Characterising an Effective Computer-Based Disease Registry

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Abstract. In this workshop we propose a discussion about issues and benefits related to the implementation and exploitation of computerized disease registries, focusing on registries as tools to improve care delivery. Achieving this goal implies to fulfill challenging requirements, both technical and organizational. Basis for discussion will be some registries in the fields of stroke and diabetes.

Keywords. Disease registry, quality of care, care process indicators

Introduction

Disease registries are systematic data collections about the incidence of a disease or disease group, the performance of an intervention within one or more geographical areas, and used for epidemiological studies, policy support, resource allocation, planning, and quality of care control [1]. They facilitate care quality and research: at the point of care; defining patients with gap in care; generating performance feedback to physicians and administrators [2]. While strengths and weaknesses of use of the routine data in primary care are well known [3], less is described about exploitation of computerized registries. The majority of them are used in diabetes, heart failure, and asthma [4]. General practitioners using registries are more likely to adhere to evidence-based guidelines [5] and stroke registries have been shown useful to control the quality of stroke care [6]. However, the quality of registry data can be negatively influenced by several factors including inadequate abstractor training and monitoring, the use of ambiguous data definitions, and accessibility.

1. Aim of the discussion

Different computerized disease registries will be critically appraised to provide exemplars of the benefit as well as to elucidate technical and organizational problems related to their development and implementation. A key success factor is a well-

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structured data collection. Topics for discussion are (but not limited to) the following: Usability of the registry websites or any other registry-related software; Improving data input and quality: Who should enter data? Which data sources are used to populate the registry? Which relation with electronic health records?; Privacy and confidentiality; Technical and organizational issues: Which roles and access?; Data quality: Proportion of missing data, accuracy of data, currency of data; Data analysis: What kind of statistics can be performed, on-line or off-line?; How to disseminate and exploit registry-based statistics?; Registries as tools for developing healthcare policy.

2. Contributions 1: Monitoring enrolment and center performance comparison

The SUN (Stroke Unit Network) is the Lombardia Stroke Registry (41 centers, 22500 cases). Through a website, it collects data about emergency, hospital stay, discharge and 3-6 months follow-up, to correlate acute care with outcomes. A set of indicators of stroke care process and outcomes has been assessed, now constantly monitored. We will comment the tool that allows users to obtain those relevant statistics, and to compare them with the overall ones. The same tool also enables the SUN coordinators to monitor the case enrollment, in order to early detect any stall problem. The website now allows documenting every center activity according to the indicators, and showing enrolment trend. Every center can see overall and its own indicators, while the coordinator can see overall and every center’s ones. Which could be the effect of publishing results like those in Table 1, tagging them with the names of the centers?

<table>
<thead>
<tr>
<th>Table 1. – Overall, best case and worst case performance on some indicators (SUN registry)</th>
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<tbody>
<tr>
<td>Indicator</td>
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<tr>
<td>% dead at discharge (IC Hemorrhages)</td>
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<tr>
<td>NIHSS measurements at admission (all)</td>
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<tr>
<td>Statins prescription (ischemic stroke)</td>
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<tr>
<td>adherence to statins at follow-up</td>
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3. Contribution 2: Diabetes registries, incentives and quality improvement

Although registries have important impact on quality improvement, their usefulness depends on the quality of the entered data. A study exploring the accuracy of diabetes diagnostic data in two UK databases identified many cases of inaccurate data, particularly in relation to the distinction between type 1 and type 2 diabetes, that can have important implications for patients and other stakeholders [7]. On the other hand, we have been able to link the prevalence of diabetes and quality of hypertension management, based on registries, to the incidence of requiring renal replacement, which had itself been derived from a national Renal Registry [8]. Discussion will thus concentrate on data quality and tools to ensure it.

4. Contribution 3: Registry Management in the Lombardy Region

In 1999 the Italian Lombardy Region initiated a project for the computerisation of the Health and Welfare System, with the goal of creating a platform for all the information
systems that partake in the supply of health and welfare services in the region. The Electronic Health Record was built on this model, to collect all data related to a patient which can, subject to authorisation, be made available to medical operatives. During the workshop, the methods and characteristics used by Lombardy to activate various projects, including registries, will be illustrated, in particular in terms of respect for the guidelines defined by the privacy ombudsman. The benefits obtained by a centralised collection of data within a regional system will be discussed in terms of appropriateness, assistance pathways, epidemiological studies, and models agreed by professionals. Particular emphasis will be given to the modality of activation of the these models within a large and complex health system like the one in Lombardy (over 150,000 health operatives).

5. Contribution 4: The SITS-MOST registry for thrombolisis in stroke

In October 2002 the European Union Commission after proposal of European Medicines Evaluation Agency (EMEA) approved a license for alteplase (rt-PA) in the treatment of ischaemic stroke within 3 hours from symptom onset. One of the conditions required by the European Union regulatory authorities for the official definitive approval of thrombolytic therapy was that treatment safety should be monitored over a period of three years by entering all treated patients in the SITS-ISTR (Safe Implementation of Thrombolysis in Stroke - Thrombolysis Register) web register, in accordance with a study protocol, the SITS Monitoring Study - SITS-MOST. The experience with this large, international registry will be reported and discussed, mainly for what concerns its impact on the recommended therapy for the acute stroke phase.

6. Expected outcome

Our intended outcome is to form a group which will develop a taxonomy for quality and access to disease registries, possibly including a checklist and rating of the global quality of a disease registry.

References: