Addressing challenges to open science: Data sharing, replication, and robustness of evidence from real world data

The case of Catalonia

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Overview and key figures of the Catalan healthcare system

- National Health Service
- Universal coverage and free at the point of use
- Funded by taxes
- Spending 9.1% of Catalan GDP
- Multi-provider system
- Relationship between Catalan Health Service (public insurance) and providers contractually full accounted (health objectives, activity, economic amount, rate (pricing), invoicing system, evaluation system). Providers have the duty to share information with both CatSalut and other providers
- Population: 7,500,000
- Life expectancy: 82.40 years
- Infant mortality rate: 2.83 / 1,000
Overview and key figures of the Catalan healthcare system

- 46 million primary care visits per year
- 760,000 hospital discharges per year
- 60 million electronic health record documents
- 100,000 convalescence discharges per year
- 2.7 million visits to emergency units
- 140 million electronic prescriptions per year

How healthcare IT landscape is organized

- 95% of primary care centers use the same IT system (eCAP)
- Hospital IT systems diversity is much greater
- Since 2005 Shared Electronic Health Record (HC3) project. Created to share information between the different IT systems, 100% of primary care centers and hospitals connected to it
- Currently sharing 60 million documents, both structured and semi-structured data:
  - Diagnosis
  - Clinical Procedures
  - Lab tests
  - Medical image (100% digitalized) and non medical image
  - Drug prescription (100% digitalized)
  - Reports of discharges (mainly PDF documents)
  - Etc.
How healthcare IT landscape is organized

• Universal healthcare card with unique personal identifier, operating since 2002
• It has to be used in all health contacts
• This allows us to easily link all datasets

4 Areas of application of health information

- **Clinical practice**
  - Improved diagnostic decisions
  - Better coordination between healthcare levels

- **Healthcare planning**
  - More capacity for planning and resource allocation
  - Planning of resources according to the needs of the population
  - Improved healthcare quality, effectiveness and efficiency
  - Promoting transparency, accountability and open data

- **Self-care**
  - Access to the personal health folder (which includes the medication plan, vaccinations, results of medical tests) promotes self-care and improves quality of life

- **Research**
  - Improved research quality, at lower cost and shorter times
  - Increased capacity to obtain competitive funds
  - Acceleration of innovation
  - Attraction of talent, generation of economic activity and job creation
What is the impact of anticoagulants consumption in the intracranial hemorrhage hospitalization rate?

- Currently, in Catalonia, there are 140,000 people taking anticoagulants.
- In the last 7 years, there has not been an increase in the intracranial hemorrhage hospitalization rate.

- To do this study with traditional methods, it would take around 10 years.
- Through the registers and information systems available in Catalonia, and relating and analyzing this information, it is possible to solve this research question in less than a year.
Healthcare planning

• More capacity for planning and resource allocation
• Planning of resources according to the needs of the population
• Improved healthcare quality, effectiveness and efficiency
• Promoting transparency, accountability and open data

Population 7,695,503

Groupers

Classification

Stratification

ID

ACG, DCG, CRG, GMA

% population | Mortality rate (per 100) | Mean PC visits | Emergency hospitalizations rate (per 100) | Mean number of drugs used
---|---|---|---|---
5% | 12,3 | 22,8 | 59,7 | 13,4
15% | 1,1 | 12,8 | 6,7 | 8,0
30% | 0,1 | 6,7 | 2,4 | 3,6
50% | 0,1 | 1,8 | 0,5 | 0,9
Healthcare planning

- More capacity for planning and resource allocation
- Planning of resources according to the needs of the population
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**% People attended at mental health centres. Catalonia, 2015**

<table>
<thead>
<tr>
<th>Category</th>
<th>Women</th>
<th>Men</th>
</tr>
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<tbody>
<tr>
<td>UE allowance expired, RMI/RAI</td>
<td>4.6%</td>
<td>6.6%</td>
</tr>
<tr>
<td>UE allowance</td>
<td>3.9%</td>
<td></td>
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<tr>
<td>UE benefit expired</td>
<td>3.5%</td>
<td></td>
</tr>
<tr>
<td>UE benefit</td>
<td>3.4%</td>
<td></td>
</tr>
<tr>
<td>Income &lt;18,000€</td>
<td>2.7%</td>
<td></td>
</tr>
<tr>
<td>Income 18,000€ - 100,000€</td>
<td>1.7%</td>
<td></td>
</tr>
<tr>
<td>Income &gt;100,000€</td>
<td>1.2%</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2.6%</td>
<td>2.6%</td>
</tr>
</tbody>
</table>

*Women: x 9 women for 10 men*

Since 2012: hospitals, primary care, long-term care, mental health care, public health, territory, emergencies, advanced health training

60 outcomes indicators per topic
Healthcare planning

- More capacity for planning and resource allocation
- Planning of resources according to the needs of the population
- Improved healthcare quality, effectiveness and efficiency
- Promoting transparency, accountability and open data

### Incidence of central venous line bacteremia in hospitals of 500 or more beds, 2009-2017

![Graph showing incidence of central venous line bacteremia over the years](image)

**Definitions**

- Incidence = Number of bacteremia by year × 1.000 / length of stay
- Hospital mortality, mean length of stay, satisfacción, c-sections, etc.

### Indicators adjusted by age, sex and risk

<table>
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<tr>
<th>Hospital</th>
<th>P25</th>
<th>P75</th>
<th>Mean</th>
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<td>74.5</td>
<td>83.5</td>
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<tr>
<td>Hospital Clinic</td>
<td>63.2</td>
<td>68.2</td>
<td>65.1</td>
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<tr>
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<td>55.8</td>
<td>60.8</td>
<td>58.0</td>
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<tr>
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<tr>
<td>Hospital Verge de la Cinta</td>
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<td>34.0</td>
<td>31.0</td>
</tr>
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<td>Centre Hospitalari (Atiballs)</td>
<td>75.5</td>
<td>83.5</td>
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<td>65.1</td>
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<td>Hospital de Terrassa</td>
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<td>Hospital d’Agullers de Cà</td>
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<td>Hospital de Malamare</td>
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<td>79.0</td>
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<td>CSIC, de l’Hospital Sant Alfonso</td>
<td>79.2</td>
<td>84.0</td>
<td>80.5</td>
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</tbody>
</table>

**Experts and Scientific Societies**

- Expert committee
- Scientific societies
- Professionals
Evaluation of the concentration of digestive oncology surgery

Background:
- Variability of results observed in an audit of rectal cancer of the period 2005-2007
- Monitoring of intrahospital mortality of complex surgical procedures in cancer from 2005 to 2012
- Dispersion of the activity
- Evidence about the relationship between volume and results

Intervention:
- Centralization of complex procedures in an orderly manner
- Identification of esophageal, pancreatic, liver and rectal metastases (among others) as areas of high specialization, following the criteria of volume of cases and procedures that require a high level of expertise
- The 21/2012 instruction of CatSalut came into effect in January 2012

30-day mortality rate
• Access to the personal health folder (which includes the medication plan, vaccinations, results of medical tests) promotes self-care and improves quality of life

Self-care

Ratio of professionals using e-consulta in a PCT

Ratio of patients that use e-consulta in a PCT
Exposure to medicines among patients admitted for hip fracture and the case-fatality rate at 1 year: A longitudinal study

Exposure to medicines among patients admitted for hip fracture and the case-fatality rate at 1 year: a longitudinal study.

Abstract

PURPOSE: To describe the demographic and clinical characteristics and the pre-fracture exposure to medicines of patients admitted for a hip fracture, and to explore their association with fatal outcome 1 year after the fracture.

METHODS: All patients 65 years old admitted for a hip fracture in a tertiary hospital in Barcelona between January 1 and December 31, 2007 were included. Data on patients’ clinical characteristics before and during hospital admission and on pre-fracture exposure to medicines were collected from the clinical records. One-year mortality was checked by approaching the patients and their families and was cross-checked with the national mortality statistics database. A Cox proportional hazards analysis was carried out.

RESULTS: Four hundred and fifty-six patients [mean age 62.9 (7.2) years, 73.5% female], were admitted with hip fracture during the study period. Almost 80% of the patients (363/796) had three or more associated conditions, and 417 patients received pre-fracture treatment with five or more drugs. The case-fatality rate during hospital admission was 4.6% (21 patients). One hundred and seven patients died within 1 year (23.5%). Advanced age, male gender, two or more associated chronic conditions, cancer, severe cognitive impairment, and treatment with opiates before fracture were significantly associated with the risk of dying. An inverse association was recorded between mortality and pre-hospital exposure to medicines for osteoporosis.

CONCLUSIONS: 1. A quarter of patients admitted for hip fracture died within 1 year after the fracture. Exposure to opiates before hip fracture was associated with an increased 1-year death rate, whereas treatment with drugs for osteoporosis was associated with a decrease in death rate. These results should be confirmed in studies with detailed prospective collection of information on exposure to medicines.

The study “Hip fracture in population older than 65 years” has been published as part of the annual report of the Results Center (“Central de Resultats”). Study carried out reusing information

Sample: 8,172 patients 65 years or older admitted for hip fracture

Sources of information: pharmaceutical information, hospital discharge records, mortality data, etc.

Information anonymized by AQuAS

The one year mortality rate was 24.5% (CI amplitude: 1.9%)
Improved research quality, at lower cost and shorter times

Increased capacity to obtain competitive funds

Acceleration of innovation

Attraction of talent, generation of economic activity and job creation

From electronic health records with patients’ informed consent. Difficult to ensure the principle of proportionality of the information.

Anonymized information coming from administrative registers. Principle of proportionality of information is ensured.

Information access

Sample size

456 patients

8,172 patients

Mortality rate

24.6% with a confidence interval 20.6% to 28.6% (CI amplitude: 7.9%)

24.5% with a confidence interval 23.6% to 25.5% (CI amplitude: 1.9%)

Time to carry out the study

More than 2 years

Few weeks/months

Time to replicate the study

Repeat the study from the beginning

Research

AQuAS: Institutional leadership, overall strategy

Public healthcare centers, public universities, CERCA centers

Code of ethics (respect to people, justice, efficiency, transparency, responsible research)

Management of data security and legal issues
New datasets roadmap (TBD)

Available clinical activity information

Available pharmaceutical information

More information to be included in the mid and long-term

- Genomics
- Proteomics
- Clinical trials
- Emergency activity

Research

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Available specific information

- Diagnosis in primary care, hospital, social health and mental health
- Life styles
- Morbidity (risk factors)
- Clinical procedures
- Mortality

- Drugs prescription
- Drugs dispensation

- Radiological image
- Non radiological image
- Results of lab tests
- Specific registries of pathologies: alzheimer disease, cancer, heart attack, stroke, etc.

http://aquas.gencat.cat

Agència de Qualitat i Avaluació Sanitàries de Catalunya
Generalitat de Catalunya
Departament de Salut