

## **Presentation: Use of Clinical Terminology to Support the UK Inflammatory Bowel Disease (IBD) Data Registry Submission - The Good, Bad and Indifferent**

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Page | 1

This abstract is intended to share with the community the implementation experience that University College Hospitals NHS Foundation Trust (UCLH), one of the largest teaching Hospital in London, gained in using clinical terminology to support the national Inflammatory Bowel Disease (IBD) Registry Data Submission.

The Trust went live with their Epic EHRS system at the end of March 2019. The ambition is to provide the staff with all the information they need across UCLH in a single patient record. Echoing the Trust's vision in delivering top-quality patient care, excellent education and world-class research, clinical data standards was one of the new elements that were introduced.

In the UK, the IBD registry is a national mandatory return. According to the IBD Registry, the return is "to improve care of patients and understanding of the treatments they receive, to enable research, and to increase knowledge about IBD in the UK."

Prior to Epic, we used a system called InfoFlex to capture the IBD data.

There are several disadvantages of this approach:

1. No clinical incentive to record the data: System largely focused on reporting requirement rather than integrating with clinical care. Clinicians lost engagement having to enter the data to serve admin reporting.
2. Delay: because it wasn't having any impact on patient care, data entry is normally done at the last minute.
3. No transparency and missing patients: clinicians don't want to engage and only very limited IBD data was entered in the system

Against the backdrop of our newly implemented EHR system, one of the key changes we would like to introduce under Epic, linking with the clinical data standards is how to merge the clinical benefits and data submission seamlessly. Clinicians record the clinical data because they see clinical benefits.

We started off with the "problem list". With support from the clinicians in the Problem List Working Group, who were able to see the benefits of clinical terminology, we overcome some local challenges through many resolutions.

However the national challenges are rather more difficult to overcome. The fact that the National IBD registry only requires three very broad diagnoses (categories) to be submitted remains the biggest challenge.

1. Clinical practice is all about details. Collecting clinical details at the local level but completely losing it at a national level, is counterproductive.

2. If the purpose of the IBD Registry is to improve patient care and enable research, how can it support research with such a limited diagnosis codeset?
3. IBD with and without complications should have been separately identified due to the different risk factors and treatment plan involved, unlike what is stipulated in the current IBD data registry.

Page | 2

We want to share our story with the community to demonstrate that patient level data capture has to be very granular because it is replacing the paper record. Clinical terminology i.e. SNOMED CT and EHRS can certainly help with this agenda. National audits and registries should embrace the same agenda by encouraging the Trusts to submit granular data using clinical terms and define the aggregation rules after receiving the data (from local hospitals) for their needs.