Research and data infrastructures: what does public health and health services research need?

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Subjects

1. Public health and health services research
2. Research infrastructures
3. Data infrastructures: national and European
4. Data protection and related issues
5. Judging public health and health services research on its merits
PUBLIC HEALTH AND HEALTH SERVICES RESEARCH
Scope of health services and public health research

**Health services research:**
- Relationships between demand for care and supply of care, as influenced by the structure and institutions of the health care system

**Public health research:**
- Influence of societal, psychological, biological and health care determinants of (population) health
Health services research

Supply of health care

Structure etiological institutions

Demand for care

Health care utilisation

Health (population)

Social influences

Biological / genetic influences

Psychological / behavioural influences

Public health research
Interaction between health care sector and research

Health care sector

Practical problem

Intermediary groups / stakeholders

Policy implications & Practical solutions

Research

Research questions

Hypotheses

Research design

Data(collection)

Analysis

Conclusions
Key elements of Public health and health services research

Double mission: Societal and scientific

- Applied and applicable
- Practice and policy orientation
- Multi- and interdisciplinary
- Public funding
RESEARCH INFRASTRUCTURE

Public health and health services research
Research infrastructures

- The ‘R&D’ of the health care sector
- Facilitating interdisciplinary research
- Creating conditions for knowledge utilization
- Research – practice/ policy networks
- Variety of organizational forms (compared to fundamental research)
Partnership programmes / co-creation

- Can be effective, especially when:
  - research users are involved from the start
  - Both sides respect each other's professional skills

But also:
- Time efforts required (e.g. align expectations, consensus)
- Difficult to balance competing agendas
- Power differences within the partnership
- Potential challenge of independence
- Co-creation between policy & other stakeholders difficult

Sources: Walter, Davies & Nutley, JHSR&P, 2003; Wehrens, 2013
Public health and health services research
Research infrastructures

DATA INFRASTRUCTURES
Data infrastructures – the example of health services research

Typical data sources

- Care registrations – electronic patient records
- (biobanks)
- Health interviews, health examination surveys
- Repeated cross-sections, panel studies, cohorts
- Claims data from health insurance

Opportunities and restrictions

- data linkage and pooling, trusted third parties, pseudonimisation
- validity of data: collected for other purposes, comparability
A national research infrastructure: NIVEL Primary Care Database

- Electronic medical record data extracted
- GP first point of contact with health care system for most problems;
- Dense network of services, covering all morbidity:
  - not only serious cases (cf hospital data or causes of death);
  - and not only reportable diseases (as in occupational health monitors).
- Routinely available and doctor assessed
- Epidemiological denominator is not a problem in countries with list system (UK, Italy, DK, NL), otherwise estimates
- Longitudinal
- Linkage to other data sources in primary and secondary care.
Linkage of geocoded data and individual health data: an example

Association between green space in the living environment and GP assessed health problems

- NIVEL Primary Care Database: morbidity in general practice
- Personal characteristics: survey data of practice populations
- Land use data in 1 and 3 km radius around centroid of 6 digit postal code

Maas et al. Morbidity is related to a green living environment. J Epidemiol Community Health, 2009
Linkage at individual level: an example

Health problems of adolescents and their educational career

- NIVEL Primary Care Database: GP consultations, health problems
- Municipal Basic Administration: income parents, household type, ethnicity
- Educational registration: secondary school diploma, level
- Statistics Netherlands as trusted third party

Uiters et al., The association between adolescents’ health and disparities in school career, manuscript in preparation
The European dimension to research and data infrastructures

Health systems research:
• From comparative case studies to Europe-wide studies
• Comparable health interview surveys
• Health care system characteristics
• Ecological studies
• Multilevel studies
Mackenbach & McKee: success of prevention policies in 43 countries

Interaction between structure of primary care and education on self-rated health

Hansen et al, Strength of primary care and individual health outcomes in Europe. Manuscript in preparation
## European research networks

### Differences with consortia in basic research

- Europe is the research laboratory
- Data collection, interpretation, implementation in all countries
- Not a combination of a few complementary centres of excellence

### Examples of research networks

- EUPHA – European Public Health Association
- HSR Europe – Health Services Research Europe
- EGPRN – European General Practice Research Network
- European Observatory for health Systems and Policies
- EHMA – European Health Management Association
European research: partnerships between research and policy

EU research agenda increasingly policy driven

**EC initiated**
- Horizon 2020
  - Excellent science, Industrial Leadership
- EIP (PPP on Active and Healthy Ageing)

**MS initiated**
- Joint Actions
- Joint Programming Initiatives (JPI)
  - Aiming at common strategic research agenda
- ERA-NET
  - Aiming at collaboration and alignment of national programmes and activities
  - Top-up funding of joint calls in selected areas with high Europe added value

Support for an ERA-NET Public health and Health Systems Research?
DATA PROTECTION AND RELATED ISSUES

Public health and health services research
Research infrastructures
Data infrastructures
Building efficient data infrastructures

• ‘Collect once, use often’
• Data linkage and pooling
  - Individual level (e.g. longitudinal)
  - Service level (e.g. practice)
  - Environmental level (e.g. exposure)
• Pseudonimization, trusted third parties

Overlap of hospital use and social care in older people in England

Martin Barrsby, Theo Georgiou, Ludovic Chassin, Garoint Lewis, Adam Staventen, Jennifer Dixon
The St Vincent Trust, London, UK; 1 University of Greenwich, London, UK

Objectives: To link pseudonymous health and social care use data in order to determine what proportion of older people access hospital and social care services.

Methods: Retrospective analysis of linked, pseudonymous, routine service use data of people aged 75 and over (n = 135,000) drawn from the operational systems of four primary care trusts and their corresponding local authorities in England.

Results: Seventeen percent of older people received hospital and social care in one year, 35% accessed NHS hospital care and 16% accessed both types of services. Most people using social care also used a hospital service (73%). This was a higher proportion than for people who did not use social care services (57%, P < 0.001). However, the use of hospitals varied by type of social care such that the residents of care homes had fewer admissions to hospital, fewer Accident and Emergency attendances and fewer outpatient visits than people receiving high intensity home care.

Conclusions: Using routine data from large populations, we have demonstrated interactions in the use of hospital care and social care for older people. Residents of care homes tend to use hospitals less frequently than people receiving high intensity home care. More detailed work is required to explain this phenomenon.

Background
Care provision for older people is a priority for health service policymakers in many countries, as is the care for younger people with long-term health conditions. People with complex needs often require both health care and social care. However, in England these two types of care service are typically funded, commissioned, and provided by different sets of organisations. This separation of services can make it difficult to coordinate health and social care, and may result in fragmentation and duplication of care.8

How social care is funded has been a subject of debate for many years, in England, calls for funding reforms have been given added impetus by perceived injustices in the social care system and by a lack of transparency and consistency in how social care funding rules are applied.9 The White Paper, Equity and Excellence: Liberating the NHS, called for an urgent review of the funding arrangements for long-term care.10 The Dilnot Commission subsequently made a number of recommendations including the introduction of national eligibility criteria for social care, postable agreements and a lifetime cap on financial contributions.11,12 The scope for substitution between health and social care services is well recognised and in some areas of England, organisations have deliberately sought to integrate health and social care functions (horizontal integration).13 For example, in areas such as Northumberland and Torbay, care trusts have been established that have responsibility for securing both health and social care for the local population. However, despite the current interest of policymakers in care integration, relatively little is known about patterns of hospital and social care use for large populations. Many previous studies have been limited in scale and timescale, describing either the experiences of individual cases or of relatively small numbers of cases.11

Local health and social care organisations typically maintain detailed databases that record which services are provided to individual members of the local
# Data protection

**Revision**

- Using personal health data for research without explicit informed consent only possible in cases of "high public interest".
- Broad consent, as currently used in research, might not be possible.
- Even pseudonymized data might be considered to be personal data.

### What is the current situation?

The current EU Data Protection legislation is under revision and will be replaced by a new General Data Protection Regulation. In 2012 the European Commission published a first proposal. In October 2013 the European Parliament passed several amendments, which could have serious negative effects for public health monitoring and research.

### What will the further process be?

- The Council aims to adopt its amendments in 2015.
- After that, the Commission will draft a new compromise proposal, which will be discussed again in the European Parliament and the Council.
- The process may be delayed due to the European elections next year, as the new Commissioner and rapporteur can decide to draft completely new proposals.

### Which amendments potentially have the most serious consequences?

- Using personal health data for public health monitoring and research (M&R) without informed, explicit consent will only be possible in cases of "high public interest". What constitutes high public interest may be defined in such a way that using data for public health purposes may be severely restricted.
- The definition of informed, explicit consent is not clear. It is therefore questionable whether broad consent, which currently is commonly applied in research, will still be possible.
- The definition of pseudonymized data is not clear. It might mean that all pseudonymized data will be considered to be personal data. If this is the case, this will complicate M&R in countries in which currently pseudonymized data are considered anonymous data if specific safeguards are met.
- If the right to be forgotten applied to M&R contexts, statistical information about public health threats would become unreliable. These amendments will seriously hamper the possibilities for doing population based research, especially research using register based data and research linking different data sources. Magnitude and quality of M&R will diminish, while costs and time scales for doing M&R will significantly increase.

### What can you, as a public health expert, do?

- Inform your MEPs and counterparts at the Ministries of Justice about the potential devastating effects of the current EP proposal on public health monitoring and research, and hence on the health of European citizens.
- Stress that it is necessary and possible to strike the right balance between public and private interests. Citizens want protection of their privacy but they want good health research as well. Good techniques and methods exist that ensure the protection of data subjects in public health monitoring and research.

### What will EUPHA do?

- Inform the decision makers, in liaison with fellow public health and research organizations.
- Support its members in their advocacy actions through making an impact assessment for the current EP proposal.

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This factsheet was produced for EUPHA by the EUPHA section on Public Health Monitoring and Reporting, with the help of Evert-Ben van Veen, MedLawconsult.
Medical ethics and research ethics committees

- Differences between European countries
- What’s legal in one country isn’t in another

Consequences:
- Long procedures
- Problems with publications

European harmonization?
JUDGING PUBLIC HEALTH AND HEALTH RESEARCH ON ITS MERITS

Public health and health services research
Research infrastructures
Data infrastructures
Data protection and related issues
Framework for the assessment of applications for public funding of new data collections

- Relevance – scientific and societal
- Necessity – no overlap with existing data collections
- Quality
- Efficiency

Improving policy and societal impact of HSR; an European working group

**Increase awareness among evaluators, researchers and other stakeholders**

- Health services and systems research should be judged on its own merits
- Define what these merits are by collecting examples of research impact
- Impact starts with research programme proposals (ex ante) and is evaluated ex post
- Focus both on EU programmes (especially Horizon 2020) and national programmes
- Make use of existing societal impact frameworks
Avoiding a narrow interpretation of societal impact

Not only a focus on economic gains
But also on social and public gains
“What number to put on improved patient satisfaction?”

But also on social and public gains
Part (extended e.g. to GP practices, hospitals etc)
## A framework for determining research impact

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<thead>
<tr>
<th>Conditions for impact</th>
<th>Dissemination</th>
<th>Uptake</th>
<th>Effect</th>
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<tbody>
<tr>
<td><strong>Policy</strong></td>
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<tr>
<td>topic on policy agenda and stakeholder involvement</td>
<td>recommendations for policy</td>
<td>use in policy doc or intended policy change</td>
<td>implemented policy</td>
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<tr>
<td><strong>Practice</strong></td>
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<td>initiative in the field of health care</td>
<td>feedback reports</td>
<td>issuing new guideline</td>
<td>quality improvement</td>
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<td><strong>Society at large</strong></td>
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<tr>
<td>addresses a societal problem</td>
<td>press releases</td>
<td>agenda setting by stakeholders</td>
<td>improved health literacy or trust in health</td>
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To conclude

What makes PHR and HSR so particular?

**We need a PILE of data**

- *Policy and research cycle* (instead of only research cycle)
- *Interdisciplinary co-operation* and policy-practice links
- *Linked data on persons in different social, physical and care contexts*
- *Evaluation on societal and scientific merits*
www.nivel.eu

www.healthservicesresearch.eu

www.eupha.org

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