



Overcoming key data sharing challenges for research

NHS-HE Forum 18th November 2015

Michael Abtar



Agenda

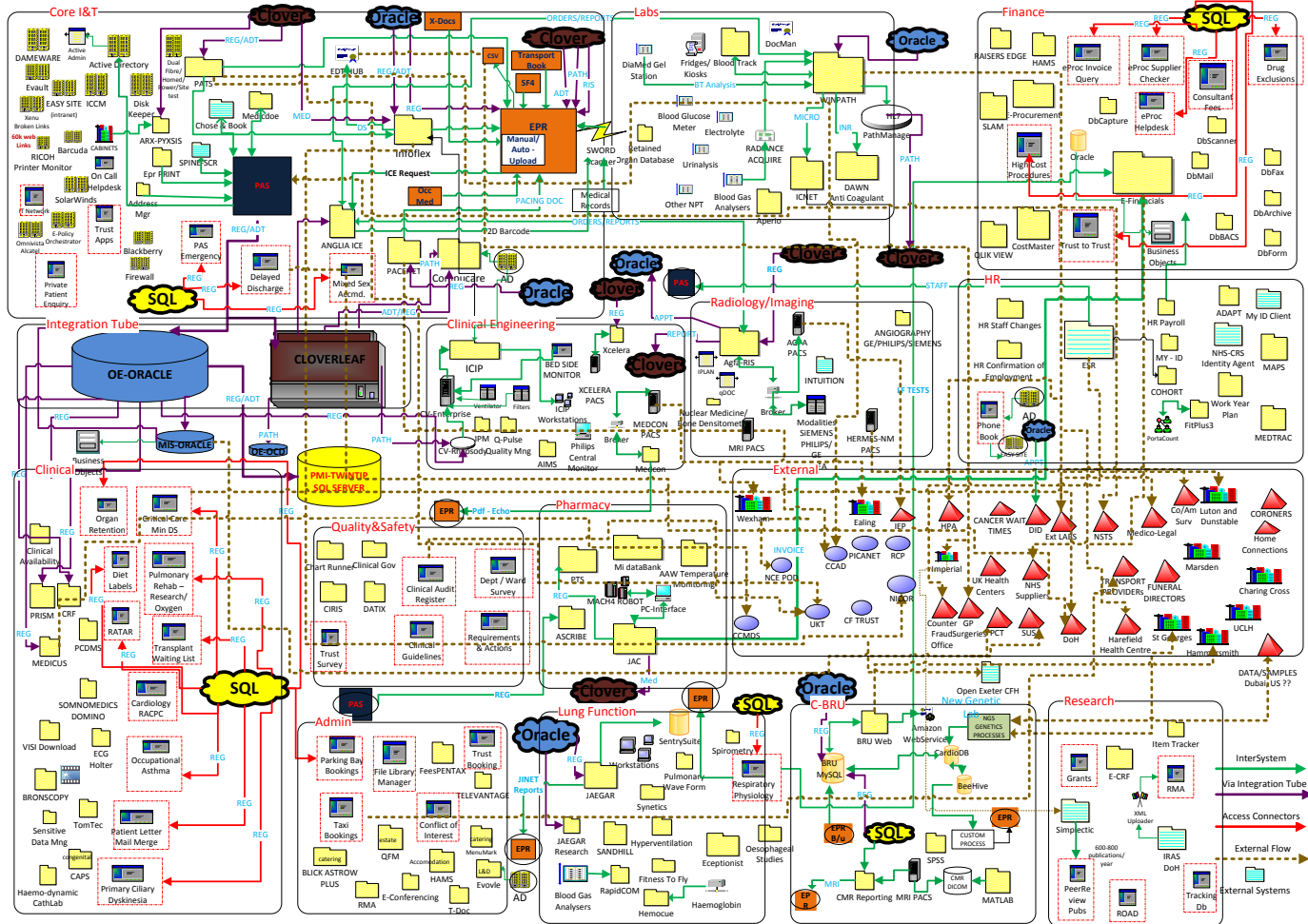
- A closer look at Big Data and IG
- The NIHR-HIC and section 251
- There has to be a smarter approach



“Big Data” IG challenges within Data Warehousing

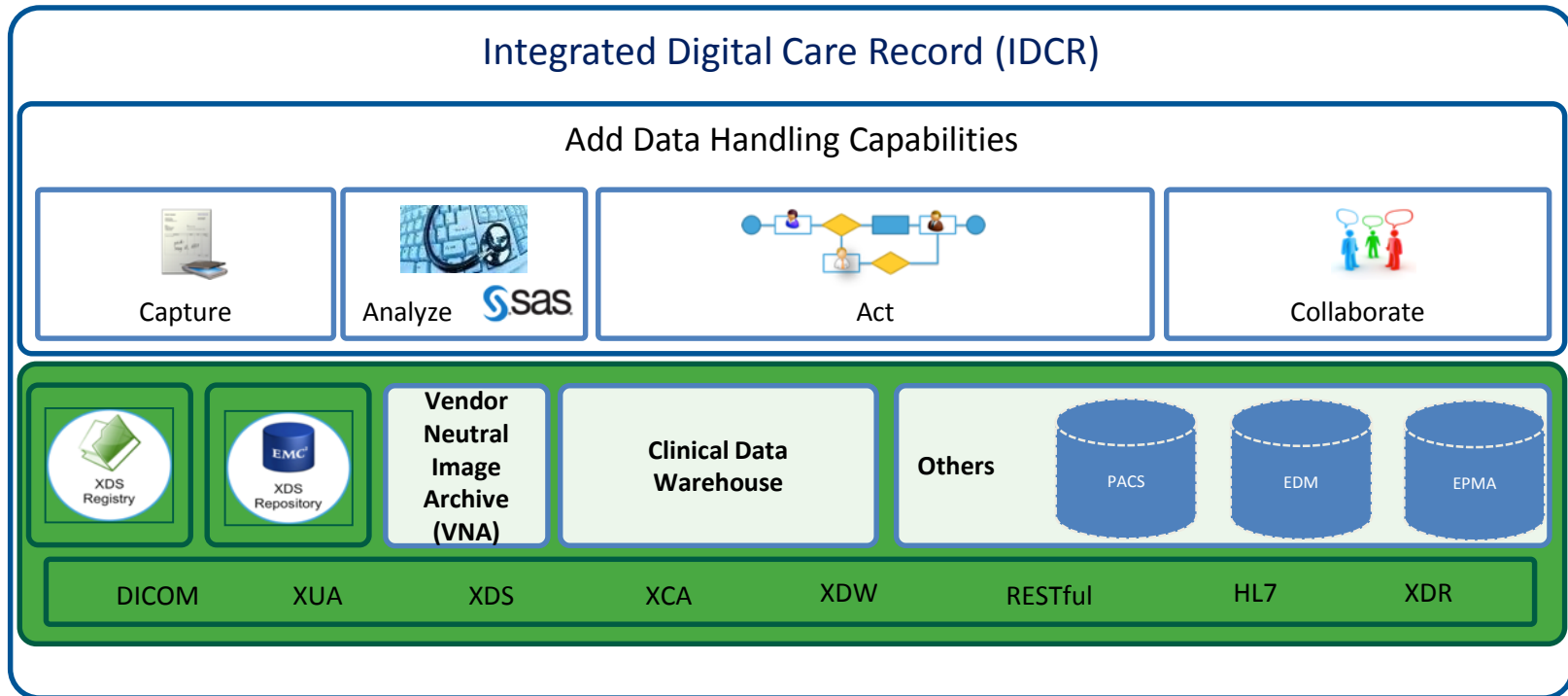


Data Data Everywhere



The “Big Data” Challenge

A vision for a Single Information Platform



Operational Systems



SAS Data Management

- Profile
- Data Quality
- Standardise
- Integrate
- ETL

Clinical Data Warehouse

Timely

Accurate

Secure

Accessible

SAS Visual Analytics

- Dashboards
- Web Portal
- Exploration
- Reporting

SAS Data Mining

- Predictive modelling
- Segmentation /Cohort
- Association analysis
- Sequence of Events

SAS Text Analytics

- Search, Classify
- ICD10 & SNOMED Decode
- Interpret, Analyse



Unstructured Data

*Data Stewards,
Data Managers*

*Data Miners, Clinical
Analysts, Researchers*

The Power of “Big Data”

- 95% of Trust data – 900,000,000 facts on >1m patients - \approx 5tb
- Single view of the patient across multiple systems
- Immediately identify patient cohorts for research
- Interrogate unstructured data – clinic letters, MDTs
- Visual performance dashboards – capacities, performance against target
- Patient and procedure level costing, referrals management, predictive ICU bed stays, patient pathway analysis, predictive high cost patients, cancelled operations, diagnosis vs outcomes



Drive Performance and Strategic Direction for Trust

IG Challenges within the CDW



Innovation
Development
Research
Strategy

Data Governance
Data Quality
Access Controls

Data governance is like going to the dentist:
Everyone has to do it - but few people really enjoy the process.

Access Considerations

- Primary use of the data – Direct patient care
- Secondary use
 - Research
 - Mandatory audit and reporting
 - Service Evaluation
 - Corporate

The Difficult Areas

- Native access to data source – is this appropriate
- Dual role clinician and researcher
- Cloud vs hosted - EU/US Safe Harbour



Anonymisation

- Sensitive and confidential data items are items which can be used to uniquely identify a person.
- In order to protect personal privacy, free access cannot be given to data which can be used to identify an individual.
- Sensitive data items include;
 - Name
 - Address
 - Date of Birth
 - NI Number
 - NHS Number
 - Hospital number
 - NOK
- Items are included even if they can only be used in combination with other items, to identify an individual.

How do we anonymise

1. Minimise the number of tables containing sensitive data items

- Only the Address and Patient_S tables will contain sensitive data items

2. Protect those tables with database security

- Although SAS metadata provides security, database security can be used to restrict access to the data from all tool sets, not only the SAS tool set.

3. Provide a “single view of the patient” through non-intelligent surrogate keys

- Providing a non-intelligent key (not related to any existing source system key) globally across all tables in the CDW, provides a powerful “single view of the patient”.
- Placing the Intelligent and Non-Intelligent keys only on the Patient_S table provides the ability to reference individuals, but only by those with access to sensitive data.



Rising to Dame Sally Davies' Challenge

Cambridge University Hospitals **NHS**
NHS Foundation Trust

Oxford University Hospitals **NHS**
NHS Trust



Imperial College Healthcare **NHS**
NHS Trust



Guy's and St Thomas' **NHS**
NHS Foundation Trust



5 themes

- acute coronary syndromes
- ovarian cancer
- hepatitis
- renal transplantation
- and **intensive care**



Section 251 for Linking HES, SUS & ONS Data

- Plan your exit strategy
- Ensure robust communications strategy for fair processing – consider social media, websites, animations, posters, local radio etc
- Do every thing that is reasonably practicable to notify data subjects (i.e. patient groups, community groups, voluntary sector organisations etc)
- Anonymisation (ensure compliance with ISB 1523



We view information governance and technology as being enablers for better and more integrated care.



Recently worked with



We help to bridge the gap through

- providing clear and concise advice
- making proportionate recommendations
- implementing pragmatic solutions



Michael Abtar

Mob: 07463 808 486

Email: michael@ig-smart.com

Twitter: @ig_smart

www.ig-smart.com

