

**National Data Opt-out
&
Primary Care information**

use MY data report

September 2018

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Introduction

The National Data Opt-out was introduced on 25 May 2018. In the initial months after its introduction, information from several use MY data members indicated that their GP practice had given either confusing or erroneous information about the National Data Opt-out and patient data choices.

While hoping that the examples were not typical, we thought it would be useful to find out by casting the net wider amongst our membership, with the aim of feeding back in the first instance to the Royal College of General Practitioners (RCGP).

use MY data has been actively engaging with primary care for some time, in order to understand the challenges primary care faces in relation to patient data and learn how members might assist in this area.

Methods

use MY data members and associate member were contacted via email to ask if they wished to share information about how their local practice was communicating information about the National Data Opt-out. Information was collected via an online survey which ran from 1 to 31 August inclusive.

There were 27 responses to the survey and the results are presented here in full.

Following the survey closing, we undertook a limited amount of research of the privacy notices relating to the general practices identified and a general search of privacy notices from practices. Findings from this research are also included in this report.

Dissemination

Dissemination is planned in two parts.

Part 1:

- use MY data's Coordinating Group
- Royal College of General Practitioners
- NHS Digital
- NHS England
- National Data Opt-out Advisory Board

Part 2:

- use MY data members and associate members
- Publication on use MY data website & associated publicity

Summary of findings

- 1) Responses indicate that limited information about the National Data Opt-out has been provided by general practices.
- 2) References, links and pages to the abolished Care.data programme are still live on several general practice websites and materials.
- 3) Where general practices provided materials about the National Data Opt-out, the materials varied in terms of style, scope and substance.
- 4) There was a clear lack of consistency in the explanatory wording used around the National Data Opt-out.
- 5) Generally (though not in all cases), there is a significant amount of information about the GDPR legal basis under which general practices operate.
- 6) There was evidence of commonality of content in privacy notices across some practices, particularly in relation to the data being processed and one's rights as an individual data subject.
- 7) In contrast, there was little specifically about the National Data Opt-out on general practice websites or privacy notices.
- 8) When they were given, the links to find more information about the National Data Opt-out were frequently incorrect (several just pointed to the NHS Choices website).
- 9) Several general practices stated that patients may still make new Type 1 and Type 2 objections, as before, and didn't highlight the new National Data Opt-out process.
- 10) There were many inaccuracies, incomplete or misleading statements about data options (examples are shown on pages 5 to 8).

Contact details

Please direct any enquires about the report to coordinator@useMYdata.org.uk

Examples of information given by general practices – part 1

Incorrect information

The statement incorrectly says that the opt-out covers the use of your data for providing local services. The opt-out only covers research and planning.

As of the 25th May 2018, residents have the right to opt out of your personal confidential information being used for the following purposes.

- Providing local services and running the NHS and social care
- Supporting research and improving treatment of care

To set an opt-out preference, NHS Digital will offer digital (online) and non-digital national data opt-out systems.

For further information and support relating to opt-outs, please contact [NHS Digital](#)

Inadequate privacy notice

This was the total extent of the privacy notice on the website.

GP PRACTICE PRIVACY NOTICE

The Practice shares your diabetes related data with the Diabetic Eye Screening Programme operated by Health Intelligence (commissioned by NHS England). This supports your invitation for eye screening (where you are eligible and referred by the Practice) and on-going care by the screening programme. This data may be shared with any Hospital Eye Services you are under the care of to support further treatment and with other healthcare professionals involved in your care, for example your Diabetologist.

For further information, take a look at Health Intelligence's Privacy Notice on the diabetic eye screening website: [www.\[website\].nhs.uk](http://www.[website].nhs.uk)

Examples of information given by general practices – part 2

Out of data information

The information describes the situation pre-National Data Opt-out and has not been updated.

Type 1 opt-out

If you do not want personal confidential data information that identifies you to be shared outside your GP practice, for purposes beyond your direct care you can register a type 1 opt-out with your GP practice. This prevents your personal confidential information from being used other than in particular circumstances required by law, such as a public health emergency like an outbreak of a pandemic disease.

Patients are only able to register the opt-out at their GP practice.

Records for patients who have registered a type 2 opt-out will be identified using a particular code that will be applied to your medical records that will stop your records from being shared outside of your GP Practice.

Type 2 opt-out

NHS Digital collects information from a range of places where people receive care, such as hospitals and community services.

To support those NHS constitutional rights, patients within England are able to opt out of their personal confidential data being shared by NHS Digital for purposes other than their own direct care, this is known as the 'Type 2 opt-out'.

If you do not want your personal confidential information to be shared outside of NHS Digital, for purposes other than for your direct care you can register a type 2 opt-out with your GP practice.

Patients are only able to register the opt-out at their GP practice.

Examples of information given by general practices – part 3

The impact of media stories

The National Data Opt-out is focused on research and planning. The statement at this practice specifically mentions the Memorandum of Understanding between the Home Office and NHS Digital. Such data releases, if made, are covered by a completely different legal basis.

NHS Digital sometimes shares names and addresses of patients suspected of committing immigration offences with the Home Office. More information on this can be found here:

<https://www.gov.uk/government/publications/information-requests-from-the-home-office-to-nhsdigital>

Extract from GP Newsletter

The extract conflates the different elements of the General Data Protection Regulation (GDPR) and the National Data Opt-out, confusing a legal requirement with a policy requirement.

It could potentially cause confusion, as some patients may read this and think they have to opt-in, to share their data (rather than only those who opted out wishing to opt back in, if they would like to share their data for research and planning).

NEWS – DATA PROTECTION

Over the past few years, some you may have chosen to opt out of sharing your NHS records for research. As you will know by now, rules for data protection changed on 25 May. However, your original decision is still valid and will be respected by the NHS, and no action is needed by you to continue opting out.

However, if you do wish to reconsider, you can opt in to data sharing on line at www.nhs.uk/your-nhs-data-matters

Examples of information given by general practices – part 4

Incorrect information – both extracts are from the same data information leaflet at a general practice

The information describes the situation pre-National Data Opt-out and has not been updated.

CARE DATA – BETTER INFORMATION MEANS BETTER CARE

For more information please go to www.hscic.gov.uk/patientconf or ask at reception

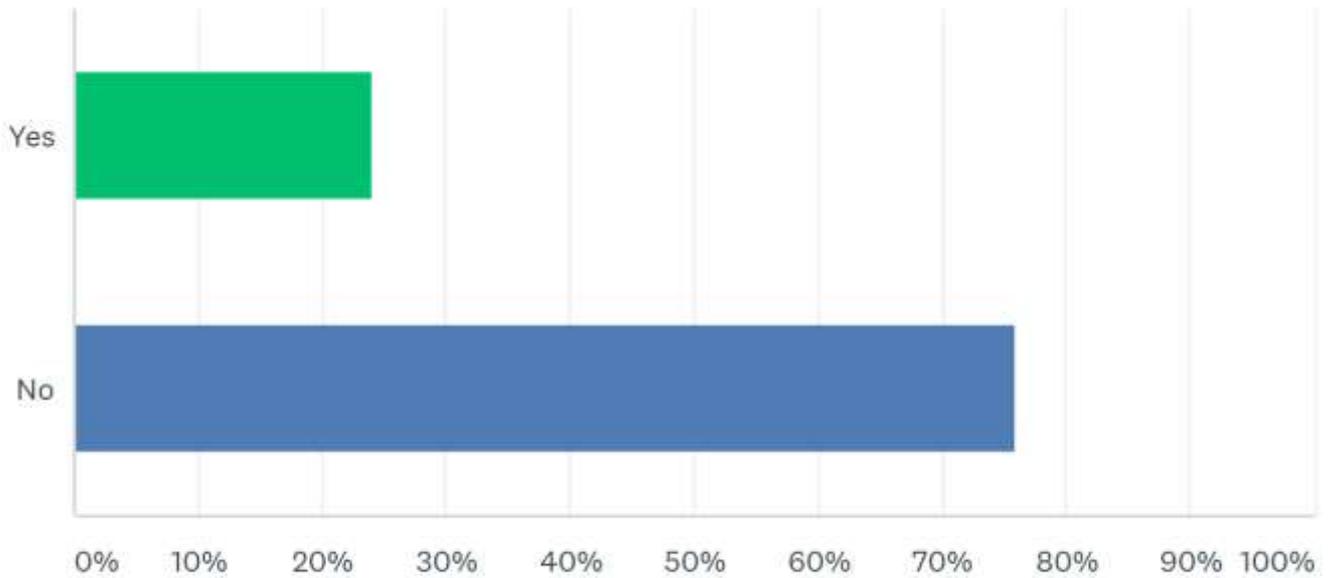
The information says that patients can opt out of “all” data collection.

You have a right to object to your information being shared. Should you wish to opt out of all data collection, please contact a member of staff who will be able to explain how you can opt out and prevent the sharing of your information. NHS Digital will enable an online national data opt out from the 25th May 2018. Information can be found out

<https://digital.nhs.uk/services/national-data-opt-out-programme>

Question 1 – Has your GP practice provided information about the National Data Opt-out?

Overview



The majority of respondents reported that their general practice had not provided information about the National Data Opt-out.

Many of the comments provided showed text extracted from websites and privacy notices. There was notable variation in the wording used regarding the National Data Opt-out, such as using the term “research” in isolation rather than “research and planning”, the term which applies to the National Data Opt-out.

Free text comments

All of the detailed comments are included here. In some cases an explanatory note has been added (in red).

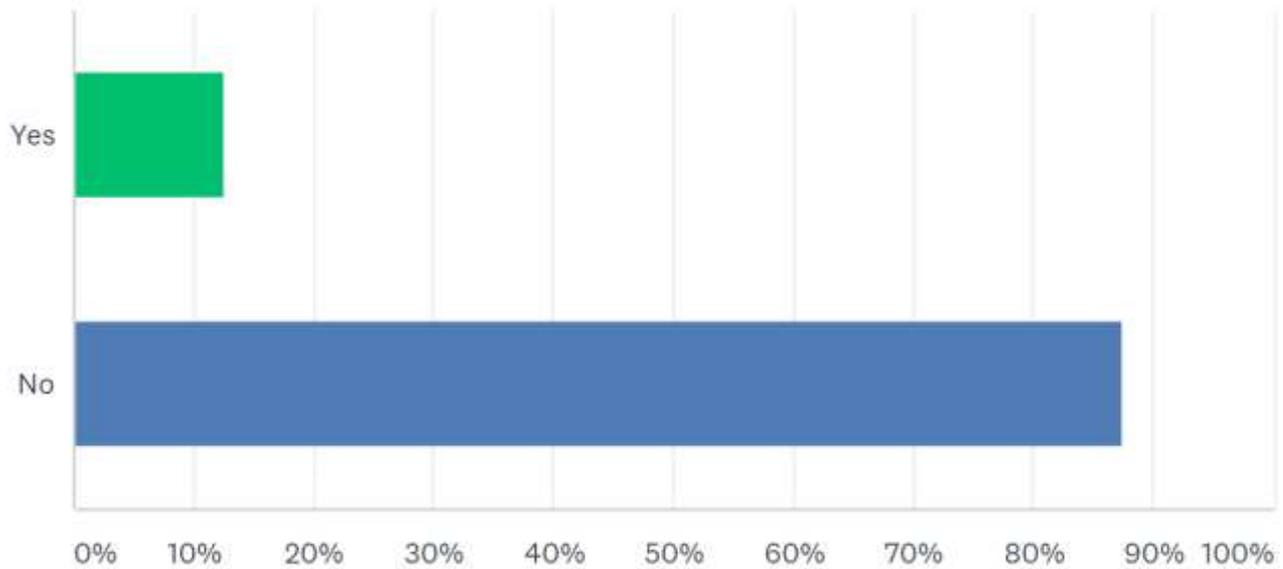
- *Leaflets and posters in the surgery*
- *Not that I am aware of...*
- *On their website under DATA it set it all out clearly ending with: If you would like to opt out of this data collection scheme, please let your doctor know and no data from your records will be collected for use in research. This will not affect your care in any way. If anything to do with the research would require that you provide additional information about yourself, you will be contacted to see if you are willing to take part: You will not be identified in any published results.*
 1. The term "research" is used, but the correct term used in the National Data Opt-out wording is "research and planning"
 2. The wording also states that if you object then data will not be collected for use in research. This is not strictly true, as the data is collected as part of your care and then supplied for research afterwards.
- *Leaflets in the surgery*
- *There should be a 'don't know' option to this question. They may well have provided information somewhere, but I don't know about it.*
- *I visited the Practice website to see if there was any information available. There is a short entry at the bottom of their 'Sharing your information' page. It hasn't been featured on their website news.*
- *Newsletter from them. Not been in surgery so don't know about posters, leaflets.*
- *In a privacy information leaflet on the reception desk. I found this when I went to a PPG meeting. The information was incorrect on two counts:*
 - 1) *It said that Care.data is still running &*
 - 2) *It said that under the National Data Opt-out patients can opt out of ALL of their information being used, rather than opting out of their confidential patient information being used for planning & research.*
 1. The Care.data programme was abolished in 2016.
 2. The National Data Opt-out is very clear that it only covers planning and research.

- The Practice website does have information, but it's not obvious to find. When you do find it, it says "You have a right to object to your information being shared". It isn't any more specific, but it does then say you can discuss it with a member of staff and it correctly states that the National Data Opt-out is done via a weblink (or call centre) from NHS Digital. The website also states, "The practice may be requested to support research; however, we will always gain your consent before sharing your information with medical research databases such as the Clinical Practice Research Datalink and Q Research or others when the law allows". I don't believe I have been asked this question.*

 1. There may be another follow-up required, about how data from general practices reaches the Clinical Practice Research Datalink or similar databases. We had been led to believe that this was a GP-level decision, but that any Type 1 or Type 2 objections would be upheld by the general practice.
 2. The Clinical Practice Research Datalink website section for general practices states that practices can "*Earn extra income for the practice by taking part in questionnaires and clinical studies*". Given the spectrum of views about the NHS 'selling' its data, this could be worth exploring, as it might provide useful evidence as to how these financial transactions are benefitting patient care.
- I have just registered with my practice after moving to a new house. I was given a leaflet to read. When I checked the website it also had a link to something called the "Sheffield Shared Record". I couldn't find the leaflet, or anything about my privacy or rights on the website at all. When I used the search function I found one link for "privacy". That then showed me a Privacy Notice.*
- I have not seen or heard any information at my GP practice. Many years ago when it started I opted out but then I changed my and gave the message that I want to opt in. Some months ago when I had the minimum health record on my website I noticed that it said opted out, so I went to the surgery I told them that I have opted in. I cannot find anything on my website (not updated). While the surgery is very good, I guess they are overloaded and most of the patients speak very poor English which cannot be helpful for this kind of exercise.*

Question 2 – Have you spoken with your Practice about the information provided?

Overview



Half of the respondents who had received some information from their general practice had contacted the practice for more details.

Free text comments

- *I checked the practice website and asked for information at reception. The receptionist was unaware of the National Data Opt-out and said she would send me any information the practice had. I have heard nothing from the practice.*
- *Staff were well-informed and very clear.*
- *Yes. I spoke to the Practice Manager - they have been delegated the task of understanding the implications of GDPR and the National Data Opt-out for the Practice.*
- *Thank you & they will look into it.*

Question 3 – If you like to provide the name of your Practice

Nearly 70% of respondents gave details of their GP or Practice:

- Albion Medical Centre, Ashton-under-Lyne, Greater Manchester
- Allerton Medical Centre LS7 4LF
- Arlington Road Surgery, Eastbourne
- Ash Surgery L17
- Bramhall Medical Park Centre
- Dr Dawoud Surgery - Clayton Le Woods
- Dr K Khatri
- Eastham Group Practice
- Haslington Surgery
- Heaton Mersey Medical Practice
- Hilly Fields Medical Centre, London SE4
- Holmes Chapel Health Centre
- Hulme Hall Medical Group
- Kenmore Medical Centre, 60-62 Alderley Road, Wilmslow, Cheshire SK9 1PA
- New Bank Health Centre 339 Stockport Road Longsight Manchester M12 4JE
- Northenden GP, Palatine road, Manchester
- Schopwick, Elstree WD6

About use MY data

use MY data is a movement of patients, carers and relatives

use MY data supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.

use MY data endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.

use MY data aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

What we do

- ❖ We promote the benefits of sharing and using data to improve patient outcomes with sensible safeguards against misuse.
- ❖ We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
- ❖ We provide learning resources for patient advocates on patient data issues, including:
 - hosting workshops for patients and the public, focussing on topics related to patient data
 - a library of resources of data security, consent
 - narratives from individuals about how collecting, storing and using data can help patients.
- ❖ We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.

www.useMYdata.org.uk
getinvolved@useMYdata.org.uk
 **[@useMYdata](https://twitter.com/useMYdata)**