transferable between systems, and able to cater for disabled groups.

<sup>53</sup> Royal College of General Practitioners. *Enabling Patients to Access Electronic Health Records: guidance for health professionals*. London: RCGP; 2010.  
[www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/-/media/Files/CIRC/Health%20Informatics%20Report.ashx](http://www.rcgp.org.uk/clinical-and-research/practice-management-resources/health-informatics-group/-/media/Files/CIRC/Health%20Informatics%20Report.ashx) [Accessed 12/12/12]



### Key messages relating to support, training and education

- The RCGP should work with patient partnership groups and other stakeholders (e.g. the Royal College of Nursing) to support the development and hosting of a range of relevant learning and communication materials. Suggested topics for exploration are listed in Box 13.
- Bodies such as the National Association for Patient Participation (NAPP), the RCGP's Patient Partnership Group and Standing Commission on Carers, and the BMA's Patient Liaison Group are recommended as the key umbrella partners for this support, in addition to the condition-specific support from patient and carer representative groups, such as Cancer Research UK, Diabetes UK, Age UK and the RNIB, during 2013–2014.

### Key messages relating to health inequalities

- The use of IT to improve or enable health and health care must be viewed alongside the effect of a digital divide and lack of eHealth literacy in disadvantaged social groups, which could lead to a widening of social inequalities. Tools, studies and research findings relating to health and eHealth literacy should be gathered during 2013–2015 to inform this.
- Evaluation of the impact of Patient Online must include an assessment of socially disadvantaged groups and involve the RCGP Health Inequalities Group and the RCGP Learning Disabilities Group, in collaboration and partnership with patient groups during 2013–2015.
- Public information about what Patient Online may involve and its implications will be of paramount importance, and will need to involve the voluntary sector as well as links between commissioning groups and their local population, ideally in association with local patient groups.



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