“Living up to Improved Performance”
The role of international projects

Britta Zander
Technical University Berlin (TUB), Germany

Based on work done together with Reinhard Busse
and all EuroREACH partners
Introduction

• EuroREACH (2010-2013): aimed to enhance cross-country comparisons of health system performance

→ by better enabling access and use of health care data for comparative research on efficiency, equity and quality of health systems

Why is this needed?

• growing number of national and international organizations spend money to collect and provide health data with different objectives

• users expect to find access to data, which are patient-level, longitudinal and detailed enough to allowing analysis on individual diseases, health care utilization, costs and quality across sectors and performance dimensions
Questions!? 

- How much do we really know about research projects, their results, success, quality and availability of produced data?

- How much do funders or governments really know about under-researched areas when it comes to research funding?

→ It is ever more difficult to maintain a global view of what is available/accessible/reliable/comparable

Inventory for disease-oriented EU research projects
Step 1: Inventory of disease-oriented EU research projects

Inclusion criteria:
- comparative cross-country projects/initiatives;
- using individual-level data;
- one or several chronic conditions (asthma/COPD, cancer, cvd, diabetes, mental health);
- quality, efficiency and/or equity;
- conducted between 2000 and 2012

Where/how did we find them?
- European Commission Public Health Projects Database (filtered by topic and year)
- Cordis (filtered by FP (5, 6 and 7) and keywords)
- a small share of projects were recommended by public health experts

→ Selection of 48 projects reviewed one by one according to inclusion criteria
a total of 48 were selected
- Clearly under-represented: primary care, mental health and equity
the health data navigator is live:  
www.healthdatanavigator.eu
### Table 2: Projects providing individual-level data information; classified by disease areas

<table>
<thead>
<tr>
<th>Disease-specific</th>
<th>Non-disease-specific</th>
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<tbody>
<tr>
<td>Ashma</td>
<td>Cancer</td>
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<tr>
<td>Cardiovascular</td>
<td>Diseases</td>
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<tr>
<td>Diseases</td>
<td>Diabetes</td>
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<tr>
<td>Mental Health</td>
<td>Various Diseases</td>
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</table>

(Allows disaggregation into disease entities)

#### Population-based

<table>
<thead>
<tr>
<th>Project</th>
<th>Description</th>
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<tbody>
<tr>
<td>ISAAC</td>
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<td>ISARE</td>
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<td>SHARE</td>
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<td>GA2LEN</td>
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<td>WMH</td>
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<td>Survey</td>
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<td>Initiative</td>
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#### Patient-based

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<td>Initiative</td>
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</table>

#### Access sectors

- **Access** sectors:
  - EuroCARE Project
  - GA2LEN-PDCNAE
  - EPIC
  - MONICA
  - De-PLAN
  - WMH Survey Initiative

#### Within hospitals only

- **Within hospitals only**
  - ONCOPOOL
  - EuroDRG
  - EuroHOPE
  - EUPHORIC
  - OECD Study
  - EuroHBP
  - EuroHOPE
  - EPHORIC

#### Within primary care only

- **Within primary care only**
  - EUPhORIC
  - DuQue
  - EUPrimeCare
  - DuQue
EuroCARE
EUROpean Cancer Registry-based study on survival and care of cancer patients, was an epidemiology research project that had collected and analyzed survival data on patients diagnosed from 1978 to 1984 (EUROCare-1), from 1978 to 1989 (EUROCare-2), from 1983 to 1994 (EUROCare-3) and from 1988 to 2002 (EUROCare-4). The main aim of EUROCare-4 was to update survival of cancer patients in Europe and to detect timely substantial changes across regions and over time. EUROCare-5 (up to 2007) continued the activity of surveillance and the comparison between survival and care of cancer patients.

Governance
Funded through the BIOMED Programme of the European Community and by the “Europe against Cancer” program.

The EUROCare Co-ordinating Centre operates at the Department of Preventive and Predictive Medicine, Fondazione Istituto Nazionale per lo Studio e la Cura dei Tumori, while the database implementation and analyses are performed at the Cancer Epidemiology Unit and Data Analysis Centre, Istituto Superiore di Sanità, Rome.

Contact: Roberta De Angelis, Tel. +39.06.49904289, Email: roberta.deangelis@iss.it
Website: http://www.eurocare.it

Coverage
Data from 93 population-based Cancer Registries in 23 European countries (Austria, Belgium, Czech Republic, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Malta, Norway, Poland, Portugal, Slovenia, Spain, Sweden, Switzerland, The Netherlands, England, Northern Ireland, Scotland, Wales).

Analysis of survival of cancer patients by means of conventional and more innovative methods: e.g. cohort relative survival; period survival analysis to estimate survival of patients with recent diagnosis; mixture survival model to estimate the proportion of patients cured.

Survival data of adult patients, cross-classified according to cancer site, population, sex, age, and period of follow-up (1- to 5-year) - observed, expected and relative survival rates are given.

Comparison of cancer survival between Europe and USA will be made available. Until now survival of the EUROCare patients has been compared with patients included in the SEER network (http://seer.cancer.gov). This comparison will now be extended to the US registries of the NCR (National Cancer Registry).

Output and results
More than 100 published articles available on website (http://www.eurocare.it)

EUROCare-4: Accordingly, survival of European cancer patients varies markedly by country, region, age and sex. Relative excess risk of death is 28% higher in Eastern Europe than central Europe; the relative excess risk of death is much higher for patients of age 55–99 years than those of age 15–54 years.

EUROCare-5: Comparing diagnostic and therapeutic procedures for cancer patients in Italy with those in other European countries at high survival by means of high resolution studies (HR).

Important long-term outcomes (from the whole EUROCare project): Reduce inequalities in cancer care and survival across Europe and provide information and increase standards.

Increasing and promote the use of cancer survival registry data. The EUROCare results will be diffused among the medical, public health and scientific communities, to the public in general, to tumour patients and to health planners.

Access to data
Only access to EUROCare-3 (1990-1994) and EUROCare-4 (1995-1999) data sorted by cancer, population, age class, time from diagnosis, sex, output indicators possible.

Data quality
An algorithm assigned standardized sequence numbers to multiple cancers → only first malignant cancers were used to estimate relative survival from registry, year, sex and age-specific life tables. Age-adjusted and Europe-wide survival were also estimated.

Linkage
Linkage of cohort data from the outside possible to a limited extend (xls, txt) for EUROCare-3 (1990-1994) and EUROCare-4 (1995-1999).

Strengths and Weaknesses

Strengths:
- There exist related projects: CONCORD (http://www.ishtm.ac/eph/hcde/cancersurvival/research/concord/phase1.html),
- EUROCHIP (http://www.tumori.net/eurochip),
- HAEMACARE (http://www.haemacare.eu),
- RARECARE (http://www.rarecare.eu)
- Project process can be reconstructed by protocols.
Step 2: Overview of project objectives and methodologies

- Once we had the distribution across domains and care settings → what about the specific research design?

- Prioritized research fields vs. Gaps -> areas for future research
Step 2: Overview of project objectives and methodologies

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<th>Benchmark Hospital Performance</th>
<th>Comparing Health System Performance</th>
<th>Investigating conditions to disease monitoring</th>
<th>Investigating conditions in health ages</th>
<th>Equity (tackling inequality)</th>
<th>Patient needs and satisfaction with service</th>
<th>Improving quality of treatment</th>
<th>Developing/coll ecting indicators</th>
<th>Establishing networks</th>
<th>Assessment of Primary Care Models</th>
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Step 4: Gaps

1. What if data is not communicated?
   - User unfriendly, not updated, non-existent or incomplete websites
   - Lacking basic information on project background, methodology and results, even upon project completion

2. Still scarce data (despite the multitude of initiatives)

3. One of the major problems we identified is the issue of sustainability:
   - Once the projects have ended, it seems that no one really feels responsible to e.g. consistently update project websites.
   - Partly due to the time-limited construction of the projects and lack of continuous funding.
Little Experiment …

To illustrate the problematic communication situation of some of the projects, we focused on the number of published papers in major literature data bases, such as Pubmed and EMBASE (as of February 2014).

- We additionally compared project webpages to compare the list of publications we found.

Results of this search can be summarized as follows:

- Projects, not listing their publications at all, or very incomplete, but have (many) hits on PubMed and/or Embase (e.g. ISAAC, EPIC, GBD);

- Projects, listing many publications on their webpage, but have only few hits on PubMed and/or Embase (e.g. WHM Survey Initiative, ECRHS III);

- Projects with updated publication lists on their webpages as well as according hits on PubMed and/or Embase (e.g. Monica)
Conclusion

→ Already many projects, but partly overlapping (e.g. disease monitoring) and leaving visible gaps

→ in particular, investment is necessary for improving data on primary care, disparities in care utilisation, mental health, patient experiences, as well as costs of services and along pathways

→ Recommended to target the quality of care of several health conditions on different levels: e.g. hospitals, regions, countries; and ideally linking the results to cost information
Conclusion

→ **strong recommendation** to all projects is to scale their work for general public, in terms of data communication, which should be seen as part of their data management strategy, which means

→ to offer guidance instead of requiring expert knowledge from the user; and

→ to render the databases user friendly and address the needs of users instead of using websites as internal communication tools only
Thank you!

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