Primary Healthcare Research Network: The Belgian ResoPrim Recommendations

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Abstract. Dedicated primary care research networks aim to gather and analyse data collected from general practitioners’ (GPs) electronic health records (EHRs). ResoPrim (2003–2008) was a Belgian multidisciplinary research project which was set up to provide recommendations for facilitating the organisation and management of these primary care research networks, assessing and improving opportunities for researchers working with available data from EHRs, and stimulating the involvement of GPs in such networks. This paper provides a short description of Resoprim’s global methodology (which included 2 pilot phases involving 64 GPs and 6 different software systems), followed by the project’s final recommendations.

Keywords. medical records, primary healthcare, data collection, computerized patient records

1. Introduction

Data gathered from GPs’ Electronic Health Records (EHRs) has many potential scientific uses, from epidemiological research and healthcare quality assessment to socio-economic studies. Setting up research networks to collect this information, however, can be challenging, due to security and privacy issues, data quality (e.g., in terms of its completeness or sensitivity), the satisfaction of participating GPs (e.g., in terms of their daily workload and useful feedback), assessing the quality of the network, and sampling methods used to select participating GPs. The opportunities and challenges involved have already been described in the existing literature [1].

Dedicated research networks have been set up in many countries with the purpose of gathering information from EHRs [1–4]. In Belgium, these networks take specific context into account, such as the numerous software systems in use (more than 19), no patients’ lists and the fact that participation in such networks is non-compulsory.

The Belgian ResoPrim project (2003–2008) acted as an experimental framework for the collection, analysis and dissemination of data taken from EHRs. Many intermediary results of the project that were related to specific research questions have already been published [5]. In this paper, we present and briefly discuss the project’s

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final recommendations. These recommendations are aimed at facilitating the organization and management of such networks, assessing and improving opportunities for researchers to use data currently available in EHRs, and stimulating the daily involvement of GPs in such research networks.

2. Materials and Methods

In order to produce the materials required to edit the recommendations, we first set up a temporary research network involving 26 volunteer GP practices and 3 software systems. In early 2005, 6 weeks’ worth of data was prospectively collected for all the patients consulting at GPs’ offices (9,472 patients, 13,814 contacts) as well as 3 years’ worth of retrospective data (18 practices, 16,813 patients, 74,878 contacts).

The temporary network ran as a true research network centred on the research theme, “hypertension and cardiovascular risk factors”. We identified research questions in various domains (such as quality of care, epidemiology, and socio-economic factors) and gave feedback individually to each of the participating GPs.

Data was collected from EHRs mainly through automatic data extraction and through electronic questionnaires filled in by GPs after each contact. The research network was a semi-anonymous network [3, 4]. A quality control procedure (using a dummy patient technique) was conducted for the extraction modules developed by each software package.

Various methods of analysis were used: a quantitative method (in order to explore the research possibilities of routine EHR data), a qualitative method (to study the expected or experienced benefits or drawbacks of participation in a primary healthcare network), and a paper questionnaire sent to the GPs themselves (in order to investigate their motivations for participating, their level of satisfaction with the network, and the effect of participation on their daily practice). All aspects of the project were extensively documented [5]. An international multidisciplinary team of experts was set up to advise the project team. An independent international project assessment was organized by the public funding service in 2005.

During 2007 and 2008 a second temporary research network was set up to help provide a more in-depth analysis. This second network, set up around the same theme, involved 33 GP practices, 6 Medical Houses, and 4 software systems. Built on the same principles, this network has mainly been used until now to study GP sampling methods, levels of GP satisfaction, and some of the security and confidentiality issues (which were also discussed several times with The Belgian Privacy Protection Commission).

Based on this material and on the experience gained, ResoPrim staff produced some draft recommendations in 2008. These were discussed and improved upon by the team of experts, and at a public workshop held in Brussels in October 2008. The final recommendations were consolidated by the ResoPrim team in early 2009.

3. Recommendations

3.1. Ethical, Privacy, and Confidentiality Issues

R1: GPs’ software homologation should include the management of secondary patient health identification numbers.
To use a primary patient ID for secondary usage of the data is not acceptable. GPs’ software systems should be able to produce and manage secondary patient IDs for specific usage. These IDs could also be produced by trusted third parties. The Belgian software homologation procedure could be used for this purpose [6].

R2: A running end-to-end encryption system should be set up.

Clinical data should be accessible only to researchers. No intermediate eHealth service provider should have access to this data. In the near future, the Belgian “eHealth platform” could provide this encryption system (see www.ehealth.fgov.be).

R3: A double coding procedure seems to be required (data should be coded for both patient and GP).

Identifying GPs could reduce the number of patients who are potentially concerned with some clinical data (mainly when some contact dates are available). Therefore, to obtain anonymous data for patients it is advised that GPs should also be anonymous.

R4: The patient should be informed of the process in a “passive” manner. This should be done through posters (to be aware that the process exists), and an information folder that can be taken home. GPs should also be able to provide additional information.

Systematically and actively informing the patient could interfere with the care process. The patient should at least have easy access to all the relevant information and this information should be organised into different levels of detail.

R5: The refusal of a patient must be explicitly recorded. After the initial consultation/information being given, a period of time must be foreseen (e.g., 15 days) in which the patient can consider his/her decision and express refusal if they so wish. GPs should also be able to express their own refusal to transmit patient data.

Without GP patient lists, systematically getting the explicit consent of all the patients could interfere with the care process, especially for non chronic patients and limited data collection periods (e.g., for a study of all patients during a six-week period).

R6: An ethical and a scientific committee should be set up. The ethical committee should include a specialist in personal health data management, a lawyer, and an MD. An annual report should be sent to the Privacy Protection Commission.

R7: GPs should sign a contract in order to restrict the potential use of anonymous data.

Once personal data has been rendered completely anonymous, it is no longer protected by privacy laws and it could even be used by third parties.

3.2. Quality of the Health Research Information Systems

R8: The content of EHRs can be improved through GP participation in (thematic) data collection networks as well as through global measures.

Improving the useful content of current EHRs is a well known concern [1, 5]. Participation in research networks seems to be effective. This observed effect may continue beyond the end of the research project. Certain global measures could also have an impact (cf. software homologation procedures [6, 7]).

R9: At this stage, it is advised to study the impact of home visits with a group of “good coders” rather than to set up a more sophisticated technical procedure.

It seems to be difficult to deploy specific means, such as PDA, to extensively gather data at home. Therefore working with GPs who are used to properly recording data related to home visits (either at patients’ homes or back at the office) seems to be an acceptable temporary procedure.
R10: Some technical tools should be used to assess the quality of the information system (in terms of content and software), to improve data interpretation and to monitor a documented improvement in overall quality. We recommend a “dummy patient” technique to assess the quality of the extraction modules, and simple, systematic electronic questionnaires to assess the quality of the extracted data [5].

3.3. Sampling Issues

R11: Whatever method is used to obtain a representative sample of GPs, stratification will be required. A stratified sampling procedure (including age, sex, university graduated from, and location) could be successfully applied to research networks such as ResoPrim.

R12: If a minimum number of (valid) data is to be guaranteed, we advise using some technical criteria related to the use of EHRs by GPs in the sampling procedure.

Technical criteria such as “use by the GP of a coding system for diagnosis” and/or “use of a drug prescription module” have little impact on GP characteristics.

R13: We recommend involving several software systems, each of them with a minimum number of around 20 volunteers and participating GPs.

This is advised where several GP software systems are currently in use.

3.4. Secondary Uses of the Current Available Data

R14: Information relating to the incidence or prevalence of health problems based on routine EHR data should be handled carefully.

Missing values or inconsistent handling of historical or insertion dates by the software are possible.

R15: If no quality control or assessment is foreseen, we presently do not recommend using routine EHR data for the identification of a target population.

Most of the data has a low sensitivity and sometimes a low positive predictive value for identifying patients’ populations (e.g., diabetic patients or hypertensive patients taking drugs).

R16: It is presently not recommended to compare the quality of care between GPs, as there is too much uncertainty about GPs’ EHR use. If, however, we assume that incompleteness of data and changes in EHR use are homogeneously spread across various groups or types of patients within any one group of GPs, then it may be possible to compare various subgroups of patients or to monitor quality of care.

3.5. Issues Relating to Participating GPs

R17: We recommend using stabilized running systems, such as Secured Medical Messaging Systems (SMMS), as much as possible. An efficient help desk is essential. Personalised helpdesks seems to be more effective, i.e., each GP has a reference person (or a small team) to encourage trust in the research network and to act as a go-between for all communicating parties (GP, SMMS, trusted third parties, and research centre). The role of each technical partner involved in the helpdesk must be defined in advance.

R18: To encourage GPs to participate in electronic research networks, the following factors have been identified as important: a personal contact who invites the GP to collaborate; exhaustive information on the project; trust in the organizers; use of anonymous data (for patients and GPs); protection of data sent (encryption); scientific
objective for the network; acceptable workload compatible with daily practice; no supplementary request from patient; an efficient helpdesk; learning opportunities or individual feedback (more controversial); and a financial incentive (also controversial). It is important to keep in mind that introducing new technologies could have an impact on the relationship between the GP and the patient, colleagues or other agents of the healthcare system (related to the specific GPs’ healthcare role). The GP’s personal feelings towards their clinical autonomy or professional role may also have an impact.

4. Conclusions

All of the ResoPrim recommendations have been issued with a pragmatic aim in mind: to go one step further in setting up primary care research information systems in Belgium. This takes into account our fast evolving national context, for instance:

- the creation of a national electronic exchange platform to provide basic health information services, such as identification of patients and health professionals, or data encryption (see www.ehealth.fgov.be)
- the creation of the new health section of the Privacy Protection Commission in December 2008 (see www.privacycommission.be).

These recommendations are therefore not comprehensive: we focused on useful recommendations that could be implemented. The recommendations will continue to be discussed and to evolve in the coming years. Due to similar problems and challenges arising in other countries [1], some of these recommendations may also be useful at the international level.

Over the coming months, these recommendations should be used to set up a broad and stable national primary care public research network in Belgium.

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