



201946 Using SNOMED CT to support the national Inflammatory Bowel Disease (IBD) Registry Data Submission - Journey of a UK teaching hospital

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Summary

This abstract intends to share with the community the journey that a tertiary referral teaching hospital went through, moving from using admin data source to clinical data source to support one of the national Inflammatory Bowel Disease (IBD) Registry Data Submission.

Audience

Clinical, Research/academic, Policy/administration

Learning Objectives

1. What was the change?
2. What is the local challenge?
3. What are the national challenges hinder the "best practice" implementation?
4. The implementation journey we went through.
5. How does the implementation feed into the national policy making.

Abstract

This abstract intends to share with the community the journey that University College Hospitals NHS Foundation Trust (UCLH), a national tertiary referral centre, went through in moving from using admin data source to clinical data source to support the national Inflammatory Bowel Disease (IBD) Registry Data Submission.

In the UK, IBD registry is a national mandatory return, based on ICD and OPCS codes. Prior to our EHR implementation, the only data source we have, in a structured manner, is the clinical coding data. Business Intelligence team has been using that data source to submit IBD data.

There are several disadvantages of this approach:

1. Delay: clinical coding is performed at post-discharge and by the time the analysis is generated, patient has departed from the hospital. Clinicians generally lost interest about patient who is “currently” not “in” the hospital. More importantly, we probably have lost the best time and opportunity to “intervene” or enhance their care.
2. Inconsistent data collection process: Clinical Coding team doesn’t normally code outpatients in the UK. Therefore the coding data can only capture “admitted patients” and failed to capture “clinic visits”. We use a complete manual approach to collect this data in the clinic setting.
3. Non-clinically validated data source: clinical coding data is not collected by clinicians rather than clinical coders. To feed non-clinical data source to national clinical database and try to generate clinical guidelines is very risky and not meaningful.
4. None clinical terminology submitted: The registry requires the diagnosis and procedures to be submitted in ICD and OPCS format. Neither ICD nor OPCS are clinical terms. They are aggregated in such a high level which means they are not granular enough to perform any meaningful clinical research should the researcher feels more granular clinical data is required.

Against the backdrop of our newly implemented EHR system, one of the focuses of leveraging the benefits to ensure EHR system is meaningful by using clinical data standards throughout the system. This journey will be challenging but worthwhile. One of the many clinical benefits we try to implement is supporting national clinical audit. Inflammatory Bowel Disease (IBD) Registry Data Submission is nationally mandatory and given it is a specialised specialty involves a group of consultants, we started off with this area.

During the implementation process, we discovered many challenges, both at the local and national level. With the support from the clinical lead, who is also the chair for the national IBD group, we are able to overcome the local challenges through many resolutions.

Some examples are:

1. Clinical engagement;
2. System configuration to make it easier for clinicians to select the specific diagnoses;
3. Using reporting tools, e.g. dashboards to educate clinicians learn to read their clinical data which is real time.

However the national challenges are rather more difficult to overcome which creates a lot of frustration to us. The main challenges are:

1. National IBD registry for data submission is not support using SNOMED CT;
2. Registry for data submission is not supporting multiple diagnoses which is common for IBD patients;
3. Changes on national policy is outside the Trust’s control;

We hope our story will help the community to understand that there are many factors which make SNOMED CT widely acceptable by the NHS, and possible future success in truly improving patient care through various EHR implementations. Some factors we can overcome at a local level, but some factors are rather contra intuitive for the organisational and national vision and will need the national and international bodies to influence the change.

