

Connected Care Records Partnership: Data Use and Rights Policy

November 2021

Subject:	Overall policy for lead controller to apply data subject rights to data sharing activities. Based around the Connected Care shared record, but can act as a template for other similar scenarios.
Description:	

Table of Contents

1: Introduction.....	3
2: Background	4
3: How do I find out what data is held about me?	5
Download the NHS App	5
Ask Your Care Provider	5
Ask the Connected Care Shared Care Record Team.....	5
4: How do I get mistakes in my data corrected?	6
5: How do I control how my data is used or shared?.....	7
6: How do I know who can see my data?.....	9
7: How do I know who looks at my data?	10
Appendix 1: Data Protection Act 2018 General Data Protection Regulations (GDPR).....	11
Appendix 2: Organisations Contributing data to the Connected Care Shared Care Record	13
Appendix 3: Information held in the Connected Care Shared Care Record	14
Document Control	15
Version History	15

1: Introduction

This document describes the rights an individual has with respect to their health and care data and how the lead controller of Connected Care will uphold those rights in conjunction with the joint controllers.

This policy is informed by the legal framework for data protection (appendix 1).

The Regional Information Sharing Agreement (www.regisa.uk) sets out that the lead controller for a data sharing initiative/activity is responsible for the development and implementation of data subject rights policy and procedures.

This policy document is supported by a procedure document that covers how the lead controller will manage and co-ordinate responses to individual data subject rights requests.

2: Background

Information about your health and care is held by a range of organisations such as your GP practice, your local hospital and your local authority. Each organisation holds different types of information and different levels of detail depending on what they need the information for. Each organisation is an appointed 'Data Controller' and must appoint a Data Protection Officer.

The Connected Care programme collates info from the organisations who have provided your care so that it can be accessed by the services providing care to you.

For more detail see [Shared Care Record - how your data is used \(frimleyhealthandcare.org.uk\)](https://www.frimleyhealthandcare.org.uk/shared-care-record/how-your-data-is-used)

3: How do I find out what data is held about me?

There are a number of ways in which you can find out about the data that is held about you.

Download the NHS App

The [NHS App](#) allows you to look at some of the data that is held by your GP, for example your allergies and your past and present medicines. It also allows you to do other things like book appointments with your GP.

Ask Your Care Provider

Your care provider might be a:

- health or care service provider, such as your local hospital or a care home, or an
- app provider that you supply information to about yourself for example a fitness app.

If you make a request to see your data you should get a reply within one month. If it is complicated to reply to your request, the organisation should tell you within a month that it might take longer and give you a timescale. Their final reply should be made within three months of the date of your request.

Each organisation can only provide information about the data **they** hold about you. They will not be able to provide data about you that other health and care providers may hold, even if they can access some of this data through the Connected Care Shared Care Record.

Ask the Connected Care Shared Care Record Team

The team can:

- Tell you which organisations provide data to the Connected Care Shared Care Record;
- Provide you with a copy of the information held on the Connected Care Shared Care Record;
- Give you details of who to contact in other organisations who have contributed to your shared care record, so you can ask them about other data they might hold about you. This is because your shared care record is not all the information an organisation may hold on you.

4: How do I get mistakes in my data corrected?

Your health and care records contain a lot of different information supplied by different people. You can ask for your record to be corrected if there any ***factual mistakes***, for example if your date of birth is wrong. You can request for an addition to your record if it contains something you disagree with.

You can make a request to the:

- Data Protection Officer for the organisation that holds the information you want corrected.
- Connected Care Shared Care Record Team, who will liaise with the organisation that the data comes from.
- Patient Held Record Application (PHR app) or other apps - if you have an app which holds health information about you, some of the data can be corrected through the app. You may be able to this yourself or you may need to contact the app supplier.

5: How do I control how my data is used or shared?

Your right to object

Under data protection legislation **you can object** to how your data is used or shared. Data about you could be used for:

- providing your individual care;
- planning health and care services;
- research to find new treatments or services.

Sharing data for your individual care

Information about you is shared between people and organisations that provide care for you. This is to make sure that all the information is available to help make the best decisions about your care and treatment.

If you do not want information about you shared between health and care organisations, even for your own care, you should contact the Data Protection Officer at the organisation who provides most of your care, or your most recent care. This could be your GP practice or local hospital. If you have concerns related to a specific care organisation, then contact the Data Protection Officer of that organisation.

Your request will be discussed with relevant staff e.g. your doctor to decide if there might be a serious risk to you if your information is not shared. They may also discuss your request with other organisations that provide care for you. If your request is agreed, then data sharing using the Connected Care Shared Care Record will be stopped, however data crucial to providing your care may still be shared via other methods such as via phone, letter and email.

It is not currently possible to share just some of your data via the shared care record, for example sharing your hospital records, but restricting the sharing of information about your mental health. This means that if you do object to the sharing of some of your information for your own care it is likely that none of your information will be shared across organisations via the shared care record.

You can remove your objection at any time. However, there may be some gaps in the data available to be shared as a result.

Your right to opt out: sharing data for planning or research

You can request to *opt-out* of sharing your data for planning or research.

1: National Data Opt-out: You can opt-out of people using your **identifiable** data for planning or research through the National Data Opt-out scheme at www.nhs.uk/your-nhs-data-matters or by calling 0300 3035678. For detail on the definition of data used, please see: <https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document/appendix-6-confidential-patient-information-cpi-definition>

If you opt-out of sharing data for planning or research, data will still be shared:

- for your individual care;
- if there is a risk to public health e.g. for control of infectious diseases like TB;

- if there is an overriding public interest, e.g. reporting gunshot wounds;
- if the law requires it e.g.
 - for investigations, such as fraud or criminal offences
 - notification of food poisoning;
- if you have consented to take part in a specific project.

2: Local Opt-out: You can also request that none of your identifiable data leaves your general practice, except when it is used for your individual care (Type 1 opt-out). You should contact your general practice directly.

6: How do I know who can see my data?

Decisions about who can see your health and care information are made by each organisation that holds data about you. Decisions about who can see your data are based on the role of each member of staff and whether, to do their job properly, they need to see data about you. For example, a doctor will be able to see more information about you than a healthcare assistant or receptionist. Health and care staff should only access your record if they need to provide care for you or to manage the systems for providing care.

7: How do I know who looks at my data?

Record systems, including the Connected Care Shared Care Record, will track every time a record is accessed: who has been looking at what, where from, when and in some instances, why. You can request to see who has accessed your record by asking the Data Protection Officer in the organisation providing care for you, or by contacting the Connected Care Shared Record Team.

Appendix 1: Data Protection Act 2018 General Data Protection Regulations (GDPR)

Data protection legislation gives individuals a set of rights over how their data is collected and used. The right to:

- 1: Obtain a copy of information
- 2: Correct factually incorrect information
- 3: Object to how information is used

Rights 1-3 are addressed in this policy.

- 4: Erasure
- 5: Restrict and/or limit usage of information
- 6: Portability of data between organisations
- 7: Not to be subject to automated decision making, including profiling

Rights 4-7 mainly do not currently apply to the Connected Care Shared Care Record and are briefly described here.

4: Right to have information erased or deleted:

“The right to be forgotten and erasure of information does not apply to an individual’s health record, or for public health purposes or research purposes.” *(NHS European Office and NHSX LHCR IG Framework)*

5: Restrict and/or limit usage of information - restriction of processing:

The right to restriction of processing applies where:

- a) accuracy is contested;
- b) processing is unlawful and the individual does not want the information erased;
- c) information no longer needs to be kept – but the subject needs the information in relation to a legal claim;
- d) the subject has objected to the processing and the objection is being considered.

5a: Accuracy

The Connected Care Shared Care Record information is essentially the same as information in the source organisation system. Accuracy will come from and should be resolved from the source system. Whilst the information is being updated/corrected, then the individual has the right to request that their information is not processed until it has been corrected. In these cases, the organisation will need to stop the information from flow from their source system into any shared record. However, the source systems are unlikely to be able to consistently apply a restriction to the level of detail relating to a rectification request (i.e. restrict just the information in question until accuracy is resolved). Therefore rectification must follow the organisational policies of partners in receipt of rectification requests.

5b: Restriction

If the source organisation receives a request from an individual to restrict the flow of their information, it needs to be established whether this information is also flowing into the Connected Care Shared Care Record. If the source system is not able to restrict the processing of the information, then the request must be considered as an 'objection' (see p 7 & 8 of this policy).

5c: Unlawful processing

Processing of data in the Connected Care Shared Record is established under the lawful functions and permitted under data protection legislation and associated regulations and therefore is not processed unlawfully.

5d: Information no longer needs to be kept, but the subject needs the information in relation to a legal claim

This should not arise as the NHS Records Management Code of Practice are based on the legal time periods for establishing claims. Connected Care Shared Care Record information is also a copy of local information, so the original source information is the information that should be kept.

5e: Objections

There will be objections to information sharing with the Connected Care Shared Care Record and these will take some time to be considered (see p 7 & 8 of this policy).

6: Portability

Connected Care Shared Care Record data is processed on the basis of 'exercise of official authority'. The right to portability only applies where data is processed based on consent of or a contract with the data subject. Therefore it does not apply to the Connected Care Shared Care Record.

7: Automated decision making including profiling

At present, there are no plans for 'solely' automated decisions, decisions that do not include any human involvement, within the Connected Care Shared Care Record. However, in the future this may happen in areas such as risk stratification and other 'decision support' tools. If this happens then this policy will be updated.

Appendix 2: Organisations Contributing data to the Connected Care Shared Care Record

Who is involved in the sharing of information?	<p>The Connected Care Shared Care Records Programme involves the following types of health and care organisations:</p> <ul style="list-style-type: none">• NHS Trusts<ul style="list-style-type: none">○ Acute service providers○ Community service providers○ Emergency services○ Mental health service providers○ Specialist service providers;• Local authorities• Independent NHS contractors (including Primary Care, Out of Hours, GP alliances and networks)• Independent sector health care providers and social care providers (adults and children)• Continuing Healthcare (CHC) Teams within Clinical Commissioning Groups• Voluntary sector providers, including Hospices (commissioned or coordinated by Local Authority and NHS organisations) <p>from the following partnership areas: Confirm the full spread...</p>
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Appendix 3: Information held in the Connected Care Shared Care Record

Information about you

Eg name, gender, date of birth, address

Information about your health

Eg vaccinations, smoking and drinking history

Information about your illnesses

Eg diagnosis and test results such as blood sugar, cholesterol or BP measurements

Care plans for your health and care

Information about medication:

Eg drugs you are taking, have taken in the past or are allergic to

Information about pregnancy, birth and contraception

Family history of illness

Information about services you use

- GP and other primary care appointments eg with the practice nurse
- Inpatient information: admissions, transfers and discharges
- Outpatient information: referrals, appointments and discharge
- Waiting list information

Document Control

Title:	Connected Care Records Partnership: Data Use and Rights Policy
Author (Creator):	
Title:	Connected Care Records Partnership: Data Use and Rights Policy
Subject:	Information on a person's data in the TVS Platform and their rights
Description:	
Publisher:	
Contributor(s):	See version history below
Date (of this Version):	November 2021
Owner:	
Document Reference:	
Document Status:	Draft for discussionFOR APPROVAL
Document Version:	0.1
Next Review Date:	
Last Major Version Date:	No previous versions

Version History

Version	Date	Author	Comments
0.1	November 2021		