Chronic Disease Registries – Trends and Challenges

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1. Introduction

There is an overwhelming need for reliable data on the occurrence of chronic disease to implement disease control actions. This applies to both the clinical setting and prevention on population level. Data on disease occurrence are of essential importance for clinical capacity planning, primary prevention actions, health economics, and health system planning, to name a few. Yet not many countries have the necessary data to drive policy and reduce the burden of premature death from chronic disease. Disease registries need the expertise from medicine, epidemiology, biostatistics as well as medical informatics, and collaboration of disciplines.

Trends in disease registration include use of new technologies, data collection integrated in clinical routine, expansion of disease registration particularly in low and middle income countries, and broadening of applications of routine data from disease registries such as risk predictions. Challenges include legal and ethical aspects and data security in the fast-changing world of computerized data collection, but also making sense of big data.

To encourage reporting about recent trends and challenges, we were seeking articles for the focus theme, addressing for instance modern concepts of disease registration, use of new technologies in disease registration, classification of diseases and its comparability across countries, synergies between different forms of disease registries, building up a disease registry, or record linkage of disease registries with other data sources.

2. Selected Papers

The call for papers was announced on the homepage of Methods of Information in Medicine in April 2016 with submission deadline in September 2016. After peer review, three papers were selected to be included in the focus theme “Chronic disease registries – trends and challenges”. Each of the three papers is presented briefly below.

2.1 Rapid Development of Specialty Population Registries and Quality Measures from Electronic Health Record Data – An Agile Framework

Creation of new electronic health record (EHR) based specialty registries are often “one-off” developments and the next registry request starts from scratch. Kannan et al. [1] developed an approach to accelerate creation of an EHR based registry. This approach follows some guiding principles such as data capture tool kits and employing a finite set of EHR data capture tool kits. Using this approach they developed a total of 43 registry request starts from scratch.

The authors conclude that concurrent design of EHR data collection tools and reporting can immediately yield useful EHR structured data for registries, replacing manual abstraction efforts. Their work showed that adopting agile principles...
and practices can help deliver high-quality features early and often.

2.2 Mapping Acute Coronary Syndrome Registries to SNOMED CT – A Comparative Study between Malaysia and Sweden

Information in medical records needs to be accurately captured and transferred for secondary use by registries. To ensure information remains in its original meaning SNOMED CT can be used as a reference terminology, with the process starting mapping registry’s data items into SNOMED CT concepts. Sulaiman et al. [2] conduct a comparative study between Malaysia and Sweden mapping two acute coronary syndrome registries to SNOMED CT. Of 101 items with equivalent meanings 42% were mapped to SNOMED CT. Mis-matches were due complexities of the registries, limitations of SNOMED CT, or were arising from the mappers themselves. The authors conclude that to ensure reproducible and reusable maps, specific mapping guidelines for patient registries need to be developed as well as maps need to be shared openly, and collaboration between clinical research societies and the SNOMED CT community needs to be established.

2.3 Boosting Quality Registries with Clinical Decision Support Functionality – User Acceptance of a Prototype Applied to HIV/TB Drug Therapy

Wannheden et al. [3] assessed physicians’ and nurses’ acceptance of a clinical decision support prototype for evidence-based drug-therapy recommendations for HIV/ tuberculosis treatment. Ten nurses and four physicians were involved in designing the prototype for future integration with the Swedish HIV registry. Several potential benefits were identified by the focus groups but also concerns were raised that could be addressed by redesign. The authors conclude that it was very useful to conduct the acceptance evaluation at prototype stage, providing rich information to improve the design.

3. Conclusions

The focus theme gives insight into new developments related to disease registration. This applies to technical challenges such as data linkage and data as well as data structure abstraction, but also the utilisation for clinical decision making.

References