

The importance of sharing research data on public health topics concerning drug dependence

La importancia de compartir los datos de investigación en temas de salud pública relacionados con la drogodependencia

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Abstract

Research data support the results and conclusions of research projects, making them available in open access allows them to be searched and potentially reused, always for responsible purposes. In the case of public health, making them available, always under the motto “as open as possible and as closed as necessary” is of relevant importance for the applications they may have in treatments and monitoring of diseases, as has already been demonstrated during the pandemic of COVID-19. There are guidelines, policies and legislation requiring open research data, but there is still some reluctance to make it a reality. This article describes some of those policies that affect Spain and the European Union, and also outlines some portals that index data related to drug addiction and drug dependence issues.

Keywords

Open research data; open science; open science policies; research data management; research data repositories; drug addiction.

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Resumen

Los datos de investigación avalan los resultados y conclusiones de proyectos de investigación, poder disponer de ellos en acceso abierto permiten su consulta y potencial reutilización, siempre con fines responsables. En el caso de la salud pública disponer de ellos, siempre bajo el lema de “tan abierto como sea posible y tan cerrado como sea necesario” es de relevante importancia por las aplicaciones que puedan tener en tratamientos y seguimiento de enfermedades, como ya se ha demostrado en la pandemia del COVID19. Existen directrices, políticas y legislación que requieren la apertura de los datos, pero todavía hay reticencias para hacerlo una realidad. En este artículo se enumeran algunas de ellas que afectan a España y al entorno europeo, y también se describen algunos de los portales que indexan datos relacionados con temas de drogadicción y drogodependencia.

Palabras clave

Datos de investigación abiertos; ciencia abierta; políticas de ciencia abierta; gestión de datos de investigación; repositorios de datos; drogodependencia.

INTRODUCCIÓN

According to the UNESCO recommendations adopted unanimously by the member states, published in 2021, Open Science is defined as an inclusive construct that combines various movements and practices aiming to make multilingual scientific knowledge openly available, accessible and reusable for everyone, to increase scientific collaborations and sharing of information for the benefits of science and society, and to open the processes of scientific knowledge creation, evaluation and communication to societal actors beyond the traditional scientific community (UNESCO, 2021). It encompasses all scientific disciplines and is based on the following pillars:

- open scientific knowledge
- open scientific infrastructures
- open engagement of societal actors
- open dialogue with other knowledge systems

Open scientific knowledge refers to open access to scientific publications, research data, metadata, open educational resources, open software and hardware. Sharing data as opened as possible and as closed as necessary is important to contribute to science communication, but also to make data findable, accessible, interoperable and reusable, i.e. compliant with the FAIR data principles (Wilkinson et al., 2016).

Sharing data and facilitating access can promote innovation and potential new uses, lead to collaboration between data users and data creators, maximise transparency and reliability, enable verification of research results, reduce costs by avoiding duplication of data, increase the impact and visibility of research, generate direct recognition for researchers like any other research output, and allows reuse of data in a safe and responsible way.

Data can save lives, open and shared research data from health sciences accel-



erate the development of new medicines and treatments for people in need. Open research data can contribute to identify risk factors and speed diagnosis, identify pathways in disease transmission, thereby preventing disease, predict outcomes and increase the effectiveness of treatments, improve the quality and safety of treatments, and improve public health strategy (Data Saves Lives, n.d.).

However, despite the advantages of data sharing, there is some reluctance among researchers to make their research data publicly available. According to the surveys conducted by Digital Science between 2018 and 2021, the most frequently cited reasons for not sharing data were fear of misuse of their data, lack of recognition for it, not being sure about the licence to assign to the data, or data protection issues in the case of processing personal or confidential data (Digital Science, 2021). These opinions are associated with the lack of trust, the lack of incentives or rewards for opening data, the lack of knowledge of how to do it, and the time involved. There are requirements to share and open research data, always under the motto “as open as possible and as closed as necessary”, which are described below that concerns Spanish scientific community.

RESEARCH DATA STRATEGIES, GUIDELINES AND LEGISLATION

The Spanish Science, Technology and Innovation Strategy 2021-2027 (Ministry of Science and Innovation, 2020) is committed to open science and promotion, in agreement with EU guidelines, of open access

to research outputs, allowing research data to be accessible, interoperable and reusable (FAIR data). This facilitates, together with the infrastructure of repositories, access to scientific advances, promoting scientific dissemination and communication to the society.

Directive (EU) 2019/1024 of the European Parliament and the Council of 20 June 2019 on open data and the re-use of public sector information, ruled that under national open access policies, publicly funded research data will be made open by default, always taking into account issues related to privacy, personal data protection, confidentiality, national security, legitimate commercial interests and intellectual property rights of third parties, in accordance with the principle “as open as possible, as closed as necessary”. This Resolution was transposed in Spain in 2021 by the Royal Decree 24/2021, which amended Law 37/2007 on the re-use of public sector information (BOE 3 November 2021). This amendment introduced a new article, Article 3.bis:

1. *The entities included in the scope of application of Article 2 of this Law and which carry out research activities or fund research projects shall adopt measures to support that publicly funded research data are fully reusable, interoperable and open accessible, taking into account the limitations that may arise from intellectual and industrial property rights, the protection of personal data and confidentiality, security and legitimate commercial interests.*

2. *Without prejudice to Article 3(3). e) and legitimate commercial interests, knowledge transfer activities and pre-existing intellectual property rights, research data shall be reusable for commercial or non-commercial purposes,*

in accordance with the provisions of this Law, when they are publicly funded and when researchers, universities or organisations carrying out research activities or funding research have already made such data publicly available through an institutional or thematic repository and, in all cases, in full compliance with current intellectual property regulations.

The new Science law passed in 2022, which reformed the previous law of 2011 (Government of Spain 2022), modified article 37 on open access. The current article is entitled open science, and the new text is a clear commitment to open access to publications and research data from projects funded mainly with public funds. Point 2 states:

Research personnel in the public sector or whose research activity is mainly funded with public funds and who choose to disseminate their research results in scientific publications, must deposit a copy of the final version accepted for publication and the data associated with them in institutional or subject open access repositories, simultaneously with the date of publication.

The Organic Law 2/2023 of the Spanish Government University System (2023a) in article 12, point 1 states:

Scientific knowledge shall be considered a common good. Public administrations and universities will actively promote and contribute to open science through open access to scientific publications, data, code and methodologies that guarantee the dissemination of research outputs.

Recently, on 3 May 2023, the National Open Science Strategy (Government of Spain, 2023b) was published with four specific objectives: to facilitate interoperable

digital infrastructures to support open science, open access to scholarly publications and research data derived from research, and to establish evaluation mechanisms that take into account open science practices.

In Europe, the European Commission has been a strong supporter of open access to publications and research data since the Seventh Framework Programme, always in accordance with the principle “as open as possible and as closed as necessary” (European Union, 2021).

The European Commission is not the only one, there are numerous funders that finance both public and private research projects with policies that require open access to publications and open research data, such as the Wellcome Trust or the American Institute of Health (NIH) among many others (see more cases in the Juliet directory <https://v2.sherpa.ac.uk/juliet/>).

In summary, we have sufficient legislation, guidelines and recommendations to get the message across to research staff that it is a duty to make research data from publicly funded projects available in open access whenever possible, and that data are as important a part of open scientific knowledge as publications can be, and therefore worthy of being treated as primary material.

WHERE TO FIND DRUG DEPENDENCE RELATED DATA

In addition to having open data available in reliable repositories that guarantee their preservation, we must also have tools for finding and accessing data for potential re-



use, consultation or verification. There are multidisciplinary directories and subject specific portals. The aim of this section is to provide some of these resources, starting with general ones, followed by some specific ones related to drug dependence. Examples of disciplinary portals are of American and European origin covering a wide spectrum of data in relation to this important public health issue.

The Re3data directory contains in its databases more than 3000 records with repositories classified by subject, content type and country, and numerous search filters. In the case of public health, it has indexed more than 350 repositories and databases.

Datacite is harvester of metadata from repositories that host, among others, research data resources and that by means of unique and persistent identifiers establishes relationships between works, people, organisations and repositories and allows searching by these four entities.

The **European Monitoring Centre for Drugs and Drug Addiction** (EM-CDDA) is the leading authority on illicit drugs in the European Union. The Lisbon based agency provides independent scientific evidence and analysis on all aspects of this ever-changing threat to individuals and society at large. It collects the latest data on the drug situation in Europe from the EU Member States.

The **European Health information Portal** contains catalogues of health information sources, national and European projects, research infrastructures, capacity building activities that help researchers find and access population health information.

The **European Health Data & Evidence Network** (EHDEN) aims to provide a new paradigm for health data discovery and analysis in Europe by building a large-scale federated network of standardised data sources. It has a catalogue of public health related databases.

The **National Institute of Drug Abuse**. Data share website (NIDA) is a digital platform that allows data from completed clinical trials to be distributed to researchers and the public to promote new projects and disseminate information to the scientific community. It is supported by the National Institute of Health with the goal of accelerating the conversion of research results into knowledge, products and procedures to improve human health.

The **Substance Abuse and Mental Health Services Organization** (SAMHSA) is the agency within the US Department of Health and Human Services. It has both public and restricted data on drugs and drug abuse.

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