Integrating data collection and analysis across the rehabilitation pathway

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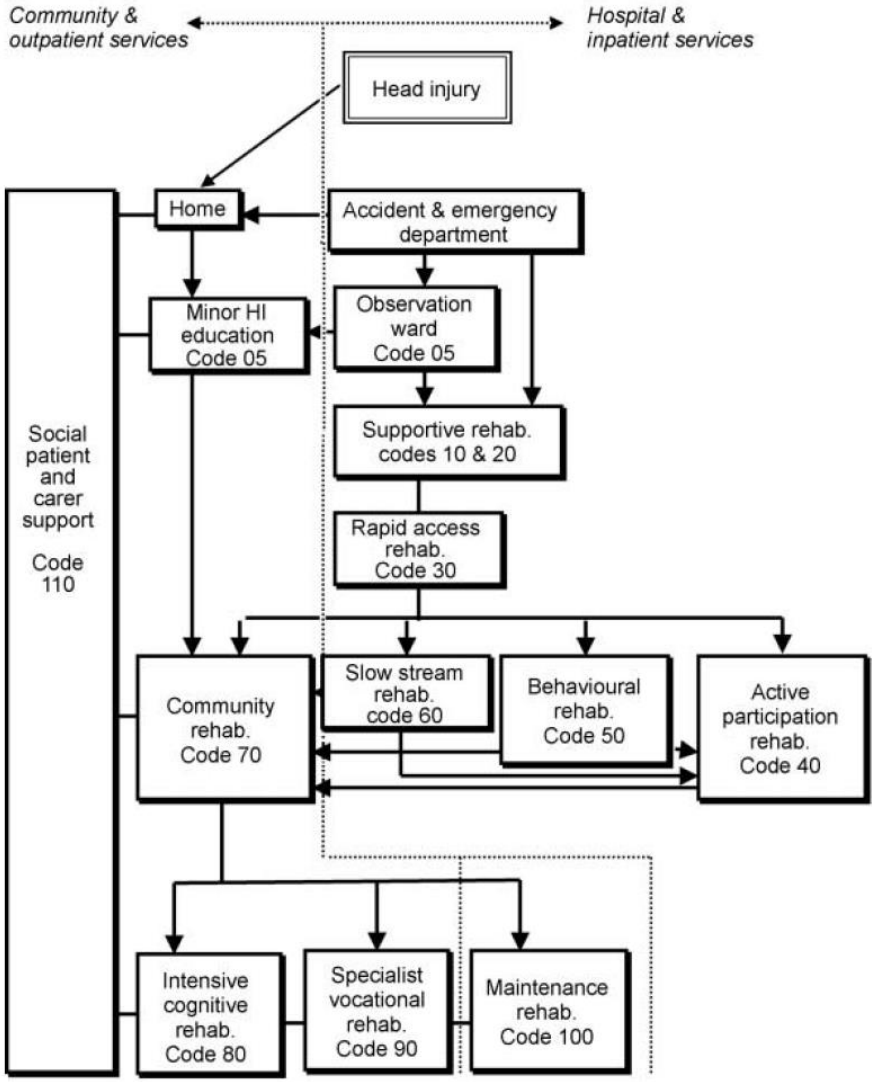
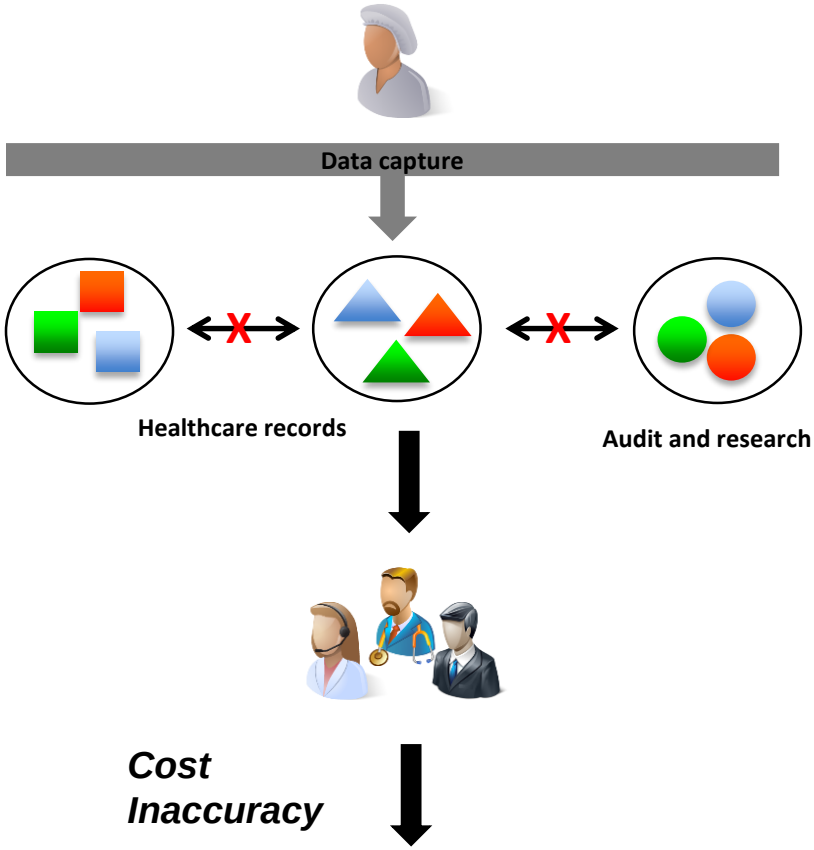
Challenge I – patient and service heterogeneity



Pickard et al., JSRM, 2004

Challenge II – repurposing clinical data without duplication



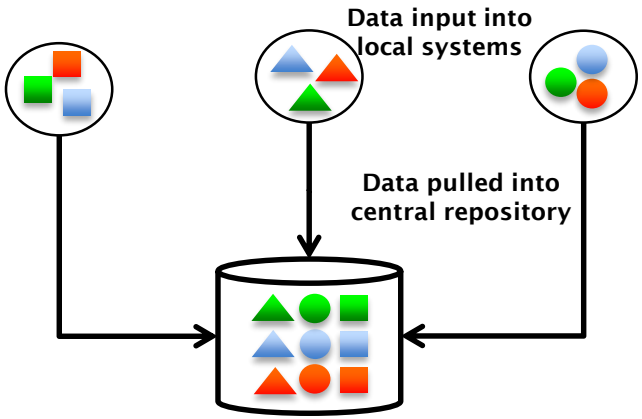
Service devolution
- across sites
- across specialties

Data duplication
- operational service
- audit and evaluation
- academic research

Technical challenges
- system compatibility
- data compatibility
- cost

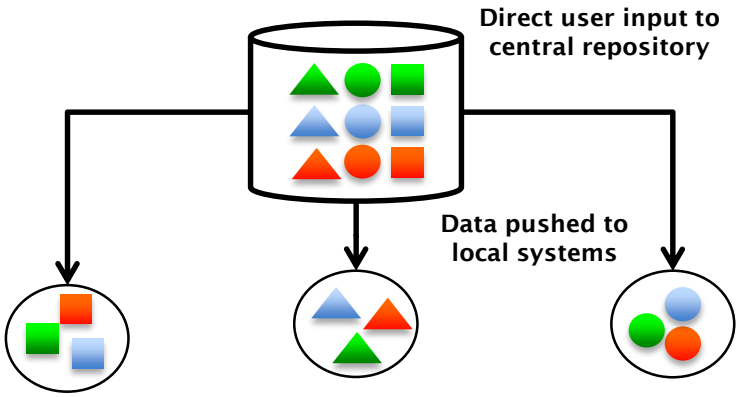
Approaches to integrated data collection

Inward central data feed



Local user familiarity
Limited by quality of local data / systems
Individual interfacing requirements
Not easily amenable to updates

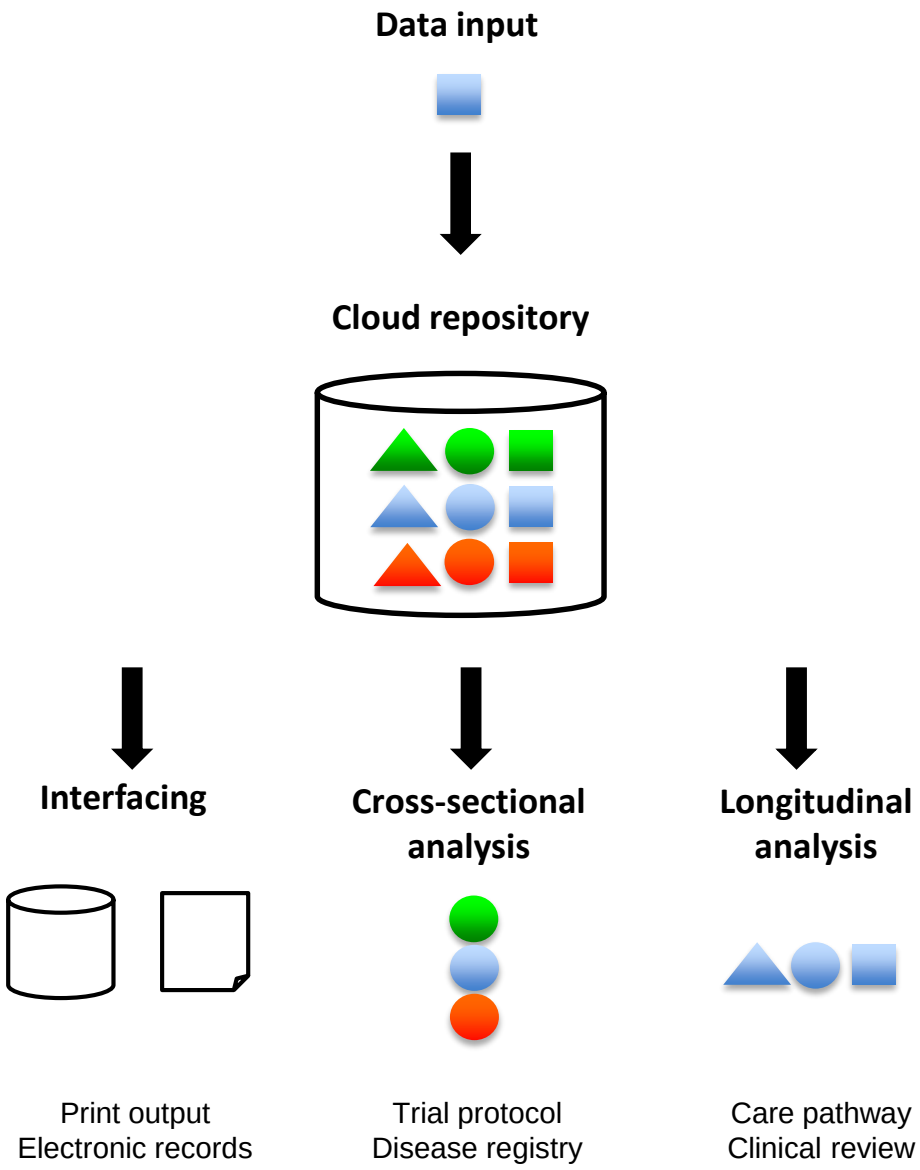
'Inverted' data feed



Control over dataset quality
Rapidly scalable and adaptable
User training
Local unit engagement

Outcome Registry, Intervention and Operation Network (ORION)

a national platform for integrating clinical data collection for multiple uses

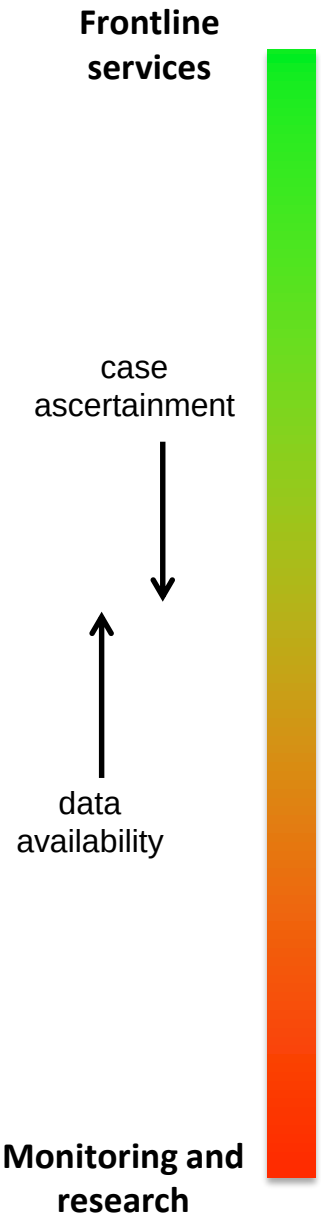


Desktop and tablet interface
No local software requirement
Two-factor authentication
Patient-facing interface

Data validation
Controlled modular access
Single common dataset

PDF, CSV, graph output

ORION project portfolio



Referral management

- Emergency calls
- Subspecialty portals

Service provision

- Trauma rehabilitation prescription
- Network referral system
- Ward tasklist

Integrated care

- DAMSEL (neuro-oncology)
- IRMA (integrated rehabilitation)
- MND-CARE

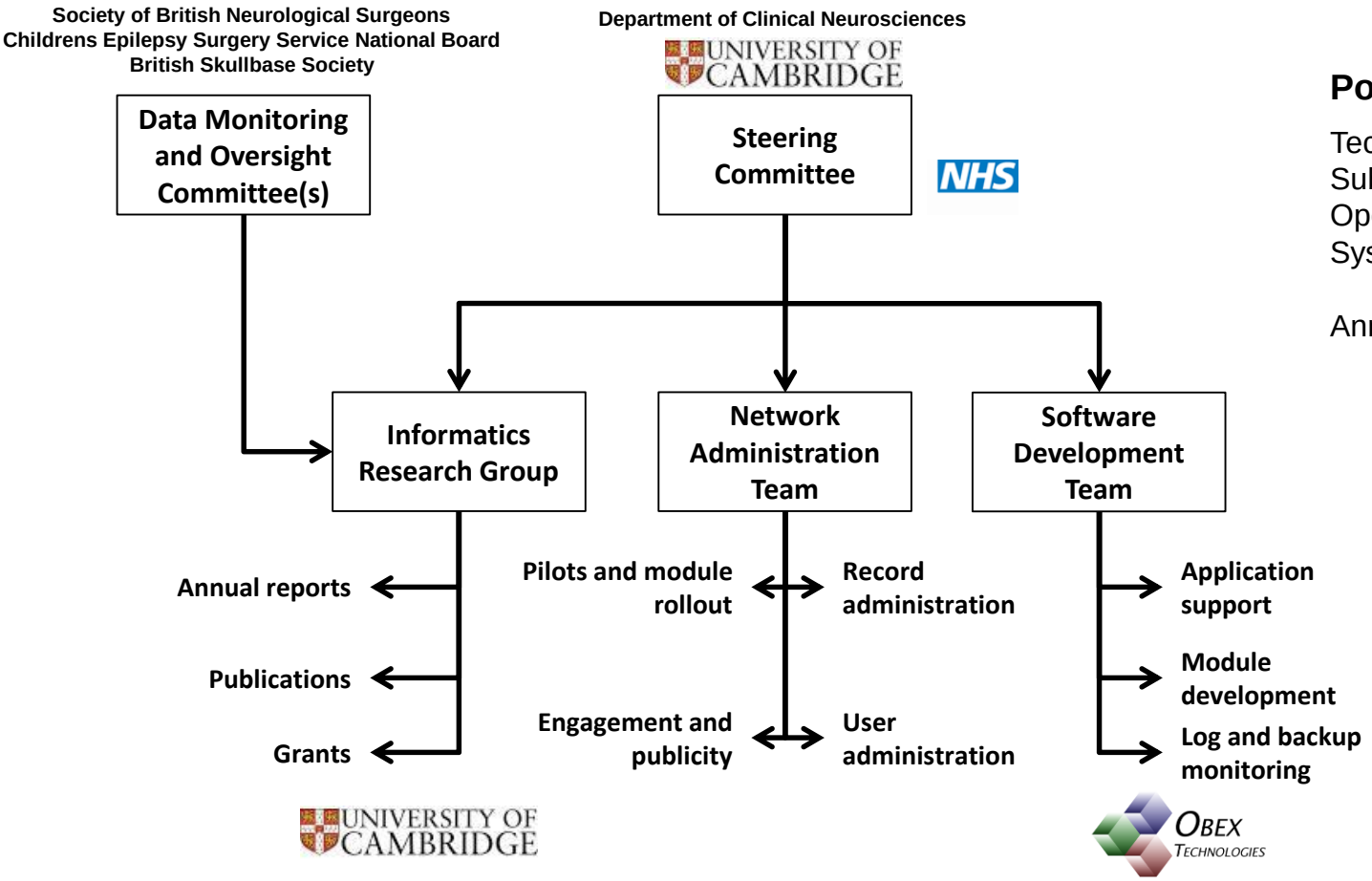
Prospective national registries

- Vestibular schwannoma registry
- CSF shunt registry
- Childrens Epilepsy Surgery Service National Database
- DBS registry

Studies and audits

- Melatools-Q
- National EVD audit

Oversight and Regulatory framework



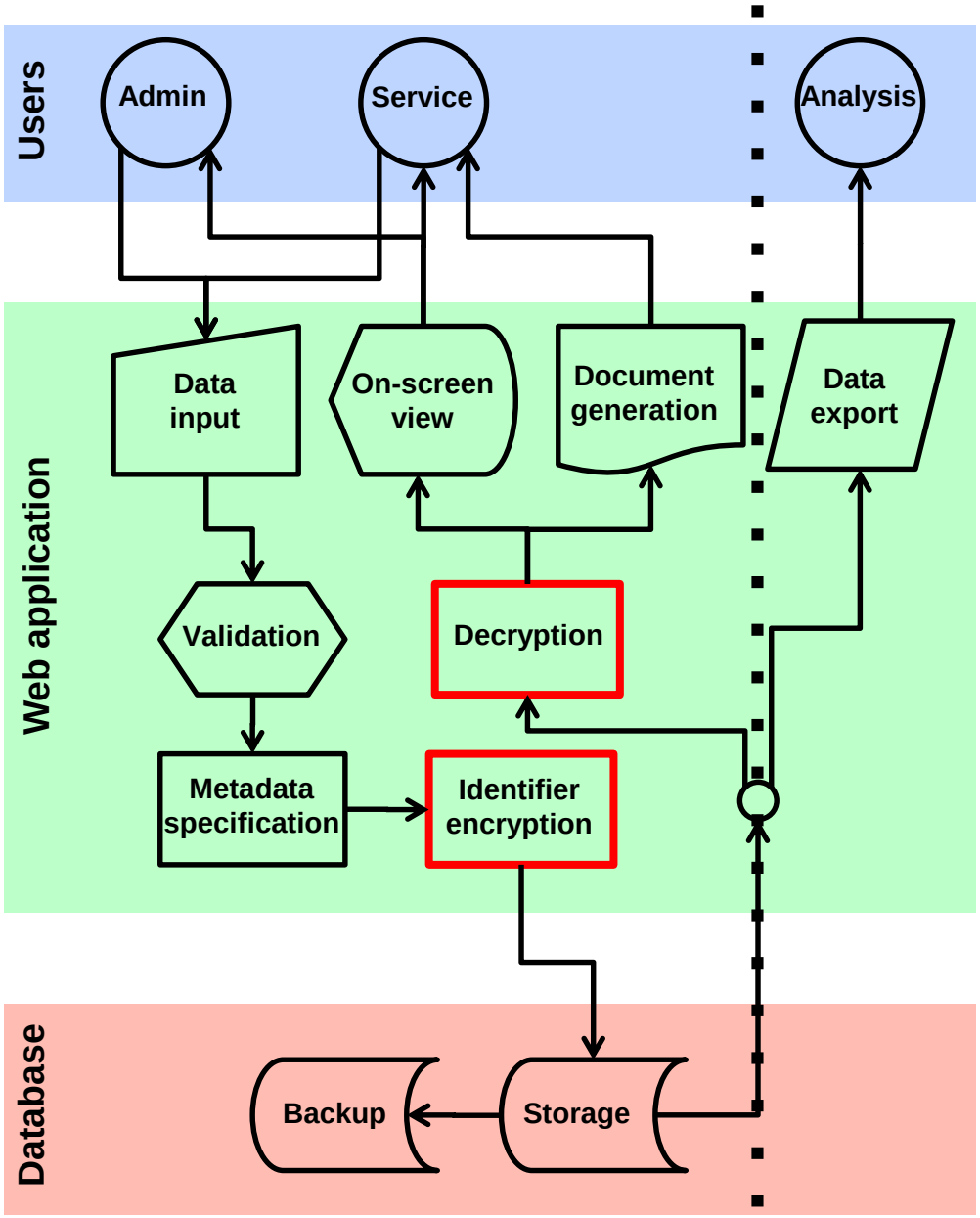
Policies and procedures

Technical and Security Specification
Subscription Terms and Conditions
Operational Policy
System Access and Data Policy

Annual IG toolkit submissions

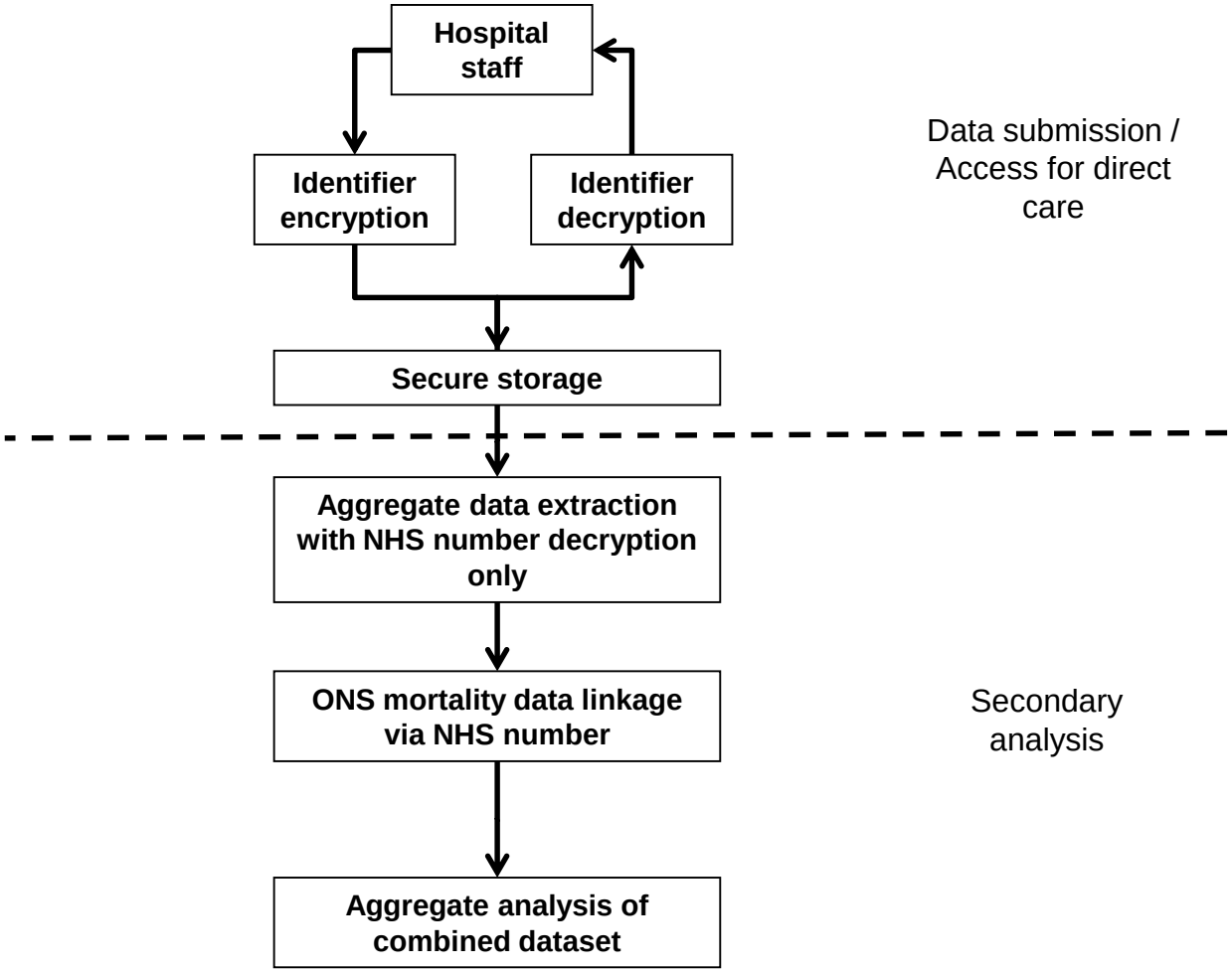
Reconciling data protection and analysis

Service used with identifier availability

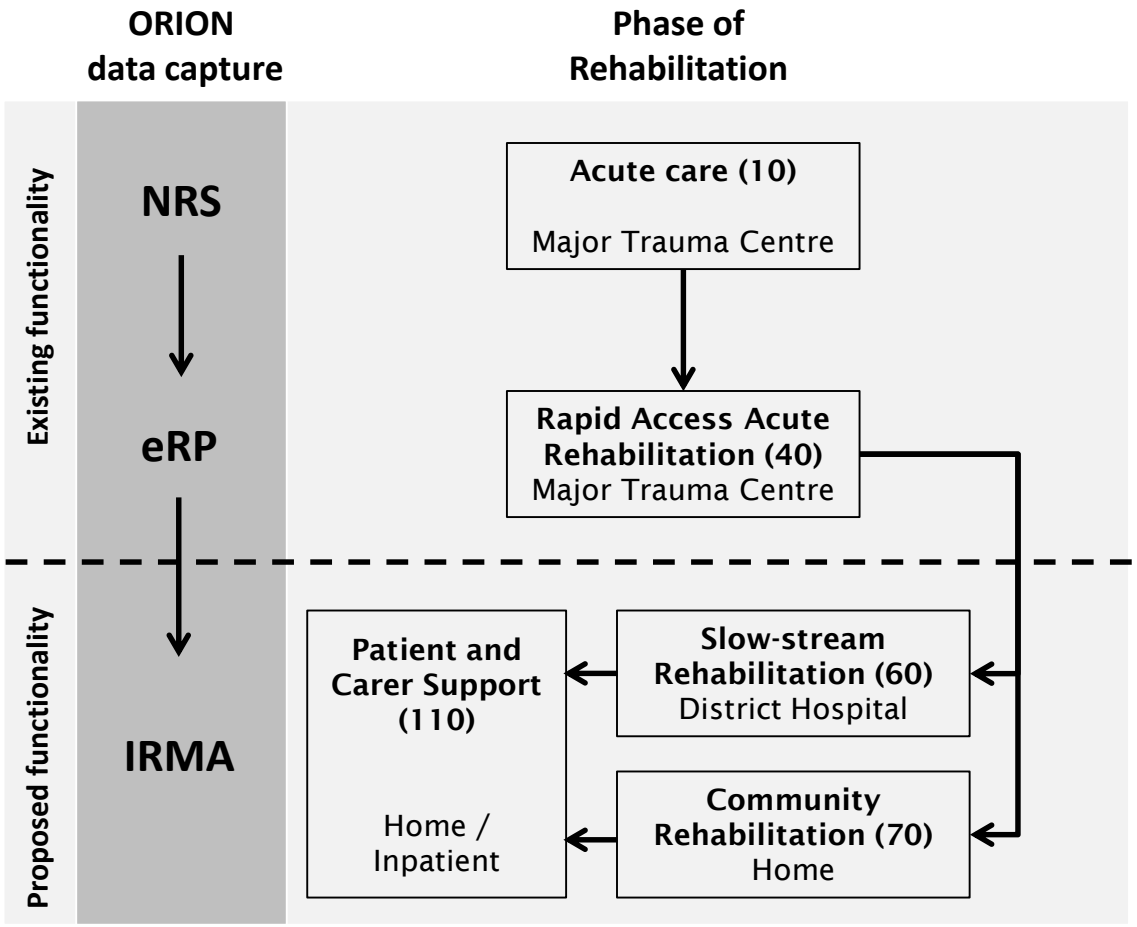


Aggregation and analysis with anonymised data

Utilising identifiable data for analysis - UKSR data flow

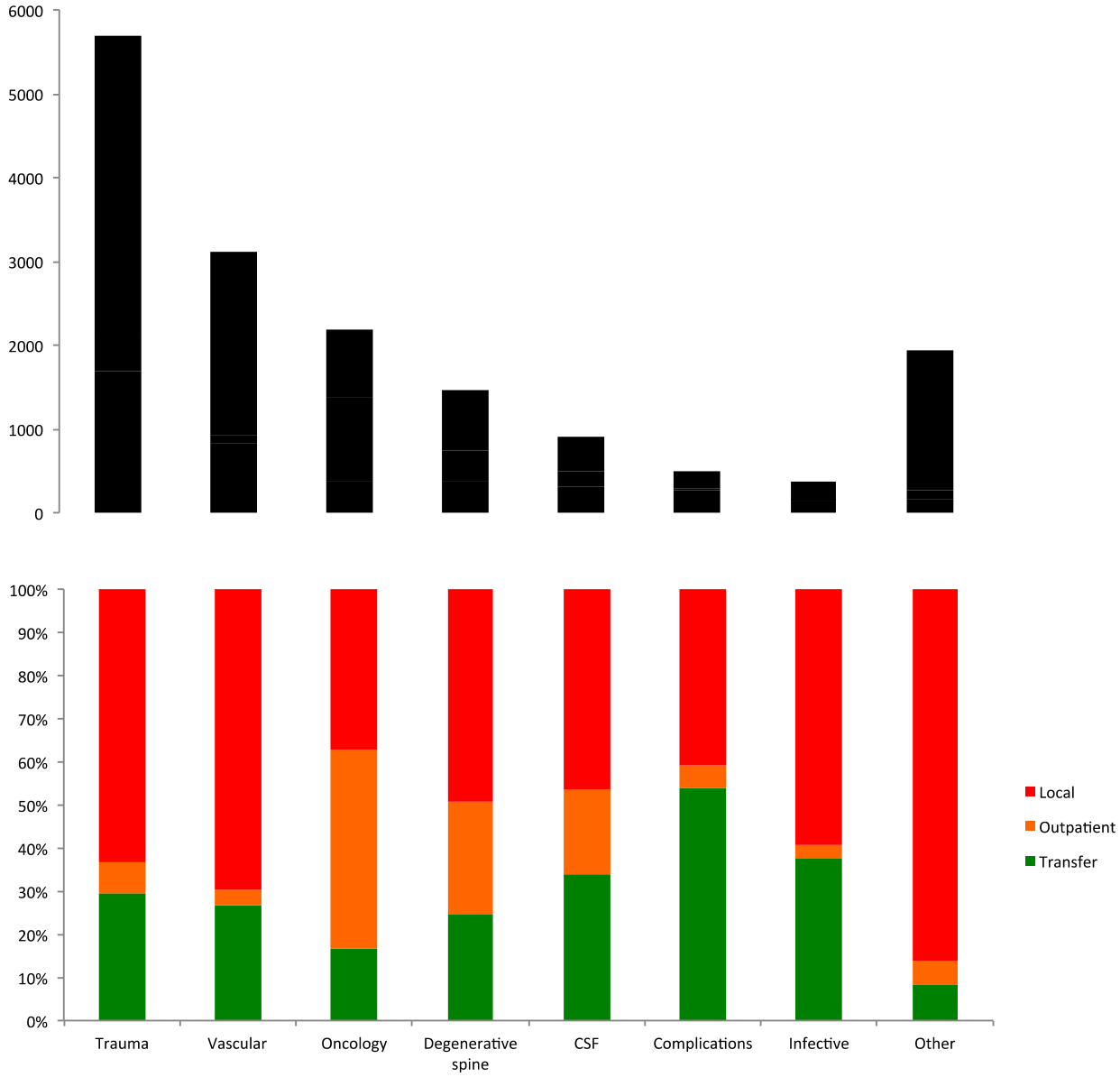


Tracking progress through the rehabilitation pathway

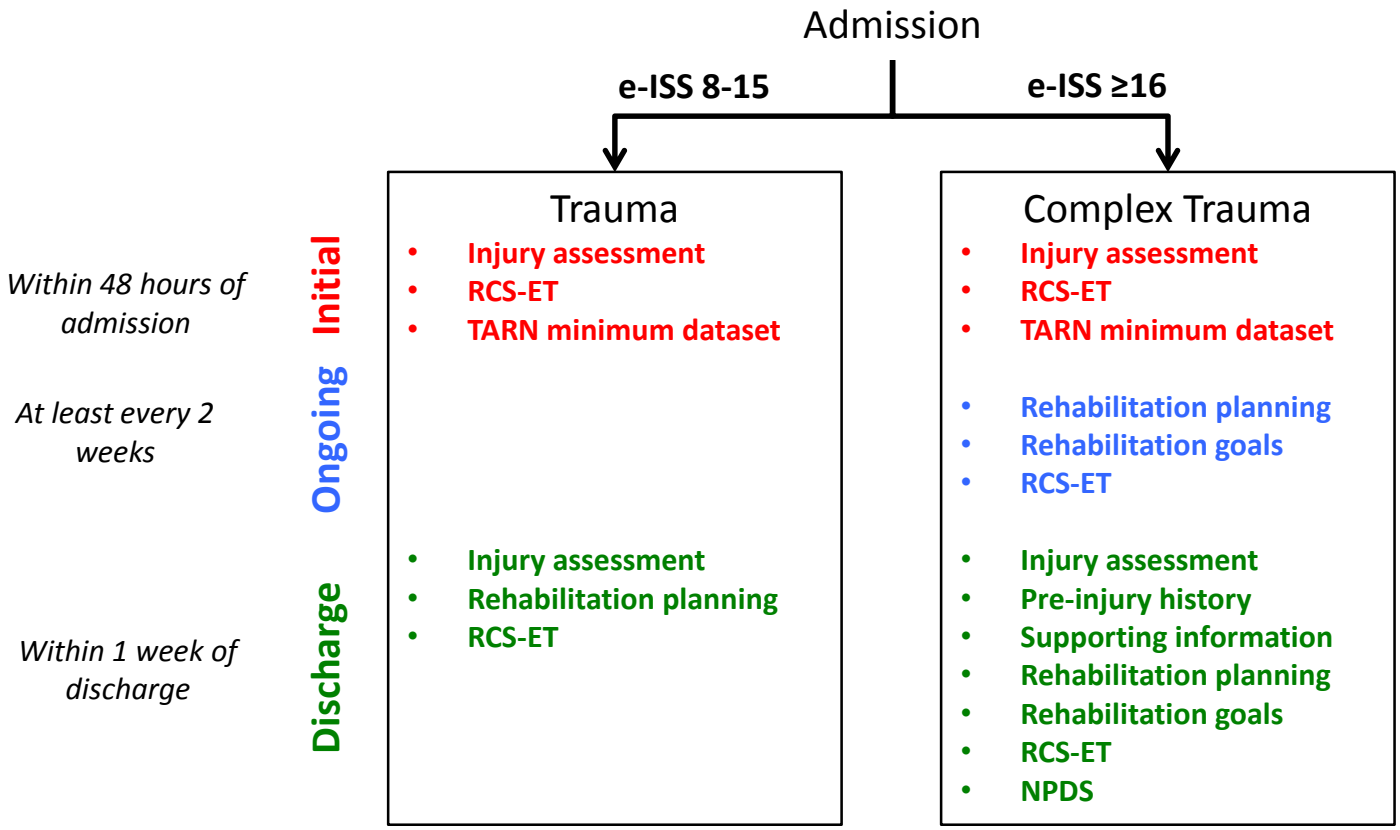


- *Data capture and patient flow*
- *Interfacing and data sharing*
- *Reporting, benchmarking and service evaluation*

Identifying patients with traumatic injury

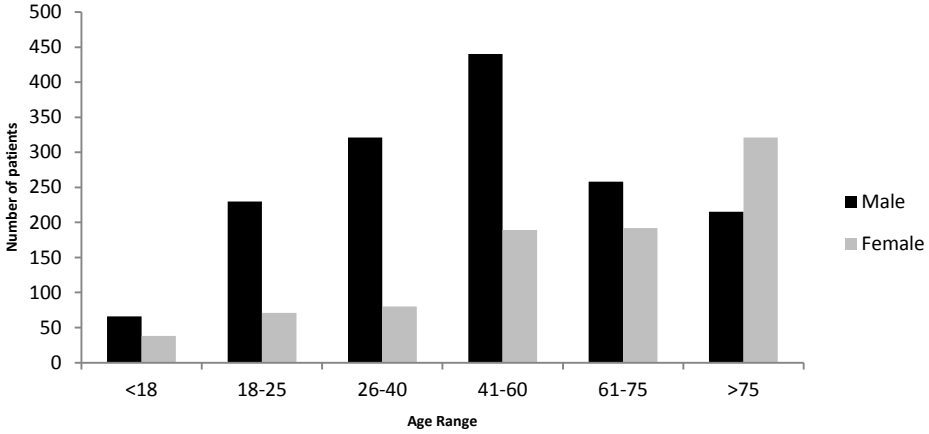


Establishing a baseline for measuring rehabilitation progress

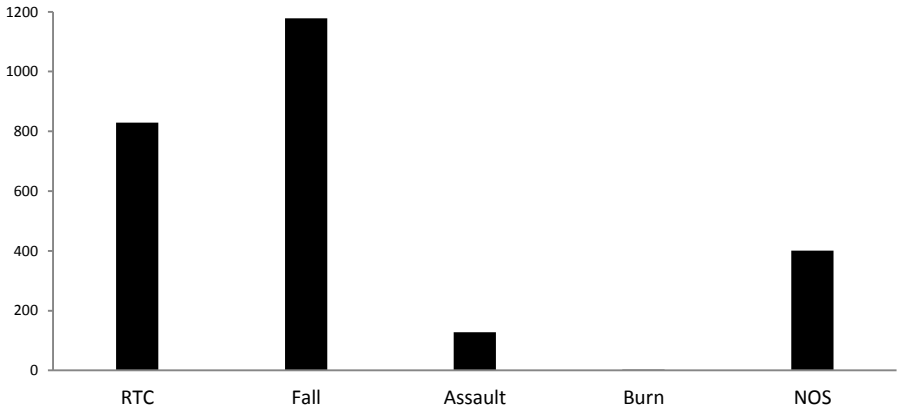


Establishing a baseline for measuring rehabilitation progress

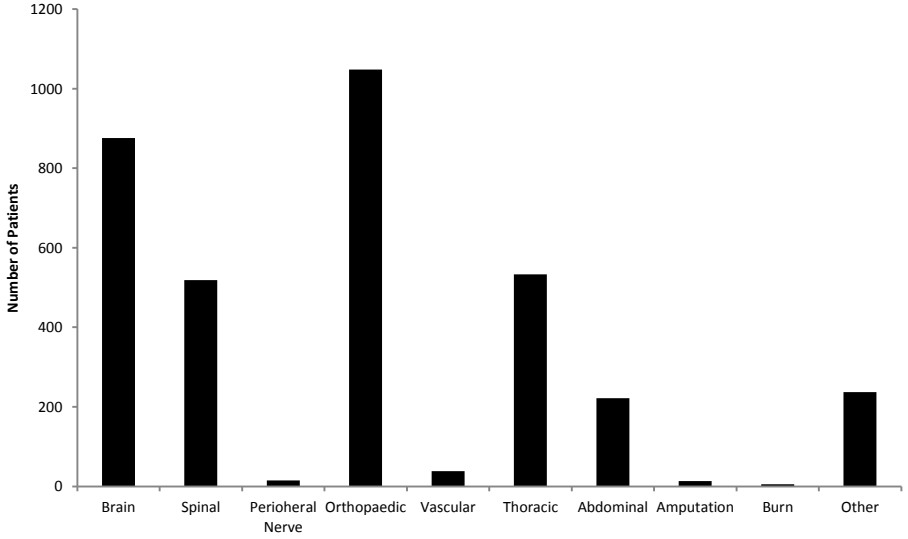
Pre-injury status



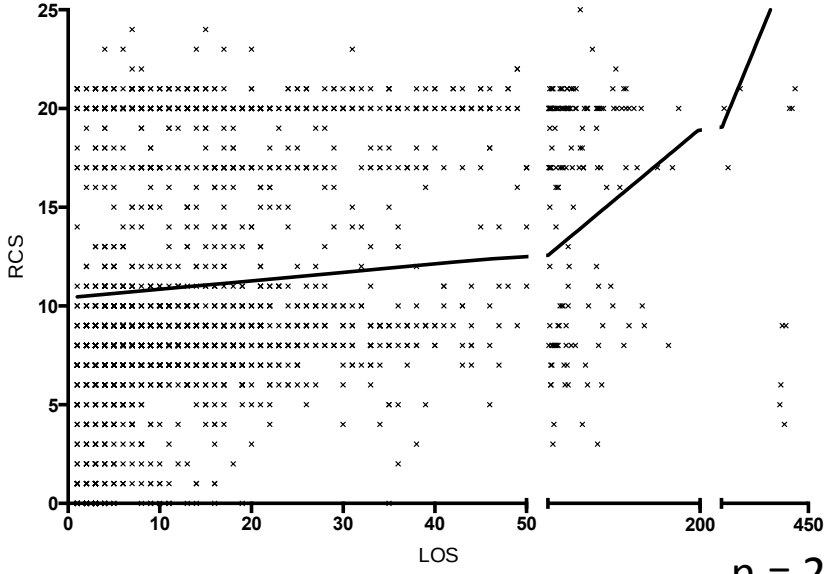
Mechanism of injury



Effects of injury

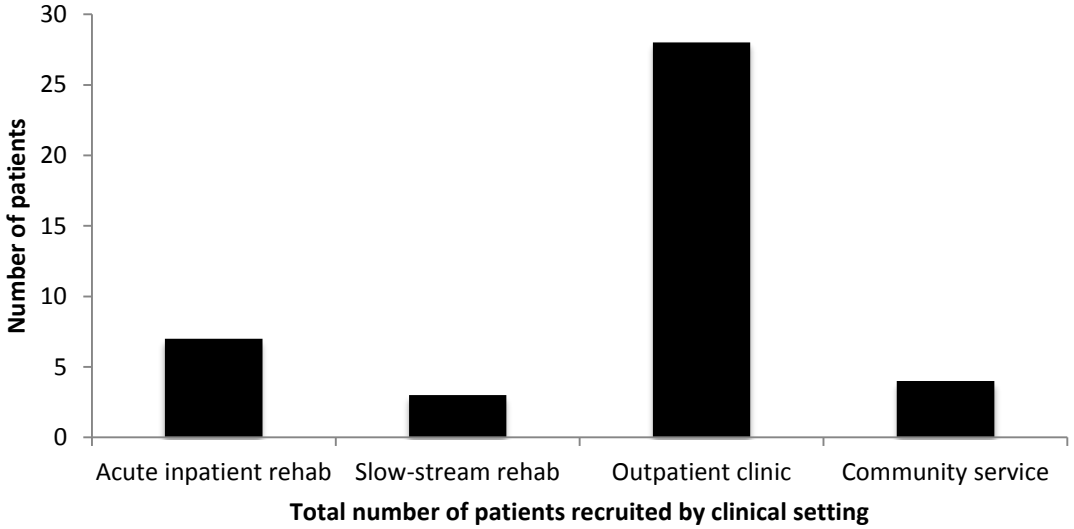


Short-term outcome

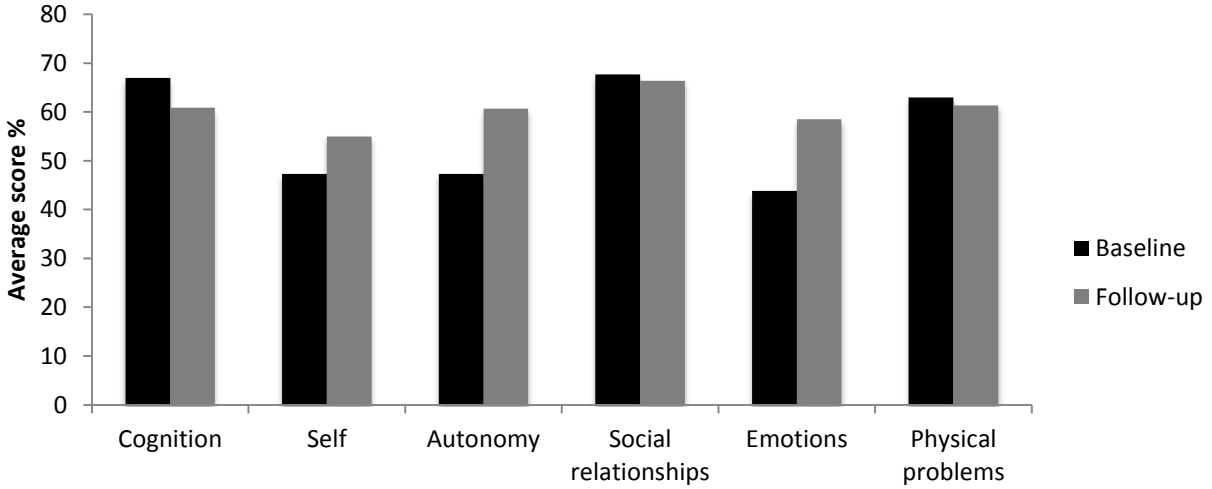


n = 2259

IRMA - feasibility study results



Total number of patients recruited by clinical setting



Average QOLIBRI domain scores at inpatient baseline and clinic / community follow-up

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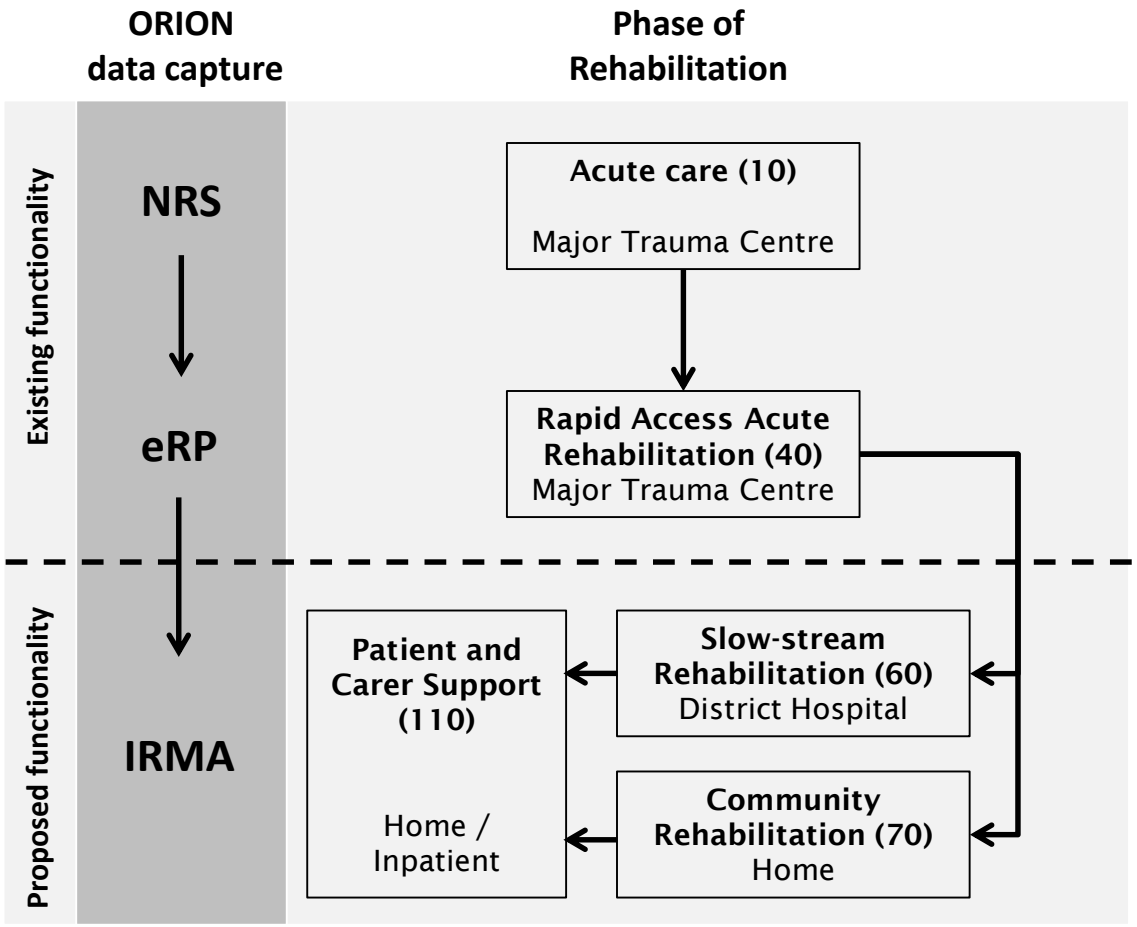

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