

Scientific
Journal of
**Applied
Social and
Clinical
Science**

**OPEN HEALTH DATA: A
CRITICAL LOOK AT ITS
AVAILABILITY AND USE**

Imelda Orozco Mares

Universidad de Guadalajara, Centro
Universitario de Tonalá, Department of
Population Health Sciences

Tonalá, Jalisco.

<https://orcid.org/0000-0002-4543-8976>

Katya Aurora Rábago Olivares

Universidad de Guadalajara, Centro
Universitario de Tonalá, Department of
Population Health Sciences

Tonalá, Jalisco.

<https://orcid.org/0000-0001-7950-1606>

All content in this magazine is licensed under a Creative Commons Attribution License. Attribution-Non-Commercial-Non-Derivatives 4.0 International (CC BY-NC-ND 4.0).



Abstract: Open data is highly useful for the planning and execution of public administration and in recent years they have acquired great relevance since they were put at the service of citizenship. They are defined as the process that puts the public data available to the administration in digital, standardized and open formats available to society. Regarding health, they are used to follow up on health indicators such as births, morbidity, among many others and that is useful for monitoring remote health services, surveillance of health and research itself, to give some examples. The objective of this work is the characterization of existing databases, in the light of international principles on open data in Mexico. There are two sites in Mexico to find open health data: INDRE and ENSALUD, the last one fed by mostly academic research. Open data are consulted to program primary care services and for research primarily. Access to information is not easy since the data is found in programs little used by citizens, including the federal government portal server is considered by users as low quality, so citizens must go directly to Health centers to participate in your care. Free data feeding requires digital education, culture of reporting health conditions, friendly and available platforms, as well as responding to international principles, especially the principle of governance and social participation and homologating information between national and international organizations.

Keywords: Open data, health, public health.

INTRODUCTION

Open data has gained importance in recent years for the planning and execution of public administration, its relevance acquires meaning when this information is put at the service of citizenship.

By definition, it is the process that puts the public data available to the society available

to the administration in digital, standardized and open formats, with a clear structure that allows its understanding and reuse (Garriga-Portolà, 2011). Open data involves an information mechanism for citizenship and favor the objectives pursued by an open government: transparency, participation and collaboration (bearts-who & Marco-Cuenca, 2020). Free data is widely used by the scientific community with a double route: they make use of them and make available their uses to favor the production of knowledge (peset-mancebo, Aleixandre-Benavent, Blasco-Gil, & Ferrer- Sapena, 2017).

In the field of public health, free access databases are used to monitor health indicators such as: births, deaths, morbidity, registration of contagious diseases and infectious infectious, maternal death and other determinants in health, gender, gender, Violence, etc., must be useful information to monitor remote health services, implement electronic applications so that the citizens take advantage of their health, to share health data between doctors and researchers, to launch more efficient health care services And his pretence has been, to get the information to the general citizens (Leavy & Swenson, 2019).

Worldwide the generation of information on this tool and administration policy of an open government, has maintained an unequal behavior. This is easily traceable when searching for information on the web, while countries and Spain provide the subject for a good number of published research that describe the behavior of open data and management of open data, in countries such as Mexico and others from Latin America, its approach as an object of knowledge is very scarce and the transition to a digitized data era has been slower, or at least unequally according to the capacity of resources that can be invested for that purpose, since there are digit barriers to save and invest in educating

citizens in data science (Pérez-Rave, Correa-Morales, & González-Echevarría, 2019).

OPEN HEALTH DATA IN MEXICO

In Mexico, free information about population health indicators in order to efficient health services and transparent health needs and conditions, is generated and made available to the general population in free access databases by The Federal Government, through the Institute of Diagnosis and Epidemiological Reference (InDRE) (<https://www.gob.mx/salud/acciones-y-programas/instituto-de-diagnostico-y-referencia-epidemiologicos-indre>).

There are other free access databases, among which a page generated by the National Council of Science and Technology and called National Computer Ecosystem in Health stands out (ENI-Salud) (<https://salud.conacyt.mx/>). The latter repositories are nourished from the results of academic research, mostly university and many of them are made prior agreement with health institutions.

GOAL

This work has as its central objective the characterization of the existing databases, in the light of international principles on open data: open data for default, timely and exhaustive, accessible and usable, comparable and interoperable, useful to improve governance and participation citizen and, for inclusive development and innovation (<https://opendatacharter.net/principles-es/>).

METHODOLOGY AND RESULTS

At first, the information with which the governing institution in the country feeds daily on its free access page was reviewed: INDRE. We find a total of 25 databases available to report data on: vector transmission diseases, infectious infectious, chronic degenerative, maternal-infant morbidity, maternal

mortality, respiratory, even information on environmental health, gender and health issues, especially From 2020 information related to SARS-COVID 19, among other topics.

Although, all information available to citizens in general and health and academic institutions, must respect the confidentiality of the subjects that it reports for the carrying of their living conditions, in the field of public health these data are highly sensitive, since in particular contexts not to protect their identities can cause considerable damage to people in case of misuse of them, which were also granted in confidentiality (Americans, 2021) in a space, in which the patient already in itself It is at a disadvantage. Our societies are still built with hybrid realities, in which tradition and beliefs with postmodernity and scientific discourse are combined, but in which their differentiation lines are so thin, that we do not just integrate respect and the right to Living with HIV, defining itself as part of a lesbian-gay community, for example.

The right to data protection and confidentiality conjugated with the low culture of making the information available to citizens, makes it difficult to open knowledge and offer such general and decontextualized data that its specific utility is scarce and makes it very difficult to comply with With this first international principle on free data. To access them it is necessary to have specific knowledge and skills, not only in terms of epidemiology or bioestadistic, but also of the technological management that allows to move in these virtual environments, to seek information and make use of it, it is necessary then to go through processes specialized learning.

As for the principle that the data is available with opportunity and that they are exhaustive, we find that the information available in the different databases, lack these characteristics, not all health indicators are

updated and adolescents of some important categories for Characterize social purposes such as data related to the income level and socio-economic profile of the population.

Download information is not an easy process that allows you to meet the basic principles of free data, the databases are in programs little used by citizens and it is not possible to discharge and access the archives, the portal of the portal itself Federal Government is valued in the quality of the server by possible users as “low quality”, as seen in the following figure.

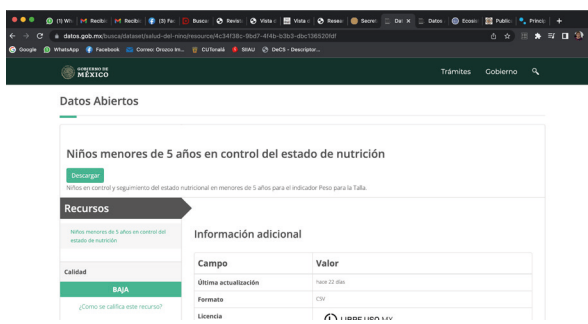


Figure 1. Assessability and quality of information contained in free health data.

We can infer that the common citizen has no opportunity to monitor the health status of their population group through these governance tools, and must be subject to first or second level health centers to participate in their care.

Health personnel were consulted (5 doctors in the quality area of 2 third level hospitals and 4 epidemiologists), about the use of databases for the organization of health services.

The results suggest that open data is consulted mainly to program primary health care services and with academic research reasons. The personnel working in hospitals commonly do not consult the information contained in the databases to manage and administer second and third level health services in daily practice.

Epidemiology personnel declared that the use of databases has gained importance from

health emergencies, in the case of Mexico, the H1N1 influenza outbreak in 2009, in some states of the Republic endemic diseases such as dengue in the case of Jalisco and, more recently the Covid-19 pandemic. They coincide with what some researchers reported, in relation to the fact that the cluster of information ended up being chaotic and inoperative, the lack of uniformity did not allow a prompt understanding of the phenomenon that was lived (Ferrer-Sapena, Calabuig, Peset, & Sánchez-Del -Toro, 2020)

One of the informants, a member of the Health Table of the State of Jalisco documented that in 2020, there was a disconnection between the data published by databases generated in the John Hopkins and the World Health Organization (WHO) and the Display day by day by the federal government and those made available to regional hospitals and local health services. Part of the experience was to recognize that we lack the culture of feeding the databases day by day to respond to health emergencies and other long-term care diseases, however, it recognizes that this culture extended to a sector of the Population, especially educational and business sectors, in order to plan work activities and implement work strategies in the digital age, a challenge for the level of basic education.

The general population learned to listen to news about the course of the disease, but not seek information by itself. They do not know the existence of free access databases and this includes health personnel not specialized in public health or epidemiology and that in this regard, until very recently it has been incorporated into the training of the Bachelor of Public Health The subject “Situational Room in Health”, but other curricula lack these courses, to such a degree that a general practitioner often ignores the operation of the INDRE, they know that when they reach their consultation some of the cases of

infection disease must be reported, but they don't know beyond and even once the emergency, they cease to be relevant and the sub-registration is important.

CONCLUSION

In the field of public health, food and its use requires:

1. Education in digital knowledge both citizens and health personnel from their professional training.
2. Citizen culture of reporting individual and collective health conditions.
3. Transit to friendly platforms with accessible and available programs on

any device: personal computer, tablet and even cell phones.

4. ensure that the information responds to the international principles of open or free data, especially the principle of governance and social participation through clear and understandable data, that respond to the needs of the population and are offered with respect to the Confidentiality

5. Approve the information offered by national and international organizations to respond to health emergencies such as the newly lived of COVID-19.

REFERENCES

- Americanos, O. d. (2021). *Principios actualizados sobre la privacidad y la protección de datos personales*. Washington, US: Departamento de Derecho Internacional-OEA.
- Bertos-Quesada, M. d., & Marco-Cuenca, G. (enero-junio de 2020). **Análisis del estado actual de apertura de datos en salud a nivel autonómico a través de los portales abiertos**. *Ibersid*, 14(1), 87-94.
- Ferrer-Sapena, A., Calabuig, J. M., Peset, F., & Sánchez-del-Toro, I. (2020). **Trabajar con datos abiertos en tiempos de pandemia: uso de covidData-19**. *Profesional de la información*, 29(4), e290421. <https://doi.org/10.3145/epi.2020.jul.21>.
- Garriga-Portolà, M. (mayo-junio de 2011). **¿Datos abierto? Sí, pero de forma sostenible**. *El profesional de la información*, 20(3), 298-303.
- Leavy, M., & Swenson, A. (2019). **Data sources**. En R. L. Gliklich, *Tools and technologies for registry interoperability, registries for evaluating patient outcomes: A user's guide*. USA: Adedum 2-Rockville-Agency for healthcare research quality.
- Pérez-Rave, J., Correa-Morales, J. C., & González-Echevarría, F. (2019). **Metodología para explorar datos abiertos de accidentalidad vial usando ciencia de datos: Caso Medellín**. *Revista Chilena de Ingeniería*, 27(3), 495-509.
- Peset-Mancebo, F., Aleixandre-Benavent, R., Blasco-Gil, Y., & Ferrer-Sapena, A. (2017). **Datos abiertos de investigación. Camino recorrido y cuestiones pendientes**. *Anales de documentación*, 20(1), doi. <http://dx.doi.org/10.6018/analesdoc.20.1.272101>.