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Lunch and Learn

How routine data can be used to better understand the needs of people who use drugs and/or alcohol

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20 Years

Welcome and housekeeping

Recording and general housekeeping



Mixed audience

Add questions into the chat



Agenda

Insights & reflections on understanding NDTMS based on current thinking and practices – Jo Kesten (University of Bristol)

Insights & reflections on using CPRD to estimate substance use and mental health issues – Kate Timmins (Newcastle University)

Future opportunities to use routine data for understanding the needs of people who use drugs and/or alcohol – Justin Yang (UCL)

NDTMS vs CPRD

National Drug & Alcohol Treatment Monitoring System (NDTMS)

National administrative dataset for publicly commissioned structured drug and alcohol treatment providers in England since 2004/5.

Held by the Office for Health Improvement and Disparities (OHID).

Client opt in at treatment entry.

Clinical Practice Research Datalink (CPRD)

A primary care database containing anonymised Electronic Health Records from over ~2,800*general practices across the UK.

Collating GP data since 1987; updates released quarterly.

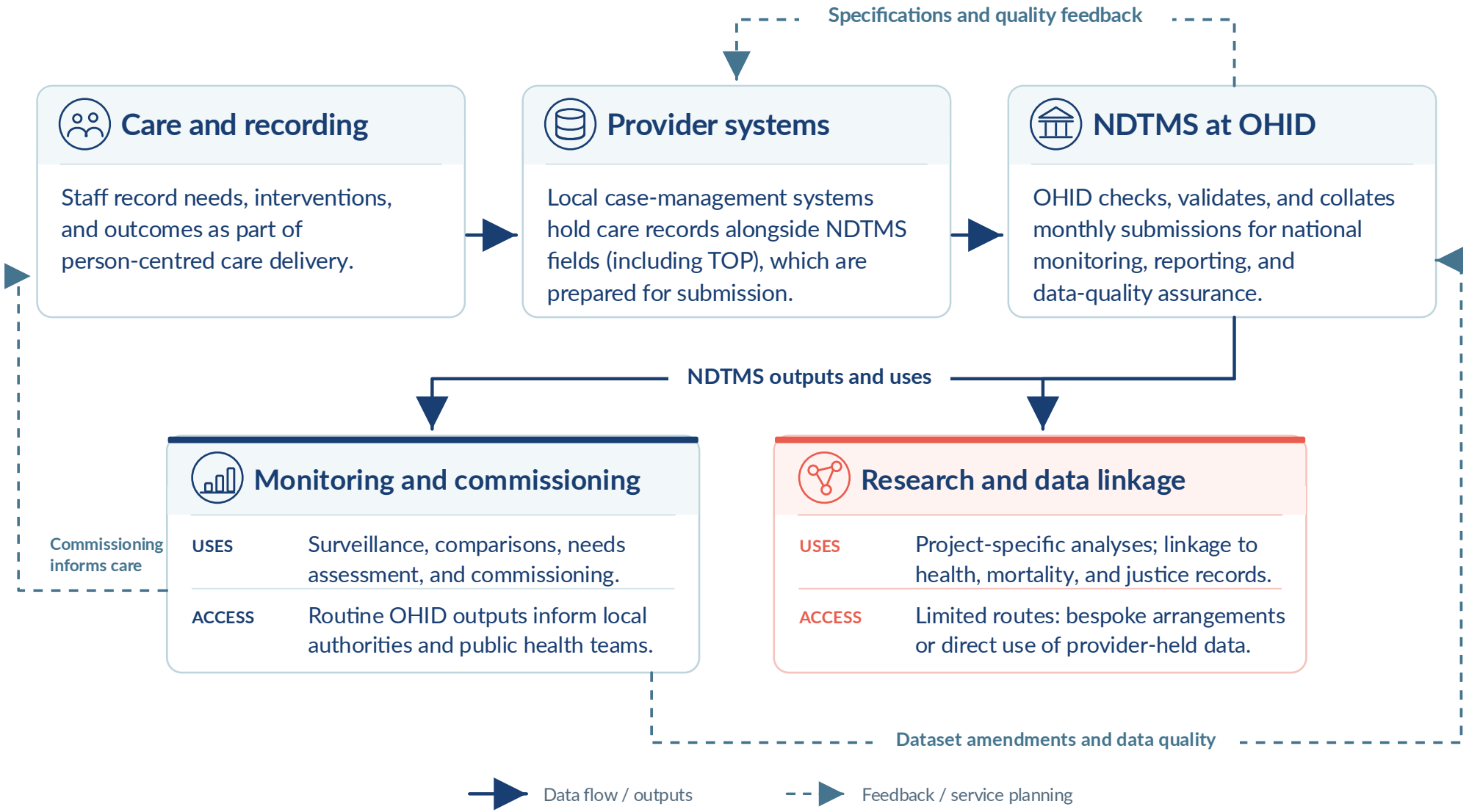
General practices have the option to opt in.

*number of contributing practices fluctuates in time

Insights & reflections on understanding of NDTMS based on current thinking and practices

Jo Kesten, University of Bristol

NDTMS


Specifications and quality feedback
Care and recording
Staff record needs, interventions, and outcomes as part of person-centred care delivery.
Provider systems
Local case-management systems hold care records alongside NDTMS fields (including TOP), which are prepared for submission.
NDTMS at OHID
OHID checks, validates, and collates monthly submissions for national monitoring, reporting, and data-quality assurance.
NDTMS outputs and uses
Monitoring and commissioning
USES
Surveillance, comparisons, needs assessment, and commissioning.
ACCESS
Routine OHID outputs inform local authorities and public health teams.
Research and data linkage
USES
Project-specific analyses; linkage to health, mortality, and justice records.
ACCESS
Limited routes: bespoke arrangements or direct use of provider-held data.
Commissioning informs care
Dataset amendments and data quality
Data flow / outputs
Feedback / service planning

Why NDTMS exists?

- Not just an administrative tool, it can influence:
  - what services record,
  - commissioning decision-making,
  - what researchers can study,
  - how people in treatment are asked to describe their lives, risks, needs, and outcomes,
  - how care is provided across services

- It provides a large-scale, comprehensive and complex dataset of people in structured drug and alcohol treatment.

What we did

Working with Change Grow Live, Turning Point, and people with lived experience, our research set out to identify ways to optimise NDTMS and improve measurement and reporting of drug and alcohol treatment data.

What we did

Scoping review of how NDTMS data are used for research, comparing routine monitoring to research use, and explain how the data are linked with other datasets and accessed by researchers.

Scoping review pre-print

Qualitative study exploring experiences, challenges, enablers and potential improvements for monitoring and reporting drug and alcohol treatment data:

32 online or in-person interviews with 20 staff and 12 people in treatment and four in-service non-participant observations across Southwest, Northeast and London.

Working in partnership with people with lived experience.

NDTMS value

*Organisations should be **assessing the needs of individuals** and NDTMS provides a framework for that … it encourages some **consistency**.* Staff 4

*I would like to think that it's [data] used to **make the service better**.* Client 8

Enabling consistency across providers nationally

*NDTMS is being used by central government to kind of analyse and **understand performance, to inform funding decisions*** Staff 2

*So it's a way to get a sense, across the country, of what's happening in those services, how much activity is going on, **how good is it, what's it achieving**.* Staff 3

NDTMS value

The value of the asset is only realised by using it. DHSC [Department of Health and Social Care] has all of the data, academia has all of the methods, and the two of them really need to meet up a bit. Staff 19

NDTMS completion

A facilitation tool or a structured template

…with my key worker, it's not like she used to sit there and do notes. We was just having a general conversation. (…). I know they've got a system, to put things in, but in terms of being told what's put on that system, that I don't know. My key worker won't say to me, "I'm going to put this X, Y and Z on your record later on." Client 8

If I'm honest, I don't think many workers are following an assessment form rigidly. I think a lot of people are filling them in after the appointment and aren't going into the appointments with the form. I think if you try to do it as was intended, I don't think many people would come back for a second appointment. Staff 6

Balancing value with practical completion

A source of tension in day-to-day front-line provision

…You could sort of sit there and privately think you're doing quite a good job. Like I had a really good appointment, I've written that up, I referred them to the service they really needed (…). But then one kind of missing data field will appear to carry the same weight. And I think that's a kind of problem with sometimes sort of the overall data management and communication of data. And I think in the long term that creates a lot of negative issues for services, whether that's shortcutting, whether that's being drawn to either guess or make things up and ultimately kind of burnout and whatever. Because you do have the other side where when people leave these jobs it doesn't tend to be in my experience that they've sort of heard too many sad stories. They've not like reached an emotional threshold with the clients. It's like oh my god, I can't keep up with the administrative side of it. Staff 9

Balancing value with practical completion

There has to be a trade-off between what's the very minimum you need to be able to make that case to government, to be able to help people with their resource allocation, given the huge amount of reports that they get. And then just having time to deal with the client, to do the job.
Staff 19

Data linkage

It's happening now and without that shared information that support wouldn't be available to me *(…) but I can see from somebody else's point of view if they're hiding from the law, from police, the courts or someone or anything I can see that they would be not so keen on the idea.* Client 3

Tension between benefits to seeing the whole person versus concerns around surveillance

If I'm going to a probation meeting and then I'm coming to a substance use meeting, ***why should I have to say all the same things about what's happened to me in my life*** *and how I am at the moment?* Staff 3

I think the other side would be well ***why do they [other services] need to know that [drug and alcohol treatment information****]? Why are they doing, again tracking, surveillance. There's a lot of clients that are very distrusting of professionals and it takes a long time to build that rapport up even for us, you know.* Staff 12

What did we learn?

There's a disconnect between perceptions of:

1. How, why and what data is collected in assessments and entered into NDTMS
2. How that data can be used and linked to other datasets.

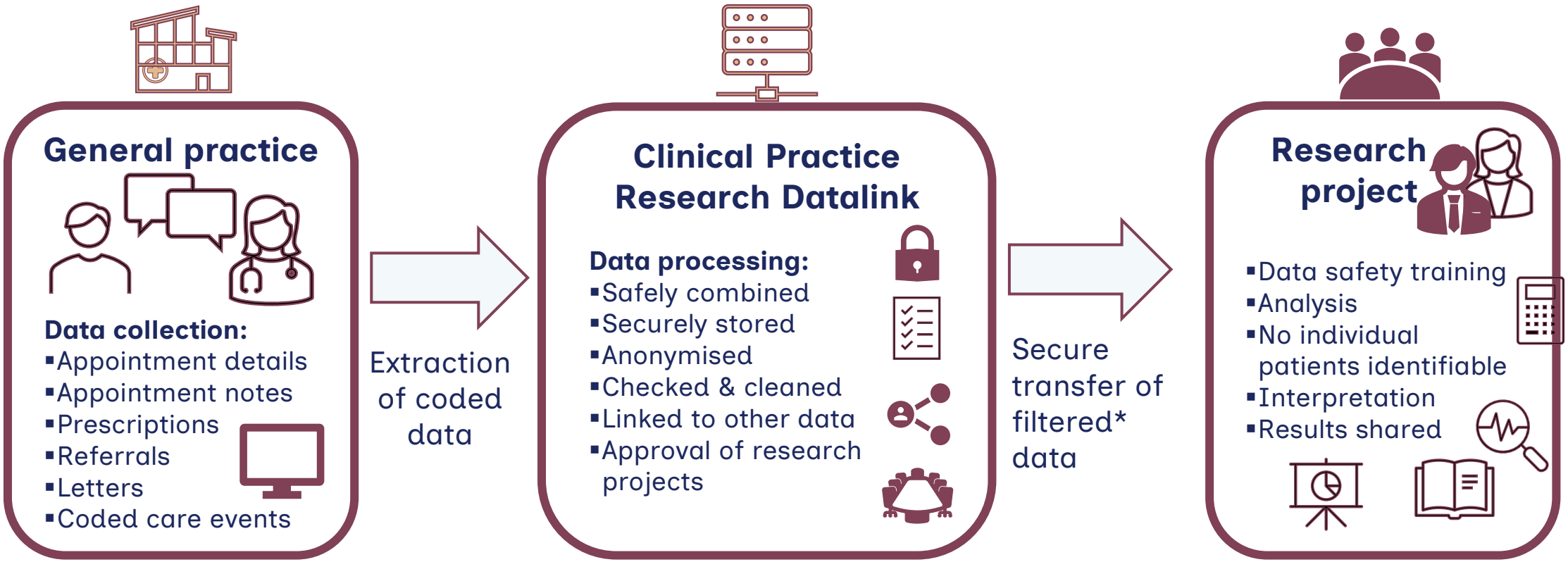
I haven't got a clue if it does benefit. Actually, I haven't got a clue. I don't know about data sharing and stuff like that. It's just, you know, it's just not something that I'm aware of. Client 1

It feels like there's this disconnect between NDTMS centrally still imagining that data collection is done through certain forms collected at certain times and in reality, for a lot of stuff, that isn't happening. Staff 3

Insights & reflections on using the CPRD to estimate substance use and mental health issues

Kate Timmins, Newcastle University

CPRD



*only the data for the group of patients that the research project needs

Why use CPRD (Aurum)

Objective

To describe the incidence and prevalence of co-occurring substance use and mental health issues, and inequalities in these.

Existing evidence

Extremely variable, depending on context: 2% to 63%.

Usually restricted to specific setting, population, condition or substance type.

Benefits of CPRD

- Representative of general (registered) population
- Scale – allowing increased granularity
- Longitudinal – allowing monitoring through time
- Reflects 'real-world' primary care interaction
- Captures other contextual factors
  - Including socioeconomic status

What we did

Aims

To describe socioeconomic inequalities in the incidence and prevalence of co-occurring substance use and mental health conditions among adults in England.

To describe the incidence and prevalence of substance use and mental health conditions in adults with ***a history of homelessness*** recorded in primary care in England.

- Patients registered (permanently) between 01/01/2010 and 31/12/2023 with a general practice contributing to CPRD, with at least 1 year of registration.
- Subset those with any codes (~900) about substance use issues, occurring any time after registration start. Of these, ascertain cases as those who also had at least one code from the list of ~1400 mental health codes.
- Index the first code from each of the two lists. Take the second of these as incidence date.
- For homelessness cohort, include non-permanent registrations, no minimum registration period; algorithm-based deduplication.

Example codes

Substance use related codes (~900)

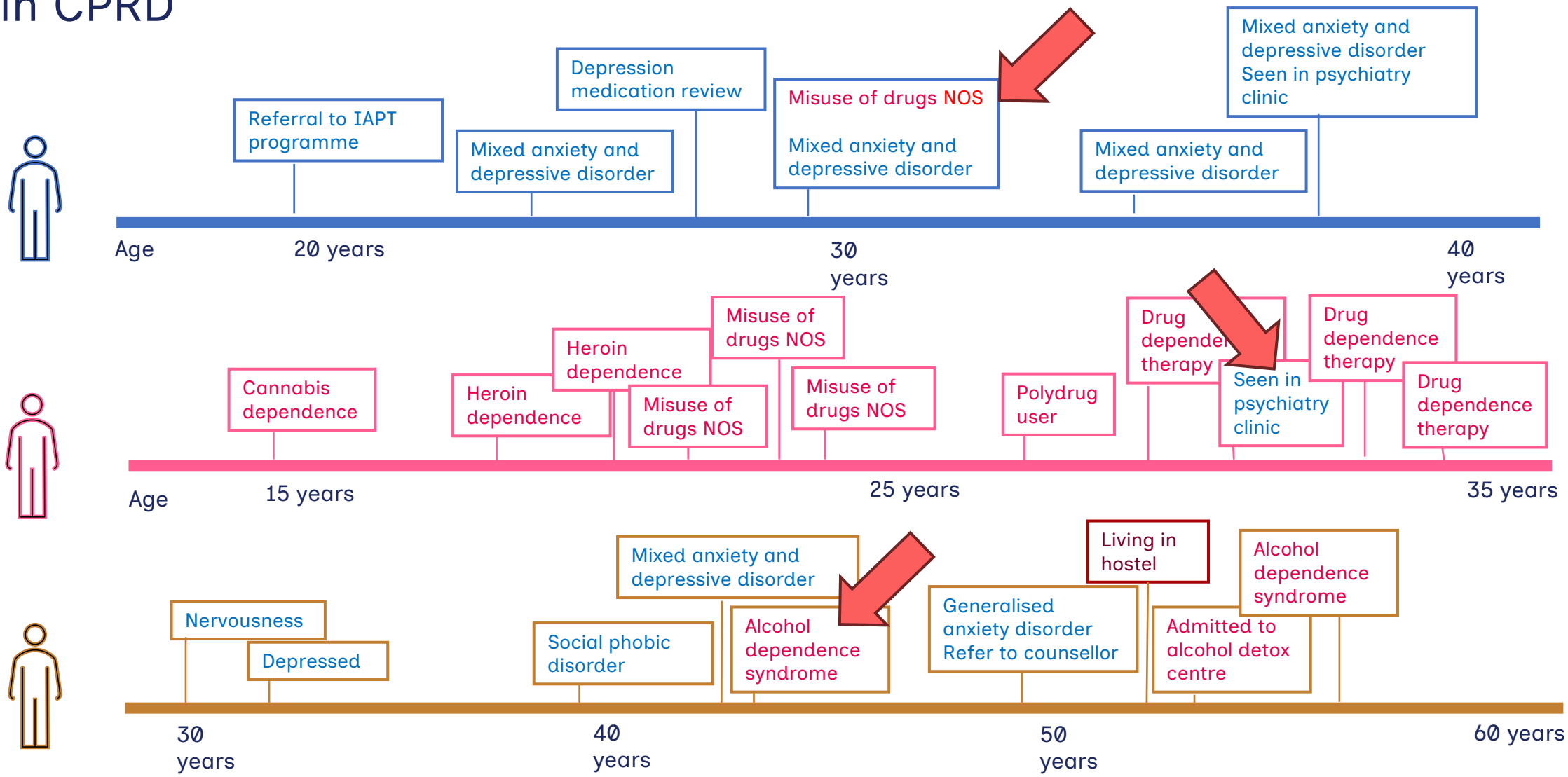
Read code	Description
Eu10200	[X]Mental and behav dis due to use alcohol: dependence syndr
E240.00	Opioid dependence
E23..00	Alcohol dependence syndrome
EMISNQMI110	Misuse of Ketamine
EMISNQMI156	Misuse of Actifed
Eu55.13	[X]Abuse of steroids or hormones
13c..00	Problem drug user
Eu10611	Korsakoff's psychosis
9k1B.00	Extended intervention for excessive alcohol consumption completed
9HC7.00	Substance misuse treatment not available
9k51.00	Shared care drug misuse treatment - enhanced services admin

Mental health related codes (~1400)

Read code	Description
E107.00	Schizoaffective schizophrenia
^ESCT1271767	[D] Anorexia
E275000	Unspecified non-organic eating disorder
1B1V	C/O - panic attack
EMISICD10F3211	Moderate depressive episode, with somatic syndrome
E202A00	Fear of flying
146D.00	H/O: manic depressive disorder
8T21.00	Referral for mental health assessment
8BM0000	Lithium annual review
9HA0.00	On depression register
^ESCTDN664997	DNA - Did not attend mental health appointment

Code lists based on: Cooper et al 2023 (substance use; doi 10.1186/s12911-023-02296-z); Cook et al 2024 (alcohol use; doi 10.2147/CLEP.S477778); Bazo-Alvarez et al 2025 (mental health; doi 10.1111/jep.14256)

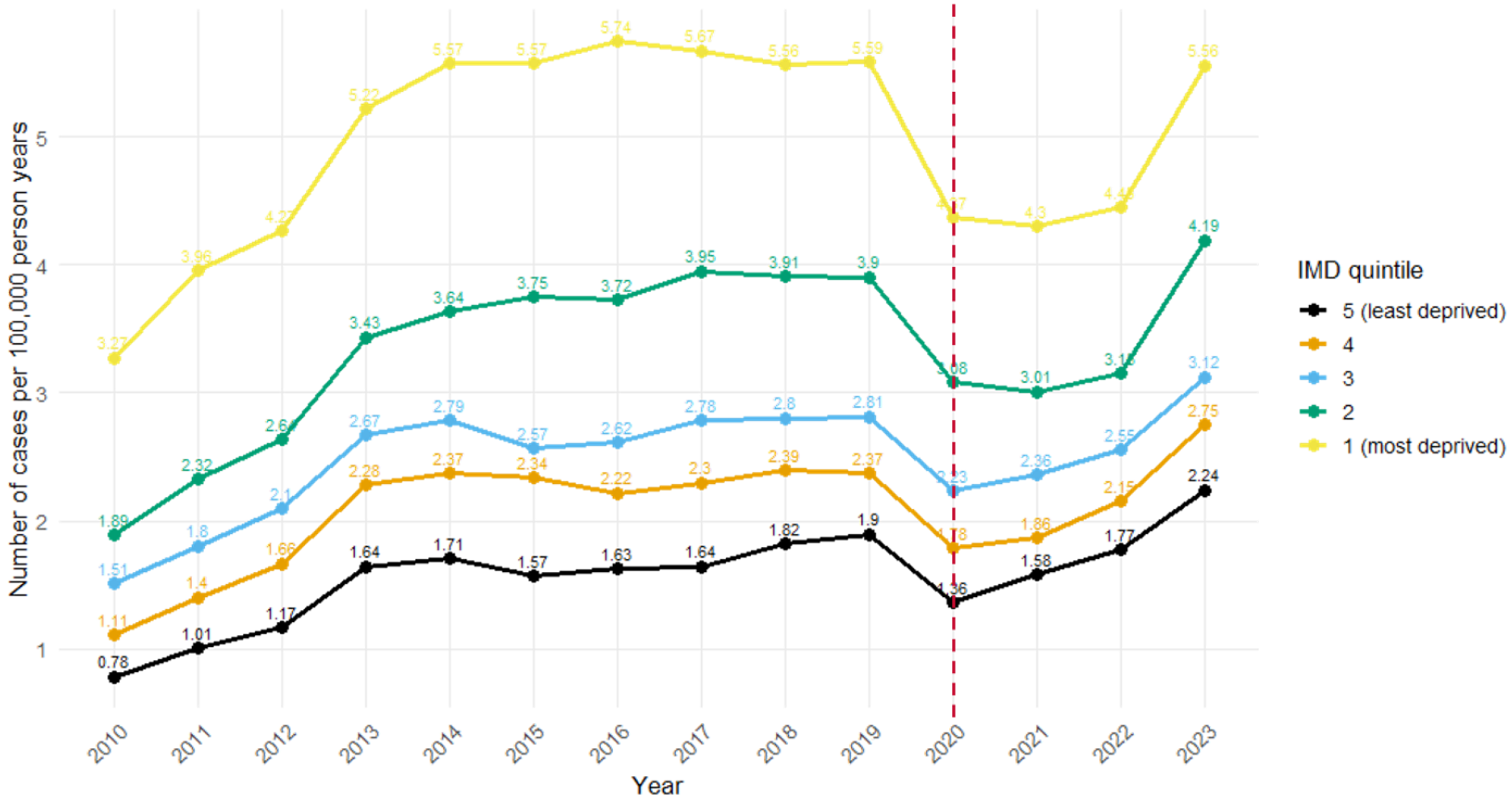
Defining cases of co-occurring mental health & substance use in CPRD



NOS: not otherwise specified

Selection of findings

Incidence of recorded cases of co-occurring substance use and mental health issues in primary care in England



Benefits of CPRD

- ✓ Longitudinal – allowing monitoring through time
- ✓ Reflects 'real-world' primary care interaction
- ✓ Captures contextual factors
  - Index of multiple deprivation

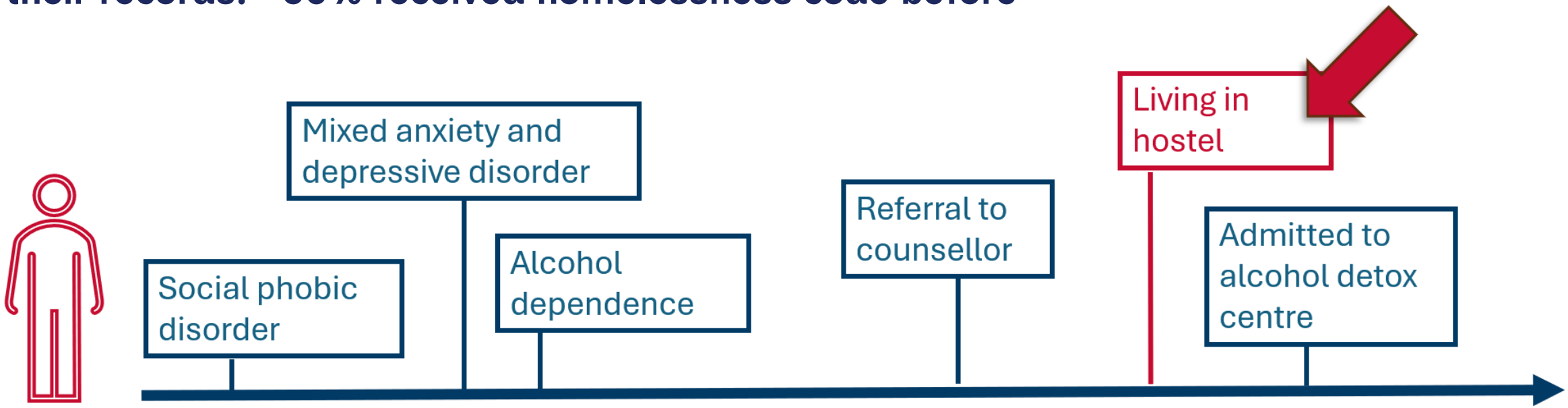
But wait...

- ✓ Coding vs experience
- ✓ Is this really incidence?

Selection of findings

45,015 patients had co-occurring substance use and mental health conditions recorded, out of 126,666 people with a homelessness code recorded at any time.

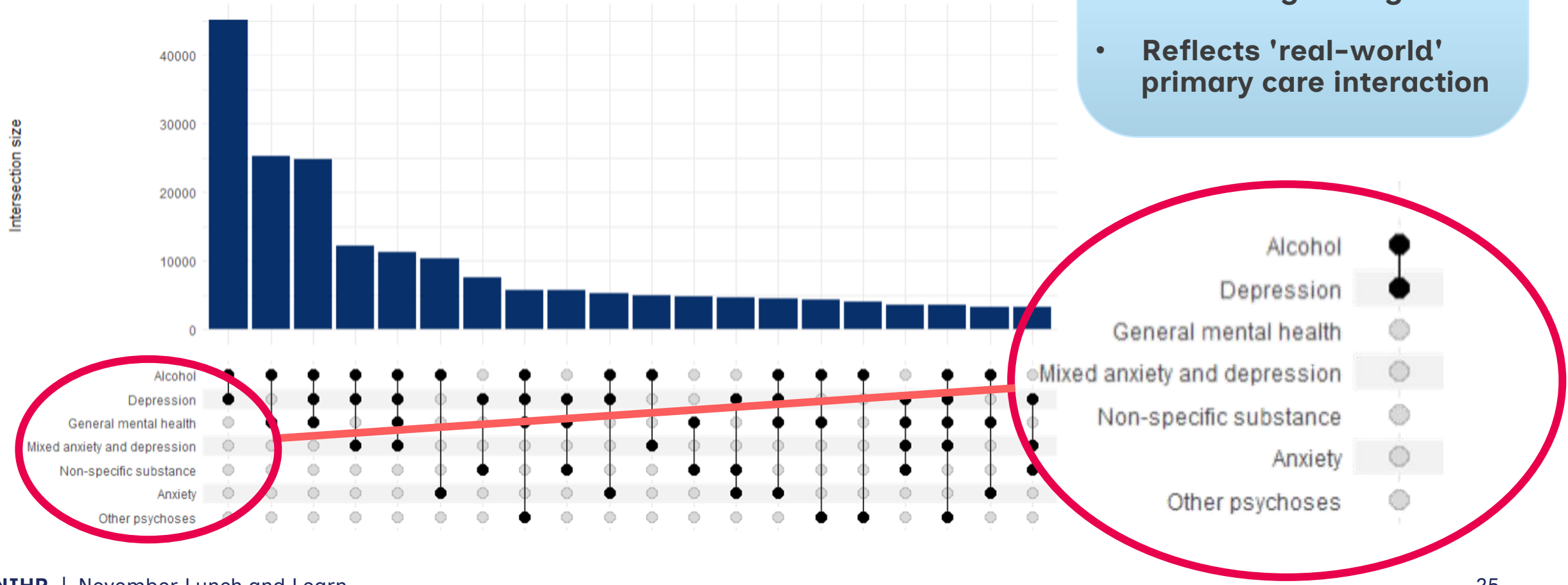
37% of these received a homelessness code after co-occurring codes appeared in their records. ~50% received homelessness code before



An example of event ordering in the healthcare records of a fictitious patient

Selection of findings

Most commonly co-occurring combinations



Benefits of CPRD

- Scale – allowing increased granularity
- Longitudinal – allowing monitoring through time
- Reflects 'real-world' primary care interaction

What could routine data still not tell us?

Co-occurrence

National prevalence

Who did *not* have co-occurring substance use and mental health issues

Timing of experience (therefore incidence)

Motivation for coding

Patient pathways

What could help?

- Sensitivity analyses
- Using multiple sources of information
- Data linkage?
- Better recording?

Future opportunities to use routine data for understanding the needs of people who use drugs and/or alcohol

Justin Yang, University College London

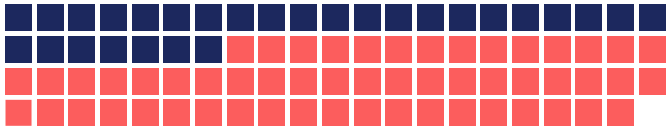
Data has enormous potential for further benefit

1,340 **records identified**
7 databases, grey literature, citations

819 **screened**
after 521 duplicates removed

103 **full texts assessed**
20 excluded

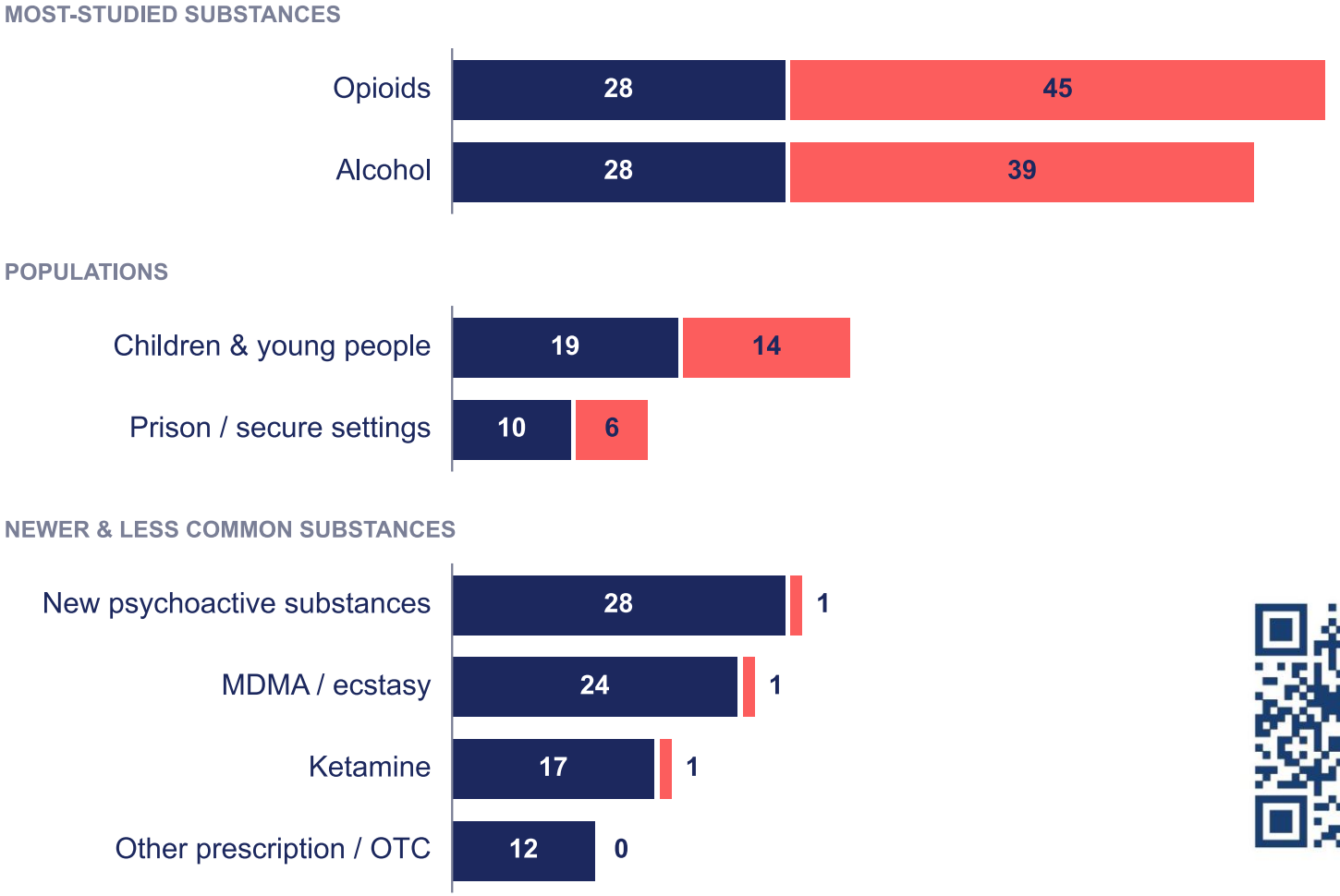
83 **NDTMS-based outputs included (2005–2026)**



28 routine surveillance reports

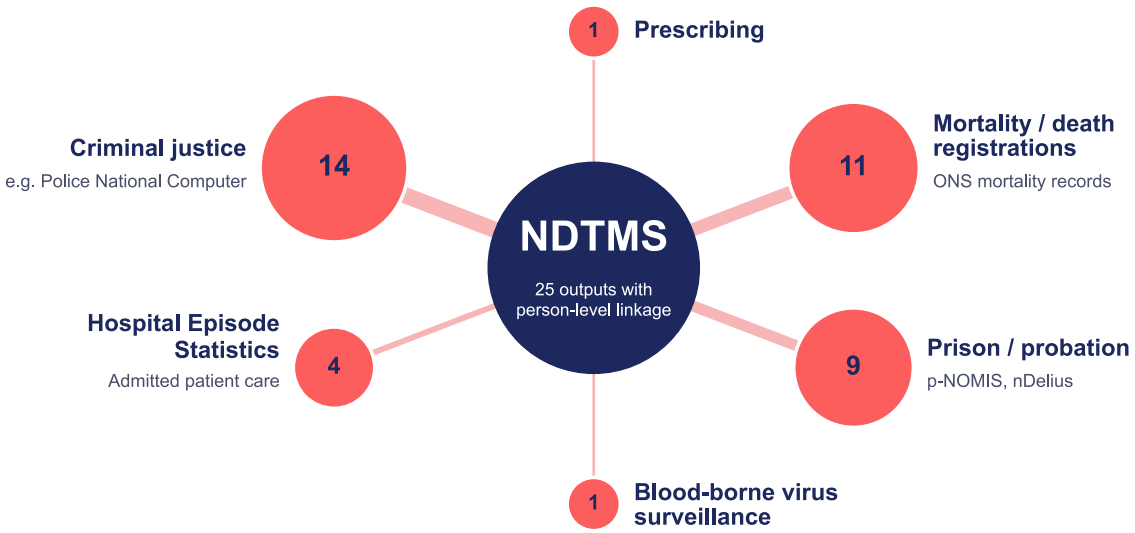
55 non-routine research outputs

45 journal articles · 34 governmental outputs · 4 doctoral theses



Number of included outputs (multi-select, so rows overlap)

Data linkages



Linkages extend NDTMS's potential beyond the drug and alcohol treatment system

30% of outputs linked person-level NDTMS records to another dataset. These examined measures and outcomes NDTMS can't record fully on its own, including offending, hospitalisation, and mortality.

To date, matching has primarily relied on initials, date of birth, sex and area. Two examples:

- Up to 22% of these minimal identifiers were shared by more than one person (Pierce 2016).
- 72.8% of eligible blood-borne virus surveillance records linked to NDTMS (Ireland 2019).

Linkage quality was reported in 20 of the 25 linked outputs.

Researcher access and capacity

Limitations on access may bottleneck research and innovation

The routes we saw fall into four groups:

- **Via the Data Owner**: Public Health England Office for Data Release, OHID, or the earlier National Treatment Agency
- **Government-held linked datasets** that only DHSC or OHID project staff can analyse
- **Project-specific multi-agency approvals**: the ONS Microdata Release Panel, or MoJ–DHSC data sharing via Better Outcomes through Linked Data
- **Regional, local or provider-held data** (e.g. through voluntary sector providers, etc.) as a workaround

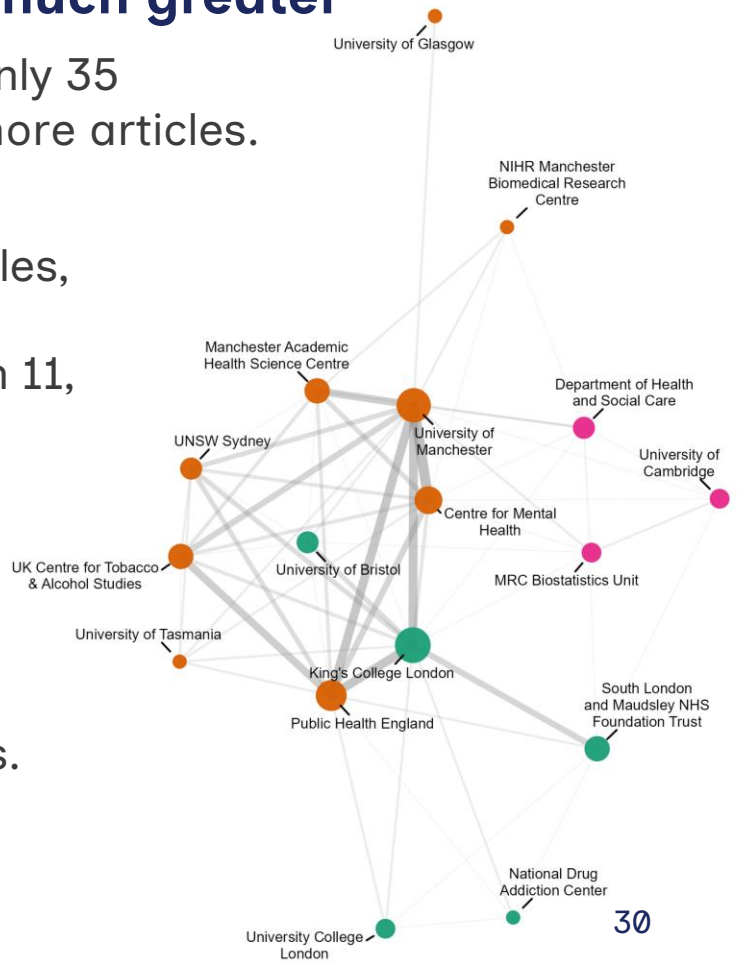
Individual and institutional capacity for research could be much greater

141 authors, of whom only 35 contributed to two or more articles.

King's College London was involved in 17 articles, Manchester in 15 and Public Health England in 11, out of 59 institutions.

Four journals published 49% of the articles.

The 3 most-cited papers received about 42% of all 1,121 citations.



Awareness & involvement of people in services

People in treatment could be more involved in, or better informed about, research use of their data

Only 11% of outputs reported patient, public or practice-partner involvement

Other transparency measures were also low:

- Protocol registration: 2.4%
- Data or code available: 28%

Updated NDTMS patient information in 2018 supports linkage with other administrative datasets for research (as reported in OHID's 2024 homicide report). Yet, clients in our interviews were often unaware of this.

Opportunities for greater engagement are possible, strengthening the data feedback loop

Involve people with lived experience and frontline staff in setting research questions (e.g. the James Lind Alliance addiction priority-setting partnership), in interpreting findings, and in judging the public value of linked data.

Feed findings back to services and clients.

Explain in plain language what is recorded, why, and with whom it is shared.

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The views expressed are those of the author(s) and not necessarily those of the NIHR, the NHS or the Department of Health and Social Care.

20 Years

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