Digital Curation and Health Informatics

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Health Informatics

- Electronic Patient Record
- Analytical Data Warehouse
- Hospital and GP systems for operational support to Patient Care
- Management Support
- Research Support
The Connecting for Health Vision

NATIONAL SPINE: patient demographics; OP booking broker; summary patient record

Patient demographics  OP Booking  Summary patient record
The Current National Situation

Acute Trust1
Acute Trust2
GP1
GP2
Patient Care

National Statistics
Office of Census and Surveys (OCS)
Department of Health

Disease Registries
Cancer
(Diabetes)
(Cardiovascular Disease)
(Child Health)

GPRD
GP Research

Little or no electronic data transfer between different areas of activity

Clinical Trials Units (CTUs)
MRC
Oxford
Cambridge
Newcastle
Southampton
Leeds
etc
## The Royal Marsden Clinical Information Systems

<table>
<thead>
<tr>
<th>System</th>
<th>Functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Administration (PAS)</td>
<td>Patient Master Index; Inpatient admissions; Outpatient appointments</td>
</tr>
<tr>
<td>Laboratory</td>
<td>Clinical Chemistry; Haematology; Histopathology; Cytology; Microbiology; Blood bank</td>
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<tr>
<td>Theatre</td>
<td>Scheduling; Reports</td>
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<tr>
<td>Radiotherapy</td>
<td>Scheduling; Summaries</td>
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<tr>
<td>Pharmacy</td>
<td>IV Chemotherapy manufacturing/ administration/ scheduling; dispensed drugs; ward drugs;</td>
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<tr>
<td>Imaging</td>
<td>X-ray, CT, NMR, Nuclear Medicine scheduling/reports; PACS</td>
</tr>
<tr>
<td>Electronic Patient Record</td>
<td>Patient case notes; clinical correspondence; electronic records</td>
</tr>
</tbody>
</table>

**Management Information Data Warehouse**

**Clinical Research/Audit Support System**

**Patient Care Systems**
Data Curation Issues

- The known vs. the unknown
- Development environment/culture
- Service vs. research continuum
- Service level
- Security and confidentiality
- Systems/data architecture
- Data retrieval/analysis
Data Curation Service vs. Research Continuum

1. Pure service e.g. e-mail provision
2. Data management specific to subject areas
3. Informatics research specific to subject areas
4. Computer science
Service Level

• Institutional vs. Individual responsibility
• Internal users
• External users
• Unanswereded technical issues?
Security and Confidentiality

- Secure access
- Patient vs. community view
- Information Governance
- Data interchange protocols (Caldicott)
- Data anonymisation
Systems/Data Architecture

- Requirements
- Infrastructure
- Internal users
- External users
- Unanswered technical issues?
Architecture?

Secure environment

Petabyte Data Store

SAN

High Speed WAN

UCL Departments

Institution wide data storage and backup service

Local Processing
CHIME

Healthcare Informatics Research

Data Curation?

Chronic Disease Management
MRC Centre for Child Heath Epidemiology

Problem Areas
- Records linkage to National Datasets
- Data anonymisation
- Information Governance
- Wide area security
- Records Architecture (CHIME)

Institute of Child Health
MRC Centre of Epidemiology for Child health
Highly Confidential Data
Fort Institution

NHS

UCL SAN