



NHS England 100,000 Genomes Project SNOMED CT Rare Diseases Datasets Project

Project Initiation Document (PID)

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1. Introduction

1.1 Purpose of Document

The purpose of this PID is to describe the aims of the Project, the rationale for undertaking the Project, the roles of all those involved in the Project, how the Project's aims will be achieved, the timings of the Project and the mechanisms for controlling the Project.

1.2 Background

SNOMED CT is the world's most comprehensive terminology for electronic health information. SNOMED CT contributes to the improvement of patient care by underpinning the development of Electronic Health Records (EHR) that record clinical information in ways that enable meaning-based retrieval. This provides effective access to information required for decision support and consistent reporting and analysis.

Patients benefit from the use of SNOMED CT because it improves the recording of EHR information and facilitates better communication, leading to improvements in the quality of care. SNOMED CT is owned, maintained and distributed by the International Health Terminology Standard Development Organisation (IHTSDO); a not-for-profit association which is governed by its national members. Each country has a National Release Centre (NRC). In the UK, the NRC is based in Leeds (under the NHS Digital's administration) and is called the UK Terminology Centre (UKTC).

2 Scope

2.1 Aims

The 100,000 Genomes Project is an exciting scientific and medical programme. It has the scope to revolutionise treatment and prevention by developing genomic diagnostics, meaning that the NHS can offer more targeted tests, drugs and care for patients. It also supports the government's aspiration to become a world-leader in the practical applications of genomic technologies and aligns with NHS England's ambition to ramp up the scale and pace of change to deliver better outcomes for patients.

The 100,000 Genomes Project is now in its second year. This involves the continued recruitment of patients in Rare Diseases and Cancer across the 13 NHS GMCs and increasing the number of Local Delivery Partners. A number of NHS Genomic Medicine Centres (GMCs) were established as part of a separate procurement to collate and manage genomes for rare and inherited diseases across the country.

This particular project primarily concerns developing fit for purpose SNOMED CT subset (s) for the existing Rare Diseases datasets, using standardised SNOMED CT terminology. The project will evaluate and develop the datasets and, where appropriate, bring them in line with the Cancer datasets. This project will ensure that the SNOMED CT subsets, are clinically and operationally relevant, useful for clinicians and researchers and to help with effective clinical coding for clinical care.

2.2 Objectives

Priorities should be identified and agreed, which must include maintenance and updating over the long term. A number of specific use cases will be developed so that it is easier to decide if a subset is fit-for-purpose.

2.3 Project Scope

This section describes the scope of the SNOMED CT Subsets Project. The Project will cover the whole of UK.

- The project will initially investigate the current work being undertaken between the IHTSDO and Orphanet in developing SNOMED CT subsets for rare diseases and determine if this work could be utilised for the 100,000 Genomes Project. The IHTSDO and Orphanet project aims to build on the existing SNOMED CT rare disease subsets and aims to increase the coverage of rare disease for the international release. The project will identify any differences between this and the rare disease data sets in use by the 100,000 Genomes Project. The project will also
- Include investigating the planned Human Phenotype Ontology (HPO) mapping to SNOMED CT.
- The scope of the Project includes terminology editing services and associated technical services required to deliver national (and international - if appropriate) subsets for rare diseases of SNOMED CT.

2.4 Critical Success Factors (CSF) and Benefits

SNOMED CT is first and foremost about the delivery of care so success factors include acceptability of the terminology to record safe and effective clinical care. The focus of this project is about the usability of the terms i.e. identifying the terms that capture clinical data and that support reliability of data records. In addition however it will include the reusability of the information for outcomes of improved efficiency and agility of services.

A Benefits Dependency Network (BDN) and benefit profiles will be produced as part of the Project deliverables. These will then be measured at an appropriate point once the Project has completed.

2.5 Outside of Scope

- Taking the deliverables through the formal NHS Information Standards approval process.
- Any subsets not stated as within scope for development (when identified)

3 Structure

3.1 Management Structure

This Project is to be delivered within the framework and management structure of NHS England (and Genomics England) with consultancy support as appropriate and external expertise.

3.2 The Project Board

The Project Board will provide overall direction to the Project and is accountable for the success of the Project and has responsibility and authority for the Project within the remit of NHS England It is responsible for:

- approving the PID
- authorising continuation of the Project at each stage
- committing resources to the Project within the agreed budget
- setting tolerances
- resolving escalated Project Issues and Exception Plans
- ensuring the Project meets its objectives
- ensuring the Project delivers the expected benefits
- ensuring the Project remains on course in terms of time, cost, quality and functionality

3.3 Project Board – Membership and Roles

The Project Board members are expected to fulfil the following roles:

- The Business Representative: has operational responsibility for the Project, ensuring value for money, balancing the demands of the user and supplier within the overall context of business requirements.
- The User Representative: is responsible for ensuring the development needs of the intended users through the assurance of the Project plan, technical specification, and final products.
- The Supplier Representative: is responsible for ensuring that proposals for products are realistic in that they are likely to achieve the results required by the Senior User, within the time and cost parameters for which the Executive is accountable.

The individuals assigned to these roles are:

- Project Executive - Kathy Farndon NHS England
- Senior Users - Angie Quinn (augmented with broader 'frontline' users as the project moves on)
- Senior Suppliers - Monica Jones - Animo Consultancy Ltd (augmented with system suppliers as the project moves on)

3.4 Project Staff

Resources including project support are to be assigned as appropriate and meetings convened for project level management.

3.5 Quality Assurance

The project will identify as part of its methodology Quality Assurance (QA) review. Where possible this will draw upon existing (and emerging) SNOMED CT subset review processes.

4 Plans

These will include a list of key deliverables with names of deliverables, description, indicative date, responsible person and acceptance criteria.

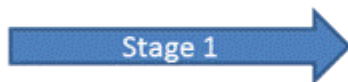
4.1 Project Plans

High Level Plan with Timelines

Start-up and Initiation – October 2016



Project Execution – November 2016 to February 2017



Transition and Closure
– March 2017 onwards



Project Stages
Start-up and Initiation: Produce development plan [within a Project Initiation Document (PID)] including high level product descriptions for discussion with colleagues at NHS England, Genomics England and the UKTC National Release Centre (NRC) - as appropriate

Project Stages

Stage 1: The first stage will involve scoping and identification of the areas to work on including:

- Review and evaluation of the existing information for rare diseases included in the Project (including the Human Phenotype Ontology (HPO) mapping to SNOMED CT)
- Investigate the existing work being undertaken between Orphanet and IHTSDO to develop SNOMED CT Rare diseases subsets and whether this work could be utilised for use in the 100,000 Genome Project.
- National and International search and review to identify whether any country has developed rare disease subsets. Support in terms of providing insight into previous related project work terminology development
- Development of a structured SNOMED CT bound information model that aligns to the Genomics England core clinical dataset(s)
- Engage members and key stakeholders to agree the areas for subset(s) development

This is expected to be fifteen days work (over a three month period including set up)

Milestones:

- Oct 2016 - Dec 2016

Stage 2: This second phase will see the development of the Genomics Rare Diseases SNOMED CT subsets including:

- Development and refinement of all subsets and datasets (including documentation)
- Data acquisition, operational testing and refining the subsets following consultation and feedback (over all project management of these activities)
- Produce a value proposition for the SNOMED CT subsets to be further developed into brief to describe the benefits to stakeholders. Benefits realisation will be included as an important deliverable for the project, and will be evaluated at both a strategic and operational level
- Detailed plan for implementation , support and training as required
- Lessons Learned – from this and previous development work to share with other groups

This is expected to be fifteen days work (over a two month period)

Milestones:

- Jan 2017 - Feb 2017

4.2 Communications Plan

There will be effective and appropriate communications throughout the Project. Stakeholders include regional and country wide groups, as well as professional networks. These are a useful and credible resource for review and consultation.

The communication plan will be incorporated into the implementation plans for NHS England and these will be coordinated through the Project Manager. The delivery of this will be throughout the duration of the Project. The Project Board, will be briefed via highlight reporting and normal risk / issue management.

5 Controls

5.1 Highlight Reports

Highlight reports will be produced monthly. These will be reviewed by the Project Team before presentation to Project Board

5.2 Variances / Exceptions

Once plans for phases have been approved, variances from the plan in accordance with the agreed tolerance limits for schedule, budget and scope will be notified to the Project Board as risks and issues and reported on risk and issue reports.

6 Risks and Issues

6.1 Risk Log

A risk log will be maintained throughout the Project, with new risks reported in to the Project Board via regular highlight reports. See Annex A for initial Risk Log.

6.2 Issue Log

An issue log will be set up and all issues throughout the Project will be recorded and notified to the Project Board.

7 Assumptions

There is sufficient budget and resources (with contingency) to carry out all activities within the scope of the Project

8 Dependencies

The ability to deliver the service is dependent on:

- Identification of rare disease domains for subset development
- Continued drive to implement SNOMED CT as the main clinical terminology within the UK health care service

- Engagement with sites and suppliers to effect the implementation of the subsets within their clinical IT and thus making them available to use in day to day practice

Other dependencies will become apparent through further development of the plan.

Annex A: SNOMED CT Subsets Project - Risk Log

ID	Short Description	Risk Statement	Risk Level	Date Identified	Expected Impact Date	Assigned To	Mitigation	Response Status
001	Importance of subsets	It is important that there is recognition of the importance of SNOMED CT subsets within the genomics community	Low	28/10/2016	01/03/2016	MJ	Link to communication plan	active
002	Actual Implementation	There must be an understanding of what the subsets are to achieve and uptake in both systems and by clinicians	Low	28/10/2016	01/03/2016	MJ	Defined use cases and education materials and guidance documentation	active
003	Communication with members	As stated in the PID communication with members and the broader community is important	Med	28/10/2016	01/03/2016	KF	Effective communication plan, speaking at events, newsletters and bulletins	active
004	Identifying sites	Identifying sites which may be able to review and test is important	Med	28/10/2016	01/03/2016	AQ	Engagement with sites (and suppliers)	active

Risk Levels:

- 1 - Low risk
- 2 - Medium risk
- 3 - High risk

These are calculated by comparing **probability** of the risk happening and the **impact** of what that would have if it happens i.e. becomes an issue