

From secondary data to Population Data Science: remembering 40 years of scientific production within CSP pages

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It was a great joy accepting the invitation to write this editorial. A special opportunity to celebrate together with Marilia Sá Carvalho, Luciana Dias de Lima, Luciana Correia Alves and the entire CSP community the 40th anniversary of this important editorial project, in which I had the honor of working for nine years as Coeditor-in-Chief. Having as main research focus the development of techniques and the use of secondary databases, reviewing the scientific production of this topic within CSP allowed me to recall articles that were fundamental references for my education and development of my research projects.

The first CSP issue appeared in 1985. Internationally the sale of personal computers (PCs) ¹ was gaining momentum, followed in the early 1990s by the opening of access to the World Wide Web (WWW) ² to the public. These advances were significant for popularizing information technologies.

Administrative databases began to be used as secondary data sources in Public Health research ³. In the 1990s, and in the first decade of the 2000s, Data Centers were implemented in Australia, Canada, and the United Kingdom. In these organizations, administrative databases are linked continuously, and the resulting anonymized datasets can be accessed by researchers to develop their projects ⁴.

In the same period, Brazil created the Brazilian Health Informatics Department (DATASUS, acronym in Portuguese) ⁵ in 1991, which contributed significantly to accessibility to the Brazilian administrative databases. The model adopted for data dissemination was, however, different from the Data Center mentioned above. Two access modalities were made available: one through an online tabulator, which allows to create tables of the main national Health Information Systems; the other by the dissemination of unidentified microdata. The databases were initially distributed on monthly compact discs (CDs), and later made available for online downloads. Information on births, deaths, notifiable diseases, primary care, outpatient and hospital care, health facilities and public budget began to be made available not only to researchers, but also to the population at large. This Open Data model is unique for its innovation, data variety, time and territorial coverage of the databases, and inclusive access. Digital format information of interest to health care also began to be made available by different institutions such as the Brazilian Institute of Geog-

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raphy and Statistics (IBGE, acronym in Portuguese), the Brazilian National Supplementary Health Agency (ANS, acronym in Portuguese), the Brazilian Health Regulatory Agency (Anvisa, acronym in Portuguese), as well as state and municipal Health Departments.

Even before digital dissemination, administrative data, especially on mortality, were used in Brazil for Public Health research. However, the ease of access provided by the adhesion of Brazilian institutions to the open data model encouraged this type of use. By consulting PubMed, I identified 461 articles published in CSP that used administrative data, of which 86 addressed quality-related topics. Among the latter, the article stemming form Claudia Risso de Araujo Lima's thesis stands out ⁶. Claudia, who was a member of the DATASUS team, was one of those responsible for implementing the health information dissemination policy in Brazil. Published in 2009, her article continues to be referenced (96 citations in the Scopus database). Her major contribution is to review quality dimensions in the evaluation of Brazilian health information systems.

Publishing articles that assess the quality of both information systems and processes for linking databases meets a growing demand for the adoption of good practices in conducting and reporting studies that use secondary data ^{7,8}. An editorial ⁹ and a perspective paper ¹⁰ reinforce CSP's editorial policy of promoting the responsible use of administrative databases in research.

CSP has also published four methodological articles presenting computational routines for database processing. Three solutions focused on record linkage ^{11,12,13} and the fourth, the Microdatasus ¹⁴ package, optimizes the download and pre-processing of microdata made available by DATASUS. In 2000, Reclink was published as a free but closed-source software ¹¹. The new OpenReclink version was published in 2015 as open source ¹². EPPD ¹³ and Microdatasus ¹⁴ are also open source, in compliance with CSP's editorial policy of adhering to open science ¹⁵.

Information technologies saw a rapid expansion in these 40 years. Advances in the capacity to capture, process, store, communicate and analyze data occurred successively, with incremental advances in each area stimulating advances in the others. Currently, we can process large amounts of information in real time. Unstructured data in different formats, such as texts in documents or social networks, images, and sensor outputs, are new sources for secondary use in research. Moreover, techniques developed by Information Science such as data mining, machine learning, and large language models (LLMs) were introduced into health research. These innovations led to the creation of a new disciplinary field, called Population Data Science ^{16,17} which, through the organization, integration, linkage, and analysis of individual and contextual data, intends to generate population level evidence valuable for society. Articles on the development or application of record linkage techniques have been published in CSP since the 2000s. Recently, with the greater dissemination in Public Health of Information Science techniques, articles using data mining, text and machine learning have been published.

In addition to technical issues, Population Data Science seeks models for managing information access that balance the right to personal information protection with the potential benefits to society of using administrative databases in research, a topic addressed by more than one article published in CSP 18,19,20.

Over the course of 40 years, CSP has published articles addressing the main topics of Population Data Science, promoting good practices in the use of secondary data in research of interest to society. Consistent with its mission, it proved to be a crucial vehicle for circulating ideas and methods in this field.

Additional information

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- McCracken H. TIME's Machine of the 13. Brustulin R, Marson PG. Inclusão de etapa 1. Year, 30 years later. https://techland.time. com/2013/01/04/times-machine-of-the-year-30-years-later (accessed on 09/May/2024).
- 2 Redator Rock Content. Conheca a história da Internet, sua finalidade e qual o cenário atual. https://rockcontent.com/br/blog/historia-da--internet/ (accessed on 09/May/2024).
- 3. Boslaugh S. Secondary data sources for public health: a practical guide. Cambridge: Cambridge University Press; 2007.
- 4. Coeli CM, Pinheiro RS, Camargo Jr. KR. Conquistas e desafios para o emprego das técnicas de record linkage na pesquisa e avaliação em saúde no Brasil. Epidemiol Serv Saúde 2015; 24:795-802.
- 5. Ministério da Saúde. Departamento de Informática do SUS. Trajetória 1991-2002. Brasília: Ministério da Saúde; 2002.
- Lima CRA, Schramm JMA, Coeli CM, Silva MEM. Revisão das dimensões de qualidade dos dados e métodos aplicados na avaliação dos sistemas de informação em saúde. Cad Saúde Pública 2009; 25:2095-109.
- 7. Leonelli S. A pesquisa científica na Era do Big Data: cinco maneiras que mostram como o Big Data prejudica a ciência, e como podemos salvá-la. Rio de Janeiro: Editora Fiocruz; 2022.
- 8. Christen P, Schnell R. Thirty-three myths and misconceptions about population data: from data capture and processing to linkage. Int J Popul Data Sci 2023; 8:2115.
- 9. Coeli CM. A qualidade do linkage de dados precisa de mais atenção. Cad Saúde Pública 2015; 31:1349-50.
- 10. Coeli CM, Pinheiro RS, Carvalho MS. Neither better nor worse, simply different. Cad Saúde Pública 2014; 30:1363-5.
- 11. Camargo Jr. KR, Coeli CM. Reclink: aplicativo para o relacionamento de bases de dados, implementando o método probabilistic record linkage. Cad Saúde Pública 2000; 16:439-47.
- 12. Camargo Jr. KR, Coeli CM. Going open source: some lessons learned from the development of OpenRecLink. Cad Saúde Pública 2015; 31:257-63.

- de pós-processamento determinístico para o aumento de performance do relacionamento (linkage) probabilístico. Cad Saúde Pública 2018; 34:e00088117.
- 14. Saldanha RF, Bastos RR, Barcellos C. Microdatasus: pacote para download e pré-processamento de microdados do Departamento de Informática do SUS (DATASÚS). Cad Saúde Pública 2019; 35:e00032419.
- 15. Carvalho MS. Aberto, por quê? Cad Saúde Pública 2015; 31:221-2.
- McGrail K, Jones K, Akbari A, Bennett T, Boyd 16. A, Carinci F, et al. A position statement on population data science: the science of data about people. Int J Popul Data Sci 2018; 3:415.
- 17 Coeli CM. Ciência de dados populacionais. Epidemiol Serv Saúde 2022; 31:e2022119.
- Ventura M. Lei de acesso à informação, priva-18. cidade e a pesquisa em saúde. Cad Saúde Pública 2013; 29:636-8.
- Ventura M, Coeli CM. Para além da privacida-19. de: direito à informação na saúde, proteção de dados pessoais e governança. Cad Saúde Pública 2018; 34:e00106818.
- 20. Keinert TMM, Cortizo CT. Dimensões da privacidade das informações em saúde. Cad Saúde Pública 2018; 34:e00039417.

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