



PRIMIS

Making clinical data work



University of
Nottingham

UK | CHINA | MALAYSIA

Uses & abuses of Terminology Data In Primary Care

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sd9dlde8sao9nt9eel81vep6u0
lgfjp8afnnla9nv3aj7sz91y84
0tj**making**a72f3ho9tde518gf0
1d06f8s**clinical**9t4**data**gla3
kmndl175nci6sbq9**work**he80kf9
q8n79dlaox41p5j7f5fqz911do



- Business Unit – University of Nottingham
- Since 2000
- Team of Data Analysts, Business Implementation Leads & Clinical Advisors
- Support National projects for NHSE, UKHSA
- Support Industry, Research & Health Charities working in & around data
- REFSETS, Data Quality, Terminology, System Artefacts....
- **Honest Brokers....**



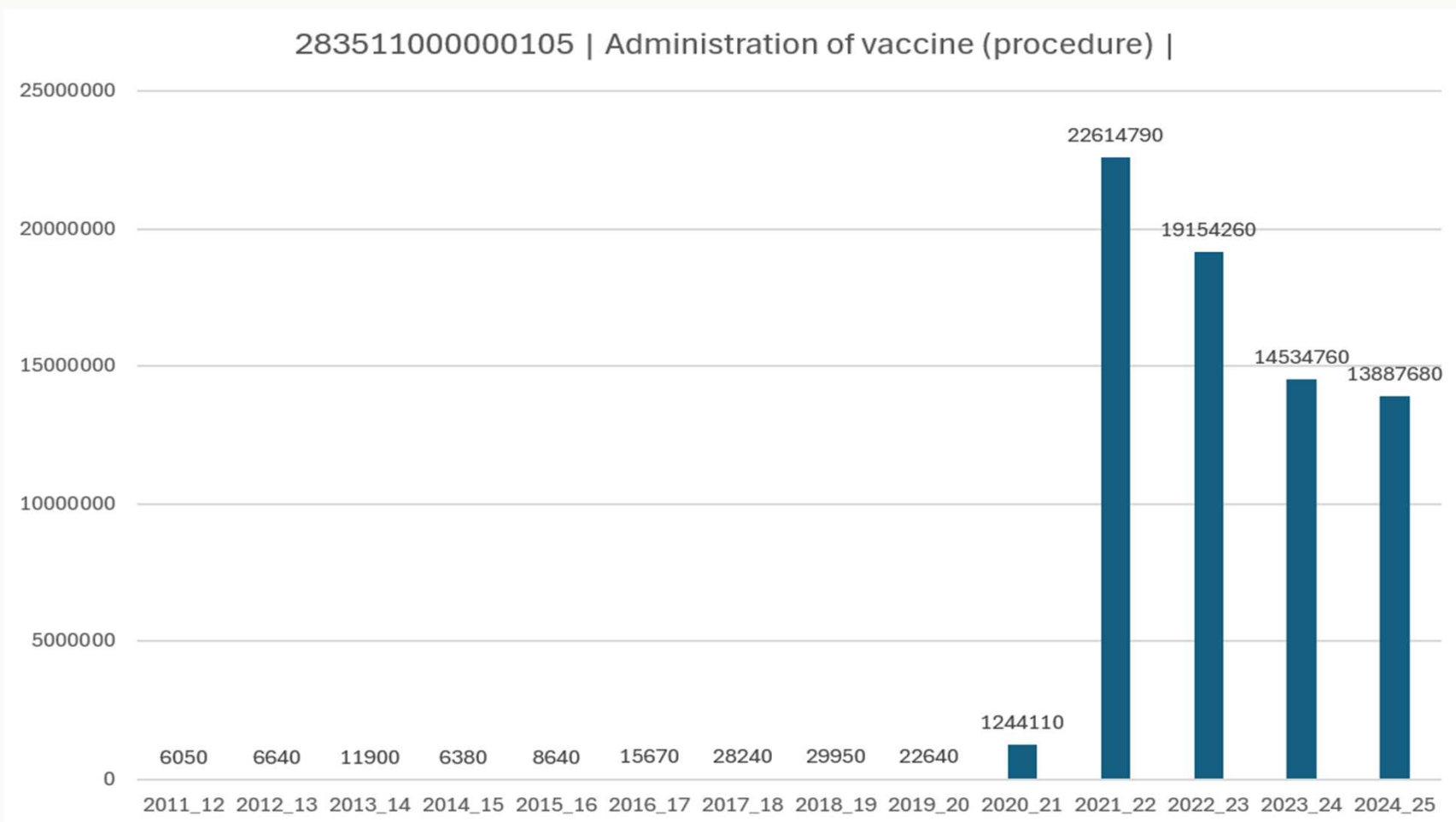
Cover

- Data Quality
- Where it can go wrong
- Implications
- Lens of vaccination programmes in UK?



Administration of vaccine (procedure)

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RSV administration

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☰ Administration of vaccine product containing only Human orthopneumovirus antigen (procedure)

SCTID: 1303503001 , Fully defined , Active

National Health Service realm language reference set (clinical part)

Term	Acceptability (GB)
F ☆ Administration of vaccine product containing only Human orthopneumovirus antigen (procedure)	Preferred
S ★ Administration of RSV (respiratory syncytial virus) vaccine	Preferred
S ✓ Administration of respiratory syncytial virus vaccine	Acceptable
S ✓ Administration of vaccine product containing only Human orthopneumovirus antigen	Acceptable
S ✓ RSV (respiratory syncytial virus) immunisation	Acceptable
S ✓ RSV (respiratory syncytial virus) vaccination	Acceptable

~56,000 patients may have been miscoded with this term as sent out as added as a code when SMS invite sent



What is Data Quality?

- It always depends on the intended use of the data
- Building a Clinical Record
- Audit
- Payment for services
- Decision support \leftrightarrow **AI**
- Mortgage Application
- Research
- Organisational management – call, recall, workload etc

- Complete
- Accurate
- Relevant
- Accessible
- Consistent
- Timely



Legal Consequences of DQ

- **GMC Good Medical Practice -69**

You must make sure that formal records of your work (including patients' records) are clear, accurate, contemporaneous⁶ and legible.

- **Information Governance & ICO**

- **UK GDPR** – 7 principles include Accuracy

- **Litigation**

- **Medical Protection Society:** guidelines for medical records emphasize:

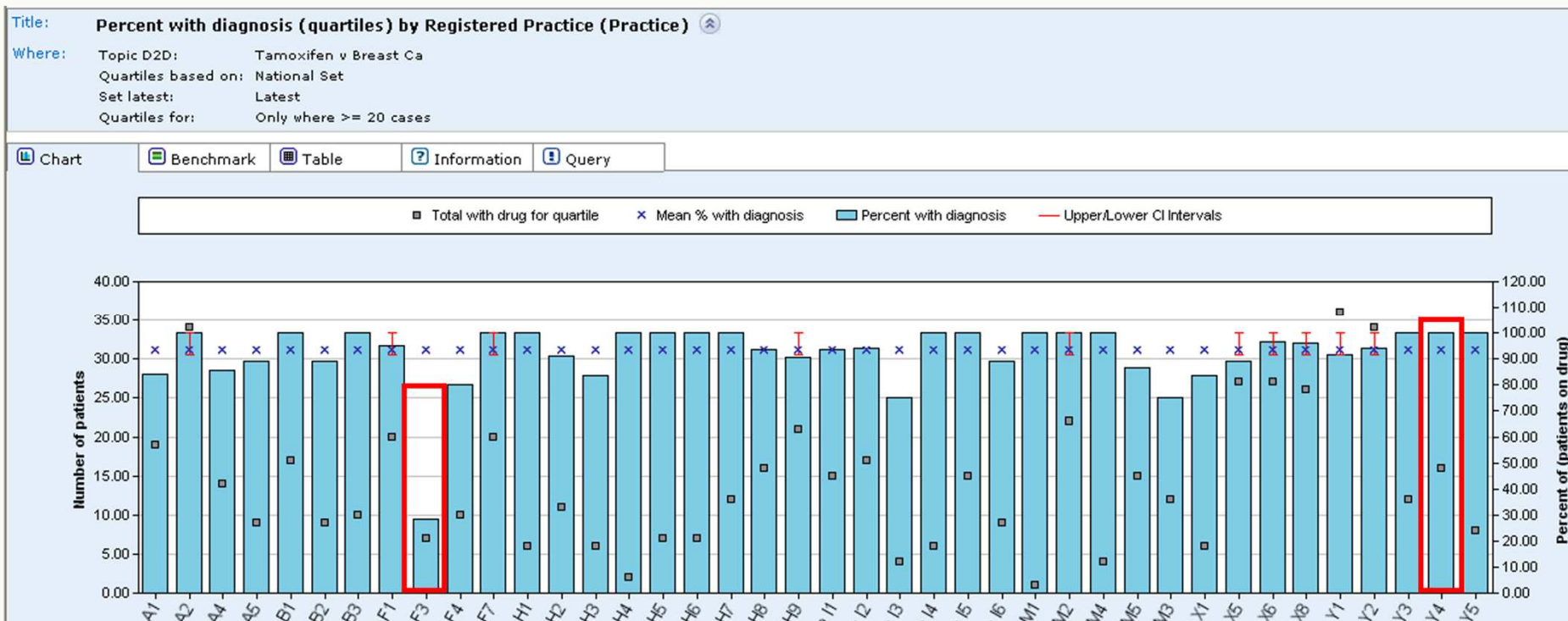
Clarity, Accuracy, and Completeness, stating that records must be legible, made contemporaneously, and detailed enough for another doctor to manage the case



Data Quality Audits & what they showed

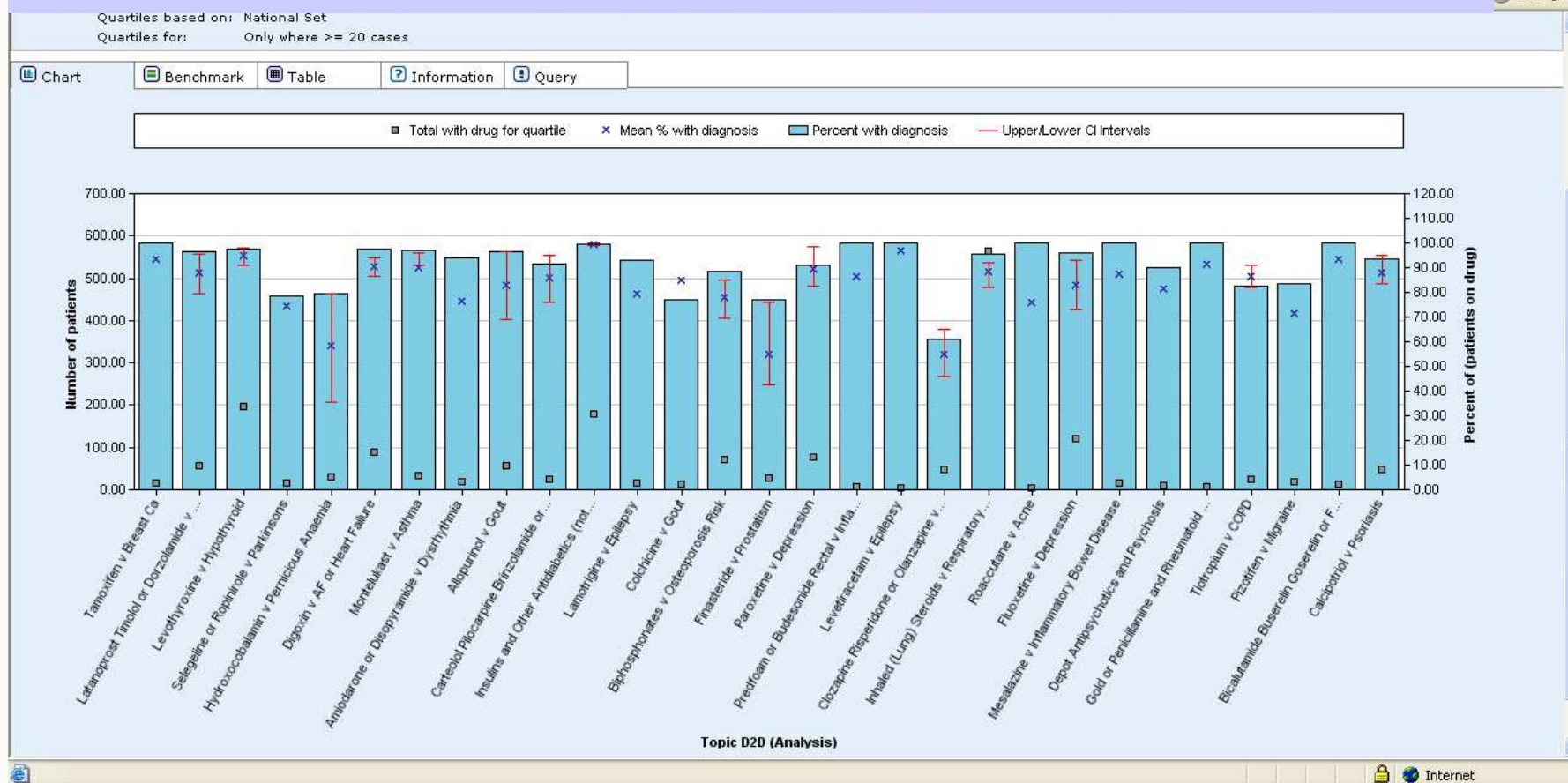
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■ Tamoxifen prescribing vs Diagnosis



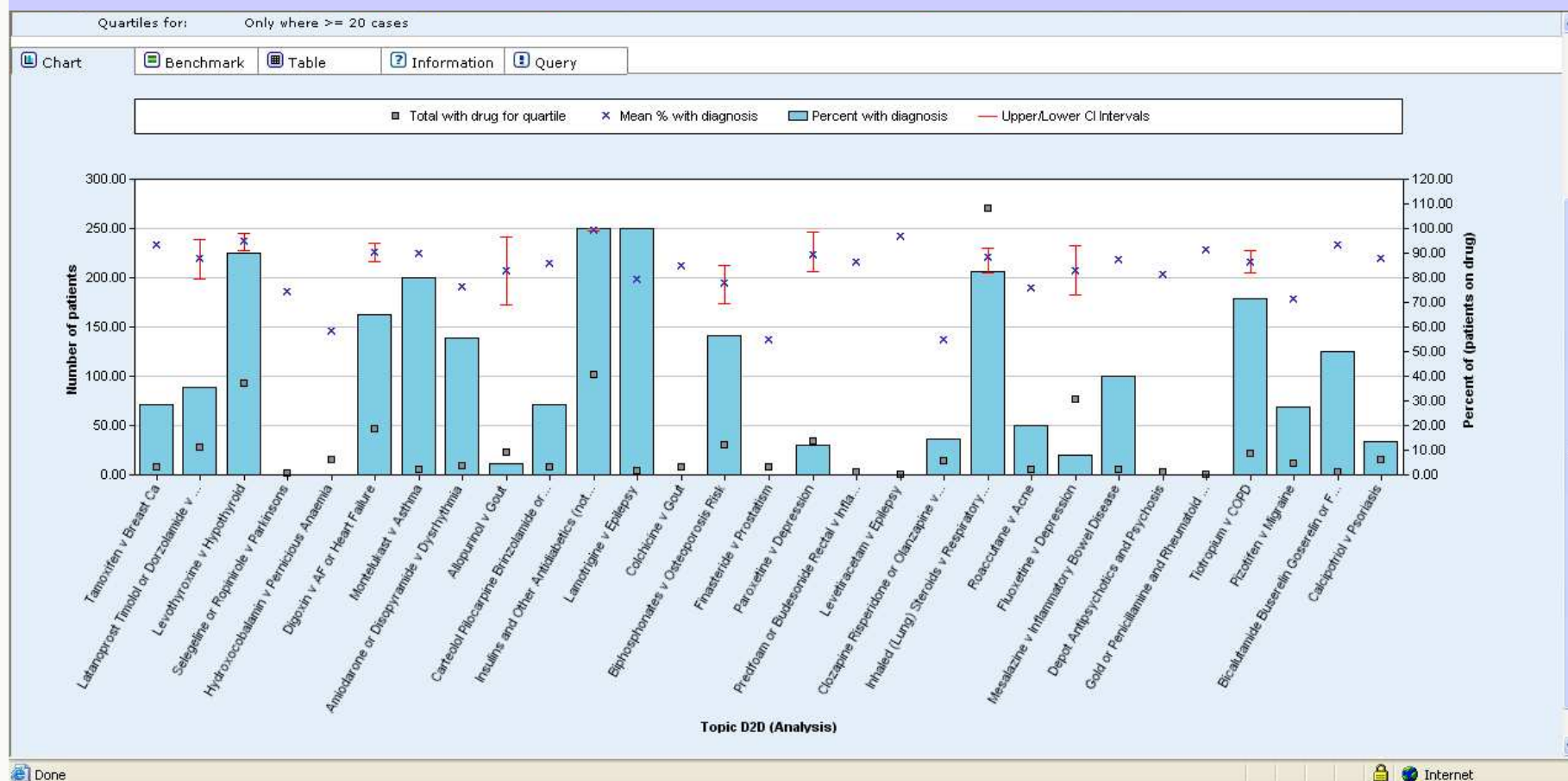


Y4 – all D2D





F3 – all D2D





Elephantine Pregnancies

348	50.0	57.81
345	50.0	72.50
346	100.0	100.00
347	100.0	82.61
349	100.0	97.94
344	0.0	26.67
020	50.0	56.05
013	50.0	72.41
004	100.0	86.59
034	100.0	83.33
011	0.0	32.52
012	100.0	92.13
010	100.0	87.50
007	100.0	88.14
005	100.0	93.24
026	0.0	25.93
024	100.0	95.00
630	0.0	15.38
016	50.0	73.47
611	100.0	75.86
627	50.0	58.82
622	100.0	88.89
624	50.0	52.94
615	0.0	47.06
023	100.0	95.41
027	50.0	75.00
019	0.0	16.92
043	100.0	77.53
018	100.0	98.39

Coding of Birth Event

% of pregnancies in the last 2 yrs, where the pregnancy commenced >42 weeks ago that now have a delivery code recorded.

An echo of current
GP Connect Problem...



The screenshot displays the IM&T DES e-Audit (National data) interface. The top section shows the user 'Sharon Snape' and various navigation links. Below this, there are tabs for 'Select Indicator', 'Organisation', 'Administrative', and 'Clinical'. The 'Clinical' tab is active, and the 'Saved Queries' dropdown is set to 'Percent of Mean Rate by Organisation (Practice)'. The 'Where' clause is set to 'Clinical condition: Diabetic Retinopathy'. The 'Chart' tab is selected, showing two charts.

The top chart, 'Percent of Mean Rate by Organisation (Practice)', is a bar chart with a secondary y-axis labeled 'Percent of Mean Rate' ranging from 0.00 to 500.00. The x-axis lists various practices. The bars are blue, and a horizontal line is drawn at 100.00. A legend indicates 'Number with condition' (black square), '100% line' (blue line), and 'Percent of Mean Rate' (blue bar). A red dot is visible on the chart.

The bottom chart, 'Number of patients', is a bar chart with a primary y-axis labeled 'Number of patients' ranging from 0.00 to 700.00. The x-axis lists various practices. The bars are blue, and a horizontal line is drawn at 100.00. A legend indicates 'Number with condition' (black square), '100% line' (blue line), and 'Percent of Mean Rate' (blue bar). A red dot is visible on the chart.



New erroneous template build non-diabetic (vascular)patient

09-May-2021	Docman
Problem	Podiatry assessment (First)
History	Diabetic neuropathy
Examination	<p>O/E - foot Skin intact no significant lesions/ Overriding 2nd digits. One thickened nail (onychauxis)</p> <p>O/E - Left foot colour normal • O/E - Right foot colour normal</p> <p>On examination - right dorsalis pedis pulse present doppler used biphasic</p> <p>On examination - left dorsalis pedis pulse present doppler used biphasic</p> <p>On examination - right posterior tibial pulse present doppler used biphasic</p> <p>On examination - left posterior tibial pulse present doppler used monophasic</p> <p>10g monofilament sensation L foot normal</p> <p>10g monofilament sensation R foot abnormal sharp sensation intact 6/10 points tested, absent in 4/10</p> <p>O/E - vibration sense left foot reduced Reduced at L/1st. Present at medial and lateral malleoli</p> <p>O/E - Vibration sense of right foot normal</p>
Comment	GP to please review
Additional	<p>Attachment @ podiatry assessment Feet First Podiatry Podiatry</p> <p>Clinical letter</p> <p>Under care of podiatrist Who & how often seen? seen by Lesley Faux 9/5/21</p>
Assessment	O/E - Right diabetic foot at low risk • O/E - Left diabetic foot at moderate risk



Question of the week?

- Which of these codes should be used in a data entry screen to reflect Pulse Oximetry value observed?
- Peripheral oxygen saturation (observable) 431314004
- SpO2 (oxygen percent saturation in capillary blood) by pulse oximetry (observable) 26801000237104

Peripheral oxygen saturation (READ V2 mapped) – 14,441,320 uses last year

SpO2 (oxygen percent saturation in capillary blood) by pulse oximetry – 147,300 uses (2023-24)



Free Text annotations

- Classic problems – diagnostic code + “excluded” free text

Also note this – re practice:

Not socially isolated

Feeling lonely occasionally feels fed up at times

Routine enquiry about domestic abuse **yes**

Independent feeding • Independent bathing

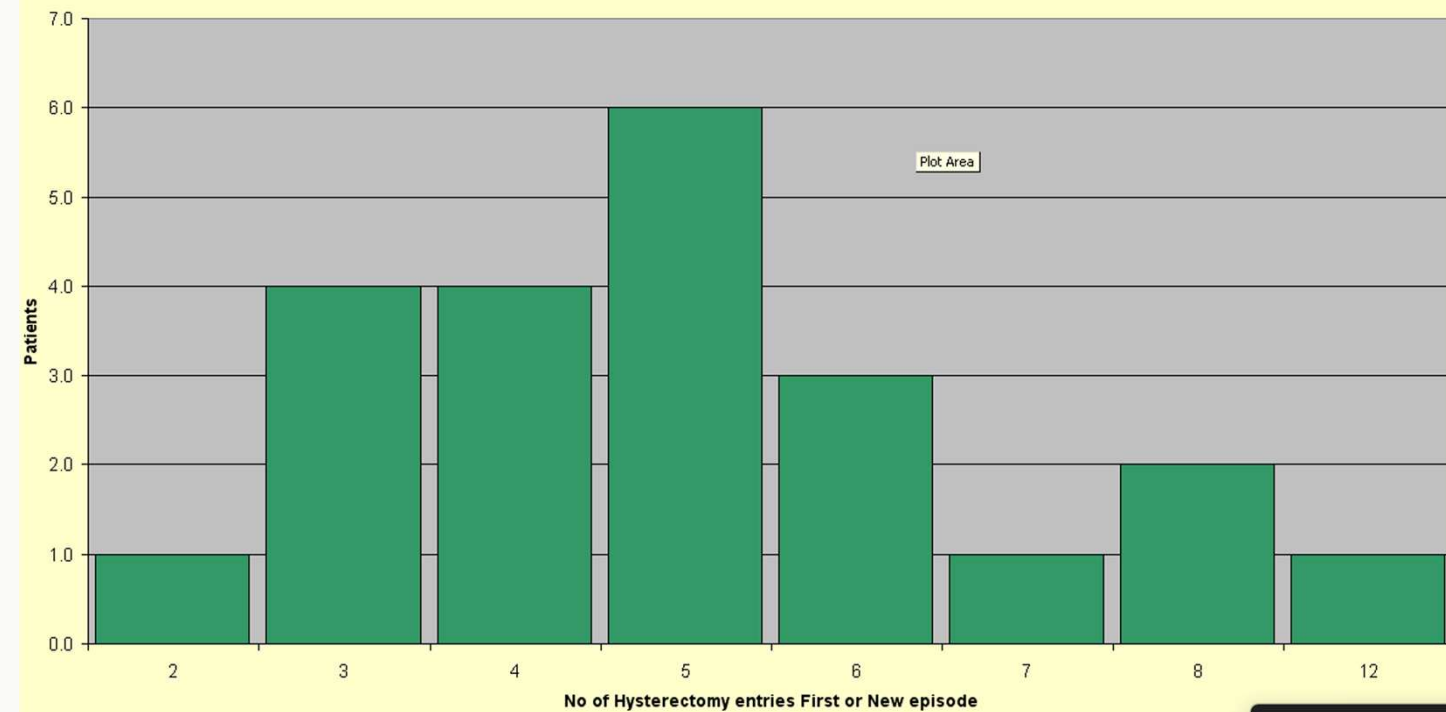
Use of bathroom aids chair and grab rails

This is where domestic abuse enquiry infers event has happened – the text should be “done” not yes

Episode Management

- First
- New
- Review or ongoing
- End
- ? Flare

No Of Hysterectomy Codes First Or New Episode



PE, MI, CVA, UTI.....



Data: Values

- AR – Weight recorded age 12 = 145kg
 - Height recorded same day = 145cm
 - BMI calculated = 69.87

- E2 – blood test result inbound with free text comment



Data: values – BMI yesterday!

	B	C	D
	Age	Value	Date
390a	64	0	28-Jul-2025
111a	15	0.2	10-Mar-2014
11b0a	73	0.4	12-Apr-2024
036	64	0.5	03-Sep-2024
162a	52	0.5	17-Sep-2025
075	0	1.2	10-Mar-2025
1f03	9	2	20-Sep-2017
36cc	17	2.7	06-Jun-2023
4fe2	19	3	19-Dec-2024
72	64	3.06	16-May-2023
327	47	3.1	11-Oct-2025
1a30	52	3.4	03-Sep-2025
1a1	86	3.7	03-Nov-2025
186f	42	3.9	17-Sep-2025
1a7d2	78	4	23-Oct-2025
e1c	56	4	24-Jan-2019
22d	61	4	08-Sep-2025
e03	29	4.4	20-Sep-2017
eea9	33	4.5	05-Jun-2025
1fd8	53	4.6	01-Jul-2025
10b6	30	4.7	20-Dec-2023
118	50	4.8	13-Feb-2025
16c91	33	4.8	17-Nov-2020
1b28	44	4.8	25-Sep-2025
16d2	19	5.3	21-Mar-2025
12175	12	5.4	11-Aug-2017
1fd9	21	5.5	22-Feb-2024
1867	80	6.04	29-Apr-2025
877d	3	7.4	05-Dec-2022
ee78	71	7.5	04-Dec-2023
1084	24	10.1	02-Nov-2005

dbbee8726	58	60.2	23-Oct-2025
15cb451f9	47	61.42	29-Aug-2025
5599afe6	19	61.6	24-Feb-2012
6d0144404	54	61.7	27-Oct-2025
848f35bce	53	63.29	18-Mar-2024
1eebc70b0b	64	63.29	09-Apr-2025
1bd2a78db3	50	65.09	25-Sep-2025
1bf3b7c45	21	67.4	04-Oct-2023
166ad6e71a	64	68.4	04-Aug-2025
1d92ad2fcb	69	68.6	13-May-2025
3174a98e	66	70.76	17-Sep-2025
17474dd9681	58	70.9	26-Sep-2025
1582c809	71	71.4	13-May-2025
a284850	16	3061.2	30-Jul-2025
3b3309672	15	62500	17-Sep-2013
160feaa41	5		16-Jun-2025
1feaf718ee	15		09-Apr-2013
e8ab93cb6	7		09-Jan-2024
1d232ac83	6		27-Sep-2022
a933675d	32		11-Feb-2021
12350568e	46		09-Feb-2021
1371e2b3	2		21-May-2024
161f58267c	6		10-Mar-2025



Data: values – solution?

- Don't use BMI in children - ? Age
- Don't use BMI more than 5 years old for computation
- If BMI outside expected range eg <15 or >47 put warning on entry
- When processing data – if missing data consider “warning” or use of appropriate “safe” replacement (31) and modulation of readings outside 15-47 to limiting values



Accessibility – Record Curation

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Active Problems	
A Lower respiratory tract infection (Minor)	27-Nov-2023
B Cough (Minor)	21-Nov-2023
C Implantation of intravenous dual chamber permanent cardiac pacemaker (Significant)	07-Sep-2023
D Hypovolaemia (Minor)	07-Sep-2023
E Acute kidney injury (Significant)	07-Sep-2023
F Supine hypertension (Minor)	07-Sep-2023
G Orthostatic hypotension (Significant)	07-Sep-2023
H Home assessment (Minor)	04-Sep-2023
I COVID-19 (Significant)	21-Aug-2023
J Fracture of thoracic spine (Significant)	21-Aug-2023
K Osteopenia (Significant)	21-Aug-2023
L Reduced mobility (Significant)	21-Aug-2023
M Bone density scan (Minor) Request	28-Jul-2023
N Did not attend (Minor)	28-Jun-2023
O Heart failure monitoring (Minor)	18-May-2023
P Chronic kidney disease stage 3 (Significant)	02-May-2023
Q Mycobacterium (Significant)	28-Mar-2023
R CT angiography of pulmonary artery with contrast (Minor)	31-Dec-2022
S Exacerbation of mild persistent asthma (Minor)	22-Dec-2022
T Productive cough (Minor)	21-Dec-2022
U Tinnitus (Minor)	12-Jul-2022
V First degree atrioventricular block (Significant)	08-Jun-2022
W 24 Hour ECG (Minor)	08-Jun-2022
X Heart failure (Significant)	20-May-2022
Y Left ventricular systolic dysfunction (Significant) (Grouped with Heart failure)	01-Jul-2022
Z Gastric polyp (Significant)	06-May-2022
1 Serum pro-BNP peptide level (Minor)	04-Mar-2022
2 Gastritis (Significant) await histology	27-Mar-2021
3 Age related macular degeneration (Significant)	17-Aug-2020
4 Aphakia (Significant) Laterality: Bilateral.	17-Aug-2020
5 Asthma (Significant)	21-Mar-2019
6 Cataract (Significant) Laterality: Left.	12-Jun-2018
7 Asthma medication review (Minor)	27-Feb-2018
8 Tinnitus (Minor)	22-Aug-2017
9 Cataract (Significant) Laterality: Right.	27-Jun-2017
Malignant essential hypertension (Significant)	23-Aug-2016
Asthma annual review (Minor)	19-Aug-2016
Essential hypertension (Significant)	16-Oct-2014
ECG (Minor)	15-Jan-2014
Late onset asthma (Significant)	07-Jul-2012
Bone densimetry abnormal (Significant) - Osteopenic	16-Jun-2010
[D]Raised blood pressure read. (Significant)	04-May-2005
Breast neoplasm screen normal (Minor) Routine Recall	Mar-2004
Excision biopsy of skin lesion (Minor) Dr Tan histo awaited	17-Dec-2001
Significant Past Problems	
Acute COVID-19 infection - 01/09/2023	07-Sep-2023
Constipation	21-Aug-2023
Ear fitting hearing aid	12-Apr-2023
Atelectasis	06-Mar-2023
CT of chest	06-Mar-2023
Suspected pulmonary embolism	29-Dec-2022
Hearing loss	24-Nov-2022
Sinus bradycardia	08-Jun-2022
Endoscopy of stomach Report	06-May-2022
Gastroscopy normal	01-Jun-2021
Abnormal breathing	30-Mar-2021
Phacoemulsification lens insertion prosthetic replacement Laterality: Left.	12-Jun-2018
Phacoemulsification lens insertion prosthetic replacement Laterality: Right.	27-Jun-2017
Hyposmolality and or hyponatraemia	07-Nov-2016
Malignant neoplasm lesion	11-Oct-2016

4 Aphakia (Significant) Laterality: Bilateral.

5 Asthma (Significant)

5 Cataract (Significant) Laterality: Left.

7 Asthma medication review (Minor)

3 Tinnitus (Minor)

9 Cataract (Significant) Laterality: Right.

Malignant essential hypertension (Significant)

Asthma annual review (Minor)

Essential hypertension (Significant)

ECG (Minor)

Late onset asthma (Significant)

Bone densimetry abnormal (Significant) - Osteopenic

[D]Raised blood pressure read. (Significant)

Breast neoplasm screen normal (Minor) Routine Recall

Excision biopsy of skin lesion (Minor) Dr Tan histo awaited



Accessibility – Record Curation -after

A	Lower respiratory tract infection (Minor)	21-Nov-2023
B	♣ Implantation of intravenous dual chamber permanent cardiac pacemaker (Significant)	07-Sep-2023
C	First degree atrioventricular block (Significant) (Grouped with Implantation of intravenous dual chamber permanent cardiac pacemaker)	08-Jun-2022
D	ECG: left bundle branch block (Past, Significant) (Grouped with Implantation of intravenous dual chamber permanent cardiac pacemaker)	05-Feb-2014
E	Home assessment (Minor)	04-Sep-2023
F	Reduced mobility (Significant)	21-Aug-2023
G	♣ Chronic kidney disease stage 3 (Significant)	02-May-2023
H	Acute kidney injury (Significant) (Grouped with Chronic kidney disease stage 3)	07-Sep-2023
I	♣ Heart failure (Significant)	20-May-2022
J	Left ventricular systolic dysfunction (Significant) (Grouped with Heart failure)	01-Jul-2022
K	♣ Gastric polyp (Significant)	06-May-2022
L	Gastritis (Significant) (Grouped with Gastric polyp), await histology	27-Mar-2021
M	Endoscopy of stomach (Past, Significant) (Grouped with Gastric polyp), Report	06-May-2022
N	Age related macular degeneration (Significant)	17-Aug-2020
O	Tinnitus (Minor)	22-Aug-2017
P	♣ Essential hypertension (Significant)	16-Oct-2014
Q	Orthostatic hypotension (Significant) (Grouped with Essential hypertension)	07-Sep-2023
R	♣ Asthma (Significant)	07-Jul-2012
S	Exacerbation of mild persistent asthma (Minor) (Grouped with Asthma)	22-Dec-2022
T	♣ Osteopenia (Significant)	16-Jun-2010
U	Fracture of thoracic spine (Significant) (Grouped with Osteopenia)	21-Aug-2023
V	Bone density scan (Minor) (Grouped with Osteopenia), Request	28-Jul-2023
Significant Past Problems		
W	COVID-19	21-Aug-2023
X	Constipation	21-Aug-2023

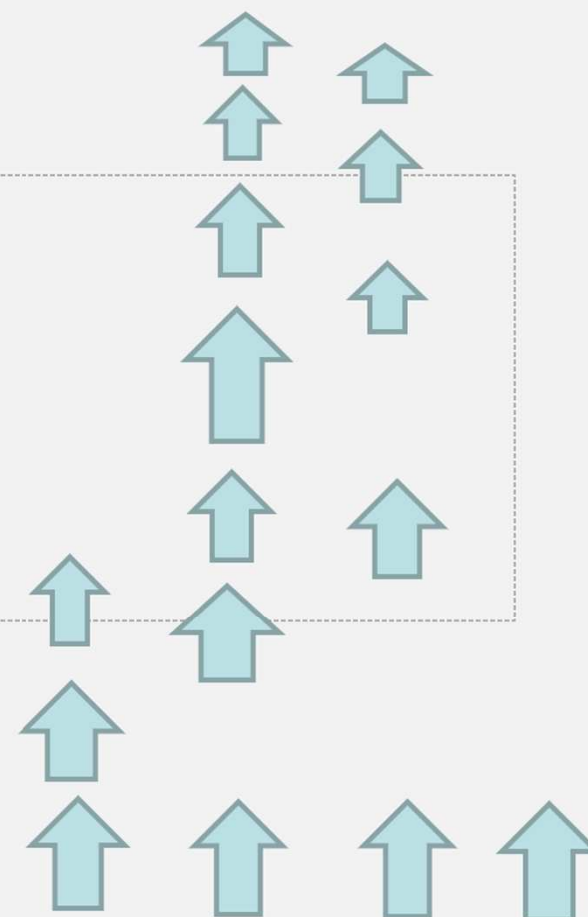


Record Curation – some advice

- Highlighting Significant issues
- Using appropriate document labelling for inbound records – therefore easier to find
- Avoiding deprecated codes
- Avoiding negative text qualifiers...
- Avoiding erroneous codes/data in prepopulated data entry screens



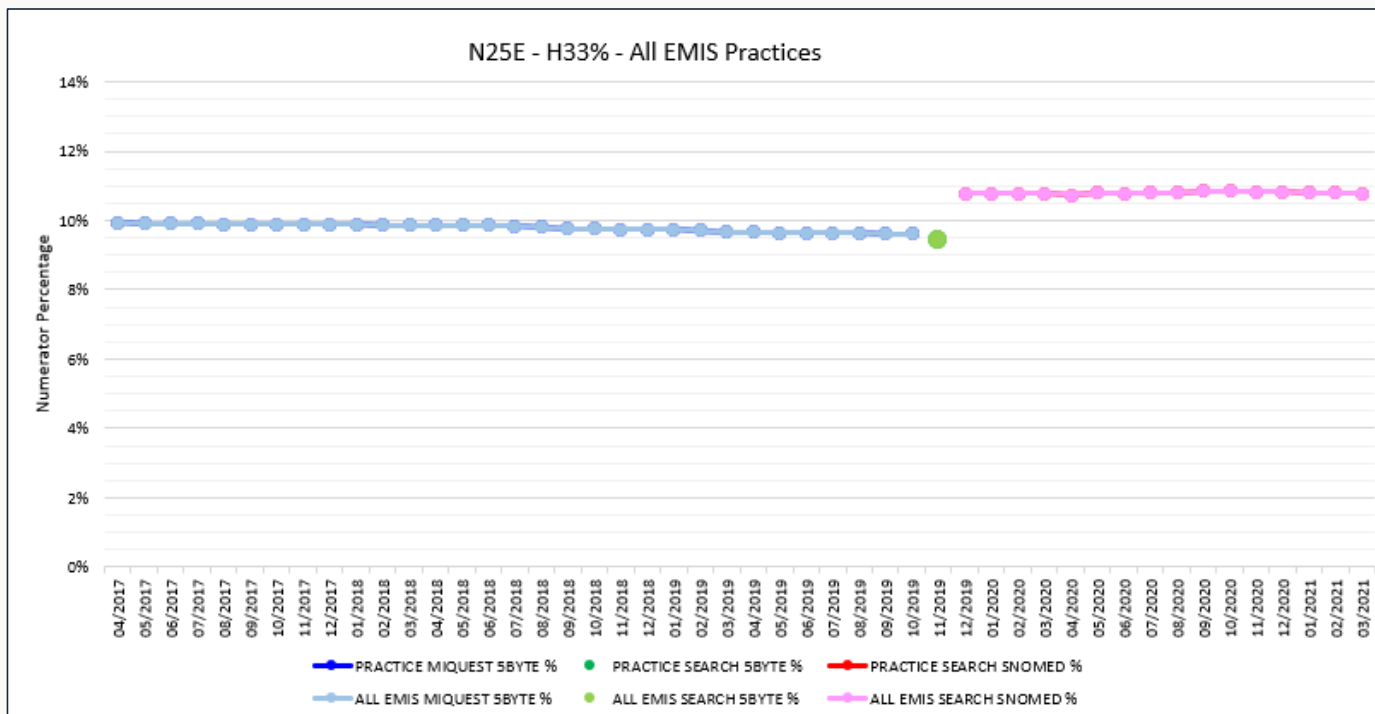
H3 H37 H36 H3-1





Terminology migration

- 4-> 5byte READ in 1990's *please see Mary*
- Back Mapping issues – SNOMED -> V2 or CTV3.....
- Bridging Study – READ to SNOMED mapping



“Wheezy
Bronchitis
→Asthma“



Newer Problems....

- Untrained individuals in wider team (students, trainees, PCN) not coding or mis-coding
- GP Connect – untrained individuals in Pharmacies entering data – maybe through inappropriately built pick lists
- Online Text/SMS consultations not being “titled” or coded



Which code to put in the artefact?

- What exactly are you trying to represent?

Examination



- O/E - blood pressure reading 124/84 mmHg
- Average blood pressure 124 mmHg
- Blood pressure recorded by patient at home no value associated
- Average home blood pressure 136 mmHg
- Standing systolic blood pressure 128 mmHg
- Standing blood pressure 136/86 mmHg
- Sitting blood pressure 118/72 mmHg
- Lying blood pressure 98/78 mmHg
- Arterial blood pressure 132 mmHg
- O/E - BP reading:postural drop no value associated
- Average ambulatory blood pressure 126/78 mmHg
- Blood pressure measured in right upper arm no value associated
- Baseline blood pressure 138/76 mmHg

1162737008 Self reported systolic blood pressure

1162735000 Self reported diastolic blood pressure



Antecedents of Poor Data Quality

- **System Architecture**
 - statin adverse events
 - childhood vaccination data entry <-> varied ways
 - deprecated code (un-) display eg [\[RFC\] Prostate Cancer](#)
- **Lack of national architecture progress**
 - prescription standards re dosage instructions
 - electronic discharge letters (encoded information)
 - gaps in adverse drug reaction codes
- **Poor use of the IT systems**
 - lack of user understanding (e.g. EPR) -> ?training, awareness
 - ignorance of those with influence to change the ecology
 - erroneous use of templates & decision support tools



Ways to Improve Data Quality..

- Training Programmes...
- Manual – Good Practice Guidelines v5
- Quality & Outcomes Framework (QoF) -> £££
- Audit -> eg IM&T DES

- Patient reviewing own records - *In-house survey*



Questions?

- What's the answer? – *better training/education, patient access to electronic record and...*



Principles of recording clinical data

- The primary purpose of recording information should be to support patient care
- All Health Professionals should participate in data recording
- All Health Professionals should enter their own data directly
- Practices should record all occurrences
- Practices should record consistently
- Regular monitoring and feedback of data quality
(coded vs text balance)

Source: DOH/ GPC Good Practice Guidelines for Patient Electronic Records, V3.1, June 2005



Vaccination Data Specification Flow

