



Thames Valley and Surrey Care Records Partnership: Data use and rights policy

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1: Introduction

This document describes the rights an individual has with respect to their health and care data and how the Thames Valley and Surrey Care Records Partnership (TVS Shared Care Records) will uphold those rights. This policy will be publicised via the TVS Partnership website and through partner organisations to help ensure that individuals are informed of their rights and are supported to exercise them.

This policy is informed by the legal framework for data protection (appendix 1), the work of the TVS Ethics and Engagement Advisory Board and the TVS Information Governance (IG) Working Group (insert hyperlink). It does not replace local policy in relation to data sharing and use.

This policy is supported by a set of frequently asked questions (include hyperlink when complete) and a series of documents describing how the policy will be put into practice (Standard Operating Procedures). If there are changes to the way data is shared locally, for example outside the Thames Valley and Surrey, this policy will be updated.

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 amounts of detail, depending on how they use the information. Each organisation must make sure that personal information is stored and used correctly. They must appoint an individual to be responsible for this; a Data Protection Officer.

The TVS Shared Care Record brings together information from a range of organisations across the Thames Valley and Surrey (appendix 2 and hyperlink to new page for list of organisations contributing data). The TVS Shared Record is a summary of information from these organisations, it does not contain all your data (appendix 3 and hyperlink to the TVS Shared Care Records data fields).

The TVS Partnership is not a legal data controller. This is the responsibility of the organisations that generate data about you. If, in the future, the TVS Care Records Partnership creates data that is not held in another organisation, this policy will be reviewed and updated.

The primary responsibility for protecting your personal information lies with the organisations that generate data about you. The TVS Partnership carries out tasks on behalf of those organisations, such as securely storing and transmitting data

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 by health and care organisations.

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

This might be:

- a health or care service provider eg your local hospital – you should ask the Data Protection Officer;
- an app that you supply information to about yourself eg a fitness app- you should contact the app provider.

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

Each organisation can only provide information about the data *they* hold about you. They will not be able to provide data about you held by other health and care providers. This is the case even if a summary of this is available through the TVS Shared Care Record.

Ask the TVS Shared Care Record Team

The TVS Team can:

- tell you which organisations provide data to the TVS Shared Care Record;
- provide you with a copy of the summary information held on the Shared Care Record;
- give you details of who to contact in other organisations to ask about data they might hold.

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 that a note is made in your record if there is something you disagree with in it.

You can make a request to the:

- Data Protection Officer for the organisation that holds the information you want corrected
- TVS Shared Care Record Team
- 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 and improving 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 who 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. They will discuss your request with staff eg 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 the TVS Central Team and other organisations who provide care for you. If your request is agreed, then this data will be removed from the TVS Shared Care Record.

If you have already opted-out of sharing data across organisations in your local area, then your data will not be included in the TVS Shared Care Record.

It is unlikely that it will be possible to share just some of your data, for example only stopping sharing your mental health information. This means that if you opt-out of sharing information for your own care it is likely that none of your data will be shared across organisations.

If you opt-out of sharing data you can change your mind and opt back in at any time. However, there may then be some gaps in the data available to be shared.

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

You can request to opt-out of sharing your identifiable patient data for planning or research. This is data that identifies you and says something about your health or treatment.

1: National Data Opt-out: You can opt-out of people using your **identifiable** (insert link to section on identifiability) 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.

If you opt-out data will still be shared:

- for your individual care;
- if there is a risk to public health eg for control of infectious diseases like TB;
- if there is an overriding public interest, eg reporting gunshot wounds;
- if the law requires it eg
 - for investigations
 - notification of food poisoning;
- you have consented to take part in a specific project.

If your data has been anonymised, so that it is not identifiable to you, it can still be shared even if you use this opt-out.

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. This opt-out is being reviewed.

6: How can I find out who is allowed to see my data?

Decisions about who can see your health and care information are made by each organisation that holds data about you - your GP practice, your hospital or local social care. These decisions 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 porter. Health and care staff should only access your record if they need to provide care for you or to manage systems for providing care.

TVS Shared Care Record

Access to the TVS Shared Care Record is controlled by the same access controls that operate within each organisation that provides data to the TVS Shared Care Record.

7: How can I find out who has looked at my data?

Record systems, including the TVS Shared Care Record, will track every time a record is accessed: who has been looking at what, where from, when and in, in some instances, why. You can ask to see who has accessed your record by making a request to the Data Protection Officer in the organisation providing care for you, or by contacting the TVS Central 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
- 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 1-3 are addressed in this policy. Rights 4-7 mainly do not currently apply to the TVS Shared Care Record and are briefly described here { DQ - do we want to include the information below in our policy?}.

5: 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).*

6: Restriction of processing:

The right to restriction of processing applies where:

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

Considerations in relation to the TVS Shared Care Record and the right to restrict:

- **Accuracy** – TVS Shared Care Record information is essentially the same as information in the source organisation clinical system, so accuracy issues will come from and 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 and/or the TVS Shared Care 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.

- **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 TVS Shared Care Record . If the source system is not able to restrict the processing of the information in question, then the request must be considered as either an objection or ‘opt out’ (see applicable sections of this policy).
- **Unlawful processing** – no processing in the TVS Shared Care Record should be unlawful, so this should not apply
- **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 minimum retention periods identified in the NHS Records Management code of practice are based around legal time periods for establishing claims. TVS Shared Care Record information is also a copy of local information, so the original source information is the information that should be kept.
- **Objections** – there will be objections to information sharing with the TVS Shared Care Record and these will take some time to be considered (see applicable sections of this policy).

7: Portability

TVS 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 TVS Shared Care Record .

8: Automated decision making including profiling

At present, there are no plans for ‘solely’ automated decisions without any human involvement within the TVS Shared Care Record platform, however developments in areas such as risk stratification and other ‘decision support’ tools could move into the scope of this right, so the TVS Shared Care Record Partnership needs to maintain awareness of this right.

Appendix 2

Organisations contributing data to the TVS Shared Care Record

<p>Who is involved in the sharing of information?</p>	<p>The Thames Valley & Surrey 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:</p> <ul style="list-style-type: none"> • Surrey Heartlands Integrated Care System (ICS) including East Surrey • Frimley Health and Care ICS • Buckinghamshire Integrated Care Partnership (ICP) • Oxfordshire ICP • Berkshire West ICP • Milton Keynes
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Appendix 3

Information held in the TVS 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