

Data Opt-Outs – CRAGS HEALTH CARE Protocol

Summary Information to give to patients:

You can choose whether your confidential patient information is used for **research and planning**. To find out more visit nhs.uk/your-nhs-data-matters. Or read leaflet available on reception ‘Your Data Matters to the NHS’

You do not need to do anything if you are happy about how your confidential patient information is used. You can change your choice at any time.

Type 1 opt-out: medical records held at your GP practice

You can tell your GP practice if you do not want your confidential patient information held in your GP medical record to be used for purposes other than your individual care. This is commonly called a type 1 opt-out. This opt-out request can only be recorded by your GP practice.

Type 2 opt-out (National Data Opt-out): information held by NHS Digital

Previously you could tell your GP practice if you did not want us, NHS Digital, to share confidential patient information that we collect from across the health and care service for purposes other than your individual care. This was called a type 2 opt-out.

The type 2 opt-out was replaced by the national data opt-out. Type 2 opt-outs recorded on or before 11 October 2018 have been automatically converted to national data opt-outs.

Detailed information for patients:

Sharing your records: your personal information

Information about you is used in a number of ways by the NHS and social care services to support your personal care and to improve health and social care services for everyone.

The Health and Social Care Information Centre (HSCIC) is the national NHS organisation with a legal responsibility to collect data as people make use of NHS and social care services. The data is used both at a local level and nationally to help with planning, managing your care, supporting research into new treatments, identifying trends and issues and so forth, and is used to try to make services better for all.

You can, however, choose not to have information about you shared or used for any purpose beyond providing your own treatment or care.

Your right to opt out

You can choose not to have anything that could identify you shared beyond your GP practice (Type 1 objection). You can also choose for the HSCIC not to share information it collects from all health providers any

further (previously known as Type 2 objection, now National Data Opt-out).

If you have previously told your GP practice that you don't want the HSCIC to share your personal confidential information for purposes other than your own care and treatment, your opt-out will have been implemented by the HSCIC from April 29 2016. It will remain in place unless you change it.

You can find more information about how the HSCIC handles your information and choices and how it manages your opt-out on the HSCIC website www.hscic.gov.uk/yourinfo

Instructions for staff:

If a patient wants a Type 1 opt-out, provide them with 'Patient Health Records – Refusal to consent' form, Appendix 1, to complete. Then pass to PM for implementation.

If a patient wants a Type 2 opt-out, direct them to nhs.uk/your-nhs-data-matters as they must now do this directly with NHS Digital.

Further Info for staff: Information Sharing

The HSCIC has a statutory role to collect and process health and social care information which is set out in the Health and Social Care Act 2012.

The HSCIC's fair processing materials, available at <http://www.hscic.gov.uk/patientconf>, explain and provide further information on:

- what HSCIC collects - the types of information the HSCIC collects and what it's used for
- personal information choices - people's rights regarding care information
- information requests from organisations - how organisations can ask HSCIC to collect or provide access to care information
- assurance bodies and processes - how the information requests HSCIC receive are carefully looked at
- examples of benefits that have been realised through the provision of such information including case studies involving breast cancer and diabetes that are available at:
<http://www.hscic.gov.uk/benefitscasestudies/extracts>

The HSCIC is absolutely committed to keeping all of the data it handles safe and secure and applies the same principle to any data that is released outside of the organisation.

Information is only ever shared with organisations that have gone through a strict application process, who can demonstrate they have a legitimate reason to access the data to use it for the benefit of health and care purposes, as per the new protections introduced as part of the Care Act 2014, and who have signed a legally binding agreement. So for example commercial companies cannot receive information for insurance or marketing purposes.

As part of the application process the Data Access Advisory Group, an independent group, hosted by the HSCIC, considers all applications for data that are identifiable or de-identified for limited access.

The HSCIC also regularly publishes a register of data releases at: <http://www.hscic.gov.uk/dataregister>, showing where data has been released, to which organisation and for which purposes.

If your patients do require any further information that is not already covered within our web pages we can be contacted by email at enquiries@hscic.gov.uk or by phone on 0300 303 5678.

Appendix 1

CRAGS HEALTH CARE Surgery

Patient Health Records - Refusal to Consent – Type 1 Objection

Type 1 Objection: I am writing to give notice that I refuse consent for my identifiable information and the identifiable information of those for whom I am responsible (delete as appropriate) to be transferred from your practice systems for any purpose other than our individual medical care.

Please take whatever steps necessary to ensure my confidential personal information is not uploaded and record my dissent by whatever means possible.

This includes adding the ‘Dissent from secondary use of GP patient identifiable data’ code (Read v2: 9NU0 or SNOMED 827241000000103) to my record.

I am aware of the implications of this request, understand that it will not affect the care we receive and will notify you should I change my mind.

Type 2 Objection (National Data Opt-out): I understand that if I do not want NHS Digital to share confidential patient information that they collect from across the health and care service for purposes other than for my individual care, I must visit nhs.uk/your-nhs-data-matters or call 0300 303 5678 to action my wishes.

Signature: Date:

Full Name:

Address:

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Postcode:

Date of Birth:

NHS Number (if known):