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Anita Burgun[a,b], Dina V. Oksen[a], Wolfgang Kuchinke[c], Hans-Ulrich Prokosch[d], Thomas Ganslandt[d], Iain Buchan[e], Tjeerd van Staa[e], James Cunningham[e], Marianne L. Gjerstorff[f], Jean-Charles Dufour[g], Jean-Francois Gibrat[h], Macha Nikolski[i], Pierre Verger[g], Anne Cambon-Thomsen[j], Cristina Masella[k], Emanuele Lettieri[k], Paolo Bertele[k], Marjut Salokannel[l], Rodolphe Thiebaut[m], Charles Persoz[a], Geneviève Chêne[a], Christian Ohmann[n]

[a] Institut Thématique Multi-organisme – Santé Publique, AVIESAN, Paris, France, [b]INSERM UMR 1138 team 22 Centre de Recherche des Cordeliers, Université Paris Descartes – Sorbonne Paris Cité, Paris, France, [c]Heinrich-Heine University, Duesseldorf, Germany, [d] Chair of Medical Informatics, Friedrich-Alexander-University Erlangen-Nuremberg, Erlangen, Germany, [e]Health e-Research Centre / Farr Institute, University of Manchester, Manchester, United Kingdom, [f]Forsker Service, Statens Serum Institut, Copenhagen, Denmark, [g]UMR912 SESSTIM (AMU-INSERM-IRD-AMSE), Aix-Marseille University, Marseille, France, [h]CNRS, UMS 3601, Gif-sur-Yvette, France, [I]CNRS/LaBRI, Université de Bordeaux, Talence, France, [j]UMR 1027 Inserm, Université Toulouse III Paul Sabatier, Toulouse, France, [k]Politecnico di Milano, Department of Management, Economics and Industrial Engineering, Milano, Italy, [l]SaReCo/University of Helsinki, Helsinki, Finland, [m]INSERM U897-Epidemiologie-Biostatistique, Bordeaux, France, [n]European Clinical Research Infrastructures Network (ECRIN), Duesseldorf, Germany

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.

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References

[1] ESFRI-European Strategy Forum on research Infrastructures, *Strategy Report on Research Infrastructures*. 2010.

Address for correspondence

anita.burgun@inserm.fr