From PROMs to prompts: Data enrichment, linkage and the role of AI in registries

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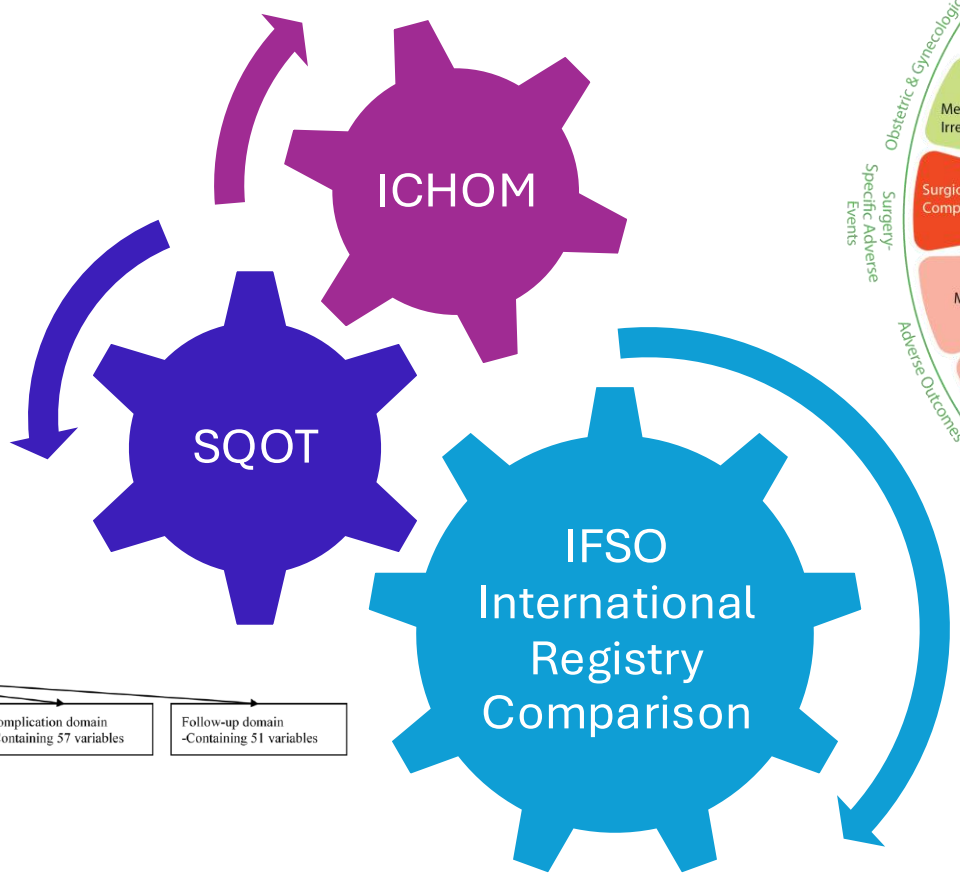
Ziekenhuis Gelderse Vallei

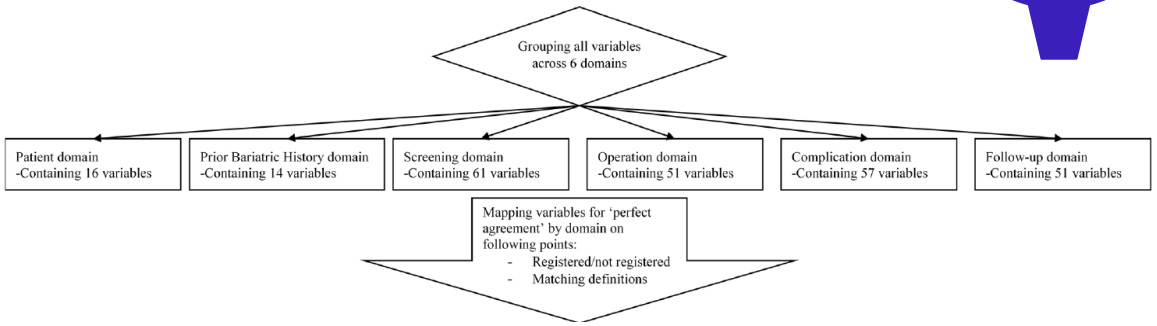
DICA Life saving data

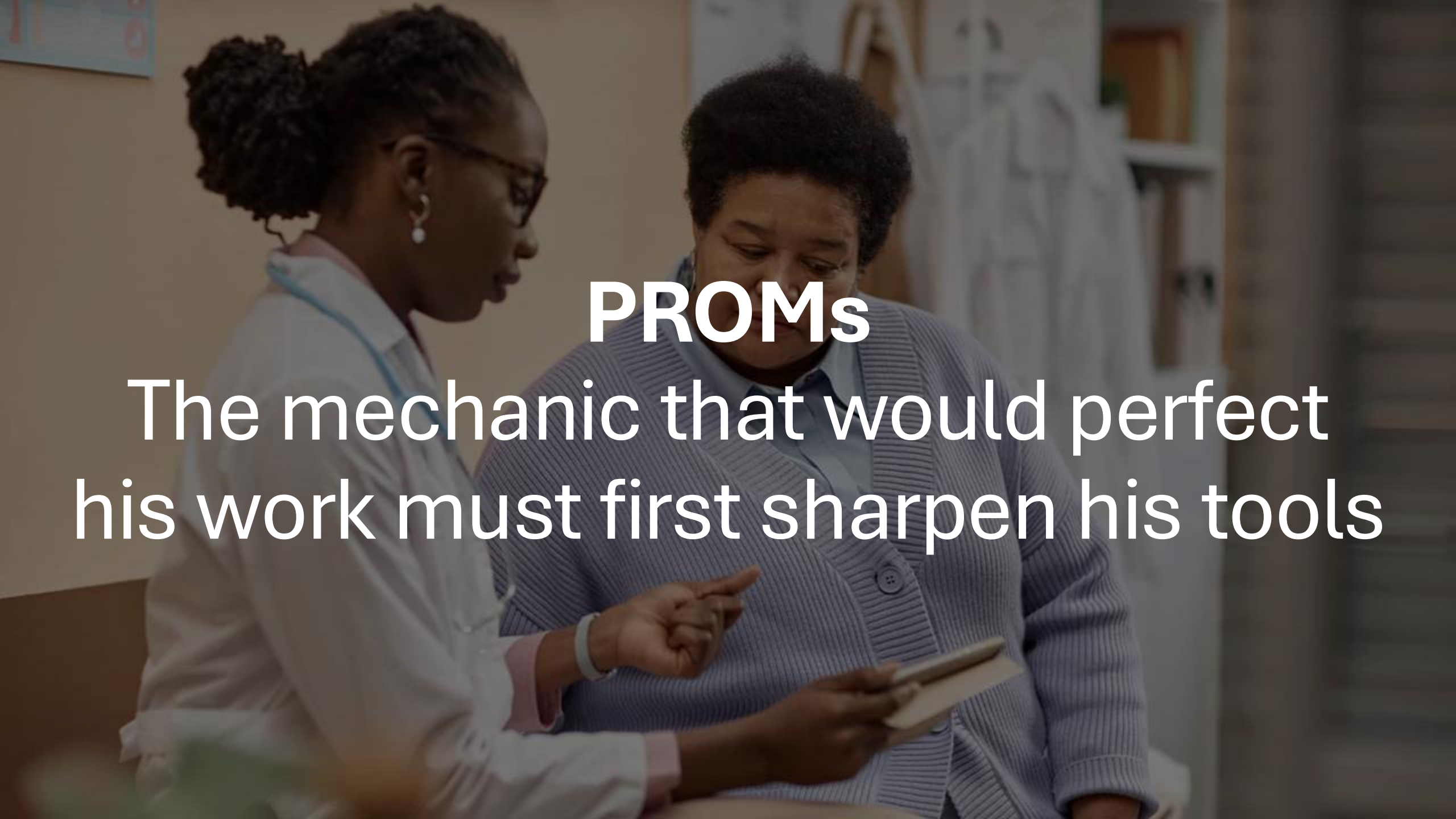
From procedure based registries to real world care pathways & patient engagement

Uniform reporting as a basis for meaningful comparisons

S.Q.O.T. Initiative






PROMs
The mechanic that would perfect his work must first sharpen his tools

Why are PROs relevant

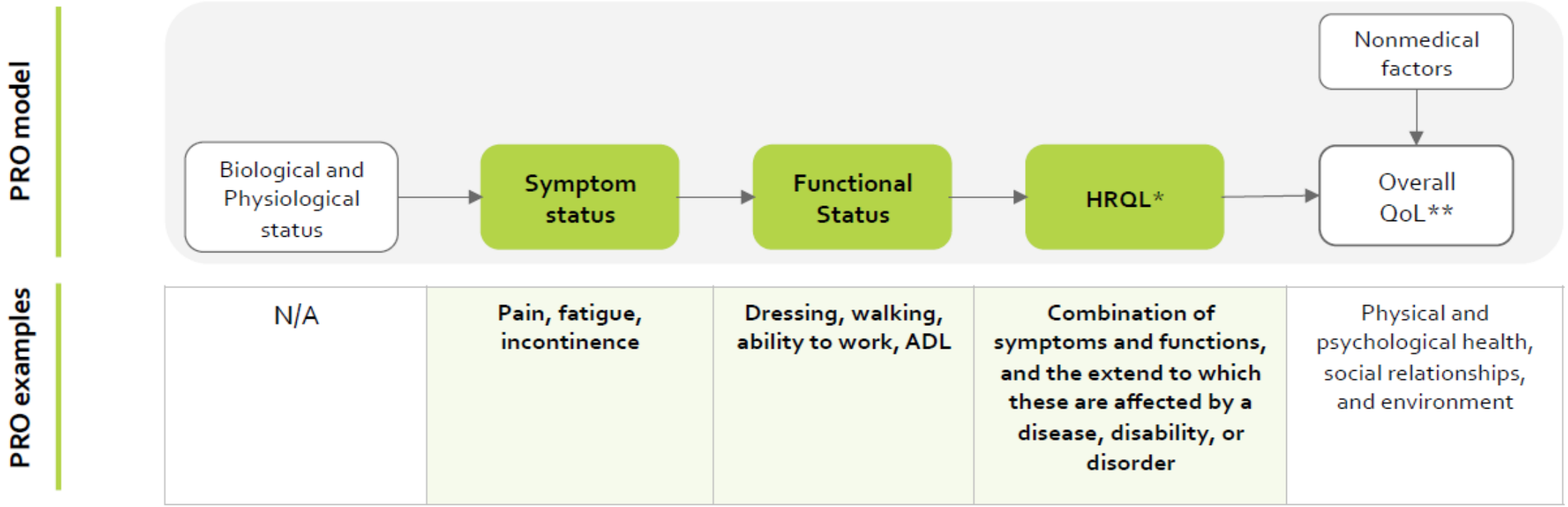
- Value based healthcare
- Help people with obesity better understand their surgical options
- Several levels

Individual care
(micro level)

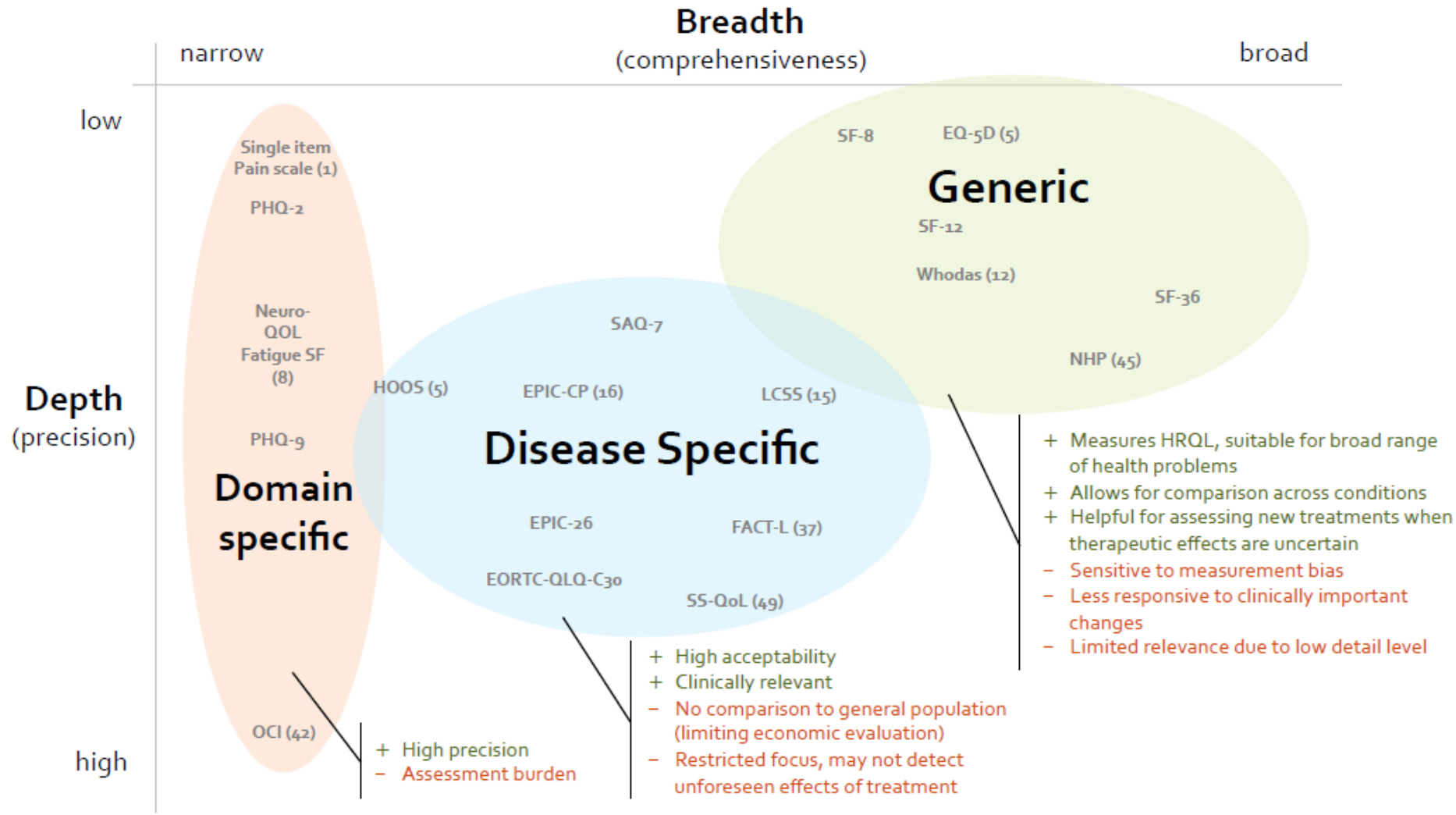
comparative effectiveness
(meso level)

quality improvement
(macro level)

PROs : Symptoms, Functional status, or a combination of these (HRQL)



The ideal PROM is determined by specific needs/goals



Known barriers to succes

lack of training

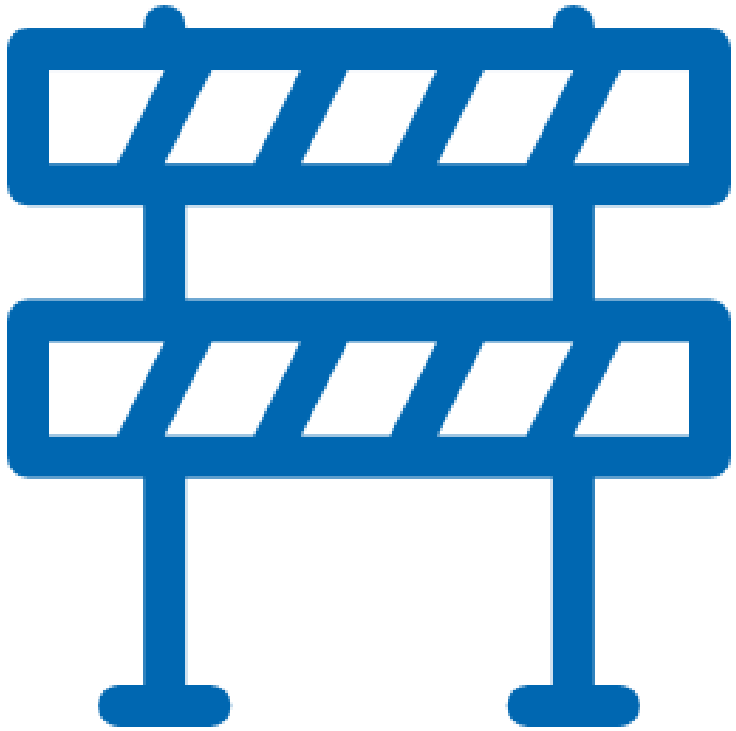
experiences are transient

implementation issues

unfiltered data

patient burden

missing Data



longitudinal data collection

cross-cultural relevance

clinician burden

meaningful metrics

liability

consistency

Engaging patients in registries

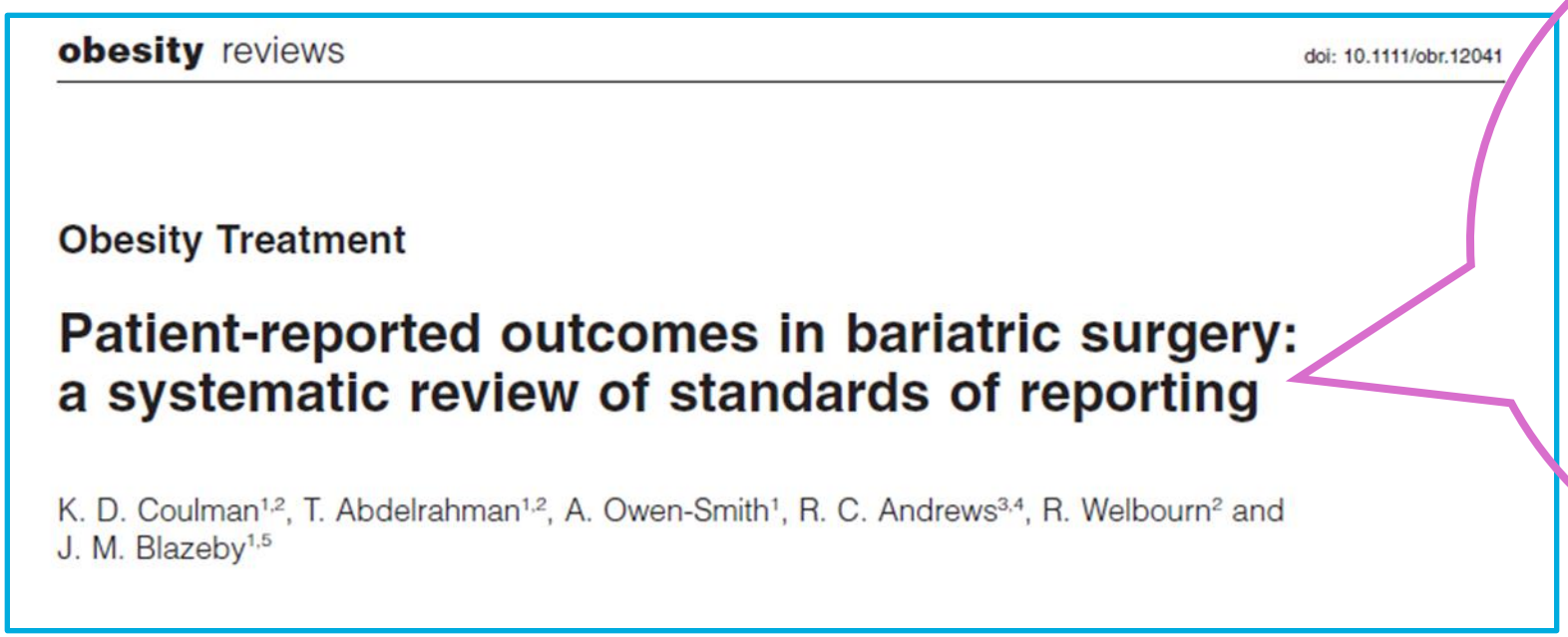
patient priorities

“democratization”

understanding barriers from the patients perspective

outcomes that matter most to patients

Lack of consistency in reporting of outcomes (1)



obesity reviews

doi: 10.1111/obr.12041

Obesity Treatment

Patient-reported outcomes in bariatric surgery: a systematic review of standards of reporting

K. D. Coulman[1,2], T. Abdelrahman[1,2], A. Owen-Smith[1], R. C. Andrews[3,4], R. Welbourn[2] and J. M. Blazeby[1,5]

....68 different measurement tools & 1897 patient reported outcomes

Lack of consistency in reporting of outcomes (2)

OBESITY Reviews

WORLD OBESITY

Obesity Surgery/Outcome Assessment | Open Access

Recommendations on the most suitable quality-of-life measurement instruments for bariatric and body contouring surgery: a systematic review

C. E. E. de Vries, M. C. Kalff, C. A. C. Prinsen, K. D. Coulman, C. den Haan, R. Welbourn, J. M. Blazeby, J. M. Morton, B. A. van Wagensveld

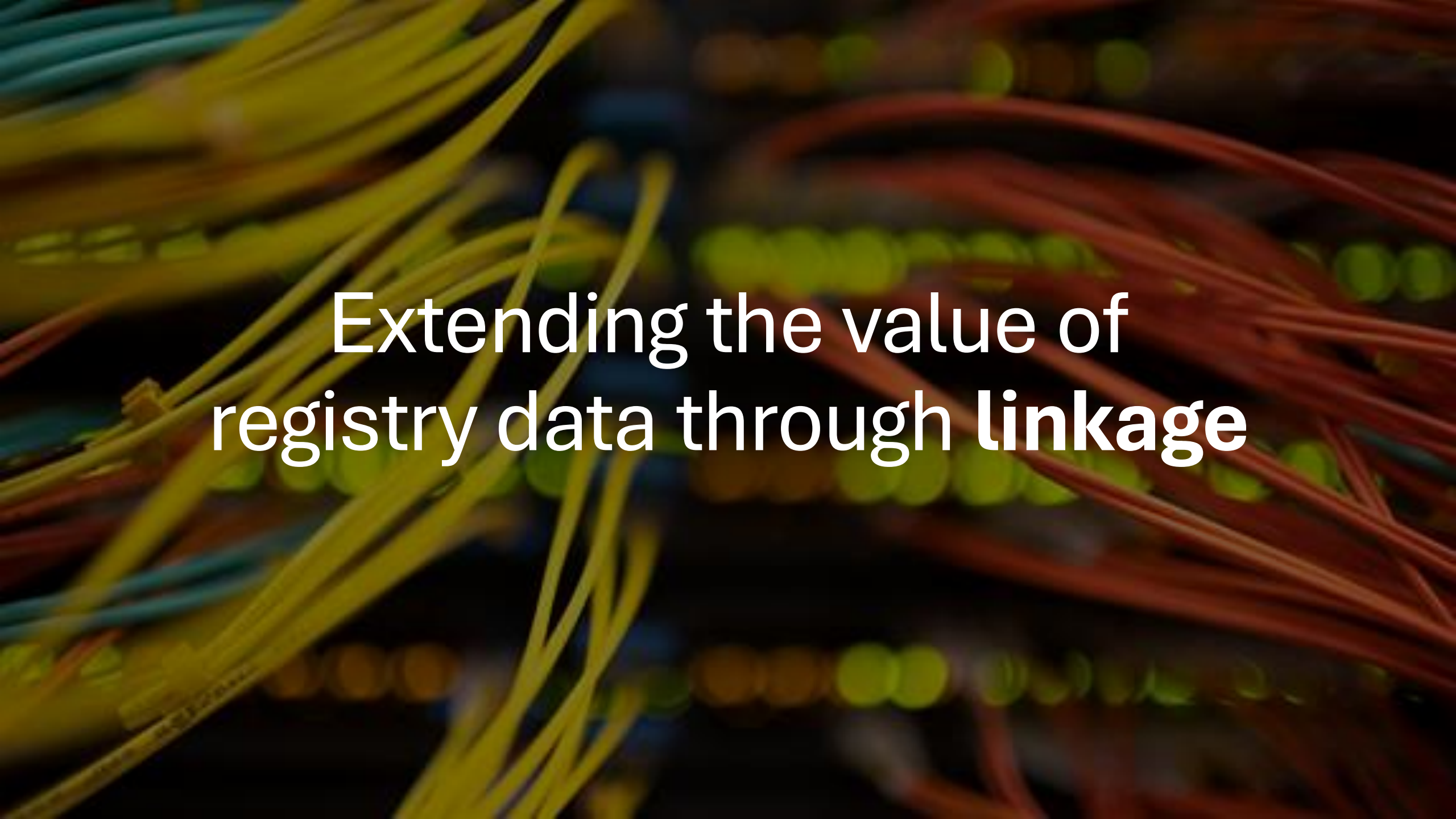
First published: 08 June 2018 | https://doi.org/10.1111/obr.12710 | Citations: 36

The BODY-Q, possessed the strongest evidence for quality of measurement properties

Patients like me dashboard

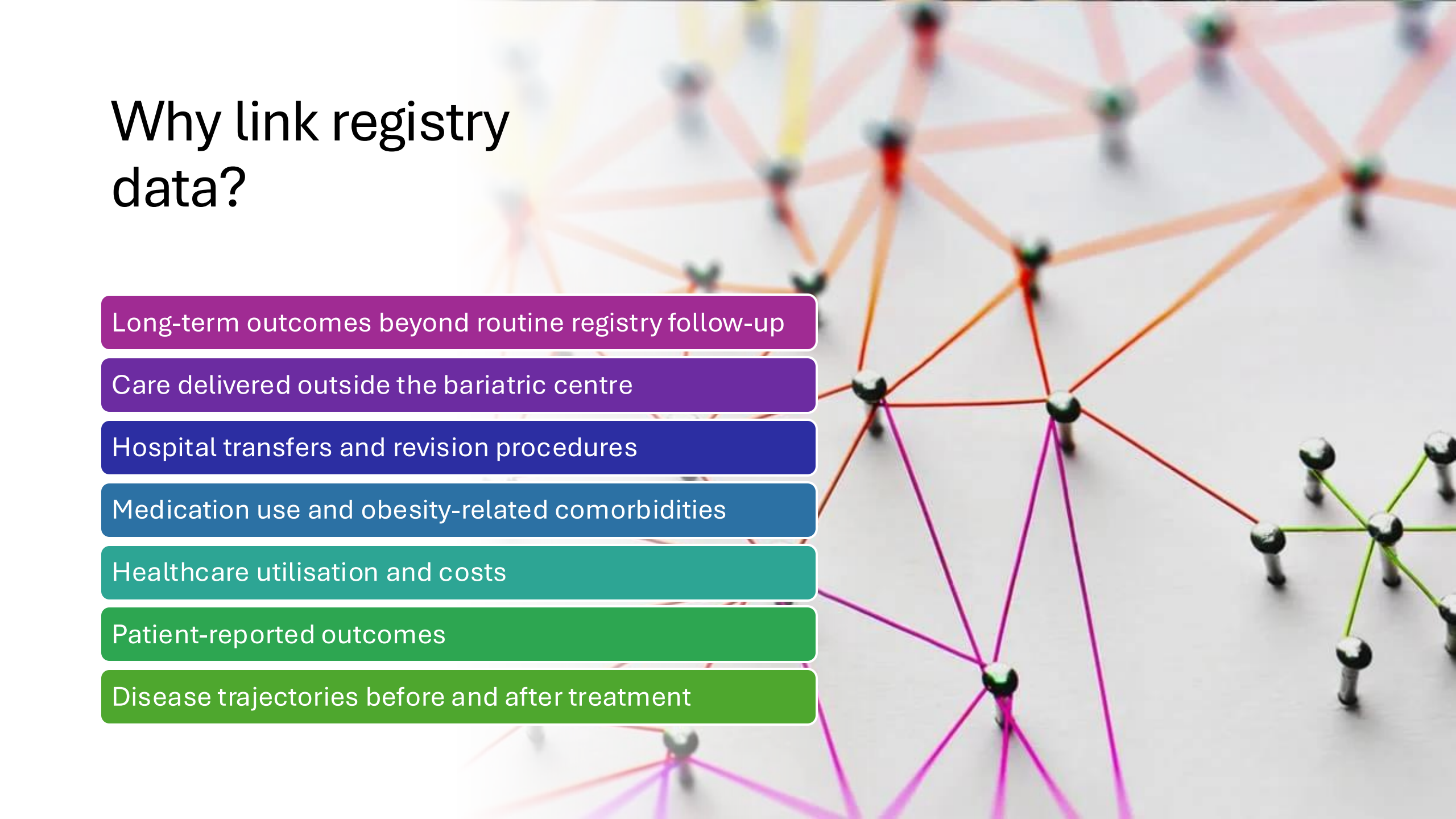
Concrete example of the standard registration of PROMs, finding its way back to the consultation room:

- Patients like me dashboard, generated from the obesity registry
- Fill out: gender, age, comorbidities, type of procedure
- Get results from all comparable patients, regarding
  - Weight loss outcomes
  - PROMs on all BODY-Q domains


Extending the value of
registry data through **linkage**

Why link registry data?

- Long-term outcomes beyond routine registry follow-up
- Care delivered outside the bariatric centre
- Hospital transfers and revision procedures
- Medication use and obesity-related comorbidities
- Healthcare utilisation and costs
- Patient-reported outcomes
- Disease trajectories before and after treatment



Data linkage:

Procedure-based registry → real-world evidence on the complete obesity care pathway

But…

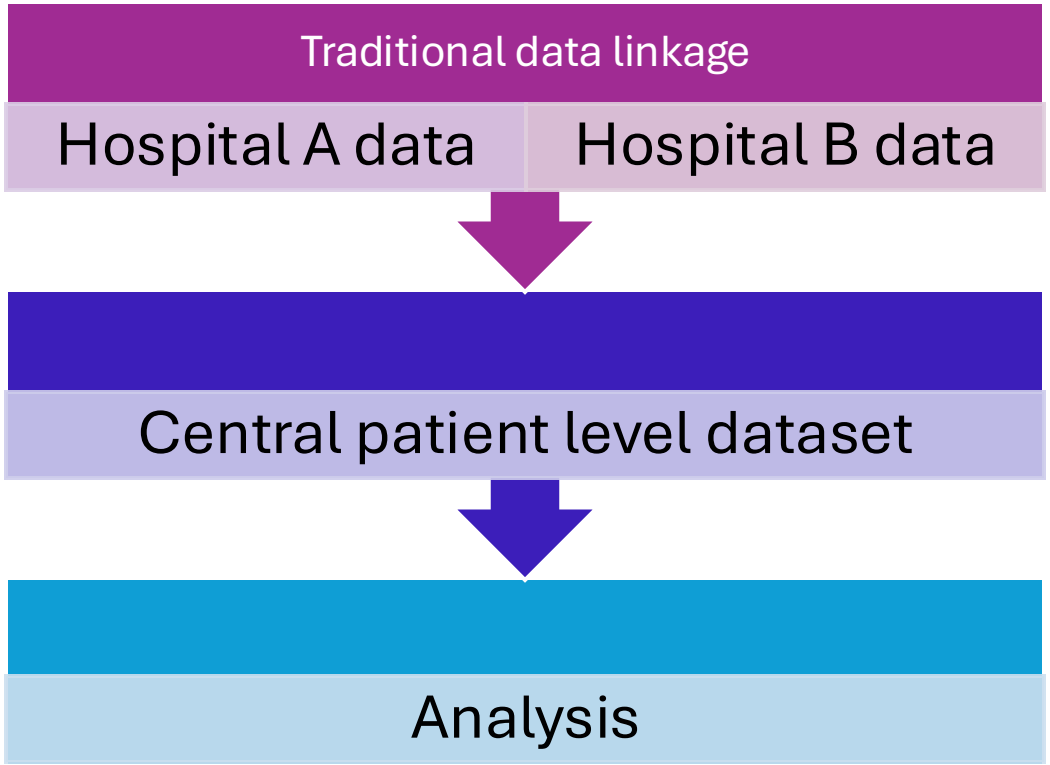
How about privacy regulations?

Privacy-preserving linkage: Multi-Party Computation

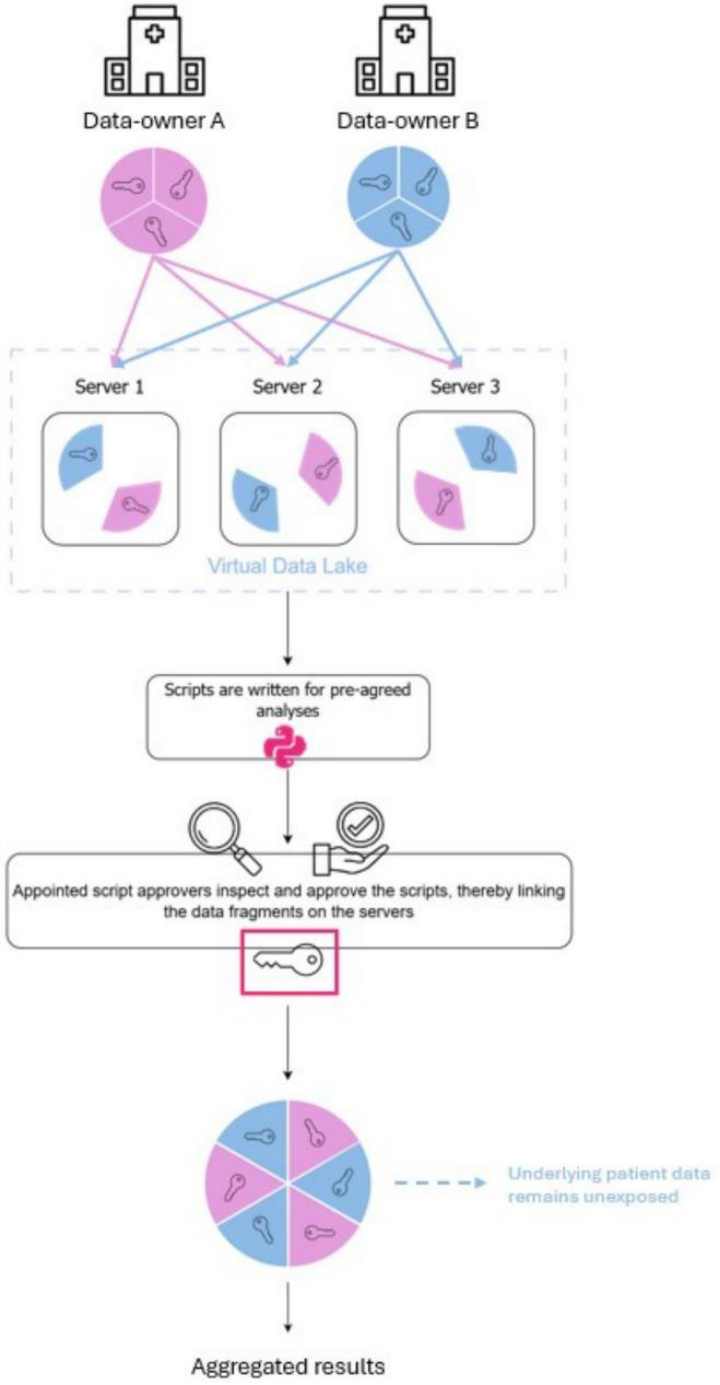
Bruinsma et al. (DATO) demonstrated how secure multi-party computation (MPC) can be used to link patient information across hospitals without exchanging identifiable patient-level data.

- Issue: revisional MBS in a different hospital can not be identified as a part of the same patients journey due to privacy regulations
  - Identifiable information can not freely be exchanged

Privacy-preserving linkage: Multi-Party Computation



VS



Bruinsma et al. Obesity Surgery, Dec 2025

What MPC adds to DATO

From: “Which procedures were performed?”

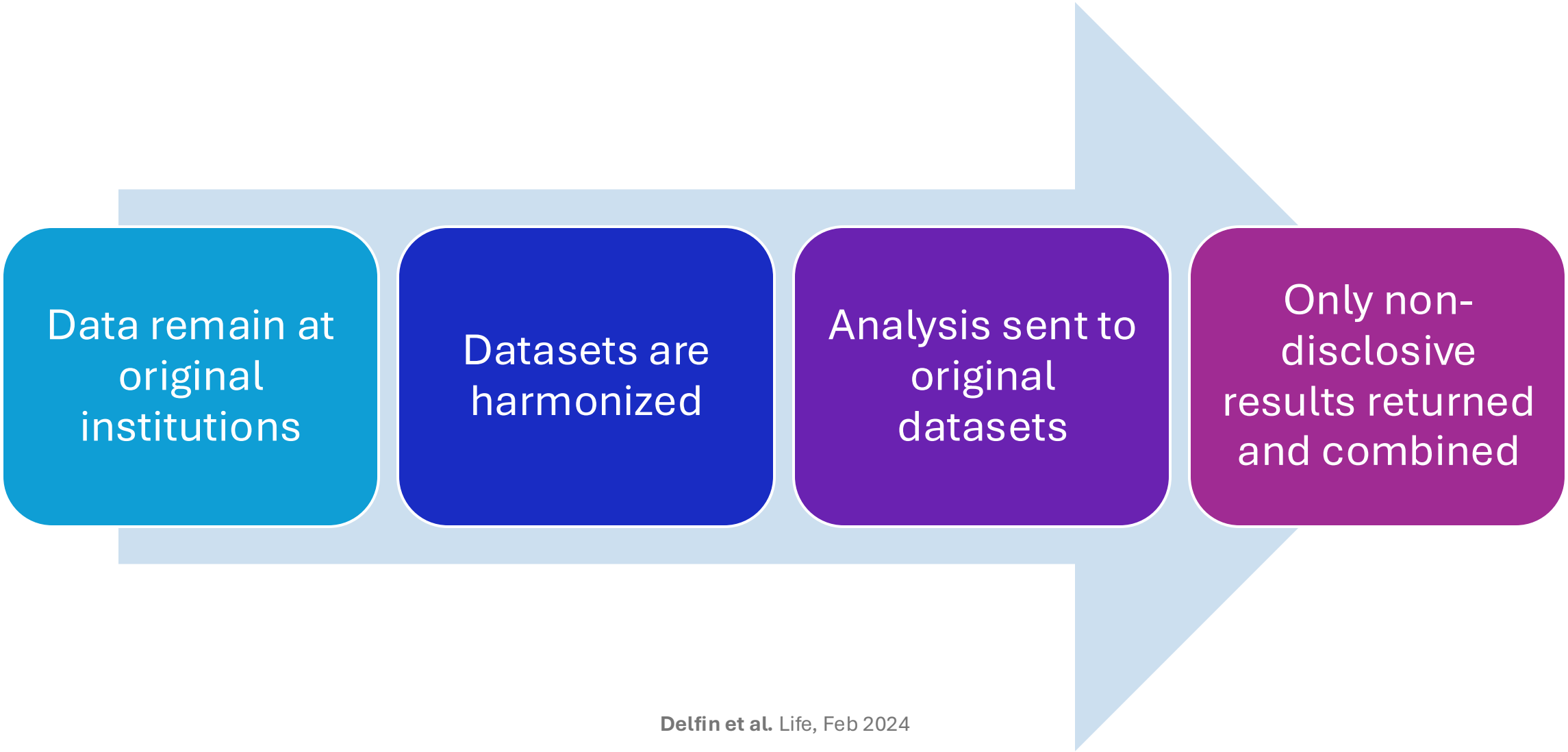
To: “How did individual patients move through the healthcare system?”

SOPHIA

Stratification of Obese Phenotypes to Optimize Future Obesity Therapy

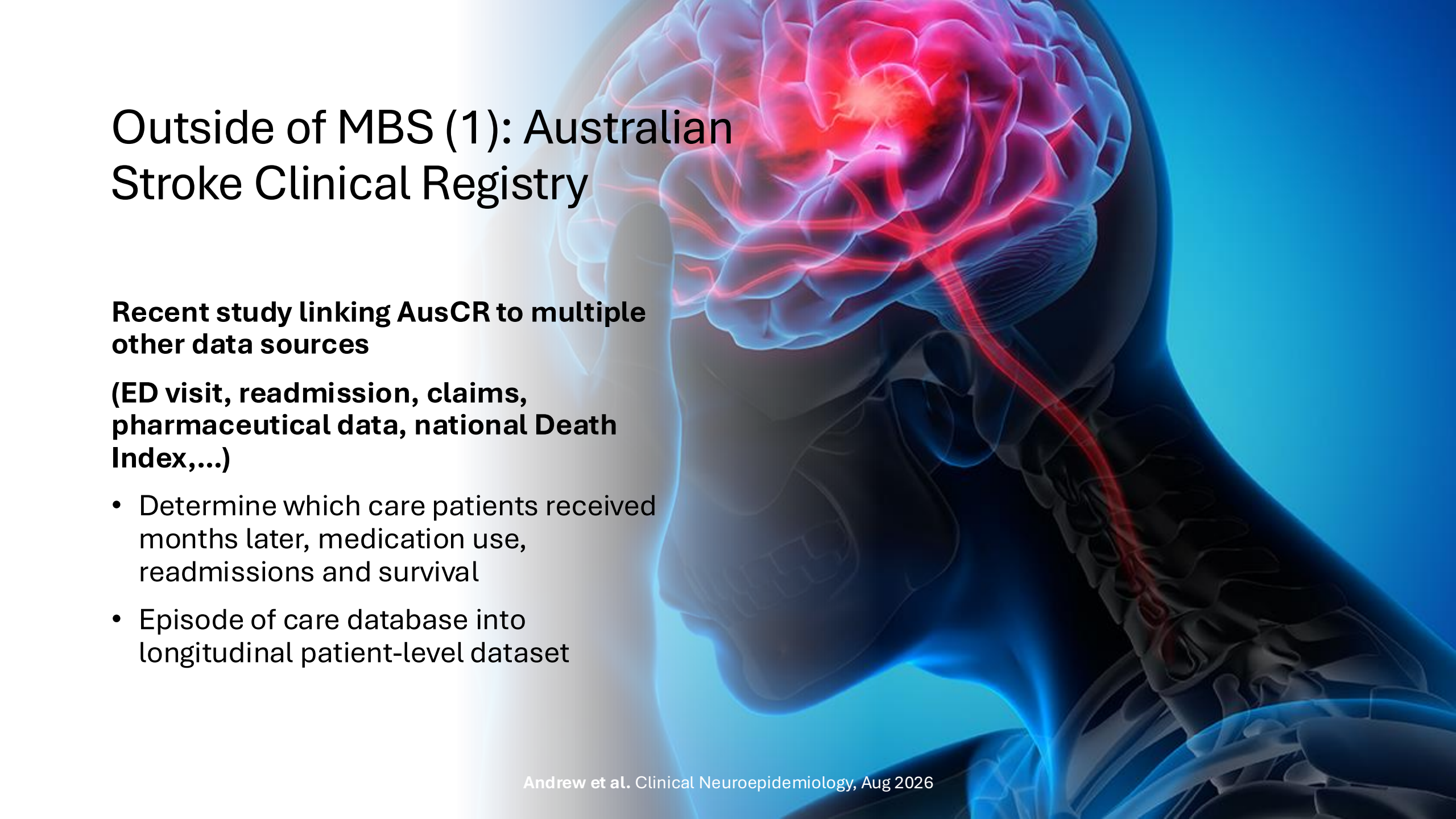
- **Federated infrastructure**
- **Combine information from different obesity cohorts**
  - Bariatric surgery
  - Clinical trials
  - Observational cohorts
  - Routine healthcare registries
  - Genomic, proteomics, metabolomics & microbiome data
- **No transferring of patient level data into a central database**

Federated data integration: the SOPHIA database



Delfin et al. Life, Feb 2024

Outside of MBS (1): Australian Stroke Clinical Registry



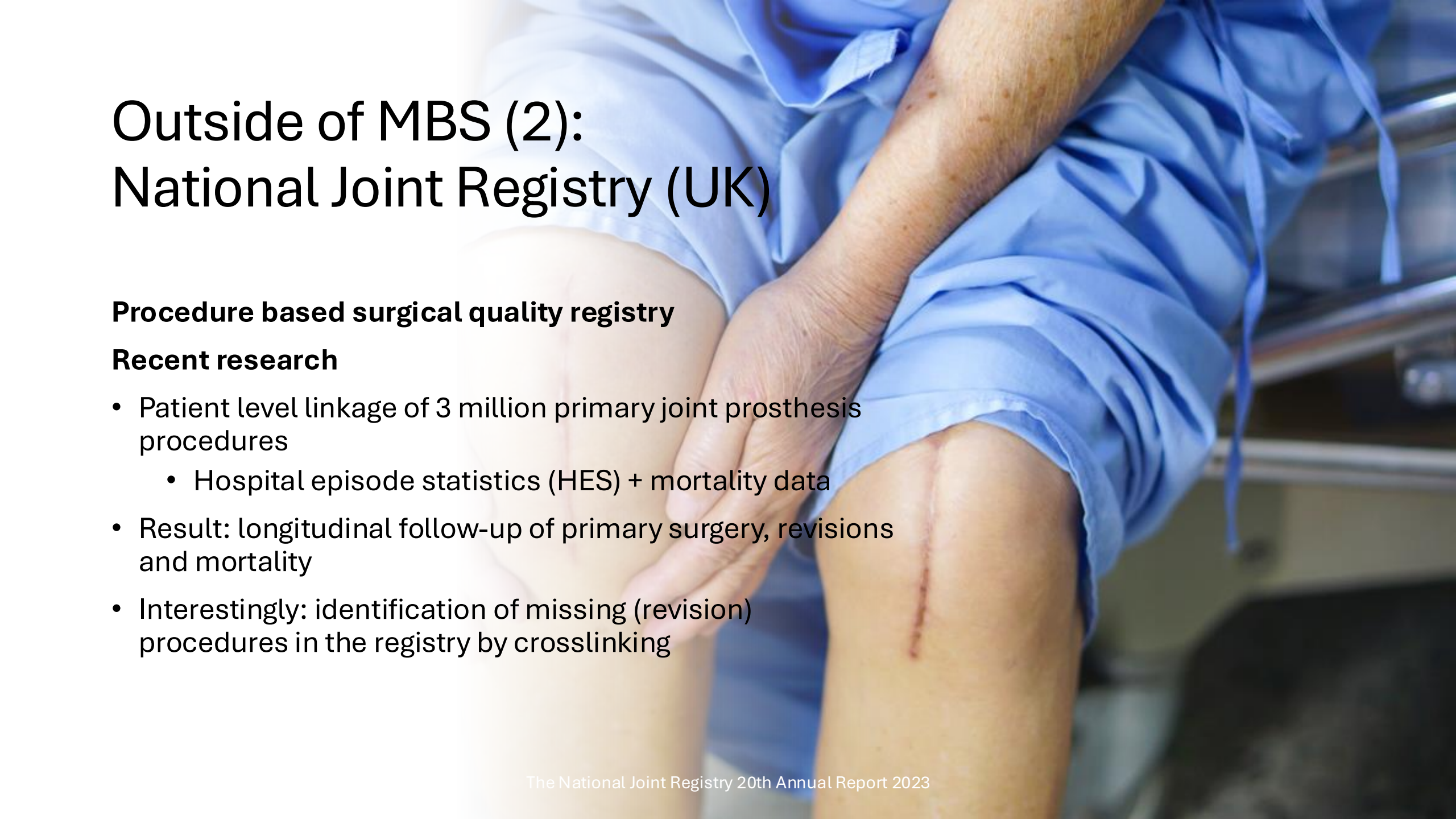
Recent study linking AusCR to multiple other data sources

(ED visit, readmission, claims, pharmaceutical data, national Death Index,…)

- Determine which care patients received months later, medication use, readmissions and survival
- Episode of care database into longitudinal patient-level dataset

Andrew et al. Clinical Neuroepidemiology, Aug 2026

Outside of MBS (2): National Joint Registry (UK)



Procedure based surgical quality registry

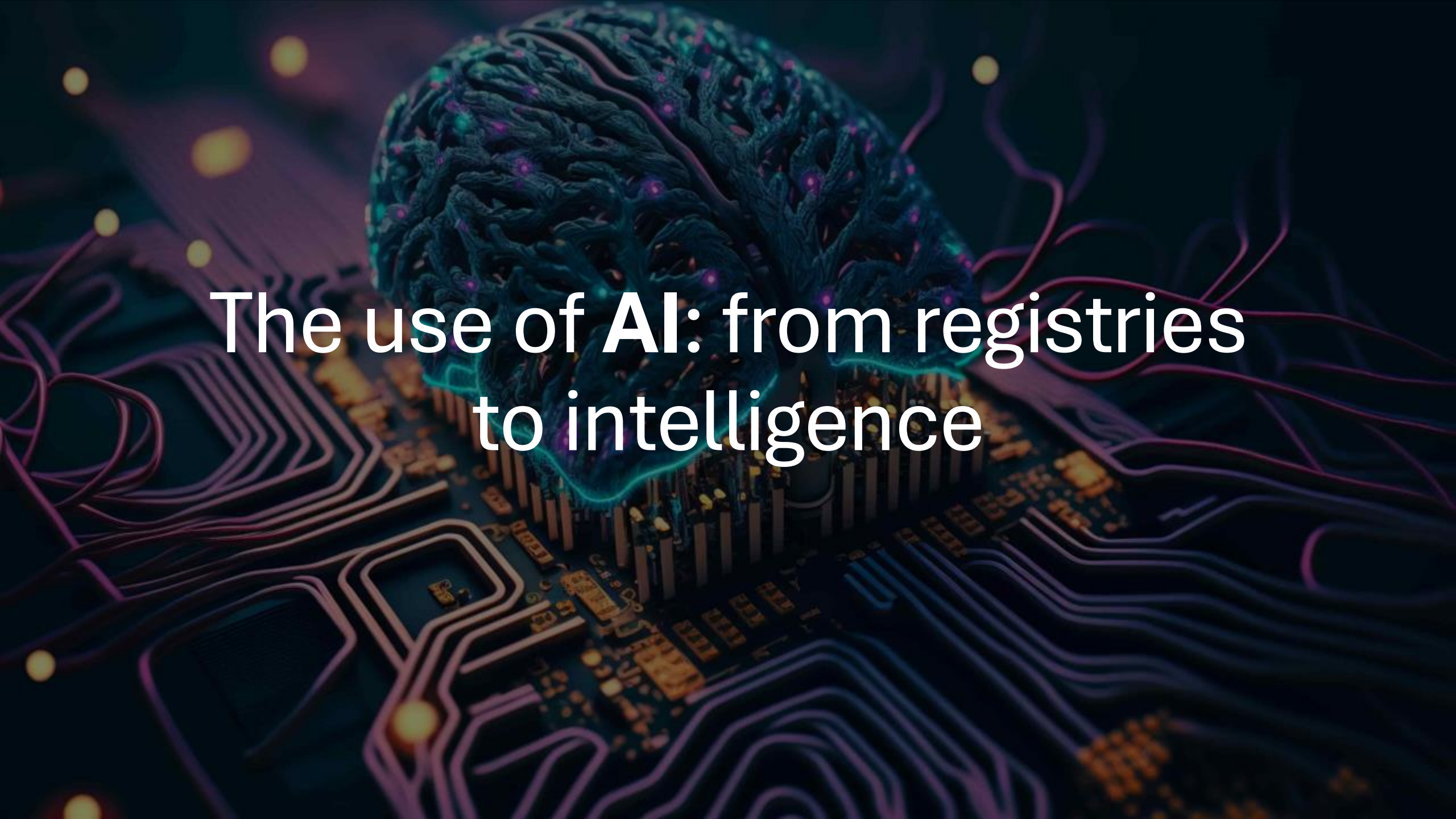
Recent research

- Patient level linkage of 3 million primary joint prosthesis procedures
  - Hospital episode statistics (HES) + mortality data
- Result: longitudinal follow-up of primary surgery, revisions and mortality
- Interestingly: identification of missing (revision) procedures in the registry by crosslinking

Challenges in data linkage?

- Legal and ethical
- Privacy & security
- Technical & methodological

The challenge is not simply to link more data, but to make data linkable, interpretable and usable while preserving patient privacy



The use of **AI**: from registries to intelligence

From a descriptive to a predictive registry

Traditionally, your registry will tell you:

- What happened?
  Complication rate, readmission rate, weight loss

AI can take it to:

- What is likely to happen?
- To whom?
- Why?
- Can we identify it earlier?

AI to predict complications after MBS

- Single centre, N=424
- Area under the curve (AUROC) for MBSAQIP-risicoscore = 0.64
- AUROC Random forrest = 0.88
- Identified several predictors for the first time
  - HbA1c, triglycerin, albumin, trombocytes en alkalic fosfatase

- AI can improve risk stratification
- An accurate model is not automaticaly a fair or clinical useful model

Zucchini et al. Obesity Surgery, Oct 2024

Predicting weight-loss and metabolic outcomes

- Recent meta-analysis regarding AI prediction models for weight loss
- The pooled AUC was 0.846 (95% CI: 0.755–0.908)
- High heterogeneity (I^2= 75.4%, p = 0.0021)
- High risk of bias, particularly in the analysis domain
  - Adherence to TRIPOD + AI reporting guidelines suboptimal

- Promising predictive performance does not yet equal clinical readiness
- Large international registries are valuable to develop and validate future models

Jinkun Wang et al. Obes Surg, Jun 2026

The future of registries?

1. Clinical registries provide high-quality structured data
2. Data linkage broadens the patient journey
3. AI can identify patterns that traditional reporting may miss
4. Uniform variables across registries enable future cooperations

Thank you for your attention!