

Dados em epidemiologia: entre a saúde pública e a medicina personalizada

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Medicina Personalizada

Wall Street Journal, 1999

Single Nucleotide Polymorphism Consortium (SNP Consortium)

“We are in the middle of a transition from a society of facts to a society of data. During this interim confusion abounds surrounding the exact status of knowledge and numbers in public life exacerbating the sense that truth itself is being abandoned.

Conspiracy theories prosper under such conditions. And while we will have far greater means of knowing how many people believe those theories we will have far fewer means of persuading them to abandon them.”

The Age of Post-Truth Politics
by WILLIAM DAVIES
The New York Times Aug. 24. 2016

“... If the currently available epidemiological estimates for all conditions were right, some people in a given age group or region would have to die twice over to account for all deaths that are claimed.”

Murray, Lopez. The Global Burden of Disease

“Human Information System”



Exposome
Social network
Clinical phenotypes
Microbiome
Epigenome
Metabolome
Proteome
Genome
Other type of data (imaging...)
Individual subjects

Big Data

➔ Integrating Big Data into a HIS &
Transform Big Data into Knowledge

Informação e conhecimento ----- Profissional de saúde ----- “Doente”
Informação e conhecimento ----- “Doente” ----- Profissional de saúde

- Personalizada
- Predictiva
- Preventiva
- Participativa

Leroy Hood, Institute for Systems Biology, P4 Medicine Institute (2010)

- Product
- Price
- Place
- Promotion

Marketing personalizado (One to one marketing vs Estratificação)

	<i>Ortodoxa</i>	Centrada nas pessoas
Grupo de Interesse	População, Grupos de risco	Agregados (comunidades, culturas)
Objectivos	Diminuir mortes prematuras, doenças e deficiências	Elevar a qualidade de vida, o bem estar, a saúde
Valores	Justiça social, equidade, direitos humanos, prevenção do sofrimento, ciência	Emancipação, auto-determinação, cultura, diversidade
Como construir o conhecimento	Epidemiologia, Base na prova	Qualitativa, quase -experimental, avaliação
Orientadores conceptuais	Risco, doença, prevenção, determinantes de doença	Público, saúde e bem estar, promoção, determinantes de saúde
Meios de intervenção	Políticas, intervenções populacionais, regulação, educação, tratamento precoce	Desenvolvimento comunitário, escolhas da comunidade a dirigir a acção, auto-determinação e acção participada
Aproximação profissional	Planeamento, desenvolvimento de políticas, decisões com base em peritos, colaboração inter-sectorial dos serviços	Facilitação das prioridades vindas da população, parcerias, assegurar controlo comunitário, procurar recursos
Sentimento geral	Científica, mensurável	Apaixonada, intuitiva

Raeburn J, Macfarlane S. Putting the public into public health: towards a more people centred approach. OUP, 2003

Purpose of Public Health Research

Evidence (Based) Informed
Context (Specific) Relevant
Resource (Sensitive) Optimising
Culturally (Compatible) Adaptative
Equity Promoting

Epidemiology in the age of Sustainable Development

Jeffrey Sachs, International Journal of Epidemiology, 2017

“Epidemiologists should be trained in the ***broader dynamics of global systems change*** to anticipate the roles of ***climate change, habitat loss, water stress, pollution, life-style changes, dietary patterns and other social determinants of health*** (including substance misuse, depression, unemployment, forced migration, social exclusion, ageing and loneliness, and so forth) in what is likely to be a rapid change of disease burden, including many new and major challenges.”

Epidemiology in the age of Sustainable Development

Jeffrey Sachs, International Journal of Epidemiology, 2017

“The global scale-up of well-trained epidemiologists must be part of the SDG agenda, and the **new generation of epidemiologists should be trained to work across disciplines with social scientists, earth-system scientists, information engineers and others**, to maximize the remarkable potential of the field.”

Exchange of electronic health records across the EU

The European Commission has adopted a Recommendation on a European electronic health record exchange format to unlock the flow of health data across borders.

The Recommendation on a European electronic health record exchange format seeks to facilitate the cross-border interoperability of electronic health records (EHRs) in the EU. It does so by supporting EU countries in their efforts to ensure that citizens can securely access and exchange their health data wherever they are in the EU.

The electronic health record exchange format will help citizens to quickly access and share their health data with healthcare professionals. For example, when consulting a specialist or receiving emergency treatment in another EU country.

Secure access to health data

Enabling citizens to securely access and share their health data across borders is one of the priorities of the Communication on enabling the digital transformation of health and care.

The General Data Protection Regulation (GDPR) underlines that citizens have the right to access their personal data and provides the legal framework for the protection of personal data. It sets out directly applicable rules for the processing of the personal data of individuals, including health data. Rules for facilitating the access to safe and high-quality cross-border healthcare are covered in the GDPR on patients' rights in cross-border healthcare.

Benefits of access to electronic health records



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[Recommendation on a European electronic health record exchange format >](#)

[Q&A: EHRs >](#)

[Press release: EHRs >](#)

[Factsheet: Impact of EHRs >](#)

[Factsheet: Transformation of health and care >](#)

The United States Department of State and the Directorate-General for Communications Networks, Content and Technology (DG CONNECT) of the European Commission signed an “**Administrative Arrangement on Artificial Intelligence for the Public Good**” at a virtual ceremony held simultaneously on 27 January 2023 at the White House in Washington DC and in DG CONNECT, Brussels.



Roberto Viola, Director General of DG CONNECT signing the “Administrative Arrangement on Artificial Intelligence for the Public Good”

Electronic health records to facilitate clinical research

Electronic health records (EHRs) provide opportunities to enhance patient care, embed performance measures in clinical practice, and facilitate clinical research. Concerns have been raised about the increasing recruitment challenges in trials, burdensome and obtrusive data collection, and uncertain generalizability of the results. Leveraging electronic health records to counterbalance these trends is an area of intense interest. The initial applications of electronic health records, as the primary data source is envisioned for observational studies, embedded pragmatic or post-marketing registry-based randomized studies, or comparative effectiveness studies. Advancing this approach to randomized clinical trials, electronic health records may potentially be used to assess study feasibility, to facilitate patient recruitment, and streamline data collection at baseline and follow-up. ([Clinical Research in Cardiology](#) volume 106, pages1–9, 2017)

Abstract

Linking records could serve as a useful tool for scientific research and as a facilitator for local policymaking. This article examines the challenges and opportunities for researchers to lawfully link routinely collected health and education data with cohort data of children when using it as a tool for scientific research in Portugal. Such linking can be lawfully conducted in Portugal if three requirements are met. First, data processing pursues a legitimate purpose, such as scientific research. Secondly, data linking complies with the legal obligations of research entities and researchers, acting as data controllers or processors, and it respects the rights of children as data subjects. Finally, data linking is based on the explicit written consent of those with parental responsibility for the child. So far, the implementation of the General Data Protection Regulation in Portugal has not facilitated record linkage. It is argued that further harmonised implementation of that Regulation across European Union and European Economic Area Member States, establishing a minimum shared denominator for record linkage in scientific research for the common good, including without explicit consent, is needed.

Record linkage of routine and cohort data of children in Portugal: challenges and opportunities when using record linkage as a tool for scientific research

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Medical Law Review, fwac040, <https://doi.org/10.1093/medlaw/fwac040>

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