Semantic Interoperability for Health Network

Deliverable 1.3
Evaluation framework for semantically interoperable resources

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<td>Incorporating text from Tony Austin</td>
</tr>
</tbody>
</table>
Table of Contents

1 Introduction .................................................................................................................. 4
  1.1 The SemanticHealthNet Project ............................................................................. 4
2 Executive Summary ...................................................................................................... 6
3 Introduction .................................................................................................................. 8
4 Heart failure data set design principles ...................................................................... 10
  4.1 Expertise .................................................................................................................. 10
  4.2 Guidelines (c & d) .................................................................................................. 11
  4.3 Development of Algorithms (e-g) ........................................................................ 12
  4.4 Developing an Algorithm: The Example of Potassium ......................................... 13
  4.5 Summary ............................................................................................................... 14
5 Clinician Validation ...................................................................................................... 15
  5.1 Building the Application ....................................................................................... 15
    5.1.1 “Patterns” ...................................................................................................... 15
    5.1.2 Derivations .................................................................................................... 17
    5.1.3 The SHN Application ................................................................................... 18
    5.1.4 The SHN Application (updated version) – Modifications ............................. 25
  5.2 Clinical reflections on the implementation experience ......................................... 27
6 Mapping to HF Audit data-set ..................................................................................... 29
7 The Future .................................................................................................................. 32
  7.1 European Heart Failure Audit Data Set, Data Capture Tool and ESC based Guidance........ 32
Appendix 1: Mapping tables relating the HF summary and HF audit data sets ............. 34
1 Introduction

1.1 The SemanticHealthNet Project

Semantic interoperability of EHR systems is a vital prerequisite for enabling patient-centred care and advanced clinical and biomedical research. SemanticHealthNet will develop a scalable and sustainable pan-European organisational and governance process to achieve this objective across healthcare systems and institutions.

A clinical focus on chronic heart failure and cardiovascular prevention in the workplan will drive the semantic resources to be developed. The exemplars in cardiology and public health are specific enough to permit comprehensive development and validation of these resources, and yet typical enough for wider generalisation of the methodology and its governance. SemanticHealthNet will capture the needs articulated by clinicians and public health experts for evidence-based, patient-centred integrated care in these domains. Existing European consensus in the management of chronic heart failure and cardiovascular prevention will then be integrated in EHR architectures, clinical data structures, terminologies and ontology by leading technical experts.

Clinical and Industrial Advisory Boards will provide links with other domains in which these results can be used beneficially. The project will investigate how best to combine and adapt informatics resources to support semantic interoperability, and how these can be developed and supported at scale. Results of this investigation will be generalised and formalised. The involvement of health authorities, clinical professionals, insurers, ministries of health, vendors, and purchasers will ensure that the project approach and results are realistically adoptable and viable. This work will also build on the SemanticHEALTH and CALLIOPE roadmaps for eHealth interoperability.

A business model to justify strategic investments, including the opportunity costs for key stakeholders such as Standards Development Organisations and industry, will be defined. Links with the epSOS large scale pilot and the eHealth Governance Initiative, will inform the shape of the Virtual Organisation that this Network will establish to sustain semantic interoperability developments and their adoption.

The consortium comprises 17 Partners and more than 40 internationally recognised experts, including from USA and Canada, ensuring a global impact.

Partners

1. Research in Advanced Medical Informatics and Telematics (RAMIT) – BE (Admin Coordinator)
2. Imperial College London (Imperial) – UK
3. University of Hull (UHULL) – UK
4. University Hospitals of Geneva (HUG) – CH
5. World Health Organization (WHO) – CH
6. The University of Manchester (UoM) – UK
7. Medical University of Graz (MUG) – AT
8. International Health Terminology Standards Development Organisation (IHTSDO) – DK
SemanticHealthNet

9. Institut National de la Santé et la Recherche Médicale (INSERM) – FR
10. Ocean Informatics (Ocean) – UK
11. Health Level 7 International Foundation (HL7 International) – BE
12. EN13606 Association (EN13606) – NL
13. Empirica Gesellschaft für Kommunikations- und Technologieforschung mbH (EMPIRICA) – DE
14. Standing Committee of European Doctors (CPME) – BE
15. European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry (COCIR) – BE
16. Whittington NHS Trust (WHIT) – UK
17. European Institute for Health Records (EuroRec) – FR (NoE Coordinator)

Project Plan

Workstream I:

WP1: Patient care exemplar (heart failure)
WP2: Public health exemplar (coronary prevention)
WP3: Stakeholder validation

Workstream II:

WP4: Harmonised resources
WP5: Infostructure and tools
WP6: Industrial engagement

Workstream III:

WP7: Adoption and sustainability
WP8: European Virtual Organisation
WP9: Project management, dissemination, promotion
2 Executive Summary

Work package 1 provides a clinical anchoring to the semantic modelling work of the project by providing the requirements for semantic interoperability from the perspective of shared care for heart failure, as an example chronic disease. Deliverable 1.1 provided considerable detail about the European data sets and guidelines that are driving and auditing the quality of heart failure care, and therefore should direct the priority information to be represented consistently, communicated and analysed. Having understood this vast information landscape, the project agreed to focus on a heart failure shared care summary, as the most important use case requiring interoperability. Deliverable 1.2 specified the data items and most important decision rules that are needed for this heart failure summary. Work package 4 has used this to develop semantic assets to represent this summary, in parallel learning about the challenges of doing this across multiple standards and specifications.

This deliverable focuses on the evaluation of the heart failure summary, with an emphasis on two different and equally important aspects of evaluation:

1. **Clinical consensus engagement** to validate and refine the clinician-oriented specification of the summary: have the most appropriate data items been included, with the necessary value specifications, and do the rules reflect accepted good practice? Furthermore is the data-set presented in a manner that appears intuitive and user friendly for the clinicians who will be using these data sets? The latter is essential if over time it is to be adopted and modified for widespread use, to ensure sustainability of this work. This deliverable reports on modifications undertaken to date as an iterative process between a number of HF cardiologists, both within and without WP1, and the engineers who have modified the application, and presents a proposal for how this evaluation will continue to be taken forward (an evaluation framework) beyond the duration of this FP7 funding.

2. **Technical validation**: do the semantic assets correctly represent the data intended to be made interoperable by the clinicians, and is it possible to transform data between specifications that retains the necessary meaning and context. This technical evaluation is largely presented elsewhere, by work package 4. Within Work Package 1, however, we have undertaken a mapping exercise between a limited number of data points, contained in the HF summary, and the relevant fields of the HF Audit data set, with a view to an actual exchange of data and demonstration of semantic interoperability.

In tackling the first of these evaluations, early attempts to engage other clinicians have shown that a written data set specification is very hard to appraise properly. We therefore decided to develop a tool that presents the heart failure summary as if it were a clinical application, so that clinicians can do more than just look at a list of data items: they can practice entering example data to verify that provision has been made to capture the data items they feel are important. The very process of developing the tool not unexpectedly revealed to the original authors of the summary data-set that their specification contained some errors, inconsistencies and ambiguities. This has in itself been useful learning, and cautions about the methods that should be adopted in the future to develop clinical data set specifications. This deliverable therefore presents a walk through of the issues raised during the development of this application, as an illustration of the pitfalls that can arise when a data
set specification is given to a software development team, especially since the close coupling of developers and clinicians that occurred on this occasion is not always possible.

Having proven our hypothesis that visualisation of the data set, through the development of a clinical application, would allow recognition of areas requiring further attention, we have now considerably modified the application, through a number of iterations involving additional UK cardiologists with expertise in HF and data-sets. The data-set that emerges is smaller than that first envisaged. This may appear counter-intuitive at this juncture, given the expansion elsewhere within the project. However, as the clinicians and engineers engaged within this process, who have considerable collective experience within the field, recognised, it is easier and more efficient to subsequently add additional data-fields to a limited but well-constructed dataset/ application, than to remove or modify larger but less well formatted equivalents.

The deliverable presented will be tested over subsequent months and years in a number of European countries, with a view to publication and sustainability far beyond the timescale of the current defined work.
3 Introduction

Information is an important branch of the science of medicine at every level from the management of a single aspect of an individual person to that of the whole planet’s population. Increasing the precision of communication and common understanding amongst health professionals, other scientific disciplines, patients and the general public is important to all aspects of healthcare. Capturing, organizing, sifting, prioritizing and communicating health-related data electronically are high priorities for healthcare at many levels. Importantly, data are not information. Smart systems should collect the data that helps achieve the desired goal and process them in an intelligent way to assist the patient and clinician.

SemanticHealthNet works on the interface between clinicians that manage patients, but have little knowledge of the complexity underlying electronic data, and information scientists who have a deep understanding of the technical issues but limited understanding of what is important for patient care. We have provided a generic road-map for others to follow who may wish to develop modular components of an electronic health record (EHR), either for specialist use or as part of a general record. This is based on a wealth of expertise generated over decades that has fostered the development of international guidelines that have been through at least six iterations over the last 20 years and a deep understanding on what information is required in the EHR in order for the clinician to make key decisions for care. Complex clinical management decisions that require long-experience to acquire have been developed into algorithms that enable the information system to provide decision support analysis. These algorithms are now being programmed into a prototype EHR. The goal of the exercise is to ensure that decades of expertise does not get lost as experts retire or die but are immortalized in the EHR. This enables those who have less expertise to improve the care they provide and new experts can build on a solid foundation of data. Because of the systematic approach and discipline that an EHR imposes, deficiencies in care, whether systematic (that may even be driven by the EHR or clinicians) or random (human error) can be observed and corrected. This should accelerate the evolution of care, improve efficiency and reduce omissions.

Perhaps one of the most important aspects of SemanticHealthNet is that it highlights the chasm between clinical and information science. Clinicians learn by bitter experience that attempting perfection in medicine often has disastrous consequences; ‘good’ is good enough. On the other hand, information scientists have difficulty with the concept that approximate knowledge or surrogate information is often perfectly adequate for high-quality clinical management; the enemy of ‘good’ can be striving for perfection.
Finally, SHN has helped to highlight that the greatest deficiency in care for patients with heart failure is not in management but rather in first reaching the diagnosis. There is evidence of huge delays in diagnosis and, for many, it is often never made. A smart EHR does not wait to be told a diagnosis; it should suggest one when a certain constellation of phenomena occur (e.g. a patient with swollen ankles prescribed a diuretic should trigger the question of what is being treated and what diagnostic steps need to be taken).
4 Heart failure data set design principles

Describing a problem accurately is an important, and often essential, step to effective management. The fundamental reason for describing a medical problem is to improve patient management, whether that is simply to provide reassurance or to explain loss of well-being, to inform the need for further investigation, to administer the right treatment, at the right time at the right ‘dose’, to adjust intervention in the light of response or to provide guidance on the risk and prognosis of occult or overt disease. Once a diagnosis has been made, good treatment often follows. Often the greatest deficiency in management is case-ascertainment; suspicion provokes diagnosis.

Heart failure is common, complex and often malignant. A considerable component of this malignancy relates to delays in diagnosis and, or, failure to implement appropriate evidence based disease-modifying treatment. There is no universally accepted single diagnostic test, but the broader HF syndrome and principles of a diagnosis are not contentious across different guidelines. A clinical presentation suggesting the diagnosis requires evidence of cardiac dysfunction, usually with echocardiography, elevated natriuretic peptides and an expected response to treatment. The second important component of a complete heart failure diagnosis is an understanding of the underlying phenotype (structural or functional abnormality) and aetiology since these determine treatment strategies and prognosis.

Even expert clinicians may disagree on various aspects of the diagnosis. An electronic health record needs to record and potentially quantify this uncertainty. The other driving principle behind the health record is collection of data that will inform management. Information that does not contribute to management can be redundant or harmful, either because it wastes time or because important information is concealed in an ocean of data, leading to errors. These problems can be overcome by smart systems that scavenge existing information residing in existing data-sets, identify what’s missing or worrying and alert the clinician and by presenting the clinician only with the information they want (or should have, even if they didn’t ask for it). Getting the right amount of information, neither too much nor too little, is important when it comes to the clinician interface with the patient record. However, clinicians will vary in the information they want. Systems that can be tailored to the individual clinician’s and patient’s needs is essential.

Anyone with enough time, skill and patience can create a comprehensive electronic health record. It takes substantial clinical thought and expertise to create a minimal data set as described in previous deliverables. This is an attempt to describe how the minimum data set, that has been the starting point of our work, was developed.

4.1 Expertise

WP1 comprises three, UK-based, international experts on heart failure with a wealth of expertise in developing guidelines and managing patients. Each has contributed to UK National and European International Guidelines, and has brought this expertise to this project. Through international guidelines each has been able to draw on the knowledge and expertise of the international community. The same heart failure experts also bring knowledge and experience of delivering heart
failure care within and across different health environments, the requirements of clinical audit and research, the development of electronic records, and work with numerous other agencies, both publicly and commercially funded.

SHN also draws upon international expertise garnered from other European Commission (EC) funded projects including SICA-HF and HeartCycle. Other EC funded projects with which SHN may interact are HOMAGE and ACT both of which are subject to substantial data-semantic challenges but also provide extensive clinical and scientific expertise.

The expertise and process of developing the minimum data set can be considered in several steps:

- a) Decades of individual clinical expertise and training in patient management
- b) Decades of networking with colleagues nationally and internationally that has contributed to the cultural ‘norm’
- c) The development of guidelines based on clinical evidence and cultural norms
- d) The distillation of the guidelines into the essential steps (Class IA evidence) for clinical management, in this case focusing on chronic heart failure
- e) The development of diagnostic and therapeutic algorithms that allow effective and safe delivery of guideline-recommendations
- f) Specific concept testing with international groups of expert clinicians in round-table formats
- g) Demonstration of prototypes at national and international meetings
- h) Application in practice in a clinical service or clinical trial.

The first two steps (a & b) reflect the professional training and experience of clinicians and it is well beyond the scope of the document to attempt to describe what should be obvious to the reader.

4.2 Guidelines (c & d)

Guidelines for heart failure vary depending on who creates them and what their purpose is. In the UK, NICE Guidelines require a formal systematic review of evidence that demonstrates both clinical efficacy and cost-effectiveness, alongside broad stakeholder representation including patients. Local guidelines often focus on implementation rather than the evidence behind a recommendation. The Guidelines on Heart Failure of the European Society of Cardiology are created exclusively by health professionals recognized by the Society as having expertise in heart failure and depend on a deep knowledge of the evidence, including systematic reviews conducted by external groups. These Guidelines have evolved since 1995 with more than ten iterations over the last 20 years and represent about 10,000 hours of expert deliberation and work. Both the European and NICE
Guidelines are subject to review and revision, albeit through rather different mechanisms, prior to publication.

For the purposes of managing heart failure, these guidelines make a relatively limited number of Class I (strong) diagnostic and therapeutic recommendations, nearly all of them related to heart failure with a reduced left ventricular ejection fraction. Symptoms, key items in the medical history and physical examination are required to guide treatment. The key guideline-recommended diagnostic tests include an imaging test (usually an echocardiogram) to assess valve function and ventricular phenotype, an electrocardiogram for heart rhythm and QRS duration and blood tests to assess renal function, electrolytes and haemoglobin.

Key treatments include:

1. ACE Inhibitors (sometimes angiotensin receptor blockers are used instead)
2. Beta-blockers
3. Mineralocorticoid Receptor Antagonists
4. Anti-coagulation for atrial fibrillation

And for select subgroups of patients

5. Cardiac Resynchronization Therapy
6. Implantable Cardiac Defibrillators

In addition, every cardiologist knows that congestion (fluid retention) must be managed and that the mainstays for doing so are diuretic agents.

Several other interventions exist that many clinicians believe are useful in heart failure including digoxin, iron and more recently, Ivabradine. However, there is considerable clinical variability in how these are viewed and used, reflecting a less secure evidence base.

The clinical data set, which underpins the heart failure summary, was devised to provide the clinician with the key data that would enable these treatments to be used.

### 4.3 Development of Algorithms (e-g)

In order to use these agents effectively and safely, a certain amount of clinical information is required. There is no disagreement amongst experts as to the need for the basic minimum data set, although application of the data will depend on differences amongst individual patients and differences amongst experts. How, the data are used should be tailored to the individual patient-clinician interaction; both are important and any expert system that is likely to be acceptable to
patients and clinicians must accommodate this philosophy. However, experts are comfortable with the concept that there should be a default position.

The initial algorithms were developed by Professor Cleland as part of the HeartCycle Programme in collaboration with Philips electronics. These were based on the essential information required to implement guideline-indicated therapy. Once the algorithms had been devised six international experts subjected them to critical review, initially by sending hard copies and subsequently by an all-day, face-to-face roundtable meeting. Neither dissent nor addition was made to the algorithm concept at this meeting. There was disagreement, as expected, about the critical values for the default values in the algorithms but agreement that a system that allowed the defaults to be changed at a service level and individual-patient level was a good solution to values that were very unlikely to be universally applicable.

The approved algorithms were incorporated into an electronic health record by Philips and subsequently implemented in a prototype home tele-monitoring system that was tested in a clinical trial including 128 patients with advanced heart failure. The system performed well, safely increasing the proportion of patients reaching target doses of disease-modifying drugs and optimising diuretic dose. However, it was noted that very often, clinicians chose a target dose different from the clinical trials and that this appeared appropriate to the patients’ vital signs, such as blood pressure and heart rate, or laboratory data, such as potassium and creatinine.

The concept and data content have been presented at international meetings in many European Countries and the USA and at an international gathering of 60 heart failure specialists in Zurich at an ESC training course.

Previous deliverables have described in detail the minimum data sets for heart failure developed in HeartCycle as above. Only one example is considered here for illustrative purposes.

### 4.4 Developing an Algorithm: The Example of Potassium

Knowing the serum potassium is an essential part of managing heart failure. A potassium that is too low or too high is lethal. Clinical observation indicates that serum potassium is often outside the ideal range. Expert systems can easily help health professionals or patients to achieve better results.

Guidelines indicate that ACE inhibitors, ARBs and MRA should be used with caution in patients with a potassium >5.0mmol/L. Clearly it is an essential component of the health record without which the safety of initiating these agents is uncertain. During follow-up, Professor Cleland considered serum potassium in the range of 4.0 to 5.0mmol/L ideal. Some of the expert international group disagreed about the range suggesting this should be extended from 4.0 to 5.5mmol/L (the limit suggested by guidelines requiring action to reduce serum potassium) or restricted to 4.2-4.8mmol/L. All agreed that the ability to flexibly adapt the default ranges for local use or for individual patients obviated the need for consensus.

All experts agreed on the appropriate course of action in response to serum potassium that fell outside the desired range.
4.5 Summary

The high degree of agreement amongst experts may be attributed to the consistency of well-developed guidelines, a strong evidence base, and a high degree of international networking over decades. Once the concept is grasped that the practical purpose of the specialist electronic health record is not to provide a comprehensive set of information but rather the set of data essential to guide the use of the treatment that the patient needs, there appears to be little or no dissent around the basic set of information required. This does not mean to say that a comprehensive electronic health record is unnecessary but rather that this should remain background information available to, but not thrust upon, the clinician. There is, probably always will be and probably should be substantial continuing diversity of opinion on how the information gathered should be used for a particular service or individual patient.
5 Clinician Validation

The development of a heart failure summary document, as outlined in the previous chapter, followed an early meeting of SemanticHealthNet where it was agreed that this artefact should form the focus of initial energies. In subsequent discussions and especially with Work Package 4, the suggestion arose that it would be useful to develop an Application illustrating the format in which it might be presented to clinical colleagues, and indeed the wider clinical and non-clinical communities. The aim here was to move from the dictionary of terms required for the heart failure summary record to a format to which clinicians could relate and through feedback modify to ensure the dictionary underlying the application was in fact fit for purpose. This has proved an interesting learning experience which may be useful for others developing similar dictionaries. Themes that emerge, alongside the need to ensure adequate semantic interoperability, are that 1) There is a very necessary requirement to ensure the engineers and others involved in this project, who may also be clinicians, are not partisan in their interpretation of the dictionary when items within it have not been adequately defined, and 2) Clinicians need to be more disciplined and prescriptive when outlining the “Dictionary of terms” that underpin a specific application and which in this instance drive the work on semantic interoperability around HF. These issues will apply to other chronic or long-term conditions and the related e technologies. To ensure others may benefit from our learning this will also be taken forward in the next chapter, as the development of a checklist.

The section that follows was written by the engineer who developed the application in its first form and raised a number of questions which are now largely addressed in the current modified application and underlying core data set at the conclusion of the project. This section is presented as written and serves as useful feedback to the clinicians who have developed the core dictionary. The following narrative includes description of the iterative process involved in moving from the first application to the revised application.

5.1 Building the Application

What follows is a brief description of how the Heart Failure Summary application was created from the Deliverable provided to us, the developers, at the outset (1.2, 4th April 2013 version). We used the printed deliverable exclusively as it was hard to see how the engineering choices embodied in other technical artefacts would help us create an application in our toolkit. We also systematically passed up offers of help and other software in an effort to focus on the adequacy of the written material exclusively.

5.1.1 “Patterns”

In order to exchange clinical information between two users of an Electronic Healthcare Record (EHR) it is obviously imperative that both parties to the exchange share a common understanding of the data content. In many legal jurisdictions it is also important to know what presentations of the data gave rise to a clinical decision. For these reasons EHR standards usually divide the
representation of the structure into two distinct portions: (1) a comprehensive description of the storage format that it is possible to ratify entirely, and which itself includes pointers to (2) a set of semantic concepts that can never be entirely enumerated because they represent constantly evolving clinical understanding and research.

The word Pattern is used in regular expressions to describe the set of constraints on an input in order to be a valid example. We reuse the same term to describe the set of constraints on a semantic concept. This is not just the data value. For example, a Systolic pressure is always presented before the Diastolic pressure and to do otherwise would confuse a clinician presented with the data. We regard the order of presentation then, as another type of constraint. The Pattern methodology specifically describes constraints applicable to a concept, rather than constraints on a reference model.

An example Pattern is shown below:

```
Valve Disease Type

@CodedOrdinal()
@DateLastVerified(TIMESTAMP verification="2013-11-06")
@DateOfIncorporation(TIMESTAMP verification="2013-11-06")
@DefinitionProvidedBy(STRING author="Tony Austin, CHIME, UCL, UK")
@Description(STRING language="en_GB", STRING description="The three key types of valve disease.")
@EN13606()
@Element()
@LibraryPath(STRING path="clinical.cardiovascular")
@PatternIdentifier(STRING identifier="ValveDiseaseType")
@PatternName(STRING name="Valve Disease Type")
@PublicationStatus(ORDINAL publicationstatus=TENTATIVE)
@Values(STRING ARRAY value=["DOMINANT_STENOSIS", "REGURGITATION", "MIXED"])
@Version(INTEGER version=1)
```

We use the ISO EN 13606 standard for healthcare systems interoperability as the information basis for modelling record structures in an EHR. Because we actually store such data in our EHR repositories we must at least use Constraints that embody those of that standard. The semantic concept is not limited to those however, and may simultaneously represent information from a number of models. They may inform persistence layers, security, data presentation, and others.

In the Pattern representation above, A Constraint has one or more Arguments (for example, the Constraint @PatternIdentifier has one argument called the “identifier” of type string), and a Pattern has a number of Constraints, whose Arguments are then instantiated for the Pattern.

Almost all of the information in the Pattern is curatorship information. The dates of incorporation and last verification are the dates of original authorship and last change respectively, there is an author noted, an (in this case) English string representing a description of the Pattern, a basic library categorisation of the concept if a full terminological categorisation is unnecessary, an identifier and name, a status, and finally a version. The latter is distinct from the release number given in the header if multiple parties are collaborating to develop it.
The light blue Constraints show that this concept is suitable for use in an ISO EN 13606 data environment. The standard defines some class-level building blocks each of which correspond to an equivalent use in the paper record. The Element class is the container for all actual data values. This “Valve Disease Type” concept is an ordinal value and if selected will have one of the three values shown.

5.1.2 Derivations

Obviously the standard defines not just Element data value content but also aggregate groupings of these. The outermost container is called the Composition and hosts the medico-legal information associated with a commitment of data. For Compositions the Pattern is also concerned with the interface between the contents of a data capture screen and the application in which the screen is deployed. A Section may appear within a Composition and enables multiple related topics to be presented within a screen (for example, for a Medical Summary). The Entry is the container for Elements and is concerned with how a data capture screen behaves to the end-user. Entries may be tabbed on-screen if it is sensible to further subdivide the display.

These can be visualised as an aggregate tree. Another example is below:

Our own tools then allow us to quickly obtain a database structure and a data capture screen directly from the definition. Our export tools are constantly evolving and are not the only structures and screens possible from the definition.

```
RS3.1=# select * from clin_primarycauseofheartfailure_details limit 0;
  identifier | cause | cardiomyopathy_type | valve_disease_type | valve | other
-------------+--------+---------------------+-------------------+-------+---------
(0 rows)
```
5.1.3 The SHN Application

Deliverable 1.2 is 58 pages in its original form. We first went through it and trimmed it to what seemed like the technical “meat”. We ended up with the 17 pages between page 9 and 25 inclusive. We then trimmed it again, removing the red (decision-support related) and most of the italicised (advanced practitioners) text. The latter was a value decision: if it looked easy to do, we left it in. Finally we went through carefully measuring the indentations (not so easy over 17 pages of liberally spaced text) to arrive at an outline of the data content.

From this we extracted the actual formal models that underpin the application. There are 102 non-container data items in the set we used. No ordering for screens is made explicit in the deliverable (and alternatively, it is not noted that the ordering is implicit in the presentation) so the models are mostly left to their default ordering.
The deliverable does not specify which screen should be the “first” one after a patient record is opened and so a framework default is used (Nota Benes). However because the need for a Nota Bene is not stated in the deliverable it is not part of SHN and consequently not selectable from the Data Capture menu.

In fact ideally there would be no “Data Capture” menu at all and instead an appropriate grouping would be visible in the header bar. However in the deliverable the only grouping “higher” than the Composition names is the “Fixed”, “Frequent” or “Occasional” status of the data. Unfortunately as noted below, it was already necessary to use that as a Composition heading in the case of the Fixed items.

**Fixed Components**

Moving on to individual Pattern models, of the components described as fixed, only height is not already a part of the demographics information in the application framework. It therefore appears by itself in this data Composition. “Fixed Components” is perhaps not a very satisfactory container name but no alternative was suggested.

**Social Circumstances**

We noted at the time that phrases like “various ways of rating, you have to choose” are not ideal
from a specification point of view. We’d hope for something a bit more specific in order for it to then appear on a screen.

Moreover, we would generally hope for all Entries to contain at least one mandatory field in order to avoid the possibility that the Entry could be committed with no actual content. We know that clinicians instinctively “do the right thing” with respect to ensuring there is data before committing but empty commits remain theoretically possible with the formulation above.

**Primary Causes of Heart Failure**

The model for this is given as the example in the “Derivations” section above. It shows very clearly how we non-clinical interpreters of the document try to arrive at an approximation to the meaning while also being faithful to the reference standard and the engineering that followed it. Under the “Occasional Updates” heading, the original document said:

**Primary Cause of Heart Failure (mark only one) (generally for information only)**

- Myocardial Infarction
- Coronary Artery Disease (other than myocardial infarction)
- Cardiomyopathy (if so, dilated, hypertrophic, other)
- Valve Disease (if so, specify valve and whether dominant stenosis or regurgitation or mixed)
- Hypertension
- Atrial Fibrillation
- Other (specify in text)

The standard’s modelling of Elements requires that each include only a single data value. It is therefore not possible for us to model for example “Cardiomyopathy” as a drop down with two levels inside it, e.g.

Primary Cause of Heart Failure ▼
  Myocardial Infarction
  Cardiomyopathy ► Dilated
    Hypertrophic
    ...

It would be possible if a bit unsatisfactory, to model it as a single menu but with single string values separated by “-”, e.g.:

Primary Cause of Heart Failure ▼
  Myocardial Infarction
  Cardiomyopathy - Dilated
  Cardiomyopathy - Hypertrophic
Since “Cardiomyopathy Type” and “Valve Disease Type” might be useful concepts to share across a wider clinical context, we created individual ordinal Patterns for these and instead used a “Cause” ordinal to select which type was appropriate. Unfortunately at the time the application was modelled, the framework included no means to enforce the “mark only one” directive with this approach and consequently it is possible to select VALVE_DISEASE as the cause and then give a Cardiomyopathy Type. The framework has since been updated with this functionality so this can be readily modelled in future.

Having chosen to introduce a new field, we then have the slight problem of what to call it. The standard demands that the Composition (screen) be named, the Entry (form) be named, and obviously the Element. Since the apparent intent was that this be one drop-down, we’re missing at least two of these. Since the visual view of an Entry is of a single form filled in at a moment in time and the visual of the Composition is of each of these Entries as a paged history, we usually apply the simple expedient of pluralising the Composition name (“Primary Causes ...” in this case). The “Cause” ordinal is simply a best guess.

Finally, we were not sure whether the specification of the valve could itself be reduced to an ordinal, or whether such preciseness was even necessary, and left it as a string.

**Cardiac Phenotypes**

In the deliverable the topmost question of this long Pattern hierarchy (available to view in detail at [http://aruchi.chime.ucl.ac.uk/pattern/tree?id=423](http://aruchi.chime.ucl.ac.uk/pattern/tree?id=423)) is “Has the patient had a cardiac imaging test?” The nature of the indentation that follows however makes clear that this question is redundant from the point of view of data capture. The answers are only yes and no and all of the content is only permissible if yes. This happens quite often actually – there is for example, a general clinical preference for a YES/NO Boolean followed by a string explanation that is only appropriate if one-or-the-other. Generally, the presence of a value for the string would have implied the one-or-the-other and the absence the opposite, without the need for the Boolean.

As the Pattern examples above show, one of the most time-consuming aspects of creating Patterns is in discovering the meaning of abbreviations and in creating descriptions that are both truthful and likely to generate hits in a future search. We were unable to find such detailed information about the “TAPSE” Element and only narrowly resisted the urge to describe it as part of a “SINKE”... We were also unable in most cases to differentiate between general statements and measured quantities based on the deliverable, and if the latter, what the preferred unit might be. For example, we made an arbitrary guess that "Tricuspid Peak Regurgitation Velocity" is a physical quantity measured in metres per second.

After the application was made live we benefitted from some time with an experienced heart failure clinician who was surprised that “Echocardiogram” did not appear among the screens. In fact a subsequent search for “echo” in the 17-page edited Deliverable turned up only one success, as part of the explanation for “Left Atrial Dimension” in this Pattern. We understand that Cardiac Phenotype
is the result of the data capture but the hierarchy should probably have been named Echocardiogram instead.

Electrocardiogram Summaries

It is fair to say that this approach of modelling clinical content imposes an overhead of time that tool support can only partially mitigate. It is certainly a tough discipline. However it has one tremendous benefit – it makes visible and public a record structure that would otherwise be hidden and impossible to reuse.

The toolkits we apply have evolved through many iterations and have underpinned applications in very diverse clinical and less-clinical domains. One of these is indeed in cardiovascular care and it includes a definition of Electrocardiograms. Below is a screenshot of the definition in the other application.
In comparison to this, the SHN one looks significantly abbreviated. We therefore relabelled it "Electrocardiogram Summaries" to make clear that fuller descriptions exist.

Within the Elements themselves there is an existing Pattern ("Pattern of Excitation") inside the previous Electrocardiogram as well as in the proposed new SHN one ("QRS Morphology") that both include “Bundle Branch Block”. This is too big a coincidence to ignore. We engineers are clinically unaware robots simply comparing the string contents but we can’t help wonder if these are really the same thing only with different options. For the time being we have reused the existing definition.

Ambulatory Electrocardiography and Chest X-Rays

Both the Ambulatory ECG and Chest X-rays appear to have no content in the Deliverable and exist only as headings and some notes about use. We have included both, as placeholders but were therefore unconcerned about omitting later items such as Coronary Angiography that were genuinely described as placeholders.

Whenever we are creating Patterns we try to keep watch for opportunities to reuse those that already exist or could exist. For example if we were asked to create a “Pain In The Leg Scale” consisting of “MILD”, “MODERATE” and “SEVERE” we would probably opt instead to create a more generally applicable “Mild Moderate Severe Scale” with those values and simply include it in the Entry with the name “Pain in the Leg”. There’s nothing pain or leg-specific about the scale as stated. The advantage of doing this is that the same Pattern can be reused in other circumstances as well and only the label given to the Pattern by the Entry need be updated.

It follows that some time is devoted to analysing incoming clinical requirements for opportunities to reuse Patterns that exist already. In the above we have elected to reuse a general “Simple Investigation” consisting of nothing but a Result as our placeholder. The advantage of reuse is that it maximises the opportunity for applications to benefit from data created beyond its borders.
Device Therapies

Although not quite a placeholder, the majority of the text under “Device Therapies” is red and out of scope for this exercise. Needless to say, as a result of the decision support work being done elsewhere more data capture may be required. This may be true not only for the inputs to the decision support and its results, but sometimes in order for long-running support to be resumed on a subsequent occasion some technical data must also be stored.

Heart Failure Symptoms

In the deliverable the NYHA Class is at the top-level in the indentation hierarchy (that is, like an Entry) but as it is itself a value it can’t be realised in this fashion. We elected to bring it inside the Heart Failure Symptoms (http://aruchi.chime.ucl.ac.uk/pattern/tree?id=435) container instead.

Our experienced heart failure clinician questioned some of the units that seemed to be apparent from the document. For example the Ankle Swelling is measured in “numbers of legs”; Breathlessness on Exertion measured in “numbers of flights of stairs”. We may simply have tried too hard for a faithful rendering of the document and these may not need a numeric result at all.

Blood Tests

The Blood Tests (http://aruchi.chime.ucl.ac.uk/pattern/tree?id=414) are helpfully subdivided in the Deliverable and are rendered as tabbed panels in the application. Units of measurement are missing in some cases but here definitions could be reused from earlier work. We added normal ranges where we could find them.
Heart Failure Care Plan

The need for a care plan is noted in the Deliverable but no data content is supplied.

5.1.4 The SHN Application (updated version) – Modifications

Recognising the limitations of the first application, consultation was undertaken with several other HF cardiologists, with a view to this being deployed clinically and of use as a data set which might form the basis of both audit and a quality improvement tool, which aligned itself with the ESC HF guidelines. This involved theoretical discussions, reviewing the application and data entry, with several iterations undertaken before agreeing upon the current deliverable. Some of this detail follows, as outlined by the engineer, but more may be made available subsequently through the SemanticHealthNet website.

The SemanticHealthNet Deliverable 1.2 describes the important data to capture when managing patients with heart failure. It is a distillation of the experience of very expert practitioners with decades of combined experience, and the description is in fine detail. However, the experts were concerned that they may have overlooked something obvious to them but less so to someone with fewer years of experience, that in particular this would be true of a layman engineer without any
experience in this discipline, and that possibly the need for some other items or the unnecessary complexity of some existing items, would only be revealed when visualised in operation. They therefore commissioned an application based on the dataset.

Software engineering isn’t like other types of engineering. Building software causes people to conceptualise their own discipline. The involvement of a software engineer is often the first time a domain expert has confronted how they do what they do. It’s not only obvious that the process of teaching a computer would change a practitioner’s perception of their own behaviour, it would be astonishing if this were not the case. So it’s unfortunate that even after decades of software engineering experience to the contrary there are still projects that hold that the expert defines some requirements, and these are handed off to a “designer” who immediately has a complete understanding of them and the environment that surrounds them, who then creates a comprehensive specification for an implementer who robotically manifests the suggested design without any further need for support. Actually, this is bound not to work.

The iterative process is the only one that does work. It requires the mutual support of clinical professionals and engineers who grow to understand each other’s discipline and together build something that will last, based on the constraints that each works under. Of course practicing clinical professionals have little time. However we have benefitted from four complete development iterations with our clinician colleagues, each of which has refined the original dataset so that the application now looks designed, with a logical flow through the screens and within each screen.

Section 5.1.1 above describes the “Patterns” methodology that we use to make explicit the model that underpins a screen. The application framework we use is model-driven, meaning that the Pattern describes exactly what a screen will present and how it will behave, and the application is derived automatically from the Pattern definitions. This enables clinicians to focus on the very best expression for their data while freeing engineers to deliver the most usable application possible. It also facilitates semantic interoperability because a recipient has a clear understanding both of the data he or she has received and the context in which it was captured. The application benefits immediately from fixes applied to any application using the same framework.

Each development iteration focused on rationalising and where necessary simplifying the Pattern model so that the engineering team could deploy a cleaner version of the application ready for the next iteration. This meant that the majority of the time was spent exactly where it should be: among clinicians considering the needs of the domain, and not among technical personnel developing the computational artefacts reflecting them. The revised dataset uses rationalised headings and lays out the display slightly differently. But consequently the most significant difference is that the number of individual data items is reduced.

Within any clinical discipline there is room for discussion about the most appropriate items to capture and it is sensible not to standardise these until there is firm approval from professionals across the discipline. It is easy to add new data elements where there were none before, but to delete or modify data elements when data has already been provided demands either outright data loss, or a complex conversion process that is itself not necessarily fully comprehensive. It is also easier to obtain broad agreement with a small dataset that is easy to visually comprehend than one that is complicated and includes portions that invites criticism and must be deconstructed. Ironically
it then becomes quicker to deliver an application that gives rise to an expanded dataset, except this time with the new data based appropriately on real practice need, rather than opinion (expert though that may be).

The original worry of the experts that led to the development of the application was prescient. The mechanical realisation of the dataset description as a real application enabled a streamlined revision of the original deliverable to be reverse-engineered from operational use. It was clear from the application screens where items were perhaps clumsily titled or aggregated and where unnecessary data complexity could be avoided. Now finalised, the revised dataset more easily lends itself to additional use cases, one of which is described in section 6.

5.2 Clinical reflections on the implementation experience

It is clear from this that there is considerable learning to be gained from the communication between clinicians using the written word and the translation into an application and the semantics which underpin the application, alongside ensuring semantic interoperability.

At the same time the development of an application allows clinicians and others to explore the facility with which a dictionary of, in this instance Heart Failure terms can be of use on a day to day basis by bringing that dictionary to life. There then begins an iterative process to ensure the dictionary is specific and detailed enough to be accurately coded, and applicable to the required domain of practice.

One of the interesting reflections to emerge from this description, of moving from the written document to the Application, is how few of these issues were raised by WP4: whilst this may reflect the clinical background of many involved in WP4 it will now serve as a prompt to ensure interpretations of the required HF dictionary items have been correctly interpreted even before the semantic interoperability is cross checked.

In contrast, whilst the heart failure clinicians have been unified in the need to be able to express clinical uncertainty, there has been a tension with those exploring the underlying semantic interoperability. They have appeared inherently uncomfortable with this concept of clinical uncertainty. The solution is beautifully provided by the Application in which the need to meet international standards, means the HF diagnosis can either be coded as a “draft” or “complete”. The former allows a degree of healthy clinical uncertainty, either because investigations are incomplete or because even with investigations there is ongoing clinical uncertainty that may only be resolved with time. The “complete” option suggests this uncertainty has been resolved, to the satisfaction of the individual completing this data entry, whilst the data collected within the electronic record allows other experts to review this conclusion when necessary. These discussions have been informative and stimulating and it might have been hoped that there would have been greater engagement and willingness to provide feedback to WP1 by those in later work packages, but alas this has not been realised as envisaged. The exception to this, in broad terms, rather than in very specific detail has come from the diversity of activities related to ensuring the sustainability of this project, and described elsewhere. In addition useful feedback from a number of UK HF cardiologists has ensured the artefact is considerably improved. The move to testing in Europe has also developed into a more
ambitious enterprise to include actual usage for data entry, and thereby audit, rather than as a purely theoretical tool for data-entry. This approach means consultation across Europe is yet to be undertaken but more likely to be sustained (as described below).
6 Mapping to HF Audit data-set

Heart Failure can be challenging at every level from the diagnosis through to the delivery of holistic care which acknowledges and implements evidence based treatments whilst recognising that individuals will have their own hierarchy of priorities that may reflect those of their clinicians, but may often be quite discordant. Too often these subtleties of best practice get lost within systems where symptomatic patients struggle to receive a diagnosis and even a minimum of appropriate treatment, underpinned by a diversity of systems capturing aspects of their clinical journey but unable to relate to each other. Key information or data, often repeatedly collected, is frequently unavailable and cannot be shared or reproducibly imported or exported between the systems. The costs of organising health care in this manner are enormous: patients suffer deteriorating health and early death, whilst departments of health and all those funding them meet the expense of inadequate health care strategies. Even the most highly motivated clinicians can find this frustrating as they struggle to deliver better care to their cohort of individual patients.

In these chapters we have described the work already undertaken to develop the required minimum data set, the translation into the first version of an Application and its subsequent iterative modification in consultation with additional HF experts into an Application more fit for purpose and with a view to engagement across Europe. The revised artefact would allow all those involved in heart failure care from patient to doctor to share a single, reliable electronic health record, underpinned by good semantic interoperability. The first test of semantic operability has emerged from the engineers’ translation of the HF clinicians’ requirements. Similar, subsequent tests have been inherent in the iterative developments of the first Application through to the current artefact. The next formed part of the recent mapping exercise of individual data items within the Application against terms in the HF Audit data set, where clinical terms with similar meanings, could not be recognised by the engineer as such. Following discussions and close working between the clinicians and the engineers, clarification has allowed a formal mapping process between the two data sets (see below). This provides the basis for assessing true semantic interoperability between the two which will be tested with data entry across selected fields.

The HF Audit dataset description is described in a detailed spreadsheet. Within this there are categories for patient registration, admission, readmission, unscheduled events, and life status. The spreadsheet goes to some lengths to record internal changes and to justify the fields that are captured. However in many cases it doesn’t differentiate between a justification for the presence of a field, the need for it to be mandatory, and the specific unit when it is a physical quantity or inclusion of each choice when it is an ordinal list.

The export dataset has been developed over many years and appears comprehensive. It is split in such a way that “core” data items can be provided in isolation. We began with this set in the expectation that any broader cohort would include items related to other domains or would be unlikely to be found in our very specific original data source. Unfortunately, being “core”, the dataset contains a majority of mandatory items which are often optional in our application. In use, clinicians prefer data to be optional so that it can be provided if known, but that known data is not precluded from entry because of items that were not known. Figure 1 shows a small sample from the core HF...
Audit dataset. The yellow fields indicate changes unique to the most recent version.

<table>
<thead>
<tr>
<th>Field sequence #</th>
<th>Core dataset</th>
<th>Changes Found in</th>
<th>Sequence #</th>
<th>Field Description</th>
<th>Short Co</th>
<th>Long Code</th>
<th>Field Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>core</td>
<td>1</td>
<td>1.03</td>
<td>NHIS number</td>
<td>10 digits (no spaces) valid NHIS Number</td>
<td>Free text</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>core (mandatory)</td>
<td>1</td>
<td>1.04</td>
<td>Patient name</td>
<td>Free text</td>
<td>Free text</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>core (mandatory)</td>
<td>1</td>
<td>1.05</td>
<td>Patient name</td>
<td>Free text</td>
<td>Free text</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>core (mandatory)</td>
<td>1</td>
<td>1.06</td>
<td>Date of birth</td>
<td>Valid MM/dd/yyyy or 1991 and 1995</td>
<td>Date (dd/mm/yyyy)</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>core (mandatory)</td>
<td>1</td>
<td>1.07</td>
<td>Gender</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
</tr>
<tr>
<td>8</td>
<td>core (mandatory)</td>
<td>1</td>
<td>1.07</td>
<td>Gender</td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
</tr>
<tr>
<td>9</td>
<td>core (mandatory)</td>
<td>1</td>
<td>1.07</td>
<td>Occupation</td>
<td>0 to 9</td>
<td>0 to 9</td>
<td>0 to 9</td>
</tr>
<tr>
<td>10</td>
<td>core (mandatory)</td>
<td>2</td>
<td>2.00</td>
<td>Date of admission</td>
<td>Date of Admission (dd/mm/yyyy)</td>
<td>Date (dd/mm/yyyy)</td>
<td></td>
</tr>
</tbody>
</table>

FIGURE 1. A (SMALL) PART OF THE UK AUDIT DATASET DESCRIPTION

To support the audit use case it must be possible to export data from a source system (in this case our revised application described in this document) to the export dataset while retaining the semantic meaning of the original data. To make this possible we did expand the application with additional data capturing the progress of an episode. This “Admission Metrics” screen provides dates of admission and discharge, and includes associated behaviour that enables a practitioner to indicate that an audit export is ready when discharge or death has occurred. This behaviour is made complex because “date of death” is modelled elsewhere as a fixed demographics field. The latest Pattern model underlying this screen can be viewed at: http://aruchi.chime.ucl.ac.uk/pattern/tree?id=610

FIGURE 2. AN EXTRACT FROM THE MAPPED EQUIVALENT
We then simplified the representation of the export dataset and performed a mapping exercise showing areas where data would have to be modified on export. Figure 2 shows an extract from this mapping document. A smattering of issues are shown here including occasions where the application data does not have the correct data type and needs further alignment (marked in yellow), ordinals where there is partial alignment only, and requests for mapped values that refer to the first or last occasions data is acquired rather than to a specific data element.

We also found in the export set items whose unit was not that of the originating application and items that have a unit in the application but are described simply as “integer” or “real” in the core dataset. These cases can certainly be catered for by a transform but in the light of our experience, we would suggest to the audit dataset providers that they might consider an app to aid comprehension of their dataset!
7 The Future

This chapter describes the work undertaken to date, but it has been explicit within the SemanticHealthNet outline that our aim was to ensure the sustainability of the artefacts. To achieve this, the HF summary needs to be adopted for specific use within and across the HF community. In parallel with this FP7 project, there has been increased interest in the use of electronic patient records, data collection driven by audit and a desire to improve patient care. It is argued that through a better understanding of the epidemiology of disease, the possibility of earlier interventions that might reduce the acute and chronic disease burden will emerge. A pleasing exemplar of this has been the pan European initiative on smoking cessation and health gains that have followed. Thus an entire spectrum of common interest from clinical through academia to the commercial world is fast emerging. Subject to appropriate clinical governance and internationally agreed standards being met there is enormous potential for collaboration across these domains with the likelihood of improved population health, and an urgent imperative at government level to achieve this in a cost-effective manner. In the context of heart failure, amongst those actively working to achieve this are numerous stakeholders including professional bodies such as the European Society of Cardiology and the related Heart Failure Association, including their relevant national counterparts across Europe.

7.1 European Heart Failure Audit Data Set, Data Capture Tool and ESC based Guidance.

The Heart failure Association of the European Society of Cardiology is interested in developing a heart failure audit data set with real time collection of the data and some clinical decisions rules and care pathway logic. The aim is to improve clinician implementation of the ESC heart failure guidelines with emphasis on those people with heart failure due to left ventricular systolic dysfunction, where there is the potential for considerable mortality and well-being benefit for the individual with heart failure. This also translates into the delivery of improved outcomes and resource utilisation for the health care communities.

The concordance between this requirement and the SHN heart failure summary data set is extremely strong at every level. The feasibility of complete convergence between the two at a European level has been explored in the final period of funding and at this juncture there is a strong likelihood that the HF summary may form the basis of pilot work across Europe and subsequent consideration as a quality improvement tool. Given the strength of the Application for the HF summary, modification as
a demonstrator application, with additional facility to provide guideline based prompts and even interactions for level 1 evidence is appealing and currently under discussion with the HFA. This Application development would be underpinned by the work undertaken to date by WP4 to ensure the standards and interoperability assets that represent the HF data set are fit for purpose.

The mapping of the HF summary data set to the HF audit, undertaken in WP1 and reported in this chapter, was undertaken to strengthen work to date and ensure appropriate concordance at every level, underpinned by suitable interoperability assets. Outside the FP7 funding it is our intention to pursue this work and incorporate it both within UK and pan-European initiatives, and to date feedback from senior members of the HFA Board has been very positive. This would allow improved audit within the UK and across other European countries, with quality improvement in both settings and potential for publication of the underlying validation.
### Appendix 1: Mapping tables relating the HF summary and HF audit data sets

<table>
<thead>
<tr>
<th>Field sequence number</th>
<th>Description</th>
<th>Values</th>
<th>Type</th>
<th>Cardinality</th>
<th>Source in original application</th>
<th>Source in revised application</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Hospital identifier</td>
<td>e.g. &quot;ACH&quot;</td>
<td>Short String</td>
<td>Mandatory</td>
<td>Export dataset not an adequate selection for a European-wide hospital list</td>
<td>Export dataset not an adequate selection for a European-wide hospital list</td>
</tr>
<tr>
<td>3</td>
<td>NHS Number</td>
<td>10 digit no space</td>
<td>Short String</td>
<td>Optional</td>
<td>subject_of_care_details.identifiers starting with &quot;id:nhs&quot;</td>
<td>subject_of_care_details.identifiers starting with &quot;id:nhs&quot;</td>
</tr>
<tr>
<td>4</td>
<td>Surname</td>
<td></td>
<td>Short String</td>
<td>Mandatory</td>
<td>subject_of_care_details:family_name</td>
<td>subject_of_care_details:family_name</td>
</tr>
<tr>
<td>5</td>
<td>Forename</td>
<td></td>
<td>Short String</td>
<td>Mandatory</td>
<td>subject_of_care_details:given_names</td>
<td>subject_of_care_details:given_names</td>
</tr>
<tr>
<td>6</td>
<td>Birth date</td>
<td>≥1901 and ≤1995</td>
<td>Date (dd/mm/yyyy)</td>
<td>Mandatory</td>
<td>subject_of_care_details:birth_time truncated to the date</td>
<td>subject_of_care_details:birth_time truncated to the date</td>
</tr>
<tr>
<td>8</td>
<td>Postcode</td>
<td></td>
<td>Short String</td>
<td>Mandatory</td>
<td>subject_of_care_details:postal_code_principality_home</td>
<td>subject_of_care_details:postal_code_principality_home</td>
</tr>
<tr>
<td>9</td>
<td>Date of admission</td>
<td></td>
<td>Date (dd/mm/yyyy)</td>
<td>Mandatory</td>
<td>Doesn't align</td>
<td>Admission/Discharge Date/Admission</td>
</tr>
<tr>
<td>10</td>
<td>Main place of care</td>
<td>1: Cardiology, 2: General Medicine, 3: Other, 9: Unknown</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
<td>Care circumstances not fully developed</td>
<td>Care circumstances not fully developed</td>
</tr>
<tr>
<td>11</td>
<td>Did the patient receive input from a multidisciplinary HF team?</td>
<td>0: No, 1: Yes, 9: Unknown</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
<td>Care circumstances not fully developed</td>
<td>Care circumstances not fully developed</td>
</tr>
<tr>
<td>12</td>
<td>Which of the following did the patient see?</td>
<td>1: Consultant Cardiologist, 2: Other</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
<td>Care circumstances not fully developed</td>
<td>Care circumstances not fully developed</td>
</tr>
<tr>
<td>13</td>
<td>Breathlessness</td>
<td>1: No limitation of physical activity, 2: Slight limitation of ordinary physical activity, 3: Marked limitation of ordinary physical activity, 4: Symptoms at rest or minimal activity, 9: Unknown</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
<td>HeartFailureSymptoms.Breathlessness alignment needed (Breathlessness at Rest, with Minimal Activity and Greater Activity differentiated)</td>
<td>HeartFailureSymptoms.Breathlessness alignment needed (Breathlessness at Rest, with Minimal Activity and Greater Activity differentiated)</td>
</tr>
<tr>
<td>14</td>
<td>Peripheral oedema</td>
<td>0: No, 1: Mild, 2: Moderate, 3: Severe, 9: Unknown</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
<td>HeartFailureSigns.PeripheralOedema alignment needed (it’s a text, not an ordinal)</td>
<td>HeartFailureSigns.PeripheralOedema alignment needed (it’s a text, not an ordinal)</td>
</tr>
<tr>
<td>15</td>
<td>Previous IHD</td>
<td>0: No, 1: Yes, 9: Unknown</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
<td>PastMedicalHistory:CoronaryArteryDisease</td>
<td>PastMedicalHistory:CoronaryArteryDisease</td>
</tr>
<tr>
<td>16</td>
<td>Previous ARI</td>
<td>0: No, 1: Yes, 9: Unknown</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
<td>PastMedicalHistory:MyocardialInfarction (presence of data)</td>
<td>PastMedicalHistory:MyocardialInfarction (presence of data)</td>
</tr>
<tr>
<td>Code</td>
<td>Description</td>
<td>Measurement Type</td>
<td>Required Level</td>
<td>Note</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------</td>
<td>--------------------------------------------------</td>
<td>------------------</td>
<td>----------------</td>
<td>----------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38</td>
<td>Previous device therapy</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
<td>Device Therapies. Device where possible</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38</td>
<td>Previous valve disease</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
<td>Any Past Medical History, Valve Disease Type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>41</td>
<td>Previous hypertension</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
<td>Any Past Medical History, Hypertension</td>
<td></td>
<td></td>
</tr>
<tr>
<td>43</td>
<td>Previous diabetes</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
<td>Any Past Medical History, Diabetes Mellitus</td>
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<td>44</td>
<td>Previous Asthma</td>
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<td>Mandatory</td>
<td>Doesn't align</td>
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<td>47</td>
<td>Previous COPD</td>
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<td>Mandatory</td>
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<tr>
<td>96</td>
<td>Height</td>
<td>Centimetres</td>
<td>Optional</td>
<td>Fixed Components. Height (converted to cm from m)</td>
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<tr>
<td>97</td>
<td>Weight</td>
<td>Kilograms</td>
<td>Optional</td>
<td>Heart Failure Signs. Height (converted to cm from m)</td>
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<tr>
<td>99</td>
<td>Heart rate on admission</td>
<td>BPM</td>
<td>Optional</td>
<td>Heart Failure Signs. Heart Rate (first instance = &quot;on admission&quot;)</td>
<td></td>
<td></td>
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<tr>
<td>101</td>
<td>Blood pressure - systolic</td>
<td>mmHg</td>
<td>Optional</td>
<td>Heart Failure Signs. Blood Pressure Systolic (new datasets request admission and discharge which is first and last reading)</td>
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<tr>
<td>108</td>
<td>Full blood count Hb</td>
<td>Double</td>
<td>Optional</td>
<td>Blood Tests. Haematology. Haemoglobin (but match units)</td>
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<tr>
<td>109</td>
<td>Full blood count urea</td>
<td>Double</td>
<td>Optional</td>
<td>Blood Tests. Biochemistry. Urea (but match units)</td>
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<tr>
<td>110</td>
<td>Full blood count creatinine</td>
<td>Integer</td>
<td>Optional</td>
<td>Blood Tests. Biochemistry. Creatinine (but match units)</td>
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<tr>
<td>111</td>
<td>Electrolytes: Sodium</td>
<td>Integer</td>
<td>Optional</td>
<td>Blood Tests. Biochemistry. Sodium (but match units)</td>
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<td>120</td>
<td>ECG</td>
<td>Integer</td>
<td>Optional</td>
<td>Blood Tests. Specialised Blood Test. BNP (but match units)</td>
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<td>123</td>
<td>QRS Duration</td>
<td>Integer</td>
<td>Optional</td>
<td>Electrocardiography. QRS Duration</td>
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<tr>
<td>128</td>
<td>ECG</td>
<td>Multiple strings</td>
<td>Mandatory</td>
<td>Electrocardiography. Heart Rhythm Type and Electrocardiography. QRS Morphology (with exception of Previous MI)</td>
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</table>

Notes:
- Cardiac Resynchronisation Therapy Defibrillator = 1, Cardiac Resynchronisation Therapy Pacemaker = 2, Implantable Cardioverter Defibrillator = 3, 4 does not align.
<table>
<thead>
<tr>
<th>Code</th>
<th>Treatment/Drug</th>
<th>Description</th>
<th>Type</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>130</td>
<td>ECHO (or other gold standard test e.g. MRI, Nuclear Scan or Angiogram)</td>
<td>0. Normal, 1. LV systolic dysfunction, 2. LV hypertrophy, 3. Valve disease, 4. Diastolic dysfunction, 5. Test not done - planned after discharge, 7. Test not done - not yet planned, 8. Other, 9. Unknown</td>
<td>Multiple short strings</td>
<td>Mandatory</td>
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<tr>
<td>202</td>
<td>Diagnosis of heart failure</td>
<td>0. No, 1. Yes, 9. Unknown</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
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<tr>
<td>210</td>
<td>HF liaison service</td>
<td>0. No, 1. Yes, 9. Unknown</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
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<tr>
<td>217</td>
<td>Cardiac rehabilitation</td>
<td>0. No, 1. Yes, 8. Not applicable, 9. Unknown, 12. Declined by patient</td>
<td>Coded Ordinal</td>
<td>Mandatory</td>
</tr>
<tr>
<td>Rule</td>
<td>Yes?</td>
<td>No?</td>
<td>Not applicable?</td>
<td>Coded</td>
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<tr>
<td>----------------------------------------------------------------------</td>
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<td>221 Palliative care</td>
<td>0</td>
<td>1</td>
<td>8</td>
<td>9</td>
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<tr>
<td>222 COTE/medical follow up</td>
<td>0</td>
<td>1</td>
<td>9</td>
<td>Unknown</td>
</tr>
<tr>
<td>223 Cardiology follow up</td>
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<td>1</td>
<td>9</td>
<td>Unknown</td>
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<td>224 GP</td>
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<td>1</td>
<td>9</td>
<td>Unknown</td>
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<tr>
<td>225 Date of discharge</td>
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<tr>
<td>227 Discharge planning</td>
<td>0</td>
<td>1</td>
<td>9</td>
<td>Unknown</td>
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<tr>
<td>228 Was a review appointment with the specialist multidisciplinary HF</td>
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<td>1</td>
<td>9</td>
<td>Unknown</td>
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<tr>
<td>229 Date of heart failure review appointment</td>
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<tr>
<td>230 Was the patient stable on oral therapy after discharge planning?</td>
<td>0</td>
<td>1</td>
<td>9</td>
<td>Unknown</td>
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<tr>
<td>231 Event date</td>
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<tr>
<td>232 Event</td>
<td>1</td>
<td>2</td>
<td>3, 4, 5</td>
<td>Other</td>
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<tr>
<td>235 Life status date</td>
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<tr>
<td>236 Life status</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>Alive</td>
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<tr>
<td>242 Patient died?</td>
<td>0</td>
<td>1</td>
<td>9</td>
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</table>