

# Summary Care Records

January 2007



## What is the Summary Care Record?

The Summary Care Record is likely to be part of your patient care record in the future. Initially, it will contain information about you, your current medications, allergies and adverse reactions. This will be uploaded on to a 'national data spine' from the patient care record held by your GP. Over time, all patient records will be held electronically.

The Summary Care Record is being created as part of the National Programme for IT (Information Technology) in the NHS in England. It will not affect people living in Wales, Scotland or Northern Ireland, where different systems are being used.

## Why is the Summary Care Record being introduced and how might it help me?

The electronic patient record system is being introduced as part of the modernisation of the NHS. Currently, patient records are held in a number of places and in many ways – some on paper and some on different computer programmes. In other countries, bringing these records together has improved patient care.

The potential benefits range from the simple, practical advantage of less frequent repetition of basic personal information to a variety of healthcare staff, through to improved care and safety especially when being cared for in a new and unfamiliar environment.

Your Summary Care Record will be accessible to those who are caring for you and have the necessary security clearance. This would be helpful if, for example, you become ill away from home and your usual records are not available. It could also improve the speed and quality of your care in Ambulances, Out of Hours Centres, Walk-in Centres and A&E Departments (although dentists are not included). However, it also means that a lot more healthcare staff could see your records than is currently possible, but only if they are prepared to break the rules on access and confidentiality.

## Why is it controversial?

There has been a lot of debate on three main areas of concern – consent, content and confidentiality. THT has been actively involved in these debates, aiming to maximise the potential benefits for people with HIV and minimise the potential risks.

## What are the issues about consent?

The main issue is whether each patient should be asked for their explicit consent for their Summary Care Record to be uploaded on to the national spine or whether,

following a public information programme, consent should be assumed and the Summary Care Record created except where a patient says this should not happen. These two positions are known as the opt-in and the opt-out approaches to consent and each has strong arguments in their favour.

## **What are the issues about the content?**

There are two main issues about the content of the Summary Care Record – how to ensure the accuracy of the record and how to deal with sensitive information. Both of these issues are particularly important for people with HIV and are discussed in greater detail below.

## **What are the issues about confidentiality?**

There are two main issues about confidentiality – how to ensure the security and confidentiality of sensitive information within each patient record and how to ensure the security and confidentiality of the new electronic record system as a whole. Again, both of these issues are particularly important for people with HIV and are discussed in greater detail below.

## **Will I be asked for my consent?**

Yes and no. During 2007, the Summary Care Record will be introduced into a small number of early adopter sites where its introduction will be tested. THT will post the locations of these sites on our website when they become known.

In each of the early adopter sites there will be a public information programme informing patients about how long they will have to review their proposed summary record. *THT strongly recommends that you ask your GP to show you a printed copy of your proposed summary and agree any corrections or amendments that should be made.* You will then be asked for explicit consent for your record to be shared in appropriate settings and uploaded on to the national spine. *You can refuse permission for this to happen at this point.*

However, after a realistic period of time, if you have not asked to see your Summary Care Record *it will be assumed that you are giving implied consent for it to be shared in appropriate settings and uploaded on to the national spine.* This is why it is vitally important to ask to see your record.

## **What will be in the Summary Care Record?**

To begin with there will be relatively little information in the Summary Care Record. There will be your name, age, address and contact details of your GP. You can check that these are accurate when you see a printed copy of your record and change them if they are not.

Crucially, the initial record can contain information about current medications, adverse reactions and allergies. Consequently, *if you are taking anti-HIV drugs and your GP has a record of them, they could be part of your Summary Care Record.*

This will not be a problem for people with HIV who want appropriate healthcare professionals to know about their HIV status, should they need to. If, for example, you

are taken to A&E and staff are able to see which anti-HIV drugs you are taking, it could avoid dangerous drug interactions or prolonged delay in continuing treatment.

For others, there will be concerns about confidentiality. While there will be no indication of any diagnosis in the summary record, anti-HIV drugs would make the diagnosis obvious to most healthcare professionals, should they see your Summary Care Record. Removing anti-HIV drugs from the record of current medications will increase confidentiality but could reduce the quality of care you receive, particularly in emergencies.

*The content of your Summary Care Record has to be agreed with you. If you do not want your anti-HIV medications listed, they will not be – but only if you ask to see your Summary Care Record and agree with your GP what will be in it.*

## **Will records at my HIV treatment centre be involved?**

No, not yet. The Summary Care Record is being created from the records held by your GP. Over time, the content will increase to include a more complete part of your GP record and also information from detailed records held by hospitals and community services. This will only happen if you want it to and there will be special arrangements to strictly limit access to sensitive information. This will be held in 'sealed envelopes' which only particular people, identified by you, will be able to look into. The whole process will take many years to complete.

## **How secure will my Summary Care Record be?**

The Summary Care Record will be much more secure than current paper records. The system is being designed with the highest levels of security and will be more secure than the systems used by some banks, for example.

Some people are concerned that large numbers of NHS staff will be able to look into health records. However, any NHS staff member who looks into your record must be involved in your clinical care and have a smartcard and an access code.

For the first time, there will also be an electronic record of everyone who has tried to look at your health record, which isn't possible with paper records. The NHS has strict rules about breaching patient confidentiality and anyone who looks at a record without a proper reason and approval should be disciplined.

## **What is HealthSpace?**

HealthSpace provides secure, online access to personalised health information over the internet ([www.healthspace.nhs.uk](http://www.healthspace.nhs.uk)). You can book some hospital outpatient appointments through HealthSpace and, over time, you will be able to tailor information and services to your own health care needs and wishes, as well as being able to see your Summary Care Record.

## **What happens next?**

A small number of areas in England will be chosen as early adopter sites to test all the arrangements for the Summary Care Record. When these are known, we will post them on the THT website.

If you are concerned, talk to your GP now and make sure that he or she knows you want to see your Summary Care Record before deciding if you want it to be up loaded onto the national spine or not.

If you do not have the kind of relationship with your GP that allows you to have this conversation, now could be a good time to think about how you want to change and improve that relationship or consider moving to another GP. You can call THT Direct on 0845 1221 200 to discuss this and any of the issues about the Summary Care Record.

12<sup>th</sup> January 2007