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Our ref: FOI-16/122

18 April 2016

Dr Neil Bhatia
request-322339-9e335134@whatdotheyknow.com

Dear Dr Bhatia

I am writing to confirm that the relevant departments have now completed their search for the information which you requested on 15 March 2016. The Trust is now able to provide you with the following information in relation to your request.

- *Please could you inform me of the types/nature of information that you are, and/or plan to be, extracting and uploading to the MCR database*

All inpatient, outpatient and Emergency Department activity plus results and referrals for the last 12 months from the point that Graphnet asks us to track the patient.

I am aware of the opt-out arrangements available at contributing GP surgeries. However, I am interested in how patients can (or if they cannot) prohibit your organisation from extracting and uploading information to the MCR database in the first place (processing of their data which would have no purpose or justification if they have already opted-out of the MCR at their GP surgery).

- *Please could you tell me process available to patients to express dissent to *you*, for this type of processing of their data, and so block extraction uploading of all their personal confidential data to the MCR database by your organisation*

Please refer to the Graphnet document 'G-Technote 23: Opt-in/Opt-out process' attached to the end of this letter.

- *Please could you tell me whether the data controller for the MCR database informs you when patients have opted out of having a shared record (e.g. having opted out at their GP surgery), which would in theory allow you to switch off your feed to the MCR database for that patient's information*

No. We do get "stop tracking" notifications that a Care Plan has ended which means we stop sending data.

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If you are unhappy with the service you have received in relation to your request please do not hesitate to contact me and I will try to resolve the situation, alternatively should you wish to make a complaint you can write to:

Elizabeth Radahd
FOI Administrator
Wythenshawe Hospital
Southmoor Road
Manchester
M23 9LT

Or you can email your comments to FOI@uhsm.nhs.uk

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Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

If you have any queries about this letter, please contact me on the details above.

Kind regards

Yours sincerely



Mandy Bailey
Chief Nurse/Executive Director for Risk & Governance

Enc

G-TechNote 23: Opt-in/Opt-out Process



As Graphnet implementations are in the main focussed on patient care by clinicians, the general approach to electronic record sharing is to assume consent. This means that unless the patient states that they do not want to have their data shared then it can be. Once a patient has recorded their objection to having their data shared then medical data cannot be extracted from the GP system for that patient and any data stored on shared locally has to be removed. The GP records an Opt-Out code to do this.

If a patient in the future wants to have shared records then they must have an Opt-In code recorded against them and their record is rebuilt.

Graphnet implementations do not upload to the national *Summary Care Record* (SCR) and therefore the consent criteria (and the Read2/CTV3 relevant codes: 9Nd1./XaXbX; 9Ndm./XaXbY; 9Ndn./XaXbZ and 9Ndo./XaXj6) applying specifically to the SCR are not relevant to Graphnet implementations.

There are a number of codes that can be applied to a patient's clinical record if they wish to Opt-out of or Opt-in to electronic record sharing, the codes currently in use are:

Read Codes (v2)

93C0.	Consent given for upload to local shared electronic record
93C1.	Refused consent for upload to local shared electronic record
93C2.	Consent given for upload to national shared electronic record
93C3.	Refused consent for upload to national shared electronic record
93C4.	Patient consent given for addition to diabetic register
9Nd1.	No consent for electronic record sharing
9Nd7.	Consent given for electronic record sharing

The 9Nd1 code and its opposite 9Nd7 code are being phased out in a number of areas due to the ambiguity of its description in the context of an assumed consent environment.

For example, does *No Consent* mean that the patient has refused consent and Opted-Out or does it mean that the patient has not expressed a preference with regard to consent and therefore should be assumed consenting?

CTV3 Codes

XaKRv	Consent given for upload to local shared electronic record
XaKRw	Refused consent for upload to local shared electronic record
XaKRx	Consent given for upload to national shared electronic record
XaKRy	Refused consent for upload to national shared electronic record

Graphnet Process

This is how Graphnet respond to the presence of an opt-out code.

At present Graphnet are not uploading data to the SCR and therefore the choice of not sharing records nationally is academic. However there is still an issue of local only permission to share (93C0. or XaKRv) being given, where Graphnet will continue to share within the local health community. In due course when Graphnet are uploading data to the spine, the approach may be re-considered.

Therefore, until Graphnet do upload to the spine and for the avoidance of doubt, Graphnet act on a set of opt-out and opt-in codes but as far as the system is concerned all codes are equally valid. This means that if you opt-out using a local code or a national code Graphnet takes this as an opt-out, the same is true for opt-ins. This results in the following behaviour:

No Opt-out or Opt-in Codes = Opt-in

Any Opt-out Code and no Opt-in = Opt-out

Any Opt-in Code and no Opt-out = Opt-in

Any Opt-out Code and a more recent Opt-in = Opt-in

Any Opt-in Code and amore recent Opt-out = Opt-out

Since Graphnet do not distinguish between National and Local codes the following occurs:

National Opt-out and **more recent** Local Opt-in = Opt-in

Local Opt-out and **more recent** National Opt-in = Opt-in

Local Opt-in and **more recent** National Opt-out = Opt-out

National Opt-in and **more recent** Local Opt-out = Opt-out

If at any subsequent time a patient changes their National "opt" status the user will have to follow this with replicating the previous local "option" action to ensure that the GP Extract continues to retrieve the local as the most recent status. **Failing to do so will mean that the National code is actioned by Graphnet instead.** Unfortunately some of the GP systems allow only the recording of a date and not a time against the "opt" action. To ensure the local one is respected it has to have been recorded against a later date (ie the following day or later).

For EMIS sites there is an additional hurdle. EMIS themselves also opt-out patients using a set of codes defined in their system. Whenever a patient is opted out within EMIS, Graphnet receive one final extract of their record, EMIS then blacklist the patient and do not send to the Graphnet implementation any more details unless an opt-in code is subsequently applied. Given this functionality it is likely that any patient with a National opt-out will not be sent to the Graphnet system irrespective of its local opt status. Graphnet do not, at the moment, have any details on how the EMIS software works with the SCR so it is not clear whether a local opt-out causes the SCR to be blocked, if this is the case then there may be issues with

blanket opting-out from EMIS sites as it may cause all such patients to also be blacklisted from the SCR as well. This is being investigated.

GP Extract

If, during the course of a GP extract upload into the repository, the process detects that a patient has an Opt-Out code and that code has not been superseded by an Opt-In code in the same record, it will perform the following:

- 1) Remove all documents that come from the GP practice
- 2) Store the knowledge of this opt-out in the journal table (where possible)
- 3) Update the patients PMI record in Graphnet to reflect the change in preference.

When the process removes the data, it will physically remove it. It will not move it, hide it or archive it. It is permanently destroyed forever. It is not possible to retrieve this data without performing a new extract at that practice.

Graphnet does not notify any other system of this preference change.

Graphnet treat data from either EMIS or non-EMIS systems in the same way.

Handling different National v. Local consents

It is possible to set a patient up to have specific consent configurations. If patients wish to opt-out of any national system but do wish to share their data locally then the GP enters the national opt-out code (e.g. 93C3. for Read2) and the following day enters the local opt-in code (e.g. 93C0. for Read2). This reason for the day "delay" is that there is no time stamp (only a date stamp) assigned to these administrative codes. If both codes were submitted on the same day then the opt-out code would always take precedence.

Manual Opt-out

Recently it has been requested that system manager can initiate the same opt-out process and it has been with reluctance that Graphnet agreed to this change¹. This process is no different to the three stages above, but the way that it is initiated is by the Sysman.

It is very important to note that although the Graphnet repository will remove these documents and flag them as opted out, that this knowledge is **not** sent to the hospitals nor the GP Practices. This means that if the practice or hospitals send data to the Graphnet repository after the data is removed, then some feeds may reverse this setting. This is because the feeds are engineered to check for the presence of these

¹ Graphnet believe that the GP should be the custodian of the Opt-In/Out process rather than a System Administrator but accepts that practicalities may intervene.

preference codes and if they cannot find one, then it is believed that the patient wishes to be opted in. So if the Trust do not inform the sending systems to make the same change to the patients record, the manual Opt-Out process may raise questions by the Trust because of this process flaw.

Auditing

If any of the records were viewed prior to an Opt-Out code removing the documents, then the audit trail will still record the fact that the document was viewed. However it will no longer be possible to determine what the user saw when viewing the document because the very nature of an Opt-Out code prohibits the data to be stored in the repository. This may impact on the depth that any investigation can subsequently take.