

Report of the  
Ministerial Taskforce on the  
NHS Summary Care Record

6 December 2006

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## Preface

Dear Lord Warner,

I am pleased to submit the Report of the Ministerial Taskforce on the Summary Care Record.

In our report we acknowledge that there are differences of opinion and approach between GPs, secondary care doctors, nurses, and patients. These are based on differences of view about the practicality, ethics and value of creating a Summary Care Record. Nevertheless the Taskforce is united in believing that a national care record service is desirable for patients, clinicians and the Health Service and that the Summary Care Record, cautiously implemented, in line with our recommendations, will bring real benefits in safety, quality, efficiency and co-ordination of care.

Our recommendations deal with several matters: implementation, patient access and consent, data quality, training for staff, equity and health inequalities, urgent care, the oversight of early adopter sites and their evaluation and public information.

There are a number of other issues which we identified which we have not addressed as they are outside the scope of this report. They appear at Annex 3.

Despite the differences of opinion and approach of the Taskforce members, we are agreed on the recommendations we make.

I believe we have fulfilled the task you set us; to make recommendations to resolve the ethical and practical differences over the implementation of the Summary Care Record.

I am personally grateful to all the members (and their deputies who attended when the members were not able to do so) for their willingness to discuss the issues openly and frankly and their clear desire to reach a resolution to them.

I would also like to put on record our thanks to our professional advisors and to our officials who have provided informed and efficient support throughout the process.



Harry Cayton  
Chair, Ministerial Taskforce on the Summary Care Record

## The Taskforce

1.1. The Taskforce on the Summary Care Record was announced by Lord Warner, Minister of State for Reform, in July 2006. It was asked to report by December 2006. The Taskforce met four times between September and December. A list of members appointed to the Taskforce appears at Annex 1.

1.2. Its stated aim and terms of reference were:

**Aim:** to resolve the ethical and practical differences over the implementation of the shared summary record and to devise a programme of work for its implementation, within agreed policies, for the benefit of patients and the NHS.

### Terms of Reference:

- To identify and analyse the problems perceived by different stakeholders
- To resolve identified problems in ways that are practicable and for the benefit of patients and the NHS
- To take account of the legal basis for storing, sharing and using records and Department of Health policy
- To take account of the technical and practical barriers to implementation
- To draw up an agreed plan for implementation of the shared summary record
- To make recommendations to ministers.
- In doing this to take account of the implementation and use of shared records by the Veteran's Administration in the USA

## 2. The Summary Care Record

2.1. The Summary Care Record is part of the NHS Care Records Service and is being implemented as part of the National Programme for IT in the NHS. Initially it will contain a small but important data set of current medications and allergies and adverse reactions which will be uploaded from GP systems, initially as text and subsequently in coded form. Over time the content will increase, subject to consent, to include a more complete data set from GPs and also information from detailed records held by other providers of care for example hospitals and community services. It is expected that independent sector organisations delivering care or services on behalf of the NHS will also supply information to the Summary Care Record.

2.2. The Summary Care Record will be available throughout England to those who need to access it to deliver care and who have the necessary security permissions. Consequently, it has the potential to bring major benefits to both patients and clinicians especially when treatment is being delivered in settings where the patient's usual records are not available, for example care delivered by Ambulance Service staff, Out of Hours Centres, Walk-in Centres and A&E Departments.

- 2.3. The Taskforce recognises that the creation of the Summary Care Record will not in any way change the professional standards or the legal frameworks which currently govern information sharing.
- 2.4. NHS Connecting for Health is securing the NHS Care Records Service, including the Summary Care Record, with the highest levels of IT security. Staff must have a legitimate relationship with the patient and a smartcard and access code.
- 2.5. HealthSpace will provide members of the public with a secure and personal health portal accessed through the internet. It was launched in 2004 to provide people with secure access to their personalised health information and to give people personalised information to support them in making decisions about their health. HealthSpace provides people with access to Choose and Book so that patients can book hospital outpatient appointments for which they have been referred. HealthSpace will enable registered users to tailor information and services to their own health care needs and wishes, as well as allowing them to view their Summary Care Record. The Taskforce recognised the opportunities to move from the present NHS clinical record to a true patient care record that were afforded by this development.
- 2.6. Before the Summary Care Record is implemented in a geographical area, a public information programme will be carried out to explain to the public how it works. The public information programme will explain how the Summary Care Record will be used, and how, if they have concerns, members of the public, following discussion of the issues with their GP, nurse, hospital doctor or other clinician, can limit the sharing of their information through the Summary Care Record.

### **3. Our Approach**

- 3.1. The Taskforce met four times between 7 September and 5 December 2006. The chair also met individually with a number of stakeholders during this time.
- 3.2. The Taskforce makes recommendations many of which should be included in the implementation of the Summary Care Record in the early adopter sites planned for 2007. The recommendations are made in the context of the wider National Programme for IT in the NHS. They are also based on our understanding of the proposals for the Summary Care Record, as described in section 2, and should be understood accordingly.
- 3.3. To inform its work the Taskforce received presentations on the content of the summary record, criteria for the early adopter sites, sealed envelopes, the experience of other countries and areas of the UK in developing electronic health records, and security systems.
- 3.4. Some members of the Taskforce visited the Veterans Health Administration in Washington to learn about the operation of their electronic patient record system (VISTA) and the pilots of their patient access approach My Health<sub>e</sub>Vet (MHV). We also obtained information about the electronic patient record being introduced in France (le Dossier Médical Personnel – DMP) and on the

approach adopted in Scotland with the emergency care record, and in the Wirral and in Hampshire where shared record systems are already in operation.

- 3.5. The Taskforce benefited from information from a number of professional advisors (see Annex 1). We are grateful to them; they have given freely of their time and have been on hand to provide technical advice on matters with which we were not all familiar.
- 3.6. We wrote to 23 clinical and patient organisations inviting them to submit evidence to the Taskforce. A list of organisations and those which replied appears at Annex 2. All the organisations which did reply supported the implementation of the Summary Care Record and of the NHS Care Record Service. The Royal College of Radiologists welcomed the introduction of the Summary Care Record as 'a real benefit to patient care' and were keen to be involved in its implementation. In particular, they felt the principal benefits of the record would include increased accuracy of information and improved quality of patient care and patient outcomes. The Royal Pharmaceutical Society of Great Britain felt that the summary record would improve patient safety. The College of Emergency Medicine wrote that the fragmentation of emergency care means that improved communications are essential. The Ambulance Service Association expressed similar views.

#### **4. The issues**

- 4.1. At the start of its deliberations the Taskforce acknowledged that there were a range of issues which were causing genuine concern to different clinical, managerial and patient groups. We wished to understand better the basis of these concerns and to make recommendations to address them. A list of the issues is shown at Annex 3.
- 4.2. In particular we acknowledge the clear difference of view between both the BMA and the Ethics Committee of the RCGP on the one hand and the Department of Health, its advisors and many Royal Colleges on the other, over issues of consent. Concerns about data quality in clinical records compounded the issue. We hope that our recommendations will allow these differences to be explored and resolved during the early adopter phase of the Summary Care Record.
- 4.3. It is worthwhile describing briefly two ethical positions on the most appropriate model of consent to be adopted for the Summary Care Record. This concerns the question of whether the creation of a Summary Care Record for a particular patient should require that patient's explicit consent, or whether, following a public information programme consent should be assumed and the Summary Care Record created unless the patient makes an explicit decision for this not to happen (or for it to be deleted at some future point). These two positions are often referred to as the opt-in and the opt-out models and each has strong ethical arguments in its favour (These are set out in paragraphs 4.4 and 4.5 below). A third approach, that of making the summary compulsory (as electronic records are in say the Veterans Health Administration in the USA), has not been considered or proposed by the Taskforce or by the Department of Health.

- 4.4. The explicit consent (or opt in) model is considered by its advocates to be preferable to implied consent (or the opt out) model. This is because it requires an explicit decision made by the patient and therefore makes it possible to be confident that information will not be available on the Summary Care Record where the patient does not wish this. An explicit decision about particular information would also make it possible for patients to check the accuracy of data and to discuss with their GP any sensitive issues, prior to their information being made available for sharing. For the advocates of the opt in model, explicit consent is real consent and it is a fundamental ethical principle of medicine that practice should be guided by consent. Explicit consent reinforces the relationship of trust between a GP and patient.
- 4.5. The implied consent (or opt out) model is considered by its advocates to be preferable because reliance on an explicit model of consent will mean that significant sections of the population, probably the most vulnerable, for example the elderly, will not benefit from the improvements in care accruing from the availability of health care information in emergency situations. Most people would wish to benefit from such information in an emergency. Thus, the advocates of opt out consent argue, the opt in model fails to take seriously the wishes of significant numbers of patients. This could also be seen to be unjust because it would disproportionately affect the most vulnerable. The advocates of the opt out model point out that implied consent is already standard practice in much of medicine. They are also concerned that the time and resources required to obtain explicit consent from the whole population individually will mean many years' delay in realising the benefits of the Summary Care Record and would not make best use of valuable health care resources.
- 4.6. We also recognise the context in which the NHS Care Records Service is being created. Clinicians, especially GPs, have a long history of IT use and many have developed significant expertise in the use of electronic record systems and see themselves as protectors of patient information. IT systems in primary care have been created bottom-up and, within their limitations, work well for individual practices. The case that the Summary Care Record is essential for modern clinical care is not yet universally accepted. The Taskforce noted the successful implementation of summary records in Scotland and a part of Wales.
- 4.7. Many patients and patient organisations recognise the potential benefits of the Summary Care Record. These range from the simple practical advantage of less frequent repetition of basic personal information to a variety of healthcare professionals, through to improved care and safety especially when accessing care in a new and unfamiliar environment. Many patients express concern about lost paper records, inefficient appointment systems and unnecessary repetition of tests. Whilst they may be worried about confidentiality they recognise that with proper management the benefits of the Summary Care Record will be considerable. The Taskforce also acknowledges that for a small number of individuals an electronic shared care record is unacceptable.
- 4.8. The content of the Summary Care Record has been a matter for debate. It must be made clear to patients that the handling of particularly sensitive data, including medications, will be agreed with them. Broadly speaking, until it is

possible to seal off parts of the record, content should be limited to non-sensitive information. The Taskforce discussed the proposal that the initial summary should contain only current medications, adverse reactions and allergies. The Taskforce is in agreement with this proposal but were clear that as the system matured the content should become more complete and include individual care plans.

- 4.9. As the first clinical data to be uploaded onto the NHS Care Records Service will be data from primary care practice clinical computer systems it is imperative for safety that the summaries uploaded in this process are accurate and are understandable by other clinicians using the Summary Care Record. The information put into the record must be of sufficient quality to be fit for sharing. Electronic health records have been widely used in general practice for years. It is clear from experience in the GP2GP record transfer project, and from data accreditation work supporting the IT Directed Enhanced Service that different clinical computer systems structure and prioritise data in different ways, and that there is inconsistency in record keeping amongst GPs. This has been recognised by both the GPC and the RCGP. Work needs to be done to define standards for patient records in general practice, from which the Summary Care Record on the NHS Care Records Service will be drawn. The Taskforce therefore recognises that the introduction of the summary record both potentially increases the risk of incorrect information being more widely shared and provides an opportunity to create a protocol to ensure that data are fit for sharing. Our recommendations address this. The Taskforce is aware of the developments in team-based care delivery and believes that the work around standards for information fit to share should support a team based approach.
- 4.10. One of our recommendations is that a Summary Care Record Advisory Group is established to oversee the issues and their resolution which derive from the early adopter sites. The Group should include significant stakeholders including patients as well as clinical and managerial users in the NHS. Such a Group will bring expertise and experience to bear on the issues and should help to bring both practical advice and user confidence to the process. It should play an important role in monitoring and learning from the early adopter sites.
- 4.11. The Taskforce noted the technical challenges of access to the Summary Care Record by mobile healthcare workers, such as paramedics and community nurses, but were clear about the value of achieving this. They were also clear that it was a responsibility of local Registration Authorities to ensure that secure and practical procedures were available to deal with all staff, including agency and bank staff, who would have a legitimate need for access to the electronic care records.
- 4.12. A public information programme which promotes real understanding by patients of the Summary Care Record is essential before any information is uploaded. The public information programme must give a clear and realistic timetable to allow patients to view the proposed summary and set limits on sharing, should they wish to do so. This could be done, for example, by contacting their GP or viewing their record on HealthSpace.

**4.13.** The Taskforce envisages that the process of creating Summary Care Records in an area would follow this outline: the public information programme should inform patients that they have a defined and realistic period of time to review their proposed summary record, for example by viewing their proposed summary on HealthSpace or by asking to see a printed copy provided by their GP, should they wish to do so. Patients would be invited to correct or amend their record and offer explicit consent for their record to be shared. Some patients may ask for their Summary Care Record not to be shared or up loaded at all. How this could be achieved should be considered by the Advisory Group described in recommendation 8. After a realistic period of time, it would be assumed that those patients who have chosen not to view their Summary Care Record are giving implied consent for it to be shared in appropriate settings.

4.14. Members of the Taskforce are convinced of the clinical, managerial and strategic benefits of the creation of the NHS Care Records Service. They felt that the Summary Care Record will bring benefits and these would be maximised as more detailed information is included. The potential for self-management and patient empowerment is very great and we welcome the development of HealthSpace. Many patients and clinicians around the world are already enjoying the benefits of electronic record systems and we note that NHS Care Record Service will provide more choice, functionality and security than many of those. However we also note that the sheer ambition of the NHS Care Record Service presents great challenges to successful implementation as does the dispersed, localised and fragmented nature of the National Health Service. The importance of building public and clinical confidence in the NHS Care Records Service and therefore societal consent cannot be underestimated.

## 5. Recommendations

- 1. The concept, implementation and operation of the Summary Care Record should be as straightforward and practical as possible.**
- 2. In implementing the Summary Care Record the programme should make haste slowly.** It is essential that problems, faults and practicalities are resolved before the system becomes widely available but also that it is implemented as soon as possible so that its benefits are realised for both service users and service providers.
- 3. The implementation of HealthSpace should be brought forward and introduced in at least half the early adopter sites.** This should give patients a reasonable period of time to view and check the information in their Summary Care Record and to take decisions about the extent to which their record is shared, should they wish to do so. The provision of HealthSpace in early adopter sites will allow comparisons to be made between both implied and explicit consent models and also allow an assessment of the value of patient involvement in data quality.
- 4. We recommend that the RCGP, working with the BMA, the RCN, patients and other key stakeholders, be commissioned to produce standards for good electronic patient summaries in general practice and a toolkit to**

**support implementation.** These standards should be evidence based, encompass the work of all clinicians, the design of computer systems, and patients' viewing of their record. All these stakeholders need to be engaged in the process, and once developed the standards should be passed to the Information Standards Board so that, once approved, they will apply in all care settings and also to the development of new systems. This toolkit could be tested during the early adopter phase of implementation.

5. **In all early adopter sites steps should be taken to ensure equity of personal access to information on the Summary Care Record for both those using HealthSpace and those not.** People using HealthSpace will have direct access to the summary. People not doing so should be able to ask to view or have a print-out of their summary record and offered an opportunity to give explicit consent or to place restrictions on sharing.
6. **NPfIT should produce a training package for staff using the Summary Care Record.** Such a training package might include the principles and application of the Care Record Guarantee in relation to the security and confidentiality of the Summary Care Record and also how patients may limit their participation in data sharing.
7. **Providers should support effective implementation of the Summary Care Record by ensuring that all relevant staff using the record receive the appropriate training proposed in recommendation 6.** The Taskforce recognises the time pressures that staff experience but believes that without effective training the full benefits of the system cannot be achieved and the possibility of risks to breaches of confidentiality are increased. Providers should take a key role, working closely with their PCTs in the early adopter sites, in ensuring that staff can be fully trained whilst standards of care are maintained, and should also establish whether training to use the NHS Care Records Service can be linked to formal professional training plans.
8. **That an advisory group of stakeholders drawn from patient, clinical and managerial interests is created to oversee the future development of the NHS Summary Care Record and to advise on its use.** Such a group should advise the NHS Care Records Programme Board. One of its roles would be to consider how best to address the issue of the small number of individuals who do not wish to have a Summary Care Record in any form.
9. **Patients must know what range of information is in the Summary Care Record and who will see it, and this process must continue throughout the development of the Summary Care Record.** Once sealed envelopes are available patients will have far more control over who will see their information. The summary record will become more valuable over time as, with consent, its content becomes more complete.
10. **The future content of the Summary Care Record should take account of the needs of clinical and patient users.** The advisory group in recommendation 8 should take responsibility for this, involving the appropriate stakeholders.

11. **The Summary Care Record should be implemented in a way that ensures equity of access to its benefits.** Some groups in society are more frequent users of emergency services and A&E than others. These people will benefit most from the availability of a Summary Care Record and it should be implemented so as to ensure that all groups, including those disadvantaged through poor English language skills, mobility or socio-economic status or those who are not currently registered with a GP, can benefit from its availability. The Taskforce intends that the advisory group identified in recommendation 8 will make suggestions on how the Summary Care Record might be generated for complex or disadvantaged patients, for example those who are more likely to have an incomplete or no GP record.
  12. **The early adopter programme should be used to assess the use of the Summary Care Record by clinical staff in the emergency ambulance services and NHS Direct.** The Summary Care Record has huge potential benefits for patients using the 999 emergency medical services and those being given clinical advice by NHS Direct. It is important that these benefits are realised as soon as practicable.
  13. **We recommend that regular reviews of the Summary Care Record Service are undertaken to ensure that it is delivering benefits and reducing risks.** This should include reporting on the percentage of those who take the opportunity to access HealthSpace and the incidence of reported inaccuracies in records.
  14. **A concerted effort to inform the public about the development of the Summary Care Record should be started immediately. In the early adopter sites, a public information programme should properly inform patients of their choices.** It should give a clear timetable for local implementation so they can discuss arrangements for setting limits on sharing should they wish to do so. Continuing delays in communicating with the public allow misunderstandings, uncertainties and anxieties to grow.
- 5.1. In addition to these recommendations the Taskforce made two interim recommendations in October 2006. These were both accepted by the NHS Care Records Service Programme Board but are recorded below for completeness.

Interim Recommendation 1 -

We recommend that NHS Connecting for Health consider the value of some variety of populations in the early adopter sites, recognising that this is an implementation and evaluation of the benefits phase

Interim recommendation 2 -

We recommend that the ambulance service be involved in the early adopter sites as early as is reasonably practicable

## **Annex 1**

### The Taskforce

#### **1. Members**

Harry Cayton (Chair)	National Director for Patients and the Public, Department of Health
Ursula Gallagher	Director of Quality, Ealing Primary Care Trust
Mr James Johnson	Chairman of Council, British Medical Association
Dr Beverly Malone	Royal College of Nursing (deputy Alison Kitson)
Prof. Mayur Lakhani	Chairman, Royal College of General Practitioners
Dr Hamish Meldrum	Chairman, BMA GP Committee (deputy Dr Richard Vautrey)
Prof. Michael Parker	Professor of Bioethics and Director, Ethox Centre, Oxford
Nick Partridge	Chief Executive, The Terrence Higgins Trust
Sigurd Reinton	Chairman, London Ambulance Service NHS Trust
Maria Shortis	Patient Advocate
Jan Sobieraj	Chief Executive, Barnsley NHS Foundation Trust
Mr Jim Wardrope	President, College of Emergency Medicine (deputy Dr Simon Eccles)

**Advisors to the Taskforce**

<b>Implementation</b>	Richard Jeavons, Director of Service Implementation NHS Connecting for Health
<b>Technical</b>	Paul Jones, NHS Connecting for Health
<b>Policy</b>	Ian Dodge, Director of Policy Support Unit, Department of Health
<b>Data Management</b>	Prof. Denise Lievesley, Chief Executive, The Information Centre for Health & Social Care.
<b>Social Care</b>	David Behan, Director General of Social Care, Department of Health
<b>Clinical</b>	Prof. Martin Marshall, Deputy Chief Medical Officer, DH  Prof. Michael Thick, Chief Clinical Officer, NHS Connecting for Health  Dr Gillian Braunold, National Clinical Lead for GPs  Dr Simon Eccles, National Clinical Lead for Hospital Doctors  Jan Laidlow, National Clinical Lead for Allied Health Professions  Susan Osborn, National Clinical Lead for Nursing  Prof. Mike Pringle, National Clinical Lead for GPs  Mr Ian Scott, National Clinical Lead for Hospital Doctors  Barbara Stuttle, National Clinical Lead for Nursing
<b>Information Standards</b>	Prof. Martin Severs, Chair of the Information Standards Board

**2. Taskforce Secretariat**

Catherine Pearson, Policy Support Unit, DH (Secretary to the Taskforce)

Pamela Marshall, PA to the National Director for Patients and the Public, DH

Ian Johnstone, Connecting for Health Lead, office of the National Director for Patients and the Public

## **Annexe 2**

### **Organisations invited to send written evidence.**

Ambulance Services Association  
British Dental Association  
Chartered Society of Physiotherapy  
Community Practitioners' and Health Visitors' Association  
Council of Deans  
Faculty of Public Health Medicine  
Independent Healthcare Advisory Services  
NHS Alliance  
NHS Confederation  
Pharmaceutical Services Negotiating Committee  
Royal College of Anaesthetists  
Royal College of Midwives  
Royal College of Nursing and the RCN Information in Nursing Forum  
Royal College of Obstetricians and Gynaecologists  
Royal College of Ophthalmologists  
Royal College of Paediatrics and Child Health  
Royal College of Pathologists  
Royal College of Physicians  
Royal College of Psychiatrists  
Royal College of Radiologists  
Royal College of Surgeons  
Royal Pharmaceutical Society  
Royal Society of Medicine

### **Organisations which have written to the Taskforce**

College of Emergency Medicine  
Faculty of Public Health Medicine  
Pharmaceutical Services Negotiating Committee  
Royal College of Obstetricians and Gynaecologists  
Royal Pharmaceutical Society  
Royal College of Physicians  
Royal College of Radiologists

### Annex 3 - Summary of Potential Issues in Implementation of Summary Records

History	Design	Ethics	Practical Implementation
<ul style="list-style-type: none"> <li>• Clinicians, GPs especially, have a long history of IT use which has been driven bottom up and feel they have not been adequately engaged</li> <li>• The case that the Summary Care Record is essential to modern clinical care has not been effectively made</li> <li>• Perceived lack of public trust in Government IT programmes</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of trust in the confidentiality, reliability and security of the system</li> <li>• Doubt about the security of Personal Demographics Service</li> <li>• What goes in the Summary Care Record – how to define the minimum dataset</li> <li>• Records need to reflect the needs of all clinicians not just doctors</li> <li>• Mechanisms for keeping parts of the record confidential (sealing) still unclear</li> <li>• The possibility of opting out of the Summary Care Record but not the detailed care record</li> </ul>	<ul style="list-style-type: none"> <li>• Differences of opinion over assumed or explicit consent for information sharing</li> <li>• Feeling that patients/public have not yet been properly informed or engaged – importance of education and communication</li> <li>• Individual preferences versus equity</li> <li>• Concern about how sensitive information, including health care professionals who use sensitive services will be handled</li> <li>• Patient choice versus staff safety</li> <li>• Any special provisions on confidentiality should be available on the basis of need rather than status</li> </ul>	<ul style="list-style-type: none"> <li>• Variable quality of information in GP systems</li> <li>• Link between opt in/opt out and data quality, if patient is seen as key to ensuring quality and accuracy of the record</li> <li>• Difficulty in uploading data that is currently free text</li> <li>• Ensuring that the proposed levels of patient participation in information sharing are real and work</li> <li>• Defining responsibility for maintaining the summary record</li> <li>• Who will have access to the Personal Demographics Service and what is it for – directory or integral part of system? Role-based access?</li> <li>• How far should the early adopters go in innovation rather than replicating the status quo.</li> <li>• How will organisational boundaries be defined and work in practice?</li> </ul>