Barriers to the Reuse of Routinely Recorded Clinical Data – A Field Report –

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Plenty of data available

"Data where?"
instead of
Data warehouse

Data existence ≠
Data access

THE GOOD THE BAD AND THE UGLY
Introduction

What do we have?
- Massive volumes of data are being stored => huge potential benefit from reuse! But: challenging in practice

What do we need?
- Quality indicators, required by government; typically require data from several sources

Goal
- Compute indicators automatically & in real-time, based on previously collected data
78% 😊

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Top Hotels

A recent review

“Great hotel in CPH”
★★★★★ Reviewed August 18, 2013
Johnny P
Field study

- **Setting:** GIOCA = Gastro-Intestinal Oncology Centre Amsterdam: patient centered, rapid diagnosis

- **Quality Indicators:** DSCA = Dutch Surgical Colorectal Audit

- **Goal:** report on barriers encountered attempting to gather source data required to compute a set of indicators for GIOCA
Set of four quality indicators. E.g.:

**Number of examined lymph nodes after resection (process indicator)**

**Numerator:** Number of patients who had 10 or more lymph nodes examined after resection of a primary colon carcinoma

**Denominator:** Number of patients who had resection of primary colon carcinoma

**Exclusion criteria:** Previous radiotherapy and recurrent colon carcinomas
Cooperation with GIOCA and ICT services

Three phases:

1. Identification of original sources of the required “raw” data elements
2. Data retrieval from the various databases
3. Analysis of obtained data and identification of quality issues that impeded its reuse
Approach – III

- Galster’s Framework (MIE 2012)
- “Why is clinical information not reused?”

A The information is not available when or where it is needed.

B The information is present, but usage of the existing source is prohibited.

C The information is present but not routinely used in its available form for ...
   1) technical reasons
   2) political reasons
   3) quality reasons

D The information is apparently present, but in the specific situation it is considered inadequate due to ...
   1) insufficient reliability
   2) inadequate relevance

- technical
- organisational
- legal
- medical
### Results – Required data

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Source System</th>
<th>Indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgical procedure: date, type, anatomic location</td>
<td>Surgical procedure system, procedure register</td>
<td>I1, I2, I3, I4</td>
</tr>
<tr>
<td>Diagnosis: anatomic location, type (primary, recurrent)</td>
<td>Diagnosis register</td>
<td>I1, I2, I3, I4</td>
</tr>
<tr>
<td>Radiotherapy: date</td>
<td>Radiotherapy system, appointment register, Procedure register</td>
<td>I1</td>
</tr>
<tr>
<td>Lymph node examination: date, number of examined lymph nodes (in pathology report)</td>
<td>Nationwide histopathology and cytopathology data archive</td>
<td>I1</td>
</tr>
<tr>
<td>Surgical procedure submitted to Dutch Surgical Colorectal Audit (DSCA)</td>
<td>National register</td>
<td>I2</td>
</tr>
<tr>
<td>Preoperative multidisciplinary meetings: date</td>
<td>EHR, appointment register</td>
<td>I3</td>
</tr>
<tr>
<td>Admission: admission and discharge date</td>
<td>Admission register</td>
<td>I4</td>
</tr>
</tbody>
</table>
Results – Barriers I

A
The information is not available when or where it is needed

- Hinderred access to data sources (technical and organizational reasons), second phase

B
The information is present, but usage of the existing source is prohibited

- Patient Numbers (legal reasons), third phase

C
The information is present but not routinely used in its available form

- Organizational / Cultural Barriers (organizational reasons), first and second phase

1) technical reasons
2) political reasons
3) quality reasons

...
Results – Barriers II

Data present but not routinely used in its available form

- Insufficient quality (organisational reasons), third phase
  - Incompleteness on database or element level
  - Incorrectness
  - Lack of interlinking of data in various sources
  - Missing provenance of data
  - Lack of inside-knowledge of “meaning of data”

- Problem of selecting patients in one system and querying their data in another system (technical reasons), third phase

Data apparently present, but in the specific situation it is considered inadequate
Discussion

- All required data available in a digital format
  - Tedious process to receive requested data
  - Data quality insufficient
- Most problems in Category C, “Data present but not routinely used in its available form”
- Newly launched research data warehouse + GIOCA data sources = solid basis to compute quality indicators
Recommendations

- Ensure availability of data and accessibility of data sources
- Ensure patients’ interests, privacy and security while allowing for re-use
- Set-up a reuse-friendly organisation and culture
- Increase data quality
- Allow for cross-database querying
Conclusions

- The data is out there, somewhere
- Policies & procedures for finding and getting data are lacking
- Data can be found, but also
  - Missing items
  - Missing data elements
  - Missing relationships to link data sources
- There are many barriers to be overcome
But barriers can be useful...