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Availability of Computerised Medical Record System Data to Compare Models of Child Health Care in Primary Care Across Europe

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Abstract. Computerised medical record (CMR) system data can be used to compare different models of health care for children. We identified sources of data from the Models of Child Health Appraised (MOCHA) project that compares family doctor led with paediatrician led and mixed models of child care using index conditions. Asthma and immunisation coverage are the first of these. We explored the extent to which an established Patient Registries Initiative (PARENT); MOCHA's own survey (MIROI); the European Centre for Disease Control (ECDC) immunisation information system survey and the European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP) registry of data sources provided data to make comparisons of child health care. Five countries had data repositories for our index conditions from paediatrician lead services, compared with 14 for mixed, and 11 for family doctor led services. PARENT identified 212 sources, MIROI 148 sources, ECDC 17 sources and ENCePP 42; with immunisation related data sources found in all four but asthma in only three. There are less sources of electronic data available to study paediatrician led systems than other models; this risks unequal sample size bias.

Keywords. Medical record systems computerised; Health, Child Health, Health Information, Surveys and Questionnaires Systems

1. Introduction

Information and communication technologies (ICT) solutions are increasingly used in healthcare across Europe. The availability of technologies and the introduction of policies to encourage computerization of health records are seen as key tools for supporting the improvement of health care delivery, especially in primary care [1]. Electronic health records (EHRs) and digital interactions, have been demonstrated to contribute to increased adherence to guidelines in clinical practice and reduce medical errors with better knowledge management and evidence-based decision making. They have also contributed to better health services integration and continuity of care with improved communication among physicians, patients and specialists with consequent savings in time and costs [1].

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However ICT implementation and applications varies across countries resulting in a heterogeneous and complex data ecosystem to study child public health across Europe [2]. This is a significant challenge for researchers who are investigating common health issues in the region. Common data models created from heterogeneous data sources are required for conducting pan-European routine data studies [3]. The aim of this study is to report the availability of data sources to compare the number available to compare family doctor, paediatrician and mixed models of child health care.

2. Types of child health service and indicator conditions

The Models of Child Health Appraised (MOCHA) Horizon 2020 project compares models of health care. The models compared are family physician/general practitioner led, paediatrician led or mixed models [4]. MOCHA uses index conditions to compare health systems. The first two being considered are the quality of asthma management and immunisation coverage.

3. Data source registers selected – PARENT, MIROI, ECDC, ENCePP:

The Patient Registries Initiative (PARENT, http://parent-ror.eu) has collected data about 227 registers [5]. It was established with the goal of enhancing cross-border interoperability of patient registries in the EU area. This initiative has collected metadata covering details about registry establishment, governance, funding, data sources, data quality indicators, standards used and interoperability.

In the MOCHA project, we have developed the MOCHA International Research Opportunity Instrument (MIROI) instrument to identify data sources that can support studies related to child health. Responses were collected through a network of country agents appointed for all participating European nations in the project. The survey instrument is an offline questionnaire in word document format which was completed by data custodians through the coordination of the country agents. In our initial data collection, we were able to collect 146 responses from 26 countries. By conducting metadata collection in multiple projects previously, we have learnt that metadata collection needs to be incentive driven in order to attain the maximum number of responses. We used the EMIF (European Medical Information Framework) web catalogue to enable sharing of the metadata collected through MIROI. The EMIF web catalogue was developed to share metadata from multiple projects using a single web-based portal (http://emif-catalogue.eu) [6].

The European Centre for Disease Prevention and Control (ECDC) recently published a technical report based on results of a survey of immunisation information systems in the EU and EEA. This survey focused mainly on implementation and system characteristics of immunisation information systems. Although the results of the survey have not been shared as a repository unlike the previous three cases, we have considered it in the comparison since immunisation in children is one of index conditions [7].

The European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP) is a network initiated by the the European Medicines Agency to support post-authorisation studies in Europe. In addition to research centres and networks, the ENCePP registry also contains profiles of a number of health databases in Europe [8].

4. Comparing MIROI and other EU metadata resources for study of child health outcomes

We undertook a comparison of metadata from PARENT, MIROI, ECDC and ENCePP based on whether the child health system was GP focused, Paediatrician focused or combined to understand the range of routine data sources profiled in each country [4] [9].

Table 1. Data sources listed in each resource based on the type of health system

Country	**Type of child health system**			**Listed data sources**			
	Paediatrician based system	GP based system	Combined system	PARENT	MIROI	ECDC	ENCePP
Austria			x	4	5	1	1
Belgium			x		4		2
Bulgaria			x	1	5		
Croatia	x			10	5		
Cyprus	x			5	4		
Czech Republic	x			1	1	1	
Denmark		x		2	1		2
Estonia		x		2	6	1	
Finland		x		12	7		1
France			x	12		1	3
Germany	x			14	5		2
Greece	x			1	6	1	
Hungary			x	13	6	1	
Iceland			x		9		
Italy			x	5	8	1	11
Latvia			x	10	7		
Lithuania			x	10	4		
Luxembourg			x			1	
Malta			x	6	6	1	
Netherlands		x		1	6	1	4
Norway		x		2	6		1
Poland			x	9	11	1	
Portugal		x		2	5	1	
Republic of Ireland		x		7	7	1	1
Romania		x		1	6	1	
Slovakia		x		1			
Slovenia		x		8		1	
Spain			x	50	10	1	6
Sweden			x	16	1	1	1
UK		x		7	7		7
Total	5	11	14	212	148	17	42

We then looked at the candidate data sources available in each EU country for specific use case scenarios (infectious disease/ chronic diseases). There is limited overlap of data sources between these resources (only 5 common databases between MIROI and PARENT).

Table 2. Data sources to support immunisation studies

	Availability of data source to support asthma studies			**Availability of data source to support immunisation studies**			
Country	**PARENT**	**MIROI**	**ENCePP**	**PARENT**	**MIROI**	**ECDC**	**ENCePP**
Austria		1					
Belgium			2			1	2
Bulgaria				1	1		
Croatia	3	3					
Cyprus							
Czech Republic							
Denmark			1		1	1	2
Estonia		2					
Finland	3	2		2		1	1
France			2				3
Germany	1		2			1	2
Greece		1					
Hungary	3	2			1	1	
Iceland		2			4	1	
Italy	1	2	7		1		5
Latvia						1	
Lithuania		2					
Luxembourg							
Malta	1	1			1	1	
Netherlands	1	1	3			1	4
Norway		1	1		1	1	1
Poland		4			1		
Portugal					2	1	
Republic of Ireland		1			1	1	
Romania		2				1	
Slovakia						1	
Slovenia	3			1			
Spain	3	2	4		1	1	5
Sweden	1	1	1		1	1	1
UK		4	4		1	1	4
Total	20	34	27	4	17	17	30

Five countries had data repositories for our index conditions from paediatrician lead services, compared with 14 for mixed, and 11 for family doctor led services. PARENT identified 212 sources, MIROI 148 sources, ECDC 17 sources and ENCePP 42; with immunisation related data sources found in all four but asthma in only three. There was a higher percentage of candidate data sources for both asthma and immunisation studies in countries with combined system compared to countries with family doctor led services. The countries with paediatrician lead services had a significantly lower representation for both index conditions considered (Table 3).

Table 3. Available data sources based on type of child health system

Type of child health system	Candidate data sources for asthma studies	Candidate data sources for immunisation studies
Paediatrician based system	10 (13%)	3 (4%)
GP based system	29 (39%)	30 (44%)
Combined system	42 (56%)	35 (51%)

5. Conclusion

Using multiple searches identifies a greater number of data sources. Whilst the MOCHA survey instrument (MIROI) identified data sources other databases added to it. Investigators should not rely on single survey instruments and repositories to identify data sources. However, a key limitation is that the data sources considered in this paper were originally created for other purposes than comparing models of child health care; their metadata fitting the aims and scope of the respective studies.

There are only a relatively limited number of data sources available describing paediatrician led child health care services. This may be because primary care was one of the first services to computerise, and it is a service that lends itself more to computer use than hospital practice [10]. This limits the scope to make comparisons between methods of care delivery.

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References

[1] S. De Rosis, C. Seghieri. Basic ICT adoption and use by general practitioners: an analysis of primary care systems in 31 European countries. *BMC Med Inform Decis Mak.* **15.1** (2015),70.

[2] H. Liyanage, P. Krause and S. De Lusignan. Using ontologies to improve semantic interoperability in health data. *J Innov Health Inform.* **22.2** (2015); 22(2),309-15.

[3] H. Liyanage, D. Luzi, S de Lusignan, F. Pecoraro, R. McNulty, O. Tamburis, P. Krause, M Rigby, M Blair. Accessible Modelling of Complexity in Health (AMoCH) and associated data flows: asthma as an exemplar. *J Innov Health Inform.* 2016;**23(1):**863. doi: 10.14236/jhi.v23i1.863.

[4] M. Blair, M. Rigby,and D. Alexander.*Final Report on Current Models of Primary Care for Children, including sections on context, Operation and Effects, and Related Business Models*. [online] Available at: http://bit.ly/2sGADH1 (accessed 8 Jun. 2017).

[5] I. Pristas, P. Doupi, H. Karanikas, M. Brkic, B Plese, M. Zaletel, M. Magajne, O. Zuriaga Llorens, C. López-Briones. The Eu Patient Registry Landscape: Survey of Registry Profiles Through Parent Ja Research And Framework. *Value Health.* **18.7** (2015), 562-3.

[6] L. A. Bastião Silva, C. Días, J. van der Lei, J.L. Oliveira. Architecture to Summarize Patient-Level Data Across Borders and Countries. *Stud Health Technol Inform.* **216** (2015), 687-90.

[7] T. Derrough, K. Olsson, V. Gianfredi, F. Simondon, H. Heijbel, N. Danielsson, P. Kramarz, L. Pastore-Celentano. Immunisation Information Systems - useful tools for monitoring vaccination programmes in EU/EEA countries, 2016. *Euro Surveill.* **22.17** (2017), 30519.

[8] K.V. Blake, C.V. Devries, P. Arlett, X. Kurz, H. Fitt. for the European Network of Centres for Pharmacoepidemiology Pharmacovigilance. Increasing scientific standards, independence and transparency in post-authorisation studies: the role of the European Network of Centres for Pharmacoepidemiology and Pharmacovigilance. *Pharmacoepidemiol Drug Saf.* **2** (2012).

[9] D. van Esso D, S. del Torso, A. Hadjipanayis, A. Biver, E. Jaeger-Roman, B. Wettergren, A. Nicholson; Primary-Secondary Working Group (PSWG) of European Academy of Paediatrics (EAP). Paediatric primary care in Europe: variation between countries. *Arch Dis Child.* **95.10** (2010), 791-5.

[10] T. Benson. Why general practitioners use computers and hospital doctors do not--Part 1: incentives. *BMJ.* **325(7372)** (2002), 1086-9.