Controlling your medical records - primary uses

You have the right to opt-out of allowing your medical record to be shared, or be directly accessible, for primary purposes - for your direct medical care - beyond your GP surgery, if you so wish.

This may limit the opportunity for certain health professionals (other than those within your GP surgery) to directly access aspects of your electronic GP record in a particular way.

However, it *in no way* limits all of the other and many ways that your medical information can be made available to those who require it.

That information can, is, and always will be made available to those who require it by your GP, whether directly, by phone, fax, text, letter, email, e-referral or e-prescription.

That information can be made available by you - the patient - directly, by temporarily giving the health professional secure online access to your medical record, or by many of the other ways in which you can share information with health professionals outside of the surgery.

You can control your personal confidential information by expressing an objection, or *opt-out*, to your GP surgery, who will then add a special read-code, or electronic flag, to your GP record.

Individual schemes sharing data between your GP record and other healthcare professionals may require individual electronic flags to be set.

Opting out of any or all of these schemes is as simple as filling in a form and getting it to your GP surgery.

You can opt back in to primary uses of your GP record at any time in the future.

You can opt back in and allow *all* the primary use schemes to extract and upload, or stream your data, or you can opt back into each scheme individually, as you prefer.

There are many such schemes, some allowing direct access to your GP record, others extracting and uploading information from your GP record to a 3rd party database, and some that you control completely.

You can find out about primary uses data sharing schemes, including the NHS Databases, and NHS data sharing in general, as well as a suitable opt-out form, at:

www.nhsdatasharing.info

When it comes to allowing healthcare professionals outside of your GP surgery access to information from your GP record, you have many *options*:

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- You do not have to allow any such access by opting out of all such schemes
- You can allow *nationwide* access to limited information from your GP record (allergies and medication) by not opting out of The Summary Care Record
- You can allow your entire GP record to be extracted, uploaded, combined with your information from hospital trusts, mental health services, social services, and community services, and made available regionally
 - Your combined data may also be used for secondary purposes (unrelated to your direct medical care)
 - You can do this, depending on where you live, by not opting out of your local clinical data repository scheme (e.g. HHR, SCR, SIR, CCR)
- You can allow your GP record to be streamed or viewable in real time, locally, without being uploaded or extracted, and with genuine control over the information shared, by allowing data streaming
- You can control access to your GP record, completely and personally, by allowing temporary secure online access to your GP record, should you have chosen to enable this
 - In theory, your information is available to healthcare professionals worldwide, should you allow it in any given situation
- If you have enabled secure online access for your GP record, then you can export your record and either print it off or save it securely on a mobile device, and then take it with you to show a healthcare professional when needed (e.g. during an outpatient appointment)
- If you live in Berkshire, Hampshire, Oxfordshire, Buckinghamshire, on on the Isle
 of Wight, then you can register to self-upload medical (and any other) information
 about yourself to the Auxilium secure database, which allows Ambulance trusts to
 access that information should they need to attend you.
 - More information about this system is available in this factsheet
- If you live in areas covered by South East Coast Ambulance Trust (SECAMB), your GP can, with your explicit consent, upload information about you, or a care plan, to their bespoke and secure IBIS (Intelligence Based Information System) database, and so allow that information to be accessible to ambulance crews to enable them to have up to date information about your health and about your care plans and needs (see video here)
- If you live in London then your GP might be able to upload a care plan about you
 to the <u>Coordinate My Care (CMC) database</u>, making that information available to
 the ambulance services (LAS and SECAMB), NHS 111 operators, GPs, out of hours
 GP services, hospitals, nursing and care homes, hospices and community nursing
 teams
- Your GP, with your explicit consent, can upload information about you, or a care plan, to your local GP out-of-hours or urgent care centre, and make that information available, via the widely used Adastra software and database, to healthcare professionals, should you have need to see someone when your GP surgery is closed
- You can choose to share information in many other ways for example, medical alert cards (such as <u>MediPal</u>, <u>Steroid alert cards</u>, <u>Biological therapy cards</u>, <u>rare</u> <u>diseases cards</u>, even <u>bus pass cards</u>), medical alert jewellery (such as <u>MedicAlert</u>, <u>SOS Talisman</u>), <u>Zaptag</u>, <u>Tap2Tag</u> and <u>EIO smart cards</u>, and personal health apps such as <u>Evergreen Life</u> or <u>SiKL</u>