

IF I DO NOT HAVE A SUMMARY CARE RECORD

You have decided that you do not want to have a Summary Care Record. The NHS will do its best to provide you with safe, efficient care whether or not you have a Summary Care Record. The purpose of this information sheet is to ensure that you are clear what your decision could mean for your NHS care.

The Summary Care Record's purpose is to ensure that anyone treating you has basic but important information about you - especially when care is unplanned, urgent or during evenings and weekends. At first this would be limited to your current medications, known allergies and any bad reactions to medicines in the past. When you next see your GP, important information about conditions such as asthma or diabetes could be added if you agreed. Over time, other significant information such as referrals, discharges, and test results will be added.

The information in your Summary Care Record could save you and the NHS time, but could also one day be lifesaving. The NHS has significant problems now with lost records and test results, treatment and prescribing errors.

With a Summary Care Record doctors and nurses would know at a crucial time:

- what medications you are taking, especially if they are many and complex
- what medications have not agreed with you in the past
- whether you have any allergies
- that new medications they prescribe may react badly with things you are already taking
- that you have a condition that means you shouldn't have certain medicines

In addition, you would have the benefits of:

- 24 hour access to your own Summary Care Record to check it for errors and to see what those who are treating you have recorded if you chose to view it through HealthSpace
- peace of mind that wherever in England you needed care, anyone treating you would have essential information even if you were distressed or didn't remember details.

And later on, as your Summary Care Record developed, you would be able use it to:

- see your test results as they come in
- check that your referral letters have been written
- remind yourself about important things said to you about your treatment
- inform NHS staff about your needs and how you want to be treated

It would be misleading to pretend that there are no risks to information held in the Summary Care Record. But it is also misleading to suggest that not having such a record is risk free. Substantial work is taking place to modernise the NHS, including the introduction of the Summary Care Record, in order to reduce errors, save lives and



improve health outcomes for a great many people. Modernising and computerising the NHS also brings with it new safeguards to ensure that information in your records is held more securely than in the past.

RISKS AND PROTECTIONS

Staff disclosing information. The NHS already shares information widely and most NHS staff are honest and trustworthy. There are occasional problems with staff accessing records and disclosing information inappropriately. With the new NHS systems, the number of staff who will have an opportunity to look at your clinical records when they shouldn't will be greatly reduced. Only staff with special security cards can log onto the new NHS systems. This allows the NHS to track precisely who has done or seen what - and you can ask for this information. Unlike today, staff will have to be involved in your care to access your records and they will only see information appropriate to their role.

Hackers. Safeguards that will protect the Summary Care Record from hackers have been designed by security experts. They are far stronger than the safeguards in place anywhere within the NHS today.

Wrong information. It is important that the information about you is accurate. All data that goes into a Summary Care Record will have to pass quality controls. Once you could access it, you too could check it and point out any remaining errors.

Access by the state. No other part of government would have direct access to your Summary Care Record. As now, any information from your record that the NHS gives to others, such as the police, would be very strictly limited by law. In fact, the Summary Care Record gives the opportunity to improve things by ensuring that any such disclosures follow consistent procedures and are recorded and monitored.

More control by the patient. The greatest safeguards for your Summary Care Record are that you will be able to see it yourself, know who else has seen it, and have more control than ever before over what it contains and who has access. You can ask for it to appear as a blank screen, or ask for information to be removed or not added in the first place. Later on, additional controls will allow you to let staff see some parts of your Summary Care Record, but not others.

The first Summary Care Records will 'go live' in Spring 2007 in one Primary Care Trust and slowly build from there. We will go cautiously and learn from these 'Early Adopters'. Yours will, of course, not be created when this happens.

We hope that the information provided has made clear the practical results of your decision. Please be assured that the Department of Health is committed to honouring your decision and doing all it can to ensure you get the best healthcare possible. You can, of course, change your mind at any time. We urge you to review your decision from time to time.

If you feel unsure about whether or not to have a Summary Care Record, or would like further information, please make an appointment to discuss it with your GP.

NHS Connecting for Health is supporting the NHS to deliver better, safer care by providing linked computer systems.

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