

Use Clinical Terminology to Support the UK IBD Data Registry Submission - The Good, Bad and Indifferent

SNOMED CT EXPO 2019

Presented by:

Leilei Zhu Clinical Data Standards Lead

University College London Hospitals NHS Foundation Trust, United Kingdom

Outline

- **Background Information**
 - University College London Hospitals NHS Foundation Trust (UCLH)
 - UCLH and our Epic Electronic Health Records System
- **Case Study**
 - UK Inflammatory Bowel Disease (IBD) Registry
- **The key clinical field**
 - The Problem List
- **Self-reflection from the journey**

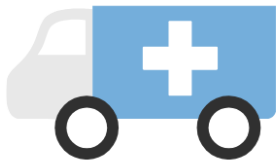
University College London Hospitals in a Nutshell



10,000 staff
from 121 countries



1,000,000+
patients each year



142,000+ visits to
Emergency Department



1,161 hospital
beds



£1 billion turnover
each year



13 sites in central
London

- One of the largest teaching Hospital in London
- Provide Specialist and local services
- Rated “good” by Care Quality Commission
- Academic relationship with UCL
- Strong partnership with University College London (UCL)
- One of 5 comprehensive Biomedical Research Centres (BRC)

Our sites

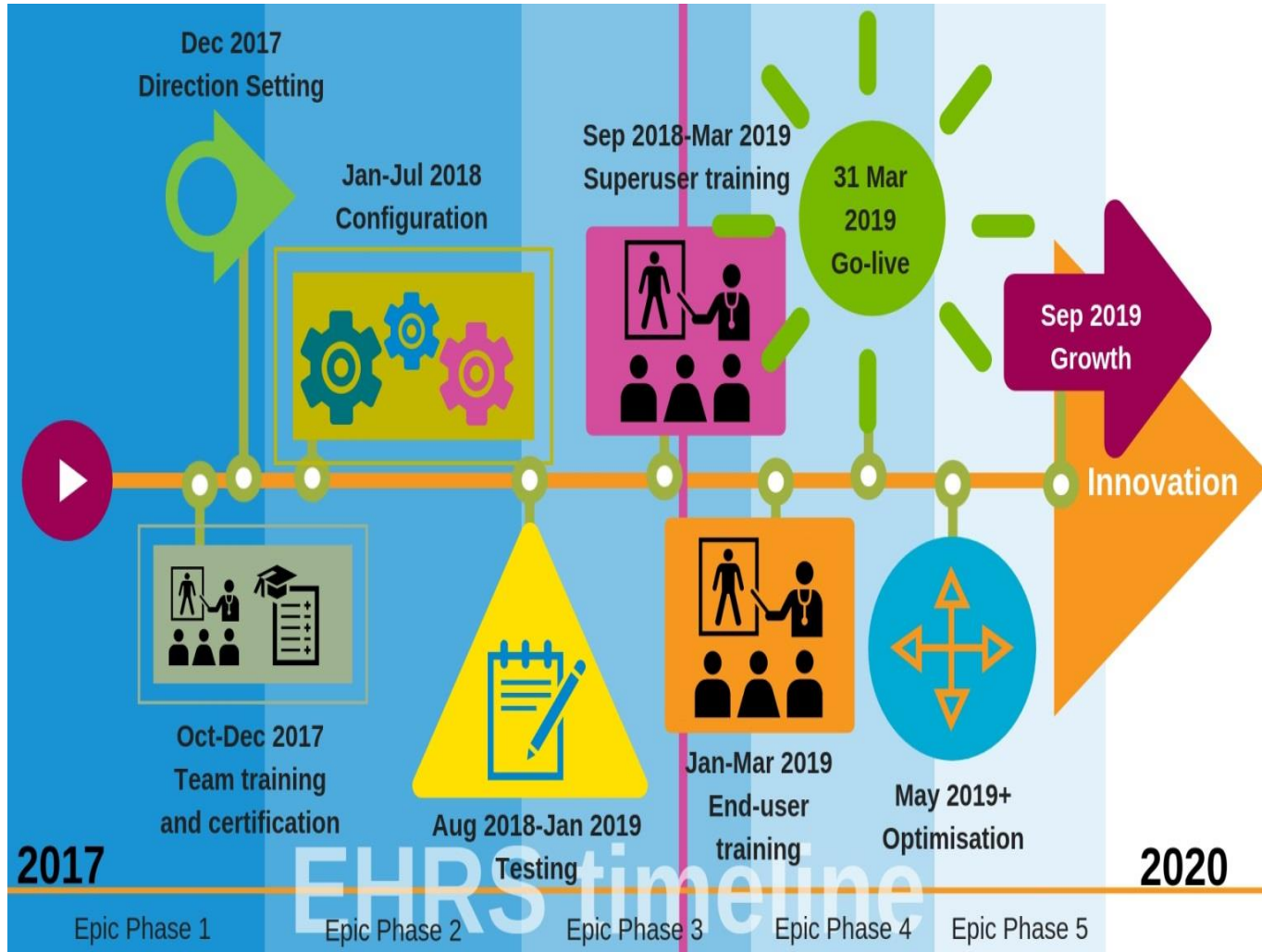


Our vision and values

We are committed to delivering top-quality patient care, excellent education and world class research

Safety
Kindness
Teamwork
Improving

Our Electronic Health Records (EHRs) Journey



We said: Our EHRIS will help improve...



UCLH Vision: A Research Hospital

- It is **not just** a hospital that does research
- It is an organisation in which research and analytics are integral and fundamental to everything we do - Valued not because staff are told to value it, but because *they can see the value*.
- A research hospital *redefines* state-of -the art care - *transformational*
- Improves patient safety, outcomes and experience through *relentless innovation - informed by **its own data***
- Learn from every *individual* case and **every element of data**, embedding the resultant knowledge into care delivery through immediate, *constantly optimising*, closed loop systems
- A “Re - search” hospital is a “*learning hospital*” - learns from what it does
- Decision support for management where “*I think*” is replaced by “*I know*”
- Patient engagement and involvement *is hardwired in*, not bolted on

(Courtesy of Dr Wai Keong Wong, Consultant Haematologist, Chief Research Information Officer)

NHS Clinical Data Standards

- The NHS standard for **clinical data records** is SNOMED CT
- Medicines and medical devices should be described using the Dictionary of Medicines and Devices (dm+d)
- The NHS standard for diagnosis based statistical analysis of hospitals is ICD
- The current NHS standard for procedure based statistical analysis of hospitals is OPCS
- The NHS standard for describing clinical tests and test results will be Unified Test List (UTL)
- All NHS digital, data and technology services should support FHIR-based APIs to enable the delivery of seamless care across organisational boundaries

(Matt Hancock, Secretary of State for Health and Social care)

Practical implementation issues

- Timing: when to incorporate standards into the EHR design?
- **Vision**
 - Board level
 - Managerial level
 - Operational level (clinical and non-clinical users)
 - EHR system program team
- Knowledge and mind-set
- “It is hard to visualise what a meaningful EHR system can do if you haven’t seen one”
- Habit (free text vs structured input)
- Endless mouse clicks, key strokes, and gaze...

So the Key question becomes: how do we sell the **clinical** benefits to clinicians?

Starting off with National Registry and Clinical Audit

Case Study

- UK Inflammatory Bowel Disease (IBD) Registry

IBD Registry

- “The purpose of the IBD Registry 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.”

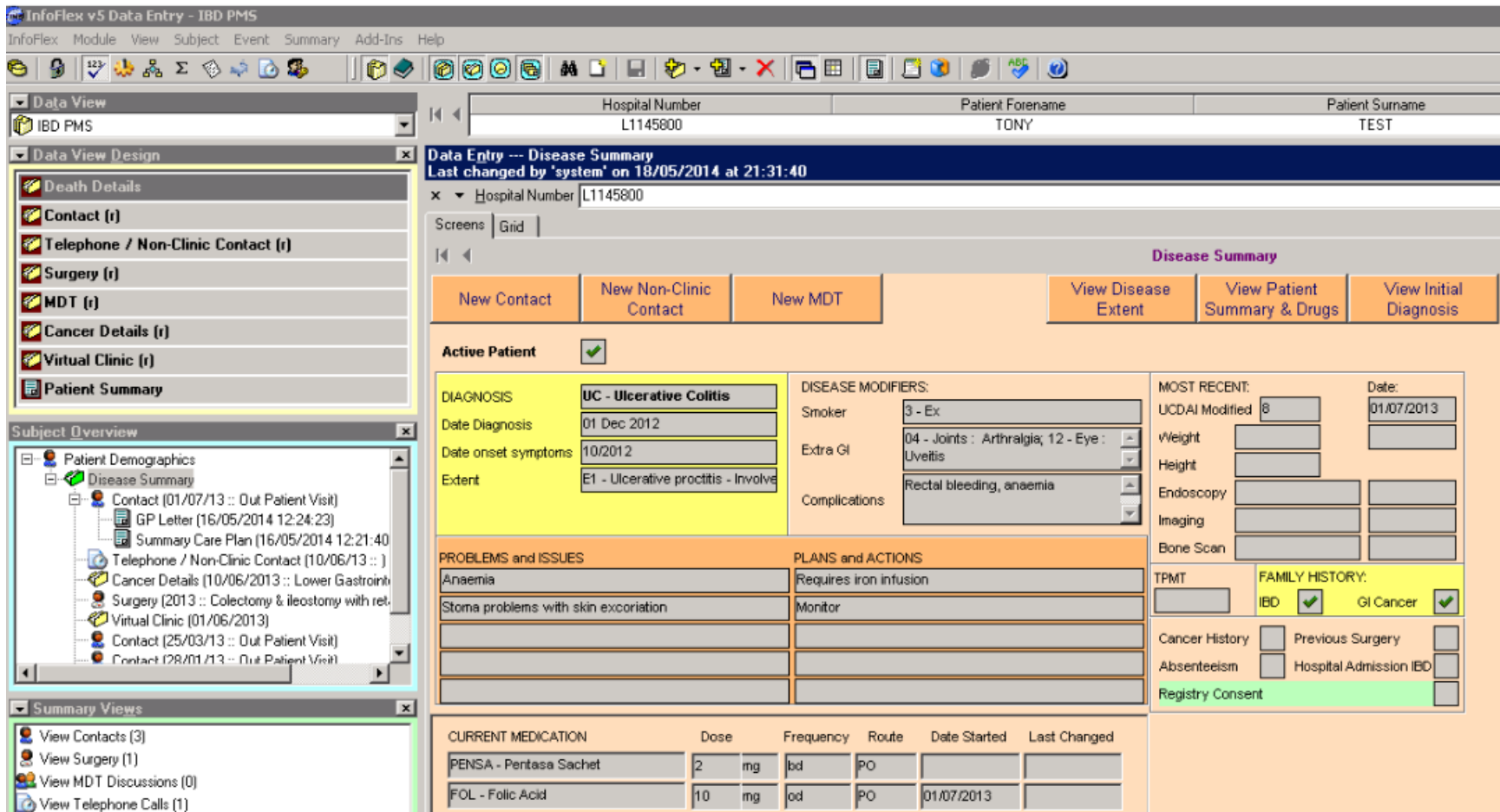
Three Levels the Registry dataset

- **Level 1** – a minimal dataset of demographic data and IBD diagnosis.
- **Level 2** – the above data, plus additional clinical information including disease classification, details of surgery, admissions, cancer diagnosis and class of drugs.
- **Level 3** – a richer clinical dataset which can only be provided by a hospital using an electronic patient management system, such as the Registry PMS or Web Tool.

List Name	Coding	Description
Diagnosis	CD UC IBDU	Crohn's Disease - K50 Ulcerative Colitis - K51 IBD type unspecified -K52
Surgery	H04.1 H04.2 H05.1 H05.2 H05.3 H06.1 H07.1 H09.1 H55.4 H55.5 H58.2 G27.2 G58.1 G73.3 G78.2 Y53.1 99	Total proctocolectomy Ileonal pouch Partial colectomy & colostomy with retained rectal stump Colectomy ileostomy with retained rectal stump Pancolectomy Partial (segmental) colectomy Right hemicolectomy Left hemicolectomy Insertion of seton Fistulectomy Drainage of perianal sepsis Gastric surgery Small bowel resection Permanent ileostomy Strictureplasty Radiological drainage of abscess Other surgery (not specified)

What was the process before?

- We have a system called InfoFlex. Screenshot below



What was the process before Epic EHRs?

- One IBD personnel was hired by the IBD clinical lead to record the data for his IBD patients only.
- **Why?**
 - IBD patients' journey starts from the outpatient clinic but outpatient diagnosis is not mandatory for national submission
 - We can't use the "Clinic name" to predict the patient's problem
 - It is impossible to troll through paper case notes to find the patients with IBD (if the data is not entered real-time)
 - Nobody wants to enter the same data at two different places
 - Because InfoFlex system is not seen as a "clinical system", rather than a reporting system, it was a "bolt-on" for clinicians

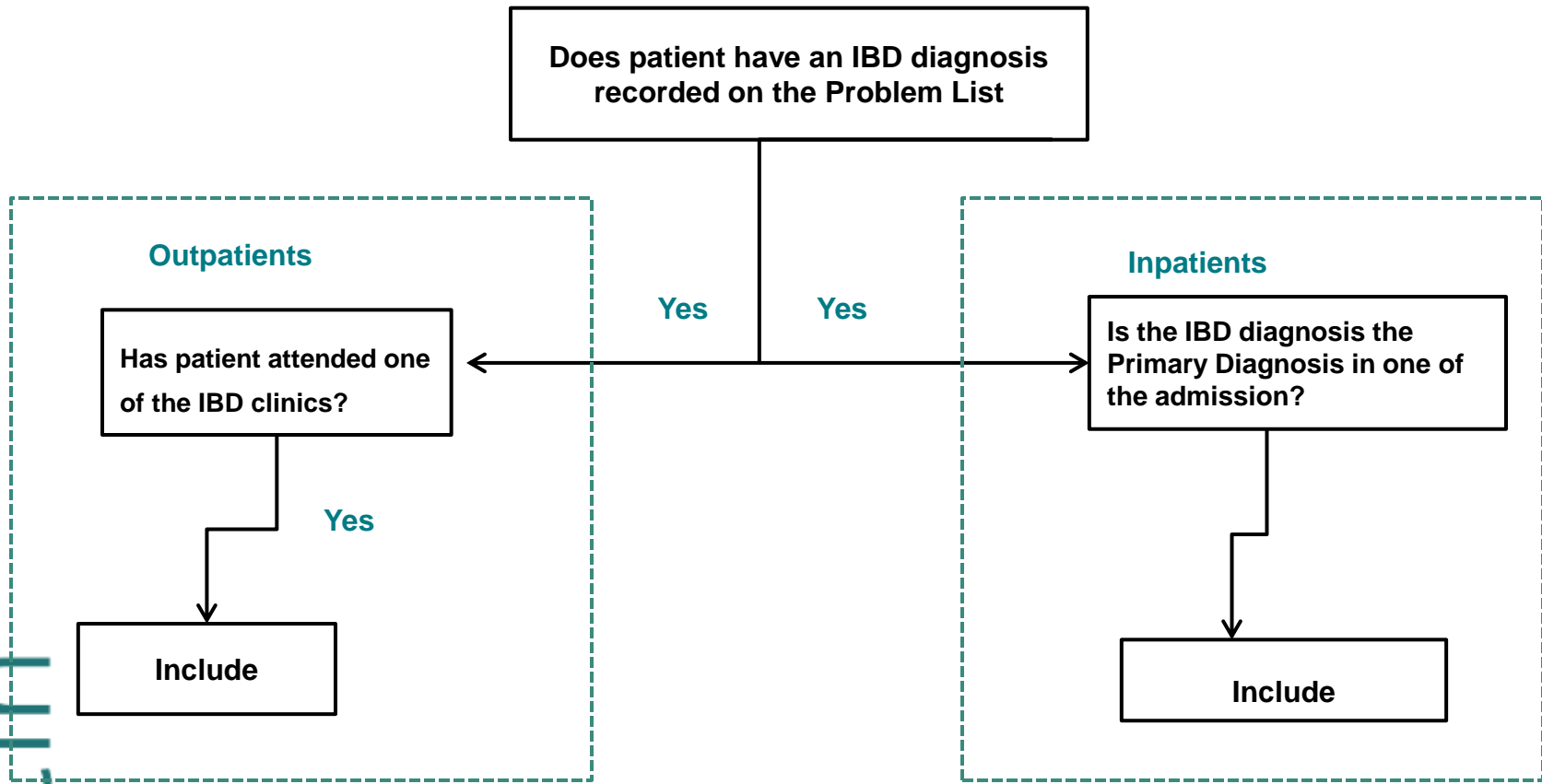
Problems with the previous process

- No clinical incentive to record the data
- Missing patients
- No transparency
- Became a complete data submission exercise

Key change we would like to make under Epic:

- Linking clinical benefits and data submission together
 - Clinicians record the clinical data because they see benefits beyond reporting

Current Process



Using the Problem List as the starting point

- An populated problem list screenshot

Screenshot removed due to proprietary right.

How did we go with the Problem List?

- **Clinicians don't embrace structured data input**

Search screen look like this:

Screenshot removed due to proprietary right.

Then more to fill in...


Screenshot removed due to proprietary right.

Nature of the game started changing...

- Change from one small specialty's data registry collection to a Trust-wide program to increase the uptake the Problem List
- Problem List Clinical Working Group formed to make recommendations
 - Short term (e.g. Configuration, Education etc.)
 - Long term (e.g. Development, Redesign of the screen)
- Engagement on both junior doctor and Consultant level
- Using a data drive initiative from the ground-up to drive better data collection at the front end
 - Picked three specialties to pilot
 - Creating performance report (for clinicians)

Design Preference List to Ease the Search

- IBD Preference List

Only Favourites 

Common DX

Inflammatory Bowel Disease Diagnoses (Common DX)


<ul style="list-style-type: none"> + Acquired short bowel syndrome + Colitis presumed infectious + Crohn's disease + Crohn's disease of both small and large intestine + Crohn's disease of duodenum + Crohn's disease of jejunum + Crohn's disease of small intestine + Diverticulitis + Exacerbation of Crohn's disease + Indeterminate colitis + Ischaemic colitis + Perianal Crohn's disease + Radiation colitis + Radiation proctitis + Short bowel syndrome + Ulcerative colitis, left sided + Ulcerative pancolitis 	<ul style="list-style-type: none"> + Coeliac disease + Collagenous colitis + Crohn's disease involving terminal ileum + Crohn's disease of colon + Crohn's disease of ileum + Crohn's disease of rectum + Diversion colitis + Diverticulosis + Exacerbation of ulcerative colitis + Infectious colitis + Lymphocytic colitis + Pouchitis + Radiation enteritis + Rectal cuffitis + Ulcerative colitis + Ulcerative colitis, rectosigmoid + Ulcerative proctitis
---	--

Smart Links to help with letter automation

Signed

Inflammatory Bowel Disease MDT meeting

Hide copied text

 Hover for details 

Referring Consultant:	Date of MDT: 03/05/19
------------------------------	------------------------------

Clinical History:

Patient Active Problem List	
Diagnosis	SNOMED CT(R)
• Ulcerative pancolitis	Ulcerative pancolitis
• PSC (primary sclerosing cholangitis)	Primary sclerosing cholangitis
• Beta thalassaemia trait	Beta thalassaemia trait
• Latent tuberculosis	Inactive tuberculosis

What is the purpose for this Review colonic biopsies
MDT Review?

Comments
 UC-PSC
 Biopsies from Oct 2018 show mild-mod inflammation.
 Indefinite dysplasia
 Pentasa increased from 2 to 4g today
 ?need to bring forward colon from Oct or leave as is?

Who has clerked most patients with most problems this week? - A data driven approach on junior doctors

Problems Created (Acute intake team, previous 7 days)

Week Ending
13/10/2019

User Name	Provider Type	Problem Count	Patient Count
THOMPSON, DAVID	Registrar - ST1-2	71	14
REID, JONATHAN	Registrar - ST3+	35	7
ROBERTS, REBECCA	Registrar - ST3+	17	6
MOLONGHINI, BENJAMIN	Registrar - ST3+	11	4
YAMAMOTO, TAKAHIRO	Registrar - ST3+	11	1
RUBABEL, MAMTA	Registrar - ST3+	8	3
LEWIS, JAMES	Registrar - ST3+	7	4
WINSTON, LOUISE	Foundation Year 2 Doctor	6	3
CRAZIGH, ERIN	Registrar - ST1-2	5	4
GURTA, DEVI	Foundation Year 1 Doctor	4	1
HARRIS, JAMES	Registrar - ST3+	4	2
KIRCHNER, SAHJ	Registrar - ST3+	4	2
MCCORMACK, LAUREN	Registrar - ST1-2	4	1
WEBB, THOMAS	Registrar - ST3+	3	1
ZELBY, MIRIAM	Registrar - ST1-2	2	1
ZELBY, CLAUDE	Foundation Year 1 Doctor	2	2
BENNETT, FRANK	Registrar - ST3+	1	1
PARKS, THOMAS	Registrar - ST3+	1	1
ABBOTT, JANE	Registrar - ST3+	0	0

What is the irony?

The codeset underpinning the IBD registry- Diagnosis (One Example Only)

List Name	Coding	Description
Diagnosis	CD UC IBDU	Crohn's Disease - K50 Ulcerative Colitis - K51 IBD type unspecified -K52

We are only allowed to submit the above three diagnoses.
 One of three is even more generic K52

“The purpose of the IBD Registry 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.”-IBD Registry

What is the irony? – The codeset

- We **lost all the clinical details** collected from the Problem List using a proper medical terminology.

Example:

Crohn's disease

Crohn's disease of large intestine

Crohn's disease of large intestine with fistula

Crohn's disease of large intestine with intestinal obstruction

Crohn's disease of large intestine with rectal bleeding

Crohn's disease of large intestine without complication

Crohn's disease of large intestine with abscess

Crohn's disease of small intestine

Crohn's disease of small intestine with intestinal obstruction

Crohn's disease of small intestine with abscess

Crohn's disease of small intestine with fistula

Crohn's disease of small intestine with rectal bleeding

Crohn's disease of small intestine with complication

Crohn's disease of small intestine without complication

All the above terms is submitted using one code-CD: Crohn's Disease

Example 2

- Acute ulcerative colitis
- Chronic ulcerative colitis
- Chronic ulcerative ileocolitis
- Chronic ulcerative rectosigmoiditis
- Chronic ulcerative proctosigmoiditis
- Ulcerative chronic pancolitis with fistula
- Ulcerative chronic pancolitis with intestinal obstruction
- Ulcerative chronic pancolitis with rectal bleeding
- Ulcerative chronic pancolitis without complications

All the above terms is submitted using one code-UC:
ulcerative colitis

What did we challenge?

“The purpose of the IBD Registry 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.”-IBD Registry

Questions we had:

- Clinical practice is all about details. Collecting clinical details at the local level but completely lose it at a national level, is counterproductive.
- If the purpose of the IBD Registry is to improve care of patients and enable research, how can it support research with such limited diagnosis codeset?
- IBD with and without complications must surely be separately identified due to the different risk factors and treatment plan involved?

What we requested:

- We requested the chair of IBD Registry (a senior gastroenterologist) to allow early implementers like us to start submitting SNOMED CT data.
- Unfortunately our wish wasn't granted

To tie in with Clinical Terminology and EHRs

- 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.

However,

- If we start from the logic that computer systems had, which is used to manipulate population level statistics, and think...
- We can continue to capture clinical data at the gross level, we are doing patients and clinicians a massive disservice.
- Imagine the clinician who has to stand up in the coroners court to justify the patient's treatment armed with a very simplistic level of recording in the EHRs if we only record at population level....
- Modern methodology means we don't need to compromise.
- National audits and registries can define the aggregation rules after receiving the data from local hospitals.

My self-reflection

- EHRS is a major step forward for any organisation
- Never forget your vision
- Vision is not just a local organisational problem
- Just because people working at the national level, doesn't mean they are visionary
- A skilful consultant ≠ Digital Healthcare Expert
- Never stop the fight!
- If the process/outcome of the fight means better patient care, it is worth fighting for

- “A research hospital is an organisation in which research and analytics are integral and fundamental to everything we do - Valued not because staff are told to value it, but because they can see the value.”

(Courtesy of Dr Wai Keong Wong, Chief Research Information Officer)