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To cite this version:

Anita Burgun, Dina V Oksen, Wolfgang Kuchinke, Hans-Ulrich Prokosch, Thomas Ganslandt, et al.. Proposal for a European Public Health Research Infrastructure for Sharing of health and Medical administrative data (PHRIMA).. Studies in Health Technology and Informatics, 2015, 216, pp.1005. 10.3233/978-1-61499-564-7-1005 . hal-01232643

HAL Id: hal-01232643

https://hal.science/hal-01232643v1

Submitted on 23 Nov 2015

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MEDINFO 2015: eHealth-enabled Health
I.N. Sarkar et al. (Eds.)

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doi:10.3233/978-1-61499-564-7-1005

Proposal for a European Public Health Research Infrastructure for Sharing of health and Medical administrative data (PHRIMA)

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Abstract

In Europe, health and medical administrative data is increasingly accumulating on a national level. Looking further than re-use of this data on a national level, sharing health and medical administrative data would enable large-scale analyses and European-level public health projects. There is currently no research infrastructure for this type of sharing. The PHRIMA consortium proposes to realise the Public Health Research Infrastructure for Sharing of health and Medical Administrative data (PHRIMA) which will enable and facilitate the efficient and secure sharing of healthcare data.

Keywords:

Europe, data sharing, public health, research infrastructure.

Introduction and background

In Europe, data on the health of the population differs greatly in terms of availability, size and content. In Sweden and Denmark, national health databases are administered by one single authority and contain information on the entire population on diverse aspects of population health. In France, the SNIIRAM holds information for almost the entire population on health insurance beneficiaries consuming care, including reimbursed prescribed drugs. In the United Kingdom, the CPRD contains observational data from the NHS, notably primary care records for around five million patients. In Germany, the Information System Secondary Use of Routine Health Data has been newly initiated, is maintained by the DIMDI and contains administrative claims data.

Methods

Aspects of data sensitivity, heterogeneity, legal and ethical issues of sharing, quality and semantic interoperability, as well as technological solutions to ensure security, need to be considered with new concepts and rigor as to enable sharing of health data on a European level. Interoperability challenges necessitate existing solutions to require European level efforts to harmonize and ensure data sharing, given data security and ownership. ESFRI [1] is a strategic instrument to develop interoperable platforms and research infrastructures (RIs). In Sept 2014 the authors began PHRIMA, a consortium to investigate a RI for sharing medical administrative data. This RI will specifically target national databases, extendable to patient and population cohorts.

Expected benefits

PHRIMA will strengthen technological development capacity and effectiveness through metadata definitions and semantic interoperability. It strives to harmonize European medical and administrative data, and propose technical solutions for data sharing; building on national solutions and other data shareable, reusable ESFRI projects. It supports collaborative research in record linkage and anonymization. The RI will provide secure, legal solutions for large-scale epidemiological research on observational health data.

Acknowledgements

This work has received support from INSERM/Aviesan Public Health Institute.

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