RESULTS OF HOSPITAL SURVEY

n=37

Georges De Moor
EuroRec, Ghent University
Which of the following best describes your organisation?

- Academic centre: 30
- Hospital centre: 6
- Other: 1
Assuming that applicable regulatory, ethical, legal, data privacy and personal data protection requirements are fully met, how favorable would your organisation be to re-use EHR patient-level data for clinical research purposes?
Considering that the EHR4CR Institute will be responsible for accrediting participating organisations, and for certifying their products and services according to the EHR4CR highest quality standards and requirements, how does this influence your perception of the reliability, robustness, and trustworthiness of the EHR4CR platform and services?
How confident are you that the EHR4CR platform and the re-use of EHR patient-level data will significantly improve the efficiency of clinical trial processes within your organisation (i.e. significant reduction in time and costs, less administrative burden, enhanced protocol feasibility assessment, faster patient identification and recruitment, more efficient study conduct and reporting of serious adverse event, enabling a greater participation in more clinical trials)?

![Bar chart showing confidence levels]

- Confident: 14
- Somewhat confident: 15
- Somewhat unsure: 4
- Unsure: 4

Electronic Health Records for Clinical Research
Which category best describes your organisation regarding the adoption of new technological value-added platforms and services?

- Early adopter: 27
- Late adopter: 10
How would you describe the current level of interest within your organisation for using EHR4CR services?
How would you describe the current level of readiness (human, technological) within your organisation for using EHR4CR services?

- High: 14
- Medium: 17
- Low: 6
Is there a single Electronic Health Record System (EHR)/Electronical Medical Record (EMR) that holds most of the medical data of a patient (excluding administrative data and appointment scheduling) that is available in the hospital?

![Bar chart showing responses]

- Yes: 28
- No, different information silos do exist in the hospital: 9
Do you use one or more commercial EHR/EMR solutions?

<table>
<thead>
<tr>
<th></th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13</td>
</tr>
<tr>
<td>No</td>
<td>24</td>
</tr>
</tbody>
</table>

Electronic Health Records for Clinical Research
Please approximate the % of the medical data coded in the EHR/EMR
Please approximate the % of the physicians in the hospital using the system regularly.

- <10%: 3
- <40%: 6
- 40% - 70%: 4
- >70%: 21
<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Lab reports</th>
<th>Medication</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dutch Hospital Data, EPCC</td>
<td>LOINC</td>
<td>ATC</td>
<td>HPO</td>
</tr>
<tr>
<td>PMSI</td>
<td>Lauris</td>
<td>probably MedDra in the future</td>
<td>OPCS</td>
</tr>
<tr>
<td>ICD 10</td>
<td>LOINC, Bulgarian National Health Insurance Fund (NHIF) coding system</td>
<td></td>
<td>ICD9 CM for procedures, Clinical pathways, Integrated system for Natural Language processing of clinical texts (Past History, Current Status, External Lab results, Medication, Discharge Letters)</td>
</tr>
<tr>
<td>ICD, ICPC, NANDA, SNOMED</td>
<td>SNOMED</td>
<td>FDB</td>
<td>Loinc</td>
</tr>
<tr>
<td>ICD-10-GM</td>
<td>HL7 version 3</td>
<td>CDAR2</td>
<td>ICPM (German OPS 301)</td>
</tr>
<tr>
<td>ICD9</td>
<td>Dx Care</td>
<td>Dx Care</td>
<td>SNOMED/TNM</td>
</tr>
<tr>
<td>ICD9-CM</td>
<td>NABM (Nomenclature des Actes de Biologie Médicales) French National Health Insurance</td>
<td></td>
<td>SNOMED CT for anatomical pathology diagnosis</td>
</tr>
<tr>
<td>SIM-10</td>
<td></td>
<td></td>
<td>LPP (French Nomenclature for Medical Devices)</td>
</tr>
<tr>
<td>national coding system (DOT)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Do you already have one or more Clinical Data Warehouses (CDW) with exported data from the EHR?

One general CDW not geared to specific projects nor to clinical research exploitation.

A group do regularly warehouse data extracted from EHR for internal use, and on demand.

National Registry for Endocrine Pituitary and Suprarenal tumors including more than 3500 patients;

Casemix (Oracle); Ascribe CDR

For Biobank purposes wide range on CDW plans - some data like diagnoses already there

SAP HANA

i2b2

i2b2 (only for cardiology and oncology)

ICD9 inpatient clinical diagnostics, clinical procedures, laboratory reports, demographic data

I don't know

Microsoft SQL Server based, TENALEA

Oracle with a QlikView front end
Do you have a central organisation to manage clinical trials?

- Yes: 27
- No: 9
If yes, is there a staff specifically dedicated to recruiting patients (trial nurses, dedicated physicians)?
Are there specific tools (applications, search tools or databases) (apart from the standard EHR interfaces) used for recruiting patients?

- Each clinic has paper records of its patients
- ALEA
- ALEA-system (FormsVision)
- Patient electronic records, Dx Care being gradually implemented from this year on. DIAMs may be used as well (patient hospitalization reports)
- Tumor conferences, participation of trained staff
- MS Healthvault
- MACRO
- Current databases and BI tools organisation wide
- Newspaper advertisement, online recruiting
- Internally developed tool
- Own database
Are there specific tools (applications, search tools or databases) for testing protocol feasibility?

- Yes: 4
- No: 33

ALEA
UKCTG
internally developed tool
Regarding the need for potential EHR4CR training within your organisation, which format would be most suitable?

- Face-to-Face: 12
- Online tutorials: 7
- Webinars: 7
- Distance learning: 4
- EHR4CR Help desk: 0
Any additional comments or suggestions you would like to share

Do you have a central organisation to manage clinical trials? Yes but the central Institution does not manage all clinical Trials. If yes, is there a staff specifically dedicated to recruiting patients (trial nurses, dedicated physicians)? That depends on the clinical department and whether the director employs dedicated trial nurses/physicians.

In view of the budgetary restrictions in France (in particular for the health service), the introduction of any new system is unlikely.

We relate these issues to Biobanking but let's continue to understand more.

Time needed to develop connectors is significant compared to time spent for database setup even when standard rules are used. Probably the main issue for interoperability will be time to develop. Connectors and high level of programming shells are necessary for data managers or IT developers with clinical data knowledge.

We operate data repository, that currently contains more than 37.9 million pseudonymised Outpatient records (Reimbursement requests) submitted to the National Health Insurance Fund (NHIF) in 2013 for more than 5 million patients, including 436,000 diabetic ones. The prototype, integrating language technologies and business intelligence tools, enables discovery of new knowledge in the NHIF repository for 2013.

In Bulgaria the Outpatient records are produced by the General Practitioners and the Specialists from Ambulatory Care for every contact with the patient. The Outpatient records are semi-structured files with predefined XML-format. Despite their primary accounting purpose they contain sufficient text explanations to summarise the case and to motivate the requested reimbursement. The Case history is presented in the "Anamnesis" as free text with description of previous treatments, including drugs taken by the patient beyond the ones that are to be reimbursed by the Insurance Fund. Family history and Risk factors are often included in the Anamnesis of diabetic patients. "Patient status" is another section containing free text. It includes a summary of the patient state, symptoms, syndromes, patients’ height and weight, body mass index, blood pressure and other clinical descriptions. The values of "Clinical tests and lab data" are enumerated in arbitrary order as free text in another section. A special section is dedicated to the "Prescribed treatment". An Outpatient record might include about 160 tags. The average length of the files is about 1 Mb.