Building Continents of Knowledge in Oceans of Data: The Future of Co-Created eHealth

A. Ugon et al. (Eds.)
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doi:10.3233/978-1-61499-852-5-61

Profiling Databases to Facilitate Comparison of Child Health Systems Across Europe Using Standardised Quality Markers

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Abstract. Models of child primary health care vary across Europe. There are three categories, primary care paediatricians, general practitioner based, or mixed. This paper describes the metadata schema used in the profiling process of candidate data sources for appraisal for the Models of Child Health Appraised (MOCHA) project using the MOCHA International Research Opportunity Instrument (MIROI). The ten clinical indicators included: asthma, antibiotic stewardship, immunisation, rickets, diarrhea, epilepsy, depression, ADHD, enuresis and care of women during pregnancy. Our metadata allows us to identify data within included data sources concerning any of the 10 clinical indicators identified for comparative analysis within the MOCHA project. From the 30 countries we found a minimum of 5 and a maximum of 36 different databases for each indicator.

Keywords. child health services, primary health care, electronic health records, surveys and questionnaires, public health

1. Introduction

The Models Child Health Appraised (MOCHA) of project (http://www.childhealthservicemodels.eu/) project seeks to evaluate health care systems to identify indicators and measures that improve the quality of primary health care being provided to children. To do this it is using key conditions such as asthma, epilepsy, and Attention Deficit Hyperactive Disorder (ADHD) as exemplars and case studies. Large datasets from a variety of countries are a vital component of these specific studies that will appraise models of care and test MOCHA hypotheses. Results of these studies could influence development and budgeting of national health systems and other policy decisions, such as World Health Organisation (WHO) mandates regarding European national health strategies.¹ We use requirements models such as surveys as a tool to provide an understanding of the dynamics of the socio-technical systems associated with studies of interest. This knowledge provides a good basis for specifying what criteria need to be considered when selecting databases for research studies. This process of assessing the appropriateness of databases to contribute to studies can also be referred to as the research readiness of a databases.²

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2. Methods

2.1. MOCHA International Research Opportunity Instrument (MIROI)

We have previously described the survey instrument called the MOCHA International Research Opportunity Instrument (MIROI) with which we identified candidate data sources across Europe.³ We formulated 23 questions collecting basic information on databases containing individual child records, such as database contact details, population, data quality and governance and organised them into the MIROI survey instrument (Table 1, supplementary file of complete questionnaire). Questions were placed into sections related to database description and database access. The database description section included questions regarding database metadata, update frequency, data custodian, data population and equity of access to healthcare. The database for access to data. We used a questionnaire to capture essential information that may be important to a researcher. We requested one database per response, although a database could include several types of data, e.g. hospital inpatient data combined with primary care data. The majority of questions requested textual answers, although some of the questions requested yes/no answers or a selection of one or more applicable terms.

2.2. Dissemination of the MIROI survey

In the MOCHA project, a country agent has been appointed to each of the 30 European countries involved. The country agents were given the responsibility of gathering evidence for the researchers of all work packages during the duration of the project. MOCHA country agents completed the survey themselves based on their own knowledge and/or liaised with public health experts in their country to distribute the survey to interested researchers. The central research coordinator channelled the information queries from each work package to the country agents and responses back via the central coordination point. The flow of queries and corresponding responses was scheduled in the project calendar, thus allowing researchers to utilise the setup mechanism in multiple iterations. The agent communication protocol also included an internal review process where work package questions were reviewed for their suitability before sending to the country agents. The MOCHA team leveraged this country agent protocol to disseminate and gather responses to the MIROI survey instrument. The survey instrument was sent to the country agents during the period between 16th November 2015 and 14th January 2016, and completed survey responses were received January through October 2016.

2.3. Quality indicators of child health care quality from large databases

We identified 10 quality indicators that were selected have been carefully selected to give an overview of the quality of care (Table 1) by reviewing literature and expert opinions.^{4,5} These indicators defined according to their potential to be readily answered from routine clinical data. Certain indicators required linking data from multiple data sources (e.g. prescribing of inhalers from primary care databases, and emergency admissions due to asthma exacerbation from secondary care data).

Quality indicator	Description					
1. Asthma care for	% of asthmatic children between 5-18 years prescribed reliever versus					
children	preventer inhalers within the past year					
2. Antibiotic stewardsh	total number of Amoxil prescriptions per year for children under 19 years/ total number of prescriptions for cephalosporins per year for children under 19 years					
3.Immunisation of children	proportion of children vaccinated for (1) DTP (diphtheria, pertussis, tetanus)(2) MMR (measles, mumps, rubella (3) HPV(human papillomavirus)					
4.Rickets care for children	proportion of children with rickets who have been prescribed Vitamin D in the last year					
5. Diarrhoea care for children	proportion of children who require admission to hospital with diarrhea					
6. Epilepsy care for children	inpatient admissions for seizures in children under 19 years in the last year/ proportion of children under 19 years with epilepsy who have had a fit review in the last year/ proportion of children with epilepsy who have been prescribed diazepam in the last year					
7. Depression care	total number of prescriptions per year for child with depression aged 10-18					
for children	years					
 ADHD care for children 	total number of children under 19 years with ADHD/ Demographics of the children with ADHD – age, sex/ Age at ADHD diagnosis					
9. Enuresis care for	total number of children under 19 years with enuresis who have had a multi-					
children	disciplinary assessment (e.g. medical, psychological, social assessment)					
10. Care of women	total number of pregnant women who are given oral folate (prescribed folate or					
during pregnancy	over the counter)/ total number of pregnant women who are smokers					

Table 1. Quality indicators of considered for assessing child health care quality

We explored the metadata collected using the MIROI survey to understand the landscape of data sources available to support these studies.

3. Results

3.1. Responses to the MIROI survey

Using the MIROI survey tool, the MOCHA study team identified 147 databases with potential to be data sources capable of supporting specific MOCHA studies. By October 2016, 26 of the 30 country agents had provided one or more database responses and a total of 147 responses were catalogued. 39% of responding countries provided 5 or more responses; Poland provided the greatest number of responses (11). Only 3 countries (Bulgaria, Czech Republic, and Denmark) provided only 1 response. All responses were entered into the MOCHA access controlled part of the online EMIF repository, and the study team was able to easily request access and browse the content.

3.2. MOCHA catalogue of database meta-profiles

We entered MIROI responses provided by responders into an online version of the instrument (<u>https://www.surveymonkey.co.uk/r/miroi2</u>) for ease of analysis. The additional free-text information was captured using additional comments fields in the online survey. We created a database of responses in Microsoft Access to run summary statistics on the responses and entered the responses into the online European Medical Information Framework (EMIF) Data Catalogue (<u>http://www.emif.eu/about/emif-platform/emif-catalogue</u>) to make information provided in the responses available to the entire MOCHA team in a user-friendly, browse-able, password-secure format.

	Paed(n=21)		GP (n=53)		Comb(n=73)		Overall(n=147)	
Quality indicator	Prim	Supp	Prim	Supp	Prim	Supp	Prim (%total)	Supp (%total)
S1.Asthma care	3	7	7	11	15	18	25(17.0%)	36(24.5%)
S2.Antibiotic stewardship	2	8	7	10	14	17	23(15.6%)	35(23.8%)
S3.Immunisation	2	7	10	10	16	20	28(19.0%)	37(25.2%)
S4. Rickets care	3	7	8	10	12	20	23(15.6%)	37(25.2%)
S5.Diarrhoea care	6	6	8	10	16	19	30(20.4%)	35(23.8%)
S6.Epilepsy care	2	8	8	13	12	17	22(15.0%)	38(25.9%)
S7.Depression	2	9	8	13	12	20	22(15.0%)	42(28.6%)
S8.ADHD care	2	9	8	13	12	20	22(15.0%)	42(28.6%)
S9.Enuresis care	3	7	7	10	12	20	22(15.0%)	37(25.2%)
S10.Care of women during pregnancy	1	4	11	9	10	17	22(15.0%)	30(20.4%)

Table 2. Availability of data sources to assess quality indicators in database representing countries representing

 Pediatrician led, GP led and those having a combination of these systems (Prim-primary data sources that can support indicator assessment, Supp- supporting data sources that fulfill certain data element required))

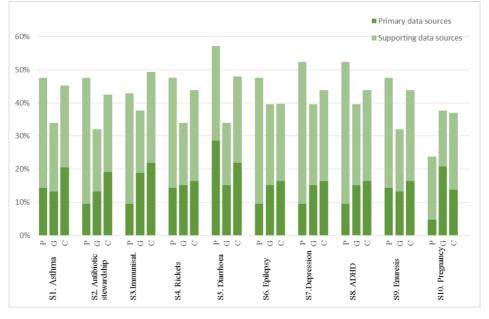


Figure 1. Graphical representation of the availability of data sources across for the 10 quality indicators

3.3. Availability of data for measuring quality indicators from routine data sources

In an initial exploration of the MIROI metadata we assessed how the MOCHA catalogue compares with other key metadata catalogue describing health data sources in Europe.³ We subsequently analysed the metadata collection against the 10 quality indicators given

in Table 1. We realised that whilst certain data sources could contribute to measure the indicators (e.g. anonymised primary care databases), there were other databases that were capable of provided certain elements required to assess the indicators (e.g. mortality databases). We have defined these two categories of databases as primary data sources and supporting data sources respectively. Table 2 presents the potential data sources across countries of different types of health systems.

4. Discussion

Our analysis demonstrates that about half of the databases in the web catalogue are capable of contributing to assessment of child health care quality indicators. From the potential databases about 15-20% of the databases can be used as primary sources of data while about 25-30% of the databases cab provide supporting evidence to conduct a complete assessment. This builds on previous work developing metadata across European data sources.

A limitation of our analysis is that the interpretation of the suitability was assessed using the metadata collected from a metadata survey and not with direct consultation of the data custodian. However, in order to operationalise the indicator assessment, we have invited database custodians to conduct feasibility assessments with respect to the specific indicators defined in this paper.

5. Conclusions

Conducting accurate comparative assessment of child health care systems largely depends on having access to good quality computerised medical records. Identifying candidate databases can be a challenging task due to their heterogeneity and variation of data quality. In the existing complex landscape of health databases, analysing meta-data repositories allow targeting specific databases that could be better contributor to routine data studies.

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