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Extent of Open Science Practices in the Reporting of Real World Evidence Research

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Abstract

Introduction
Open sharing of research methods and software code is fundamental to open science principles and reproducible research practices and has long been the norm in some scientific disciplines. Increasingly, scientific publishers are introducing policies to encourage or mandate sharing of research protocols and analytical code. Code sharing is especially important when research data cannot be shared, as is often the case in research using population data. However, the prevalence of protocol and code sharing in population data science research has been underexplored.

Objectives
To assess open science practice usage by authors in real world evidence (RWE) research published in the International Journal of Population Data Science (IJPDS).

Method
We reviewed RWE research articles publishing estimates of associations in the IJPDS from January 2019 to October 2024. We determined the proportion of published articles reporting (i) a link to a study protocol, (ii) a link to a pre-registered study protocol, (iii) a statement about the availability of the data, (iv) a link to the analytical code, and (iv) reference to a reporting checklist or guideline.

Results
None of the 41 eligible articles met all five open science domains. One article included a link to the study protocol and none cited a pre-registered protocol. Fourteen (34%) articles included a statement about data availability. No articles included a link to the analytical code, although one included it in supplementary material and two indicated availability on request. Five (12%) articles referred to using a reporting checklist. There was no clear evidence of increasing adoption of open science practices over time.

Conclusions
Researcher alignment with international best practice for open science was poor among RWE articles published in IJPDS. Potential solutions to encourage an open science culture include increasing awareness through training and education, building Communities of Practice, providing incentives and implementing open science publication policies.

Keywords
real word evidence; reporting guidelines; reproducibility; transparency; open science; data science; data sharing; software

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Introduction

In recent years, there has been a push towards open science practices to make research openly available and publicly accessible for others to reuse. Although there can be many interpretations of what open science entails [1], common practices include open access publishing, pre-registering analyses, and sharing research outputs such as protocols, data and code [2]. Open science practices aim to improve the overall quality of research by increasing accessibility and promoting research transparency, reproducibility, reliability and collaboration [3]. They provide researchers the means to verify analyses, replicate results and reduce duplication and research waste as existing knowledge is built upon [4]. Open science practices can also democratise access to high-quality research tools and methods, particularly benefiting researchers in resource-limited settings [5].

The adoption of open science practices has been facilitated by journals, funders, and institutions who have been progressively transitioning to open access publication models and introducing policies to encourage and sometimes mandate sharing of protocols, data and code. Furthermore, the FAIR (Findability, Accessibility, Interoperability and Reusability) principles [6] which guide best practice scientific data management to support open data are increasingly being adopted by research organisations. An adapted version for open code, the "FAIR for research software (FAIR4RS) principles," are similarly gaining traction amongst the research community [2].

Open science practices are routine or mandated by many scholarly societies and publishers, including genetics [7], environmental science [8], geophysics [9], astronomy [10], life sciences [11], biological/physical/social sciences [12] and computer science and chemistry [13], where there is a long tradition of making data and code available. However, there is little evidence to demonstrate the openness of research within the population data science community, despite the field being well-suited to benefiting from an open science approach. Enhanced transparency, reproducibility and collaboration would help drive policy development informed by population data studies given the field's multi-disciplinary nature and its use of data drawn from privacy-sensitive sources [14]. Code sharing in particular is important for supporting reproducibility in situations where research data themselves may not be readily shared to protect the privacy and confidentiality of individuals and organisations.

In health and medical research, open data and sharing of code or software remain uncommon [15–17], despite many researchers being aware of the advantages of open science and research reproducibility [4]. The situation is likely to be similar for real world evidence (RWE) studies, and indeed a framework for an explicit transparency statement for these studies has recently been proposed [18]. Despite several assessments of the open science practices in specific fields of research (e.g. cancer, surgery) [15, 19, 20], the extent of openness in RWE research has been underexplored to date. Therefore, this study aimed to examine the degree to which open science practices have been adopted amongst RWE research published between January 2019 to October 2024 in the *International Journal of Population Data Science* (IJPDS). Within this context, RWE research refers to studies that generate evidence from data collected from routine healthcare delivery.

Methods

We performed a review of all RWE 'research articles' and 'methodological developments' papers published in the IJPDS (https://ijpds.org) from January 2019 to October 2024. To be eligible for this review, an article reported estimates of association based on individual-level routinely collected observational data, including administrative, electronic medical record, and registry datasets, using a single dataset or linked datasets. Ineligible articles were non-original research articles such as perspectives, commentaries and literature reviews, and case studies, protocol papers, data resource profiles, as classified by the journal. Each original research article was reviewed and manually categorised by the authors; research that was qualitative only, that described only data linkage methods or algorithm development or reported only descriptive statistics, was also ineligible for inclusion.

Two authors (NK and CMV) independently reviewed each published article for eligibility and extracted standardised information from eligible studies. For each published article we extracted the article digital object identifier (DOI), first author name, and year of publication. For ineligible articles we recorded the reason for ineligibility. For eligible articles we extracted information for each of the five transparency domains for RWE studies proposed by Wang and Pottegård [18], as described in Table 1. Wang and Pottegård selected these domains based on their alignment to the Transparency and Openness Promotion (TOP) guidelines, and because they are actions researchers can take to facilitate reproducible research [21]. Differences between reviewers regarding study eligibility, extracted information and transparency coding were resolved through discussion and confirmation against the published article. We then calculated the number and proportion of all eligible articles that met each domain.

Results

A total of 41 eligible and 139 ineligible research articles were published in IJPDS over the study period. Details of the ineligible studies, and the reasons they were judged to be ineligible, are given in Supplementary Table 1. The data abstracted from the eligible studies are given in Supplementary Table 2.

No eligible RWE articles satisfied the reporting requirements for all five open science domains and correspondence with individual domains was low (Table 2). There was no clear evidence of increasing reporting against any of the domains over time. Additionally, there was no apparent correlation between the open science practices. Adhering to one of the domains did not increase the likelihood of the research following the other practices.

Two articles referred to a study protocol; one included a link to the study protocol and the other noted the protocol was available on request. No articles stated the study protocol was pre-registered. Fourteen articles included a stand-alone

Table 1: Domain elements and data abstraction for eligible RWE articles

Open science domain [18]	Domain relevance to transparency and reproducibility in RWE research	Information abstracted
Protocol	The a priori scope of the research question(s), study design, data sources and analyses. Plus, version control showing any improvements or additions, including justifications for these amendments. The use of structured protocol templates (e.g., the Harmonized Protocol to Enhance Reproducibility, HARPER [22]) facilitates use of best practice approaches. This transparency reduces the risk of presenting a post hoc hypothesis as an a priori hypothesis, and the selective presentation of evidence.	Did the article refer to a study protocol? If so, did the article include a weblink to the study protocol, or was it available from the authors on request?
Pre-registration	A time-stamped, accessible protocol. This transparency also helps reduce research waste and publication bias. It is most valuable for inferential analyses.	Was the study protocol pre-registered and if so, was a weblink provided?
Data	The location where others can find or regenerate the source data. As individual-level health information is rarely publicly available or able to be shared, researchers can include guidance on how to regenerate the sourced data, including version information and the date of the data extract(s). Alternatively, privacy-preserving synthetic data could be provided. This information or data will enable analyses to be reproduced.	Did the article include a data availability statement, and if so, were the details of the data repository given?
Code sharing	Shared code that is well annotated allows others to reproduce the study. Ideally it includes the code used to generate the analytical dataset from the source data, as well as the code that creates results, tables and figures. The generation of reproducible code is facilitated by open source version control systems such as Git.	Did the article include a statement about the availability of analytical code, including whether it was included with the article, available on request, or available online (with a weblink)?
Reporting checklist	Lists the most critical elements of research that must be included in publications to allow an assessment of the research quality and allow it to be reproduced. The current best practice checklist is the Reporting of Studies Conducted using Observational Routinely Collected Health Data Statement for Pharmacoepidemiology (RECORD-PE) [23].	Did the article state whether the research had been written up in alignment with an international checklist or guideline?

statement about the availability of the data and six of these articles included access details. No articles included a weblink to the analytical code, although one included the code in supplementary material (link not currently functional) and two indicated it was available on request. Five articles referred to using a reporting checklist.

Discussion

This paper reviewed RWE research articles recently published in the IJPDS to gain insight to the extent of contemporary open science practices in population data science. Given the IJPDS is itself an open access journal, we focused on evaluating the five open science domains described by Wang and Pottegård as the key building blocks for transparency and reproducibility in RWE studies [18]. These domains are based on the Transparency and Openness Promotion (TOP) guidelines, which outline best practice recommendations for research practices and are used as indicators to measure research reproducibility [21].

Overall, we found a low prevalence of studies reporting these open science practices, suggesting their limited adoption in the population data science community. Reporting of study protocol pre-registration was particularly poor with no articles including a statement on this. However, these numbers may reflect an underestimation of the practice if researchers had pre-registered their study protocol without reporting it in their publications. This could similarly be the case for reporting checklists, although in both cases research transparency and reproducibility is reduced without publicly sharing and providing access to this information.

Although data availability had the highest prevalence with 34% of articles including a stand-alone statement, this proportion was lower than expected when considering the IJPDS' requirement for all research articles to include a

Table 2: Proportion of eligible IJPDS RWE articles reporting open science domain practices, January 2019 to October 2024

Open science domain [18]	Number (%) of articles meeting the domain	Publication year of article(s)
Included a statement about access to the study protocol	2 (5%)	2024, 2021
The study protocol was pre-registered	0 (0%)	
Included a stand-alone statement about the availability of the data	14 (34%)	2024 (5), 2023 (1), 2022 (1), 2021 (4), 2020 (2), 2019 (1)
Included a statement about the availability of analytical code	3 (7%)	2024, 2021 (2)
Included a statement about aligning to reporting checklist or guideline	5 (12%)	2024, 2022, 2021, 2019 (2)

'Data Availability Statement' when publishing. Reasons for this discrepancy are unclear but could be lack of awareness and inconsistent enforcement of the policy. It should also be noted that inclusion of a data availability statement does not necessarily mean the data were directly accessible, and only six of the 14 articles with a data availability statement provided access details. Similar trends have been observed across other journals and funding agencies where mandating publishing of data, source code and/or software [24, 25] has not always led to a meaningful uptick in sharing rates [15, 26].

RWE studies using individual-level health data are typically unable to publish their datasets in open access repositories due to legislation and policies designed to protect the privacy of individuals and institutions. Indeed, privacy concerns and risk of data misuse have consistently been identified as one of the top barriers to sharing by public health researchers [4]. One potential solution is the use of synthetic data, which can preserve the key statistical properties of the original data whilst mitigating privacy risks [27].

Sharing of analytical code generally poses minimal risk of disclosing the identities of individuals or health care organisations, or revealing sensitive health information. As such, code can often be made publicly available even if the underlying unit record data cannot. Releasing well annotated research code alongside data availability statements enables analyses to be reproduced using the same or periodically updated data, a major advantage when open data access is not possible.

However, code relating to some machine learning models may pose additional privacy risks. For example, training data may inadvertently be embedded within model descriptions or parameters, requiring careful review prior to release to ensure privacy is maintained [28]. Barring such exceptions—or licensing restrictions that explicitly prohibit the redistribution of code—there is little reason why RWE researchers using standard statistical methods, like the articles reviewed here, should not share code.

Despite this, we found that the proportion of articles reporting code availability was even lower than those reporting data availability. Moreover, none of the articles that included a statement on the availability of code provided open access to it. Statements that the code is "available on request", fall short of best practice, as this approach lacks transparency, version control, and long-term accessibility.

Commonly cited barriers for code sharing include a lack of knowledge, experience, incentives and time, as well as concerns about the inclusion of potentially sensitive information [4, 29, 30]. Additionally, emotional barriers such as feelings of embarrassment or fear are powerful disincentives towards openly sharing code [29]. Many researchers are reluctant to publish work they do not believe is "polished" or of an acceptable standard to publicly share, [31] highlighting the need to provide safe environments for researchers to learn and develop the confidence to share their work. There are also fears regarding the consequences of the detection of errors, as well as loss of control over research outputs.

Shifting the culture

The Centre for Open Science has a strategy for implementing culture change, [32] which describes a pyramidal model of five progressive intervention levels: 'Infrastructure, user interface/experience, communities, incentives, and policies.' Advancements in tools and technical infrastructure have lowered barriers to sharing data and code. Open access repository-hosting platforms including GitHub or GitLab are highly accessible and allow for easy publishing of data or code. Furthermore, digital repositories such as Zenodo, Open Science Framework and Figshare offer persistent identifiers (e.g.DOIs), enabling researchers to archive versioned code for longer-term preservation and receive academic credit through citation.

At the community level, institutions, professional societies, networks, and conference organisers can play a key role in increasing the visibility and awareness of open science practices by actively promoting their benefits. Offering training courses and workshops, particularly for early career researchers, will help ensure the next generation of researchers are advocates for reproducible research practices which will be important in shaping the culture in the long-term [4]. Early career researchers are also likely to have more time to undertake training and can in turn support more senior researchers in adopting these new practices. Establishing Communities of

Practice, wherein researchers can share knowledge, skills and code in a supportive environment may reduce apprehension about public sharing [29]. The Carpentries are an exemplary example of a Community of Practice that delivers data and coding workshops that build capacity and promote open, reproducible research practices [33].

Incentives, policies, and mandates can further reinforce open science practices. Incentive mechanisms from other disciplines can readily be adapted to population data science research. For instance, open data badges used to recognise data sharing have been demonstrated to increase data sharing within some scientific disciplines [34, 35]. Whilst comparable studies for open code and open materials badges are limited, some journals or institutions already offer these badges [36, 37] as a motivational incentive and to recognise researchers' efforts in sharing their software. Such incentives should be underpinned by rigorous checks or peer review to ensure quality, executability, and so on, to build trust and accountability. Badges are only one possible approach. Communities, journals, and professional societies should consider other forms of awards such as grants or prizes for code sharing. For example, EarthCube, a geoscience research community, annually review open source computational notebooks and award the best example code [38].

At the top of the culture change pyramid is the implementation of mandatory code sharing policies, such as journals implementing requirements for releasing code alongside publications [39, 40]. An increasing number of journals are already adopting such policies. Funding agencies can also consider mandating code to be shared as a condition of projects receiving grants, akin to the United States National Institutes of Health model which requires data sharing plans to be submitted with grant applications [41].

Adequate financial and technical support is essential, as preparing data and code for sharing is technically complex and resource-intensive. Data sharing platforms can be designed not only to support sharing through technical means, but also to address policy barriers [42]. Artificial-Intelligence (AI)-powered tools also present the potential to facilitate sharing by automating aspects of code and data preparation [43].

These considerations reinforce that effective code sharing requires careful implementation. While sharing code can enhance transparency and reproducibility, potential risks include the facilitation of "sloppy science" through reuse without adequate understanding of underlying assumptions and modelling choices, and the propagation of misinformation through misleading or poorly contextualised reanalyses of data [44].

International initiatives

Whilst low code sharing rates are seen across health research in general [16], internationally there are several successful initiatives that could be adapted to help encourage code sharing. The United Kingdom (UK) has OpenSAFELY, an open source platform for analysing sensitive health data. Researchers are given access to synthetic data for the purpose of developing their statistical analysis software and are required to openly publish this software for review before it can be run against the real data [45]. As researchers are not provided direct access to the real data, the risk of disclosure in the code is negligible whilst the open release of the code facilitates transparency, reproducibility, and confidence in the health research. However, development and maintenance of the OpenSAFELY infrastructure has required substantial investments from research funding agencies and the UK government [46].

Another tool used broadly across the UK, USA and Canada is the 'concept library'. These are platforms or portals that compile and curate standard concepts, code, or algorithms for reuse across multiple projects. For example, a standardised definition for phenotyping clinical conditions using administrative records [47–49]. Concept libraries are a simple way of openly sharing best practice code and encouraging consistency across the sector. However, building a concept library does rely on researchers' contributions and thus are subject to the cultural and resource barriers discussed above.

Limitations of the study

There are several limitations to our study. Firstly, we acknowledge the pool of articles reviewed was small and from a single journal, therefore we cannot generalise these results across the field. Furthermore, given the small sample size, we did not break down the articles into study types. However, future research could explore whether certain types of RWE studies, data sources, settings and funders are more likely to demonstrate open research practices.

We are hopeful these findings provide a starting point for discussing and improving the use of open science practices within this discipline. Understanding the barriers and enablers of open science practices amongst the population data science community, as well as implementing and evaluating cultural shift strategies, could be valuable areas of future work.

Conclusion

In summary, our analysis of RWE articles recently published in the IJPDS has provided an indication of the low prevalence of open science practices amongst population data science research. Code sharing in particular is uncommon. Culture change is an often-overlooked barrier to increasing code sharing rates. To enable a cultural shift, we must work towards normalising the practice through increasing visibility and creating supportive spaces and Communities of Practice to share knowledge and build trust. Introducing incentives and policies to reward and reinforce code sharing as a standard practice will help to sustain this culture and contribute towards improving transparency and reproducibility in population data science research. We recommend that (i) all journals publishing RWE research require articles to explicitly comply with or at least report on the five open science indicators and display Open Science Badges on publications [18], and (ii) reviewers explicitly report on the indicators when reviewing manuscripts submitted for publication. Our findings highlight an opportunity to enhance transparency in RWE research published in the IJPDS, and the need to foster a stronger culture of open science within the population data science community, so this becomes the norm.

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AI Statement

An author used Perplexity and ChatGPT for research and language editing recommendations. All text was written and edited by the authors.

Statement on Conflicts of Interest

The authors have no conflicts of interest to declare.

Ethics Statement

The research did not require ethical approval because it used publicly available information that is not personally identifiable.

Data Availability Statement

The data collected for this article can be found in Supplementary Tables 1 and 2.

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Abbreviations

RWD:	Real world data
RWE:	Real world evidence
IJPDS:	International Journal of Population Data Science

Supplementary Table S1: IJPDS articles judged as ineligible for inclusion in RWE review

Article DOI	Year	First author name	Reason ineligible
https://doi.org/10.23889/ijpds.v9i1.2163	2024	Bethania de Araujo Almeida	Literature review
https://doi.org/10.23889/ijpds.v9i1.2389	2024	Joseph Lam	Described steps required to generate synthetic identifiers for a RWD collection
https://doi.org/10.23889/ijpds.v9i1.2368	2024	Danielle A Southern	Described a new centre for health informatics
https://doi.org/10.23889/ijpds.v9i1.2181	2024	Rachel Burns	Described a linkage process and linkage rates
https://doi.org/10.23889/ijpds.v9i1.2137	2024	Richard J Silverwood	Described the quality and population-representativeness of linked data
https://doi.org/10.23889/ijpds.v9i1.2378	2024	Anderson Wong	Developed and proposed an ontology for Census data
https://doi.org/10.23889/ijpds.v9i1.2358	2024	Naomi Hamm	Applied and compared trend control charts
https://doi.org/10.23889/ijpds.v9i1.2377	2024	Ava Phillips	A cohort profile paper reporting unadjusted descriptive statistics
https://doi.org/10.23889/ijpds.v9i1.2385	2024	Amanda Clery	An assessment of the completeness of a community services dataset
https://doi.org/10.23889/ijpds.v9i1.2394	2024	Kasper Bonnesen	Described agreement/validity of exposures and outcomes in a Registry
https://doi.org/10.23889/ijpds.v9i1.2380	2024	Deepak Louis	Described agreement/validity of variables in a dataset
https://doi.org/10.23889/ijpds.v9i1.2372	2024	Kimberlyn McGrail	Described a deliberative public engagement
https://doi.org/10.23889/ijpds.v9i1.2412	2024	Anousheh Marouzi	Reported descriptive statistics only
https://doi.org/10.23889/ijpds.v9i1.2398	2024	Jo Davies	Reported descriptive statistics only
https://doi.org/10.23889/ijpds.v9i1.2381	2024	Sarah Harding	Described stakeholder engagement
https://doi.org/10.23889/ijpds.v9i1.2379	2024	Gillian Harper	Described a method for deriving households from electronic health records
https://doi.org/10.23889/ijpds.v9i1.2370	2024	James Ayles	Case study
https://doi.org/10.23889/ijpds.v9i1.2375	2024	Julia Burt	Described stakeholder engagement
https://doi.org/10.23889/ijpds.v8i1.2072	2023	Fiona Lugg-Widger	Described data linkage
https://doi.org/10.23889/ijpds.v8i1.2151	2023	Julie-Anne R. Smit	A perspective, not original research
https://doi.org/10.23889/ijpds.v8i1.2113	2023	Francesca L. Cavallaro	Described lessons from two observational studies using linked administrative data
https://doi.org/10.23889/ijpds.v8i1.1771	2023	Themba Mutemaringa	Data linkage algorithm and data completeness
https://doi.org/10.23889/ijpds.v8i1.2134	2023	Iffat Naeem	Qualitative, interviews only
https://doi.org/10.23889/ijpds.v8i1.2144	2023	Alexander Hartenstein	Algorithm development
https://doi.org/10.23889/ijpds.v8i1.2130	2023	Piotr Teodorowski	Qualitative, interviews only
https://doi.org/10.23889/ijpds.v8i1.2122	2023	Rainer Schnell	Described linkage quality
https://doi.org/10.23889/ijpds.v8i1.2165	2023	Felix Ritchie	Disclosure risk of outputs from machine learning models, literature review and public engagement
https://doi.org/10.23889/ijpds.v8i1.2156	2023	Zeina Jamaluddine	Described data linkage with birth and education records
https://doi.org/10.23889/ijpds.v8i1.2115	2023	Peter Christen	Described myths and misconceptions of data linkage
https://doi.org/10.23889/ijpds.v8i1.1843	2023	Jeanne Sinclair	Data linkage validation study
https://doi.org/10.23889/ijpds.v8i1.2176	2023	Olawale F. Ayilara	Comparison of synthetic and real data
https://doi.org/10.23889/ijpds.v8i1.2153	2023	Bekelu Negash	Review article

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Supplementary Table S1: Continued

Article DOI	Year	First author name	Reason ineligible
https://doi.org/10.23889/ijpds.v8i1.1901	2023	Jamie Danemayer	Review article
https://doi.org/10.23889/ijpds.v8i1.2158	2023	Claire Little	Review article
https://doi.org/10.23889/ijpds.v8i1.2139	2023	Jing Wang	Protocol paper
https://doi.org/10.23889/ijpds.v8i1.2129	2023	Nadine Andrew	Protocol paper
https://doi.org/10.23889/ijpds.v8i1.2121	2023	Shona Kerr	Protocol paper
https://doi.org/10.23889/ijpds.v8i1.2125	2023	Nakia Lee-Foon	Commentary
https://doi.org/10.23889/ijpds.v8i1.2131	2023	Julia Nadine Doetsch	Commentary
https://doi.org/10.23889/ijpds.v8i1.2116	2023	Lindsay Pearce	Commentary
https://doi.org/10.23889/ijpds.v7i1.1727	2022	Theodora Kokosi	Overview of uses of synthetic data and methods used to generate it
https://doi.org/10.23889/ijpds.v7i1.1690	2022	Winifred Badaiki	Overview of partnership and data to study psoriatic disease
https://doi.org/10.23889/ijpds.v7i1.1712	2022	Fiona Victoria Lugg-Widger	Described curriculum development for researcher training
https://doi.org/10.23889/ijpds.v7i1.1693	2022	Gwenllian Moody	Qualitative study on attitudes to the collection and linkage of maltreatment data
https://doi.org/10.23889/ijpds.v7i1.1689	2022	Claire de Oliveira	Described social and health data linkage strategy
https://doi.org/10.23889/ijpds.v7i1.1724	2022	Rowena Griffiths	Described administrative and clinical data linkage
https://doi.org/10.23889/ijpds.v7i1.1749	2022	Charlotte Baker	Described data linkage methods
https://doi.org/10.23889/ijpds.v7i1.1713	2022	Benjamin Daniels	Validated registry records against original electronic medical records
https://doi.org/10.23889/ijpds.v7i1.1708	2022	Eva Graham	Pathways of healthcare use for overdose deaths, descriptive only
https://doi.org/10.23889/ijpds.v7i1.1721	2022	Sara Giro Correia	Data quality study and thematic analysis of crime data
https://doi.org/10.23889/ijpds.v7i1.1700	2022	Laura Schummers	Comparison of methods to identify abortion in administrative records
https://doi.org/10.23889/ijpds.v7i1.1722	2022	Peter Brandon	Comparison of methods to identify same-sex couples in household survey data
https://doi.org/10.23889/ijpds.v7i1.1757	2022	Marcello Nesca	Review article
https://doi.org/10.23889/ijpds.v7i1.1718	2022	Louise McGrath-Lone	Review article
https://doi.org/10.23889/ijpds.v7i1.1732	2022	Natalie Wray	Described development of online application system
https://doi.org/10.23889/ijpds.v7i1.1694	2022	Alexandra Lee	Data resource profile
https://doi.org/10.23889/ijpds.v7i1.1752	2022	Gemma Allnatt	Data resource profile
https://doi.org/10.23889/ijpds.v6i1.1376	2021	Alice Rose Dawson	Described data linkage processes and challenges
https://doi.org/10.23889/ijpds.v6i1.1679	2021	Georgina M Chambers	Described data linkage methods and performance
https://doi.org/10.23889/ijpds.v6i1.1397	2021	Natalie Wiebe	Described results of hospital chart review
https://doi.org/10.23889/ijpds.v6i1.1406	2021	Amani F. Hamad	Described crosswalks for three ICD versions
https://doi.org/10.23889/ijpds.v6i1.1674	2021	Gill Harper	Described an evaluation of an address matching algorithm
https://doi.org/10.23889/ijpds.v6i1.1671	2021	Nicolás Libuy	Described linkage process and quality
https://doi.org/10.23889/ijpds.v6i1.1654	2021	Dr Catherine R Hanna	Described the process of creating a national linked dataset
https://doi.org/10.23889/ijpds.v6i1.1650	2021	Sylvia Aponte-Hao	Described a validated definition of frailty using primary care records
https://doi.org/10.23889/ijpds.v6i1.1672	2021	Ming Ye	Descriptive study of chronic disease incidence using linked datasets

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Supplementary Table S1: Continued

Article DOI	Year	First author name	Reason ineligible
https://doi.org/10.23889/ijpds.v6i1.1665	2021	Matthew Jose	Descriptive study of chronic kidney disease using linked datasets
https://doi.org/10.23889/ijpds.v6i1.1387	2021	James Rafferty	Descriptive study of diabetes mellitus using linked datasets
https://doi.org/10.23889/ijpds.v6i1.1378	2021	Kathleen Lamont	A multi-country survey of birth and perinatal data collection
https://doi.org/10.23889/ijpds.v6i1.1373	2021	Laszlo Trefan	A methodological study to determine alcohol-related hospital admissions
https://doi.org/10.23889/ijpds.v6i1.1410	2021	Meghan O'Neill	Descriptive study of health and health service use by homicide victims
https://doi.org/10.23889/ijpds.v6i1.1398	2021	Shaun Francis Purkiss	A comparison of methods to determine incidence and prevalence of treated diabetes
https://doi.org/10.23889/ijpds.v6i1.1381	2021	Heather J Baldwin	Validation of maternal medical conditions in admitted patient data
https://doi.org/10.23889/ijpds.v6i1.1418	2021	Juliana de Oliveira Costa	Review article
https://doi.org/10.23889/ijpds.v6i1.1686	2021	Naomi Hamm	Review article
https://doi.org/10.23889/ijpds.v6i1.1362	2021	Zahra Ahmed	Review article
https://doi.org/10.23889/ijpds.v6i1.1653	2021	Cynthia Kendell	Protocol paper
https://doi.org/10.23889/ijpds.v6i1.1419	2021	Tyler Lane	Protocol paper
https://doi.org/10.23889/ijpds.v6i1.1400	2021	John Cunningham	Protocol paper
https://doi.org/10.23889/ijpds.v6i1.1678	2021	Heather Higgins	Case study
https://doi.org/10.23889/ijpds.v6i1.1412	2021	Marcelo Urquia	Case study
https://doi.org/10.23889/ijpds.v6i1.1680	2021	Kamala Adhikari	Described variable harmonization strategies
https://doi.org/10.23889/ijpds.v6i1.1386	2021	Valerie Nicholson	Described approach to Indigenous community leadership in research
https://doi.org/10.23889/ijpds.v6i1.1417	2021	Robyn Rowe	Described approaches to linkage of Indigenous population health data
https://doi.org/10.23889/ijpds.v5i1.1339	2020	Rhodri David Johnson	Described data linkage between justice and health data
https://doi.org/10.23889/ijpds.v5i3.1352	2020	Natalie Wiebe	A chart review to identify missing discharge summaries in electronic medical records
https://doi.org/10.23889/ijpds.v5i1.1144	2020	Shabnam Asghari	A narrative case study of developing a database of people living with HIV
https://doi.org/10.23889/ijpds.v5i1.1100	2020	Bridgette J McNamara	A comparison of methods to identify Indigenous children
https://doi.org/10.23889/ijpds.v5i1.1152	2020	Benjamin Daniels	A validation study of dispensing records to identify incident cancer cases
https://doi.org/10.23889/ijpds.v5i1.1155	2020	Yves Payette	A validation study of self-report vs administrative data for health conditions
https://doi.org/10.23889/ijpds.v5i1.1156	2020	Laura Rasmussen-Torvik	A methodological study of the number of visits to be included in an observational study cohort
https://doi.org/10.23889/ijpds.v5i1.1340	2020	Mhd. Wasem Alsabbagh	Development of algorithms to measure primary care indicators using administrative data
https://doi.org/10.23889/ijpds.v5i1.1345	2020	Anushka Vidanage	Evaluated a privacy-preserving record linkage technique
https://doi.org/10.23889/ijpds.v5i1.1160	2020	Yan Wang	A method to estimate population sizes
https://doi.org/10.23889/ijpds.v5i1.1344	2020	Tyler Williamson	Development and validation of a frailty algorithm using primary care data
https://doi.org/10.23889/ijpds.v5i1.1355	2020	Lauren Cross	Thematic analysis of requests to link data in the UK

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Supplementary Table S1: Continued

Article DOI	Year	First author name	Reason ineligible
https://doi.org/10.23889/ijpds.v5i1.1347	2020	Shaun Francis Purkiss	A comparison of disease prevalence estimates from administrative and survey data
https://doi.org/10.23889/ijpds.v5i1.1121	2020	Christian Schnier	A descriptive study of dementia incidence using linked data
https://doi.org/10.23889/ijpds.v5i1.1157	2020	James C Doidge	A comparison of Downs' syndrome prevalence in linked administrative and surveillance datasets
https://doi.org/10.23889/ijpds.v5i1.1151	2020	Tony Whiffen	A comparison of methods to identify Indigenous children
https://doi.org/10.23889/ijpds.v5i1.1346	2020	Rowena Griffiths	A validation study of identifying cystic fibrosis in linked administrative datasets
https://doi.org/10.23889/ijpds.v5i1.1128	2020	Harry Hemingway	Review article
https://doi.org/10.23889/ijpds.v5i1.1158	2020	Iffat Naeem	Review article
https://doi.org/10.23889/ijpds.v5i1.1145	2020	Rohan Borschmann	Protocol paper
https://doi.org/10.23889/ijpds.v5i1.1119	2020	Georgina M Chambers	Protocol paper
https://doi.org/10.23889/ijpds.v5i1.1154	2020	Fiona V Lugg-Widger	Protocol paper
https://doi.org/10.23889/ijpds.v5i1.1338	2020	Nadine J Dougall	Protocol paper
https://doi.org/10.23889/ijpds.v5i1.1353	2020	P Alison Paprica	Described requirements for data trusts
https://doi.org/10.23889/ijpds.v5i1.1125	2020	Lucia Otero Varela	Described distributed data network
https://doi.org/10.23889/ijpds.v5i1.1159	2020	Stuart Bedston	Described a new data resource
https://doi.org/10.23889/ijpds.v5i1.1374	2020	Lindsey Todd Dahl	Commentary
https://doi.org/10.23889/ijpds.v5i1.1099	2020	David Youens	Commentary
https://doi.org/10.23889/ijpds.v5i1.1126	2020	Kate Marie Lewis	Commentary
https://doi.org/10.23889/ijpds.v5i1.1150	2020	Allison Feely	Commentary
https://doi.org/10.23889/ijpds.v5i1.1123	2020	Seungwon Lee	Described a new electronic health record system available for research
https://doi.org/10.23889/ijpds.v4i1.939	2019	Carla Medalia	Described the development of an income dataset
https://doi.org/10.23889/ijpds.v4i1.586	2019	Mhairi Aitken	A consensus statement on public involvement and engagement with data-intensive health research
https://doi.org/10.23889/ijpds.v4i1.1093	2019	Miranda Jane Mourby	Described issues and solutions linking health data for research
https://doi.org/10.23889/ijpds.v4i1.1103	2019	Jack Teng	Results of a deliberative public engagement event
https://doi.org/10.23889/ijpds.v4i1.1095	2019	Adrian P Brown	Evaluated bloom filters for probabilistic linkage
https://doi.org/10.23889/ijpds.v4i1.1109	2019	Kerina H Jones	Review article
https://doi.org/10.23889/ijpds.v4i1.1127	2019	Charini Nanayakkara	An evaluation of group-based record linkage
https://doi.org/10.23889/ijpds.v4i1.1124	2019	Mark Smith	Described tools and techniques to support a population research data repository
https://doi.org/10.23889/ijpds.v4i1.1094	2019	Sean Randall	Evaluation of a protocol for privacy preserving linkage
https://doi.org/10.23889/ijpds.v4i1.1104	2019	Sophie Jane Clark	A learning log and semi-structured interviews regarding data linkage without patient identifiers

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Supplementary Table S1: Continued

Article DOI	Year	First author name	Reason ineligible
https://doi.org/10.23889/ijpds.v4i1.579	2019	Karen Susan Tingay	Linkage rates and descriptive characteristics of cohorts
https://doi.org/10.23889/ijpds.v4i1.1107	2019	Suneela Mehta	Overview of a linked data resource build with cohort descriptive statistics
https://doi.org/10.23889/ijpds.v4i1.587	2019	Kerina Helen Jones	A qualitative survey of challenges using linked administrative data for research
https://doi.org/10.23889/ijpds.v4i1.1074	2019	Theodore Adrien Walls	Review article
https://doi.org/10.23889/ijpds.v4i1.1101	2019	Matthew Alexander Jay	Protocol paper
https://doi.org/10.23889/ijpds.v4i1.582	2019	Nichola McCullough	Protocol paper
https://doi.org/10.23889/ijpds.v4i1.581	2019	Laszlo Trefan	Protocol paper
https://doi.org/10.23889/ijpds.v4i1.1092	2019	Charles Rahal	Protocol paper
https://doi.org/10.23889/ijpds.v4i1.1097	2019	Nadine E Andrew	Protocol paper
https://doi.org/10.23889/ijpds.v4i1.1108	2019	David Alexander Gunn Henderson	Described dataset linkage rates
https://doi.org/10.23889/ijpds.v4i1.1116	2019	Jacqueline Kathleen Kueper	Defined a population health concept across different datasets
https://doi.org/10.23889/ijpds.v4i1.937	2019	Zachary H Seeskin	Described tools to evaluate the quality of administrative data
https://doi.org/10.23889/ijpds.v4i1.465	2019	Kiran Pohar Manhas	Commentary
https://doi.org/10.23889/ijpds.v4i1.1106	2019	P Alison Paprica	Commentary

Supplementary Table S2: Data abstracted from IJPDS articles rated as eligible for inclusion in the RWE review

Article DOI	Publication year	First author name	Protocol available	Referred to using guideline or checklist	Data availability statement	Details of data repository	Syntax available
https://doi.org/10.23889/ijpds.v9i1.2132	2024	Nicolas Libuy	No	No	Yes	Yes	No
https://doi.org/10.23889/ijpds.v9i1.2374	2024	Waleed Mohamed Abdeldayem	No	No	Yes	No	No
https://doi.org/10.23889/ijpds.v9i1.2362	2024	Ian Farr	No	No	Yes	No	No
https://doi.org/10.23889/ijpds.v9i1.2179	2024	Elizabeth Lemmon	No	Yes	No	No	No
https://doi.org/10.23889/ijpds.v9i1.1770	2024	Jen Murphy	No	No	No	No	No
https://doi.org/10.23889/ijpds.v9i1.2364	2024	Elizabeth Darling	No	No	Yes	Yes	Yes; available from authors on request
https://doi.org/10.23889/ijpds.v9i1.2180	2024	Hsei Di Law	Yes	No	Yes	No	No
https://doi.org/10.23889/ijpds.v9i1.2143	2024	Ana Miller	No	No	No	No	No
https://doi.org/10.23889/ijpds.v8i1.2150	2023	Samanta J. Lain	No	No	No	No	No
https://doi.org/10.23889/ijpds.v8i1.2118	2023	Sarah Ahmed	No	No	No	No	No
https://doi.org/10.23889/ijpds.v8i1.1768	2023	Katharina Diernberger	No	No	No	No	No
https://doi.org/10.23889/ijpds.v8i1.1751	2023	Branislav Igic	No	No	No	No	No
https://doi.org/10.23889/ijpds.v8i1.2152	2023	Jinette Comeau	No	No	Yes	No	No
https://doi.org/10.23889/ijpds.v8i1.2123	2023	Alan Katz	No	No	No	No	No
https://doi.org/10.23889/ijpds.v7i1.1756	2022	Jacqueline K Kueper	No	Yes	No	No	No
https://doi.org/10.23889/ijpds.v7i1.1725	2022	Daniela K Schlüter	No	No	No	No	No
https://doi.org/10.23889/ijpds.v7i1.1723	2022	Rhodri David Johnson	No	No	No	No	No
https://doi.org/10.23889/ijpds.v7i1.1717	2022	Amrita Bandyopadhyay	No	No	No	No	No
https://doi.org/10.23889/ijpds.v7i1.1735	2022	Jennifer Enns	No	No	Yes	No	No
https://doi.org/10.23889/ijpds.v6i1.1385	2021	Rachel Pearson	No	No	Yes	No	No
https://doi.org/10.23889/ijpds.v6i1.1342	2021	Orla McBride	No	No	Yes	Yes	No
https://doi.org/10.23889/ijpds.v6i1.1676	2021	Francis Mitrou	No	No	Yes	No	No
https://doi.org/10.23889/ijpds.v6i1.1685	2021	Stuart William Jarvis	No	No	No	No	No
https://doi.org/10.23889/ijpds.v6i1.1407	2021	Natasha Ruth Saunders	Yes; available from authors on request	No	Yes	Yes	Yes; available from authors on request
https://doi.org/10.23889/ijpds.v6i1.1403	2021	Peter Murchie	No	No	No	No	No
https://doi.org/10.23889/ijpds.v6i1.1649	2021	Emma Curran	No	No	No	No	No
https://doi.org/10.23889/ijpds.v6i1.1414	2021	Shaun Purkiss	No	Yes	No	No	No
https://doi.org/10.23889/ijpds.v6i1.1401	2021	Jen Murphy	No	No	No	No	No
https://doi.org/10.23889/ijpds.v6i1.1395	2021	Jason E. Black	No	No	No	No	Yes; supplementary material (link not working)
https://doi.org/10.23889/ijpds.v5i1.1114	2020	Carol Anne McInerney	No	No	No	No	No
https://doi.org/10.23889/ijpds.v5i1.1388	2020	Nicholas Quinn	No	No	No	No	No
https://doi.org/10.23889/ijpds.v5i1.1147	2020	Daphne N. McRae	No	No	No	No	No
https://doi.org/10.23889/ijpds.v5i1.1153	2020	Sunil Kumar Bhat	No	No	No	No	No
https://doi.org/10.23889/ijpds.v5i1.1337	2020	Stephanie Todd	No	No	No	No	No
https://doi.org/10.23889/ijpds.v5i1.1343	2020	Sabrina Wong	No	No	Yes	No	No
https://doi.org/10.23889/ijpds.v5i1.1351	2020	Lauren E Wallar	No	No	Yes	Yes	No
https://doi.org/10.23889/ijpds.v4i1.453	2019	Jennifer Christine Fairthorne	No	No	No	No	No
https://doi.org/10.23889/ijpds.v4i1.461	2019	Lynn Robertson	No	Yes	Yes	Yes	No
https://doi.org/10.23889/ijpds.v4i1.584	2019	Jamie C Brehaut	No	No	No	No	No
https://doi.org/10.23889/ijpds.v4i1.1102	2019	Neeru Gupta	No	Yes	No	No	No
https://doi.org/10.23889/ijpds.v4i1.1122	2019	Michael Rosato	No	No	No	No	No