

16. GOFAIR BRAZIL HEALTH NURSING NETWORK: WHERE ARE WE, AND WHERE DO WE WANT TO GO?

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16.1 INTRODUCTION

Discussions about the production of knowledge and scientific work, as well as reflections on relations among science, technology, data, and information are themes that have been constantly evolving since the last century. Nowadays, these themes have been adopting new configurations in the form of evaluation, management, dissemination, and storage molding themselves to the trends of the digital world, aimed at common, collective and collaborative knowledge.

It is in this context that a new paradigm has been taking place in the scientific field, corroborating open scientific practices, which integrate technological and human actors, aimed at the collective, encouraging the sharing, reuse and digital preservation of data. There is, however, the need to rethink new guidelines and policies that can better meet the demands of this new reality focused on Open Science, considered an international phenomenon, the result of the trends of democratization of knowledge.

Among all Open Science practices, open research data are considered inputs of scientific work that have gained greater prominence and importance today, due to the need and urgency of sharing them, as soon as they are generated, in strategic areas such as health, aiming at their reuse whenever possible. This possibility provides greater speed, transparency, and agility to research, leveraging the production of knowledge and science.

However, due to the complexity of data and the specificities of each field of knowledge, the need for data contextualization and organization, as well as the detailing of their provenance, increases to ensure their long-term preservation and reuse in other research. It is within this context that FAIR principles emerge, internationally regarded as guiding good practices in managing research data and initiatives aimed at their dissemination and implementation.

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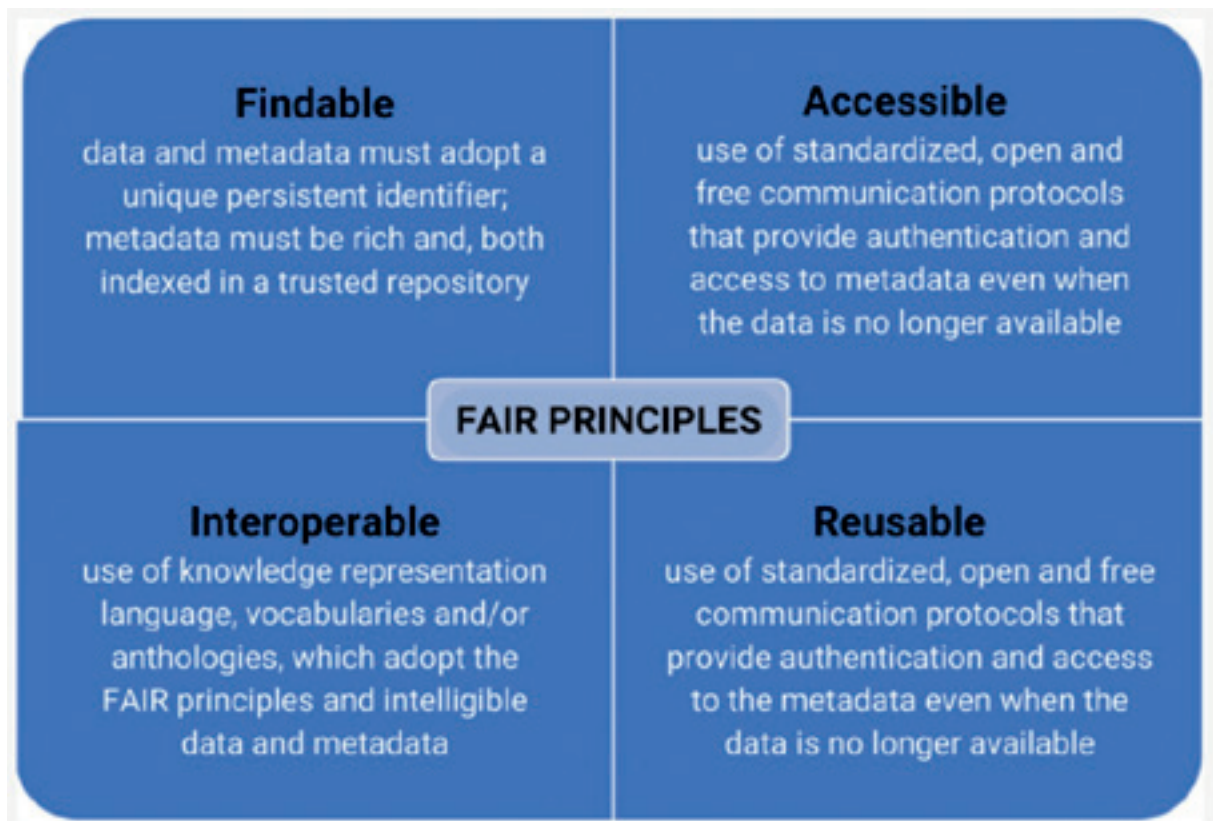
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This report aims to situate GO FAIR Brazil Health Nursing, describe its implementation trajectory so far, and articulate the mechanisms of action of this international initiative in the Nursing field. Therefore, a brief introduction of FAIR principles, GO FAIR international initiative, GO FAIR office in Brazil and GO FAIR Brazil Health Network, which constitute the content of the next sections, is necessary.

16.2 FAIR PRINCIPLES AND GO FAIR INTERNATIONAL INITIATIVE

In January 2014, the first manifestations of issues related to data management emerged when a group of experts, scientific editors, representatives from academia, research funding agencies and the industrial field gathered in a workshop entitled *Jointly designing a data FAIRPORT*, at the Lorentz Centre, in Leiden, the Netherlands. This meeting was marked by the high level of discussion around the creation of a global infrastructure that could support the publication, discovery, sharing, and reuse of research data. As a result of this meeting, a set of guidelines for good data management practices called “FAIR Principles” was designed. Such principles are actually an acronym for Findable, Accessible, Interoperable and Reusable (FAIR) and were only officially published in 2016, in *Scientific Data* magazine, in the article by Wilkinson *et al.* (2016) entitled *The FAIR Guiding Principles for scientific data management and stewardship*. Figure 1 briefly presents the FAIR principles.

Figure 1 – FAIR Principles



Source: Wilkinson *et al.* (2016), adapted by the authors.

It is possible to observe that these principles, by themselves, do not bring Much clarification regarding their implementation. They only describe a set of desired attributes for good practices in the management and treatment

of digital resources. Mons *et al.* (2017, p. 50) clarify that they “deliberately do not specify technical requirements, but rather a set of guidelines for an increasing continuous reuse, through different implementations”.

Considering that scientific research is being conducted by increasingly complex data, requiring not Only better treatment and organization, but also greater capacity of machines, appropriate software, better trained human resources and high financial resources to deal with such reality, the *Global Open FAIR* (GO FAIR)¹⁶⁸ emerges in 2017 with the aim of disseminating FAIR principles and services and providing basic guidelines for their implementation in this data science scenario.

This initiative adopts a bottom-up approach as methodology of implementation, that is, it encourages the creation of independent and autonomous networks willfully created by the Scientific Community, following its philosophy and guidelines.

16.3 GO FAIR BRAZIL HEALTH NURSING NETWORK: WHERE ARE WE?

The first GO FAIR Brazil initiative meeting took place on September 25, 2018, in São Paulo, during the 20 years of the *Scientific Electronic Library Online* (SciELO) where the Brazilian Institute for Scientific and Technological Information (IBICT) was established as the coordinator of the GO FAIR office in Brazil. Several stakeholders representing Brazilian universities and research institutes were present, as well as representatives of GO FAIR International (Sales *et al.*, 2020).

However, its official launch to the scientific community took place the following month, December 10, 2018, during an event promoted by the Ministry of Science, Technology, Innovation, and Communication (MCTIC). GO FAIR Brazil¹⁶⁹ is responsible for disseminating, supporting and coordinating the activities for the adoption of strategies to implement FAIR principles, respecting the specificities of the different fields of knowledge, throughout the national territory.

GOFAIR Brazil Health Network¹⁷⁰ is the first Brazilian implementation network, considered today the most active, being responsible for elaborating strategies for the adoption of FAIR principles in health domains. Its coordination is under the responsibility of the Institute of Communications and Scientific and Technological Information in Health (ICICT), of the Oswaldo Cruz Foundation (Fiocruz) and has the participation of several institutions in the fields of Public Health, Sanitary Surveillance, Information, and Communication in Health, History of the Cultural Heritage of Science and Health, Oncology, Nursing, and Professional Education in Health.

In the nursing field, the first steps for the composition of GO FAIR Brazil Health Nursing subnetwork began to be traced, considered one of the branches of the GO FAIR Brazil Health network, in March 2019, When researchers

168 Available from: <https://www.go-fair.org/>. Access on: 3 dec. 2020.

169 Available from: <https://www.go-fair.org/go-fair-initiative/go-fair-offices/go-fair-brazil-office/>. Access on: 3 dec. 2020.

170 Available from: <https://portal.fiocruz.br/go-fair-brasil-saude>. Access on: 3 dec. 2020.

from Alfredo Pinto Nursing School (EEAP), from the Graduate Program in Health and Technology in the Hospital Environment (PPGSTEH) (professional Master's program), from the Graduate Program in Nursing (PPGENF) (academic Master's program) and from the Graduate Program in Nursing and Biosciences (PPGENFBio) (PhD) met for the first time with representatives of the GO FAIR International initiative, GOFAIR Brazil and GO FAIR Brazil Health Network, to agree on the creation of GO FAIR Brazil Health Nursing Network (Henning, 2019).

Since then, several actions have been developed to strengthen and implement it. First, the "International Seminar on Health Research Data Management - GO FAIR Brazil Health and GO FAIR Brazil Health Nursing", which took place throughout the month of June 2020, was offered to the Brazilian nursing community and was attended by more than 250 participants. The scientific program of this event was conceived using the modality of webinars and delivered by speakers from institutions in Brazil and the Netherlands, with recognized intellectual production and trajectory on the subject.

Figure 2 - International Seminar publicity flyer

**INTERNATIONAL SEMINAR ON
HEALTH RESEARCH DATA
MANAGEMENT**

**GO FAIR
BRASIL SAÚDE**

**GO FAIR
BRASIL SAÚDE**

Initiative of the Graduate Program in Health and Technology in the Hospital Environment (PPGSTEH) at UNIRIO in partnership with the Graduate Program in Information and Communication in Health at the Institute of Scientific and Technological Communication and Information in Health (ICICT) of Fiocruz aiming at promoting the discussion, among researchers from institutions in Brazil and the Netherlands, on data management in the perspective of GOFAIR Brazil Health and GOFAIR Brazil Health Nursing Network.

The event will be held always at 3pm following the schedule below:

- 07/07 - Introduction of Research Data - Dr. Maria Simone Menezes de Alencar
- 07/09 - Introduction of FAIR Principles and Initiative GO FAIR - Dr. Patrícia Corêa Henning
- 07/14 - Data Management Plan in the context of COVID19 - Dr. Viviane Veiga and Ms. Simone Faury
- 07/16 - Research Data Repository in the context of COVID19 - Dr. Viviane Veiga and Dr. Washington Luis Segundo
- 07/20 - Data Preservation and Curation - Dr. Luana Sales and Dr. Luiz Fernando Sayão
- 07/22 - Data Interoperability - Dr. Claudio José Ribeiro
- 07/27 - FAIR Technologies for reproducibility of research - Dr. João Moreira
- 07/29 - VODAN Brazil Project - Research Data Network to fight COVID10 - Dr. Viviane Veiga and Dr. Maria Luiza Camposo

Register through the link: <https://bit.ly/SeminarioGoFairEnfermagem>

Logos: UNIRIO, PPGSTEH, PPGICIS, PPGENF, PPGEnFBio, ICICT, SUS, PRO.

Source: UNIRIO (2020).¹⁷¹

171 Available from: <https://www.unirio.br/cchs/ppgsteh/eventos/seminario-internacional-sobre-gestao-de-dados-de-pesquisa-em-saude-1>. Access on: 3 dec. 2020.

The program content of this Seminar was planned to cover all the practices related to research data management and FAIR principles, distributed in eight modules. Module 1: Introduction to Research Data¹⁷²; Module 2: Introduction to FAIR Principles and the GOFAIR Initiative¹⁷³; Module 3: Data Management Plan in the context of COVID19¹⁷⁴; Module 4: Research data repositories in the context of COVID19¹⁷⁵; Module 5: Data Preservation and Curation¹⁷⁶; Module 6: Data Interoperability¹⁷⁷; Module 7: FAIR Technologies for research reproducibility¹⁷⁸; Module 8: VODAN Brazil Project– Research data network to fight COVID19.¹⁷⁹ All videos of the presentations are available at Fiocruz ARCA Repository and on YouTube pages of Alfredo Pinto Nursing School.¹⁸⁰

It is important to note that GO FAIR Brazil Health Nursing Network is coordinated by the Graduate Program in Health and Technology in the Hospital Environment (PPGSTEH), in collegiate management with Alfredo Pinto Nursing School (EEAP), by the Graduate Program in Nursing and Bioscience (PPGENFBIO) and by the Graduate Program in Nursing (PPGENF), at the Federal University of the State of Rio de Janeiro (UNIRIO).

After collegiate deliberation with the coordinators of the Graduate programs in Nursing at UNIRIO, a group of professors was formed to integrate the programs with the aim of monitoring and implementing the activities for implementing GO FAIR Brazil Health Nursing Network. The group is formed by the following professors: Dr. Eliza Macedo, Dr. Patrícia Henning, Dr. Maria Simone de Menezes Alencar, Dr. Sônia Souza, Dr. Danielle Galdino, Dr. Taís Vernaglia and Dr. Inês Meneses. Among the actions of the group, we can mention: meetings for strategic implementation planning; meeting with a representative of FIOCRUZ for the procedures of the Technical Cooperation agreement; registration of GO FAIR Brazil Health Nursing Research Project at UNIRIO Research Department; elaboration of a project aimed at undergraduates interested in the subject, to act as scholarship holders, already sent to the Dean of Student Affairs, which offers academic incentive; and registration of the actions at the Dean of extension, both at UNIRIO.

Two months after the International Seminar on Health Research Data Management, GO FAIR Brazil Health Nursing Network was launched, on September 22, 2020, during the celebrations of the 130th anniversary of Alfredo Pinto Nursing School, at UNIRIO. The launch was opened with the participation of the coordinators of GO FAIR Brazil, GO FAIR Brazil Health and GO FAIR Brazil Health Nursing, and with the dissemination of their manifesto of adherence to the Network. A number of 144 professionals with varied profiles attended, from researchers, professors, graduate and undergraduates, librarians, archivists, administrative technicians to health professionals

172 Available from: <https://www.arca.fiocruz.br/handle/icict/45046>. Access on: 3 dec. 2020.

173 Available from: <https://www.arca.fiocruz.br/handle/icict/45049>. Access on: 3 dec. 2020.

174 Available from: <https://www.arca.fiocruz.br/handle/icict/45050>. Access on: 3 dec. 2020.

175 Available from: <https://www.arca.fiocruz.br/handle/icict/45052>. Access on: 3 dec. 2020.

176 Available from: <https://www.arca.fiocruz.br/handle/icict/45058>. Access on: 3 dec. 2020.

177 Available from: <https://www.arca.fiocruz.br/handle/icict/45059>. Access on: 3 dec. 2020.

178 Available from: <https://www.arca.fiocruz.br/handle/icict/45060>. Access on: 3 dec. 2020.

179 Available from: <https://www.arca.fiocruz.br/handle/icict/45061>. Access on: 3 dec. 2020.

180 Available from: <https://www.youtube.com/channel/UCH-mOJCsxwnHQweoPkNV-g>. Access on: 3 dec. 2020.

from universities, research institutes and hospitals. At the end of the presentations, the participants were invited to fill out a registration form and sign the Open Manifesto for joining GO FAIR Brazil Health Nursing Network¹⁸¹.

Those interested in participating in the Network only needed to sign the Manifesto and be willing to work collaboratively. The coordinators will contact them and insert those interested in the planning dynamics and future actions of the Network.

Figure 3 – GO FAIR Brazil Health Nursing Network Launch Flyer



Source: Fiocruz (2020).¹⁸²

Continuing with the action, the Graduate Program in Health and Technology in the Hospital Environment (PPGS-TEH), aiming to seek new adhesions to GO FAIR Brazil Health Nursing Network, offered to the Nursing scientific community, on December 03 and 12, 2020, the workshop “GO FAIR Brazil Nursing Network: where we are and where we want to go”¹⁸³. This event aimed to present to the nursing scientific community and to those interested in working in the health field in general the actions that have been developed within the scope of GO FAIR Brazil Health Nursing Network, aimed at nursing research data management, within the scope of Open Science.

181 Available from: <https://bit.ly/GOFAIRENFERMAGEM>. Access on: 3 dec. 2020.

182 Available from: <https://portal.fiocruz.br/noticia/seminario-virtual-marca-o-lancamento-da-rede-go-fair-brasil-saude-enfermagem>. Access on: 3 dec. 2020.

183 Available from: <http://www.unirio.br/news/workshop-ira-discutir-gestao-de-dados-de-pesquisa-em-enfermagem>. Access on: 3 dec. 2020.

Figure 4 – Promotional flyers of GO FAIR Brazil Health Nursing Workshop



Source: UNIRIO (2020).¹⁸⁴

As described in its Manifesto, this Network proposes to work on strengthening and disseminating FAIR principles in the field of nursing, in an articulated and collaborative way with its members. Currently, the first guidelines for the Network actions are being drawn up, which will be organized through specific work groups with the participation and voluntary action of the Brazilian Nursing community.

16.4 GO FAIR BRAZIL HEALTH NURSING NETWORK: WHERE ARE WE GOING?

GO FAIR Brazil Health Nursing Network seeks its development and consolidation through the strengthening and promotion of management, Nursing research data sharing and reuse, within the Brazilian Graduate Nursing Programs, which are the main generators of Nursing research data. For that purpose, the goals are:

- a. Promote research, in the nursing field, focused on specific metadata, standards of technological and semantic interoperability of data such as use of controlled vocabularies and ontologies in the field; data management plan templates; national and international research data repositories, which can reliably store nursing research data; application of use licenses, in accordance with Brazilian regulatory frameworks;
- b. Develop methodologies aimed at FAIR products and services practices, which meet disciplinary and operational needs of the nursing field;

¹⁸⁴ Available from: <http://www.unirio.br/news/workshop-ira-discutir-gestao-de-dados-de-pesquisa-em-enfermagem>. Access on: 3 dec. 2020.

- c. Promote meetings, courses, workshops, and seminars aiming at boosting and disseminating FAIR principles among the members of GO FAIR Brazil Health Nursing Network;
- d. Create voluntary and collaborative work groups, together with members, who will develop training actions, technical and technological development actions and political actions aimed at expanding the Network;
- e. Work in an articulated and collaborative way with GO FAIR Brazil Health Network, together with Fiocruz.

These goals, designed during the meeting of the Network coordination, are medium and long-term, with the possibility of new goals being designed throughout the process as new demands begin to emerge for the sustainability of the Network. Biweekly meetings are being scheduled for the start of activities in 2021 with the aim of bringing members together in the development of activities.

It is considered that there is still a long way to go to achieve the much desired FAIR data management. For this purpose, Graduate Nursing Programs must, in parallel, integrate research data management content into their curricula. In addition, they should also follow suggestions proposed by Raszewski *et al.* (2020, p. 7), who claim that by creating an infrastructure of policies, practices, and curricula that address data management, they will train researchers prepared to meet the data competence expectations of health systems, primary care clinics, in the community and academia.

The interest of Nursing communities in implementing FAIR principles is evident with the large participation of health professionals in various activities developed in a short period of time, such as the International Seminar on Health Data Management and the GO FAIR Brazil Health Nursing Network Workshop. This indicates a promising future in the name of good management of nursing research data, focused on studies, infrastructure development and participation in national and international forums.

16.5 FINAL CONSIDERATIONS

It is known that several types of data are used as research input, from governmental, administrative, private companies, scientific data, as well as those in the health field, where Nursing stands out. In the scope of Open Science, research data must be processed and opened as soon as possible, respecting the disciplinary and legal specificities. In addition to the obstacles inherent in opening research data, such as the lack of understanding of the legal definitions of intellectual property and the lack of standardization in the definitions and configurations of research data, the health field, given its specificities, has one more challenge: the necessary protection of sensitive data, which is a sore point for researchers who are not yet familiar with the subject, requiring adequate software and training.

In this scenario full of doubts and opportunities in Building a new culture that addresses all stages of data life cycle, GOFAIR Brazil Health Nursing Network seeks to overcome such obstacles, appropriating the “FAIR Data Management” theme, aiming to develop a set of skills to guide students and researchers from the Graduate Programs in Nursing in the creation of new content with a focus on data and later, develop infrastructure to support the development of data management plans and storage in repositories of appropriate data

By realizing the importance of this scenario that expands and strengthens, the Graduate Program in Health and Technology in the Hospital Environment (PPGSTEHE), in collegiate management with Alfredo Pinto Nursing School, the Graduate Program in Nursing (PPGENF) (academic Master's program) and the Graduate Program in Nursing and Bioscience (PPGENFBio) (PhD) begin, through the coordination of GO FAIR Brazil Health Nursing Network, the first steps towards the insertion of research data in nursing in the process of sharing and reusing data in line with FAIR principles, which will promote culture and bring impact and visibility to data produced by the Nursing field, articulating local action with global thinking.

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