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11 July 2018

Dear Mr Rawlins

Re: Freedom of Information request

Reference: FOI.18.NWS048

Thank you for your request under the Freedom of Information Act 2000 (the Act). This response is provided on behalf of NHS North West Surrey Clinical Commissioning Group (CCG). Your request along with the CCG's response is detailed below.

Referenced in these questions are the FAQs, available here:- <http://surreyheartlands.uk/our-priorities>

1) The FAQs state "CAN I OPT OUT OF THIS ALTOGETHER - Yes. If you want to opt-out of the Surrey Care Record you can contact any participating organisation who will ensure that the sharing of your Surrey Care Record is disabled. This will however mean that other professionals involved in your care will not be able to access shared information about you through the Surrey Care Record. If you have already opted out of the national Summary Care Record, you will automatically be opted out of the Surrey Care Record."

Please could you clarify whether this means: a) you will not have a Surrey Care Record at all;

If a patient has already opted out of the Summary Care Record via their GP Practice, their GP data will not be included in the Surrey Care Record. A Surrey Care Record will still be created for those patients,

but this will only be populated with data from other participating health and social care providers, for example Acute hospitals. Details of all the participating organisations who will be sharing information about their patients into the Surrey Care Record will be available on Surrey Heartlands website (www.surreyheartlands.uk) in due course. Patients who do not wish to have any data about them shared via the Surrey Care Record can still choose to opt-out if they wish. They can do this by contacting any participating organisation who will be able to disable all sharing of their data. This will however mean that other professionals involved in the patient's care will not be able to access shared information about them through the Surrey Care Record. Data will however remain within the Surrey Care Record but will not be accessible by any organisations.

b) you will have a Surrey Care Record but sharing will be disabled;

If a patient has already opted out of the Summary Care Record via their GP Practice, their GP data will not be included in the Surrey Care Record. A Surrey Care Record will still be created for those patients, but this will only be populated with data from other participating health and social care providers, for example Acute hospitals.

If a patient wishes to disable the sharing of their records, data will remain within the Surrey Care Record but will not be accessible by any organisations.

c) whether it means only data from GPs will not be uploaded but data from other locations will;

Yes – this is correct. Please see the previous two responses for full details.

d) if any organisation can disable sharing, whether any organisation can then re-enable sharing, and what is to prevent an organisation re-enabling sharing without a patient's knowledge or consent, even if they lack capacity?

Individuals can make a request to any participating organisation that the sharing of their Surrey Care Record is disabled, or subsequently re-enabled. This request can only be processed by the organisation's Privacy Officer and is not something which can be carried out by health or social care professionals or

teams. This means that professionals or teams cannot re-enable sharing themselves. All changes to an individual's sharing preferences are auditable.

Where an individual has requested that more granular restrictions are placed on their record (for example that a specific professional team/organisation is restricted from accessing a patient's record), professionals do have the ability to override these preferences, but must record the lawful basis on which they are relying to do so:

- Explicit Consent
- Implied Consent
- Mental Capacity (patient lacks capacity under the Mental Capacity Act)
- Court Order

This functionality exists to ensure that patients can amend any restrictions in place at the point of care. This is fully auditable should any changes made by a professional need to be reviewed or scrutinised.

2) As in question 1 above, does your response include children under the age of 13?

The response to question 1 covers all individuals of all ages. For anyone under the age of 13, those with parental responsibility are legally able to exercise their rights on their behalf.

3) If the answer to question 2 is affirmative, what happens when a child reaches the age of 13? Do they remain opted out, or does their opt-out become void, or do they get written to asking what their preference is?

13 is the age at which individuals are able to begin making decisions independently regarding their privacy. This aligns to the approach taken by the General Data Protection Regulation (GDPR) and Data Protection Act 2018 in relation to 'information society services' (i.e. online services), and other national initiatives such as the National Data Opt-Out (Your NHS Data Matters): www.nhs.uk/your-nhs-data-matters/.

When a young person reaches the age of 13 any previously registered preference relating to the Surrey Care Record will remain in place. This aligns to the approach taken by the national Summary Care Record programme.

4) If a person is automatically opted out, and they would like to have a Surrey Care Record, what should they do?

Anyone who has previously registered an opt-out with their GP Practice for other record sharing initiatives (e.g. the Summary Care Record), but would like a Surrey Care Record, have two options:

- 1) They can choose to revise their previous decision to opt-out via their GP Practice and ask that this restriction is removed from their GP record. This will result in the individual having both a Summary Care Record created and enable information from their GP record to be shared via the Surrey Care Record.
- 2) They can choose to leave the opt-out in place with their GP Practice. A Surrey Care Record will still be created for them; however this will only contain information from other health and social care providers and will not contain any information from their GP record.

Unfortunately, it is not possible for information from an individual's GP record to be shared via the Surrey Care Record if they have registered an opt-out with their GP Practice in relation to other record sharing initiatives.

5) If child under 13 as per question 2 is automatically opted out, but a parent would like their child to have a Surrey Care Record, what should they do?

For anyone under the age of 13, those with parental responsibility for them are legally able to exercise their rights on their behalf. Please see the response to question 4 for the options available to individuals.

6) If a parent of a child under 13 opts-out of opting-out of not having a record as per question 5, but wishes to exclude certain organisation(s) of having access, is this possible, and how would they go about it?

For anyone under the age of 13, those with parental responsibility for them are legally able to exercise their rights on their behalf.

7) Can a patient opt-out of having a Surrey Care Record by contacting the organisation in charge of the Surrey Care Record directly, without going through a GP?

Patients who do not wish to have any data about them shared via the Surrey Care Record can choose to opt-out if they wish by contacting any participating organisation who will be able to disable all sharing of their data.

8) Which organisation is in charge of the Surrey Care Record?

The project is sponsored by the three NHS Clinical Commissioning Groups (CCGs) within the Surrey Heartlands Health & Care Partnership (NHS North West Surrey CCG, NHS Guildford & Waverley CCG and NHS Surrey Downs CCG), together with NHS East Surrey CCG.

NHS North West Surrey CCG is acting on behalf of all four CCGs as the account holder for the Surrey Care Record programme. Therefore, to avoid duplication and your own resources, you may wish to direct all future enquiries in relation to the Surrey Care Record to NHS North West Surrey CCG.

9) Would patient data be included in the Surrey Care Record if an NHS number is unknown - e.g. a patient who presents at A&E but whose NHS number cannot be identified (or who doesn't have an NHS number)?

Only patients with a validated NHS number will be included in the Surrey Care Record

10) Who can have a Surrey Care Record - is it people living in Surrey; people who have a GP in Surrey; people who receive treatment in Surrey but don't live or have a GP in Surrey (for example people who turn up in A&E on their way through the county)?

All individuals registered with a GP Practice within the Surrey Heartlands and NHS East Surrey CCG areas will have a Surrey Care Record created (unless they have registered an opt-out with their GP Practice). All individuals who have been treated at a participating organisation from 29 August 2018 onwards will also have a Surrey Care Record created (where a verified NHS Number is recorded). Information about the Surrey Care Record will be displayed in public areas and on the websites of all participating organisations sharing data into the Surrey Care Record.

11) Would one organisation be permitted to obtain data from the Surrey Care Record to update their details about you - for example, would the School Nursing Service be allowed to check the record to see a child's immunisation records from a GP to update their own immunisation records?

Any professional accessing the Surrey Care Record must have a lawful basis under confidentiality law in order to access a specific record. Professionals are required to record the reason for access at the point they access the record:

- Explicit Consent
- Implied Consent
- Mental Capacity (patient lacks capacity under the Mental Capacity Act)
- Court Order

This is fully auditable should a professional's access to an individual's record need to be reviewed or scrutinised. Professionals will be trained to ask for an individual's permission prior to accessing their Surrey Care Record.

12) If one particular organisation is 'blocked' from accessing the Surrey Care Record by a data subject, is that particular organisation able to override that block, or does it have to be done by a different organisation?

Were an individual has requested that a specific organisation be restricted from accessing their Surrey Care Record, the restriction would be applied at a team level. For example, if an organisation had multiple teams which were each configured to access the Surrey Care Record, each team would be

individually restricted from accessing the individual's record within the Surrey Care Record in order to achieve a total restriction for that organisation.

Where a professional team has been restricted from accessing a patient's record, they have the ability to override this preference, but must record the lawful basis on which they are relying to do so (please see our response to question 11 for the lawful basis which a professional could rely upon). This is so that a patient can amend any restrictions in place at the point of care where a previous restriction had been set. This is fully auditable should any changes made by a professional need to be reviewed or scrutinised. Where a patient has requested to disable all sharing of their data via the Surrey Care Record, this cannot be altered by any professional teams. This can only be altered by an organisation's Privacy Officer at the request of an individual. Professional teams cannot re-enable sharing themselves.

13) If a data subject has a particular organisation 'blocked' from accessing their Surrey Care Record, what happens when contracts are changed between providers? For example, First Community currently supplies School Nursing services in East Surrey, but how would any restrictions be transferred between providers during contract changes, and how would data subject be advised of this?

As restrictions are applied at a team level, were a contract to change, any restriction placed on a team would continue to apply under the new organisation.

As part of any contract change, commissioners and the incumbent service providers are currently required to notify service users where there is to be a change of provider. This ensures service users are informed of who the service provider is for services they are involved with, enabling them to revisit their sharing preferences if they wish.

14) If, as per question 13, a data subject's provider of care is transferred between providers, but that data subject also has a relationship with a provider in a different aspect (such as School Nursing in that question, but a child may also be under some other care with First Community that is not transferred between providers), how would any restrictions apply in that case?

As per the response above, restrictions on access to an individual's Surrey Care Record are applied at a team level. Were an individual's care to transfer between providers, the restriction placed on the team would continue to apply under the new organisation.

15) I see in your FAQs a list of organisations which it is expected will participate in the Surrey Care Record in the future, but in the event of any organisations not listed participating in the future, what procedure is in place to ensure that data subjects will be made aware of the expansion of the Surrey Care Record?

Organisations wishing to join the Surrey Care Record will be subject to validation, scoping and signing off by the project's senior leadership team.

Details of all the participating organisations that will be sharing or accessing information as part of the Surrey Care Record will be made available on the Surrey Heartlands website (www.surreyheartlands.uk). For organisations which are permitted to access to the Surrey Care Record, any professional wishing to access an individual's record must have a lawful basis under confidentiality law in order to access it (please see the response to question 11 for the lawful basis which a professional could rely upon). Professionals are required to record the reason for access at the point they access the record. This is fully auditable should a professional's access to an individual's record need to be reviewed or scrutinised. Professionals will be trained to ask for an individual's permission prior to accessing their Surrey Care Record.

16) Also, in the FAQs, it states that there will be a full consultation with the public in the event that data will be used for any purpose other than providing direct care - but what process is in place to advise data subjects of any potential consultation, and what process is in place to advise data subjects of any potential change of use of their data?

There are no plans to use the Surrey Care Record for other than direct care.

17) Under the question in the FAQs 'Can I Opt Out of this Altogether?', it states that I can contact any organisation to disable sharing. This implies a Surrey Care Record will still exist for a particular person,

just that it won't share any information. Is it possible to prevent a Surrey Care Record being created in the first place?

It is not possible for an individual to prevent their information from being stored within the Surrey Care Record system if they have been treated by a participating organisation. It is however possible to ensure that information within the Surrey Care Record is not shared with any other providers.

18) How would a data subject who has a 'S-Flag' set up on the NHS's PDS database be affected by the Surrey Care Record? Would the S-Flag prevent any organisation from accessing, or uploading, data to the Surrey Care Record in the first place?

The Surrey Care Record does not interface with PDS. All information within the Surrey Care Record is provided by individual participating organisations' systems. Each participating organisation is responsible for ensuring that appropriate data is shared into the Surrey Care Record.

19) Can a data subject (or someone acting on their behalf) place a restriction on an organisation that will (or may) become a participant in the Surrey Care Record in the future from accessing a person's record, before that organisation is a participant? For example, could I place a restriction on First Community Health & Care now, so that when that organisation does have access to the Surrey Care Record, it will not have access - or does one have to wait until FCHC becomes a participant? If so, will data subjects be advised of when certain organisations will be becoming participants?

Individuals cannot place restrictions on individual organisations accessing their Surrey Care Record in advance of that organisation participating. Where an organisation is granted access to the Surrey Care Records however, any professional wishing to access an individual's record must have a lawful basis under confidentiality law (please see the response to question 11 for the lawful basis which a professional could rely upon). Professionals are required to record the reason for access at the point they access the record. This is fully auditable should a professional's access to an individual's record need to be reviewed or scrutinised. Professionals will be trained to ask for an individual's permission prior to accessing their Surrey Care Record.

Details of all the participating organisations that will be sharing or accessing information as part of the Surrey Care Record will be made available on Surrey Heartlands website (www.surreyheartlands.uk).

20) What would happen in the scenario that currently separate organisations become merged, and one has a restriction on data sharing, and one doesn't? Which setting becomes dominant?

As per the response to questions 13 and 14 above, restrictions on access to an individual's Surrey Care Record are applied at a team level. Were two organisations to merge, the restriction placed on the team would continue to apply under the new organisation.

Any professional accessing the Surrey Care Record must have a lawful basis for doing so under confidentiality law, in order to access a specific record (please see the response to question 11 for the lawful basis which a professional could rely upon). Professionals are required to record the reason for access at the point they access the record. This is fully auditable should a professional's access to an individual's record need to be reviewed or scrutinised. Professionals will be trained to ask for an individual's permission prior to accessing their Surrey Care Record

21) With regards to consent to view - if you decline consent for someone to look at your Surrey Care Record, would any data collected by that member of staff or organisation still be uploaded to the Surrey Care Record?

In time it is hoped that health and social care providers across Surrey Heartlands and East Surrey CCG will both share and access data via the Surrey Care Record. Technically however, it is a more complex task for an organisation to configure the sharing of data into the Surrey Care Record than it is for an organisation to be granted access to this.

Throughout the project therefore, there will be instances where teams within an organisation are able to access records (where a lawful basis exists) via the Surrey Care Record, but will not yet be configured to share data into the Surrey Care Record. In this scenario, an individual could decline consent for a professional to view their Surrey Care Record and information recorded by that professional within their local record keeping systems would not be shared into the Surrey Care Record.

Where an organisation is configured to both access and share information via the Surrey Care Records, were an individual to decline consent for a professional to view their Surrey Care Record, information recorded by that professional within their local record keeping systems would be shared into the Surrey Care Record for other authorised health and social care professionals to access (where a lawful basis exists).

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NEL CSU,
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The Information Commissioner,
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Water Lane,
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SK9 5AF

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Yours sincerely,

Sue Hiscock

FOI Officer

