



TVS - Scope of data-sets for the care records platform

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1. Introduction

This document outlines the target scope of data-set types for inclusion in the Thames Valley and Surrey Care Records platform (in Graphnet Care-Centric hosted on Microsoft Azure). It provides context in terms of national LHCR and TVS goals, national scoping of data-types, and finally a TVS set of heading for data types based on mapping to CareCentric. The data-scoping described supports the goals outlined below (both national and regional for the programme), with the early focus on individual care within the TVS region ('journey 1' of the national IG guidance). The programme is also progressing against 'journey 3' (use of anonymised data for population health intelligence) where agreed with partner areas of the programme. 'Journey 2' (LHCR to LHCR sharing), and 'Journey 4' (data for research) are not currently being pursued in this financial year but are in the long-term goals of the programme.

2. Over-arching LHCR goals

National context [NHSE LCHRE guidance]:

Local Health and Care Record programmes will develop and deliver digital capabilities that address core outcomes for the national LHCR programme;

- a) Health and care professionals involved in a person's care have safe and secure access in near real-time to a comprehensive care record and care plans that have been linked, de-duplicated and normalised to standard coding terminologies, comprising the pertinent individual level information they need to inform their care decisions, when and where they need it, fed from local systems and with links to the other Local Health and Care Record programmes.
- b) Citizens and carers are empowered to manage their own care through having access to, and being able to contribute to, their own health and care records.
- c) De-personalised information from the records is being used for real-time decision making to support the delivery of population health management approaches.

- d) Solutions are based on open standards and create a common longitudinal record for an individual regardless of the source systems contributing to that record.
- e) Demonstrating the ways in which the LHCR has engaged and communicated to the public and professionals with evidence that those messages have been heard and understood, and any feedback acted upon with the aim of ensuring that solutions are used, usable and useful.
- f) Local Health and Care Record solutions will be sharing, interoperating and consolidating relevant records with the other Local Health and Care Record solutions located in other regions.

TVS Care Records – original high level goals (from the programme Business Case and reflected in the TVS Partnership Agreement, Feb 2019):

- **Sharing data across borders to improve individual care, both within TVS and our neighbouring LHCR areas in London, Wessex and potentially the South West.** *[nb – LHCR to LHCR sharing now out of scope for TVS in 2019/20].*
- **Developing a TVS-wide data platform that will be a foundation for using data to improve direct care and population health applying advanced analytics and Population Health intelligence.**
- **Supporting and promoting a set of digital services and innovations that enable individuals to manage their health and stay healthy, working with the locally based shared-records programmes and Person Held Records developments.**

3. TVS LHCR Funding Agreement with NHS England: Annex C - Minimum Functional Expectations

Introduction

This annex sets out the minimum functional expectations that all Exemplars are expected to meet.

Expectations

- 1) Access to the comprehensive longitudinal care record across the Exemplar footprint for the core common data elements of a longitudinal care record (See **Error! Reference source not found.**)
 - Delivery of an initial longitudinal care record based on integration from existing digital sources to show early progress – March '19
 - Delivery of normalised data layer across the Exemplar footprint to support joined up care and population health – March '20
 - Provision of citizen access through the NHS App and the ability for patients to express preferences and provide their readings relevant to a set of care pathways being enabled - March '20

Demonstration of functionality such as care planning and real-time algorithms along STP priority pathways of care that use the longitudinal care record such that the solution

is “used, usable and useful”

underpins transforming and not just digitising pathways of care

is demonstrated in at least two localities within an Exemplar footprint to ensure repeatability

includes clear plans for spread across the rest of the Exemplar footprint

Ability to link to genomic summary reports for individuals in their Exemplar

Capability for patients to contribute content into the Exemplar record to enable pre-population of information prior to an encounter (e.g. pre-op assessment data, personal health status readings)

Capability to provide a facility to support data extract, subject to compliance with national and local Opt-out, consultation and information governance requirements, by March '20.

4. TVS LHCR Funding Agreement with NHS England: Annex D - Datasets

1. Introduction

While the detailed content of the longitudinal record will evolve over time, there are some key data items which are expected to be included as part of an individual record and form the basis of the initial longitudinal record referenced in **Error! Reference source not found.** The data required to populate the initial longitudinal record may be drawn a variety of sources including national and local systems.

2. Data

A longitudinal record is expecting to address the following common core datasets

- Demographics
- Examinations
- Care plans
- Procedures
- Assessments
- Diagnoses
- Allergies
- Investigations
- Correspondence
- Problems
- Medication
- End of life plans
- Social care
- Link to genomic reports¹

¹ This is a specific data class requirement and is expected to simply include link to reports held elsewhere rather than detail.

The detail of this content of each of these datasets will be progressively defined through a process of Exemplar collaboration, and subject to appropriate assurance to ensure that they comply with the information governance framework.

In addition, we expect that there will be additional datasets which extend the common core and which are associated with specific care pathways including, but not limited to,

- Cancer
- Maternity
- Mental health
- Urgent and emergency care
- Patient data

Subject to further discussion and agreement, and in line with meeting the requirements of the information governance framework and in particular meeting requirements for a clear legal basis for collection and sharing, the record may extend over time to include datasets relating to

- Specialist clinical content
- Clinical research related data
- Patient provided data
- Data relating to the wider determinants of health for an individual – e.g. housing, education etc

In addition, we would anticipate LHCREs developing their plans for populating the longitudinal record from existing digitised sources including, but not limited to:

- Historic data reported to SUS/HES including
 - historic diagnoses
 - historic procedures
 - past appointments
- Data in near real-time including
 - pathology results, medications, image reporting
 - waiting list additions
 - hospital admissions and discharges
- The full record from GPs and other digitised care settings.

5. TVS Care Records – data-set types by sector

Target data-set types for inclusion in the TVS care records, based on data-mapping with CareCentric:

Acute				
In Patients	Out Patients	A & E	Patholgy	Radiology
1.1 Admissions	2.1 Referrals	3.1 Attendance	4 Test Results (Pathology)	5 Test Results (Radiology)
1.2 Transfers	2.2 Appointments	3.2 Discharge		
1.3 Discharges	2.3 Appt Attendance			
1.4 Waiting Lists	2.4 Discharge			

Community	Mental Health	Adult social care	Children's social care
6.1 Demographics	7.1 Demographics	9.1 Demographics	10.1 Demographics
6.2 Immunisations	7.2 CPA Episodes	9.2 Core Data	10.2 Core Data
6.3 Care Plan	7.3 CPA Level	9.3 Care Plans	
6.4 Problems	7.4 Notes		
6.5 Interventions	7.5 Diagnosis		
6.6 Diagnosis	7.6 Mental Health Act		
6.7 Medications	7.7 Risk Assessment		
6.8 Alerts	7.8 Risk Scores		
6.9 Contacts	7.9 Risk Plans		
6.10 Referrals	7.10 Early Intervention in Psychosis		
	7.11 Alerts		
	7.12 Contacts		
	7.13 Referrals		
	7.14 Appointments		

GP Data
8.1 Demographics
8.2 GP Medication
8.3 GP Results
8.4 GP Vital & Measurements
8.5 GP Lifestyle
8.6 GP Encounter Summary
8.7 GP Problems
8.8 Vaccinations & Immunisations
8.9 Contra Indications
8.10 OTC & Prophylactic Therapy
8.11 Family History
8.12 Child Health
8.13 Diabetes Diagnosis
8.14 Chronic Disease Monitoring
8.15 Medication Administration
8.16 Pregnancy, Birth & Post Natal
8.17 Contraception & HRT
8.18 Allergies

6. PRSB Core Information Standard

The programme is working over the longer term to address the Core Information Standard developed by PRSB (Professional Records Standards Body) through a consultation exercise in 2018/19 -

<https://theprsb.org/standards/coreinformationstandard/>

V1 27 November 2019

V2 3 December 2019 – updated to include Social Care data-set types.