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A proposal for a set of attributes relevant for Web portal data quality: The Brazilian Rare Disease Network case

Filipe Andrade Bernardi[a,b]*, Domingos Alves[b], Mariane Barros Neiva[b] Diego Bettiol Yamada[b], Vinicius Costa Lima[b], André Vinci[b], Giovane Thomazini[b], Rui Rijo[b,c], Têmis Maria Felix[d]

[a]*Bioengineering Postgraduate Program, University of São Paulo, São Carlos, Brazil*
[b]*Ribeirao Preto Medical School, University of Sao Paulo, Ribeirao Preto, Brazil*
[c]*Polytechnic Institute of Leiria*
[d]*Medical Genetics Service, Porto Alegre Clinics Hospital, Porto Alegre, Brazil*

Abstract

Despite widespread growth in the use and complexity of web portals, insufficient attention is paid to their quality. Thus, this paper aims to describe the validation process of the Brazilian Network of Rare Diseases Portal and identify a set of data quality attributes required for psychometric evaluations that will support the portal implementation. This protocol describes a cross-sectional study of mixed nature divided into three steps: A usability evaluation, a Delphi consensus, and an electronic service quality assessment. Also, the RE-AIM model will be applied at various stages of evaluative research. We hope the improvement carried out during the validation of RARAS can contribute to the dissemination of knowledge in the area and include, based on scientific knowledge and clinical experts, offering clear, attractive, and accessible information for the population. A research gap exists in determining components of integrated e-service quality, usability, and user experience evaluation model in general, and for rare disease web portals, in particular. Users of the RARAS Portal need to get validated content and the required reliable online services without doing exhaustive searches or visiting multiple sources, with the main focus on e-service quality.

Keywords: Rare Diseases; Data Quality; Implementation Science; Software Validation; User-Centered Design

* Corresponding author. *E-mail address:* filipepaulista12@usp.br

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1. Introduction

A web portal is a web-based repository of data, information, facts, results of analyzes, and knowledge [1]. Its main objective is to provide an active working environment for the user, that, in the context of this work, can be a researcher, policy maker, manager, or healthcare professional, among other stakeholders [2]. According to the World Health Organization (WHO), in the health domain, these portals also can be understood as health observatories as long as they gather information relevant to a given health phenomenon of a population, with the potential to generate population indicators capable of supporting public health policies [3].

Web portals in health stand out due to the isolated and non-interoperable character that data in this area tend to present [2] and the potential of such portals to mitigate these problems [3]. Still, repositories of epidemiological data are useful and contribute to the planning of public health programs [4]. Also, a web portal is the most effective and efficient form of dissemination and communication, allowing the generation of knowledge and intelligence in various areas of health [2].

Given the relevance of health web portals, great care is required with the information contained therein. Stakeholders must accept such information as valid, objective and scientifically sound. Also, it must be useful and relevant to health policies, actions, plans, programs, and projects as they must be valid, reliable, coherent, representative, sensitive, understanding, and ethical [5].

However, when managers, researchers, and professionals in the health area try to identify the population's health needs and measure, evaluate and monitor the impact of health actions and policies, they often encounter relevant issues in health data [3]. Such a problem is the deficiency in accessibility, lack of quality [6] and the non-interoperable character of data [2] in this area.

Deepening the discussion for the specific case of Rare Disease (RD) in Brazil, their data also show problems. In this case, after the institution of the Brazilian Policy for Comprehensive Care for People with Rare Diseases by the Unified Health System (‘SUS’; Portuguese: ‘Sistema Único de Saúde’) in 2014 [7], the lack of structured data on RD in Brazil became evident. To mitigate this problem, the Brazilian Network of Rare Diseases (‘RARAS’; Portuguese: ‘Rede Nacional de Doenças Raras’) project was established in 2020 aiming to conduct a national survey regarding the clinical overview, epidemiology, diagnostic and therapeutic resources, and costs for RD of genetic and non-genetic origin in Brazil and to create a national surveillance network of RD [8].

The project has its funding from the Ministry of Health of Brazil through the National Council for Scientific and Technological Development of Brazil and encompasses many health centers that carry out RD diagnosis and treatment across all five Brazilian regions [8].

In addition, the RARAS survey had two phases, the first being a retrospective data analysis of patients who attended RDs centers between the years 2018 and 2019 and the second being a prospective analysis of the patients assisted in 2022, between April and September [8]. The standardized electronic Case Report Forms (eCRFs) were designed in Research Electronic Data Capture (REDCap) to collect data from the health centers in order to structure the collection and analysis processes and to provide data quality monitoring [9].

In this context, the literature highlights the relevance of validating a health web portal. Despite widespread growth in the use and complexity of web portals, insufficient attention is paid to their quality. The purpose of this paper is to describe the validation process of the RARAS Portal and identify a set of data quality attributes required for psychometric evaluations that will support the portal implementation.

2. Related Work

RDs represent a complex public health problem worldwide. The multidisciplinarity required in this area makes the task of establishing local and isolated information solutions impracticable. In this context, according to the WHO, to overcome these barriers, the research and development in the RDs must involve collaboration networks, and this can be done through health web portals and observatories, which generate indicators capable of helping the public health policies [10].

Thus, since the 1990s, important initiatives have been developed to meet these demands. In 1997, the French National Institute for Health and Medical Research (INSERM) established the first scope of the Orphanet platform,

a unique web service that gathers and produces knowledge about RDs, to improve procedures related to diagnosis, care, and treatments of people with RDs [11].

The Orphanet (https://www.orpha.net/) offers validated and quality information with easy access. In addition, maintaining and supporting standardized terminology for RDs (ORPHA code) is an essential tool to highlight and categorize the intrinsic and specific characteristics of RDs, improving their visibility and interoperability in health information systems. This initiative became a continental project in Europe from 2000 onwards. Currently, 41 European countries contribute to this project [11]. This platform also offers information services to align development and research processes in this area, such as Orphanet Rare Disease Ontology (ORDO), a structured dictionary for RDs, and Orphadata, a web resource with data related to orphan drugs [12].

After that, other initiatives started to emerge. The PhenomeCentral (https://phenomecentral.org/) is a web portal created to enable secure sharing of the recording of phenotypic descriptions of patients with RDs. It is still possible to identify clinical characteristics associated with genes in the database of this web service. PhenomeCentral incorporates data from over 1,000 patients with rare genetic diseases and has already been used to identify RD-causing mutations in many patients. EpigenCentral (https://epigen.ccm.sickkids.ca/), is a free web resource for biomedical researchers, molecular diagnostic laboratories, and clinicians to perform the classification and interactive analysis of DNA data related to RDs. It allows users to search for patterns associated with known diseases in their data and classify the pathogenicity of genetic variants to aid molecular diagnosis or analysis patterns [13].

All these projects use, at some level, a method of evaluating their functionality. In this paper, we will describe scientifically validated methods and guidelines for this type of evaluation and the model for their application in our web portal, the RARAS Portal.

3. Methods

3.1. Study design and participants

This protocol describes a cross-sectional study of mixed nature divided into three steps that will occur asynchronously and independently. The first phase will involve participants from centers eligible for electronic data gathering of the RARAS study and who are indirectly engaged in the construction of the portal, including coordinators, fellows, volunteers, supervisors, and focal points (local officials). For the second phase, specialists from universities in all regions of Brazil and servers/technicians from the Ministry of Health will be invited to participate in three distinct moments in the portal evaluation process. The third phase will involve institutions and patients' associations, as well as members of civil society and the pharmaceutical industry that will see the final version of the portal for the first time after being validated by members and specialists.

The proposed protocol is composed of a set of instruments and steps. The adoption of the instruments follows the criteria: (1) instruments must be based on recognized international organizations' standards, good practice guidelines, and quality data principles; (2) instruments used in several other studies published in renowned publications; and (3) the instruments must assess desirable psychometric qualities such as reliability, validity, and sensitivity. The adoption of the steps for the present protocol follows the following criteria: (1) the steps should allow the use of the protocol in different health research areas; (2) the protocol should include all procedures of the selected instruments; and (3) the protocol should indicate how to use the results of the application of each instrument. To achieve this task, we perform a brief literature review to identify the existing key works to evaluate the main process, metrics, and guidelines for assessing a health web portal quality.

3.2. Evaluation Process, Metrics/Measures and Guidelines

Based on a thorough literature review, the selected instruments are the key renowned instruments that met the criteria indicated in the literature. Therefore, we chose to evaluate usability in the first stage; user experience and consensus in the second stage, and e-Service quality in the third. These aspects are critical components of software

quality, but they are often overlooked during the development stage and can hamper the results in software products with poor usability, user experience, and quality of service.

First Stage: Usability

According to NormanGroup, a world-leading research-based User Experience (UX) organization, usability is one of the most important factors in the Human-Computer Interaction (HCI) field. Nielsen defines usability in five dimensions: learnability; efficiency; memorability; few errors; and user satisfaction [14]. This classical definition or a usability framework is the most widely adopted and cited since it provides a detailed articulation of usability aspects that can be objectively and empirically verified through different evaluation methods.

There is a need to determine what constitutes usability in terms of its components or dimensions and how it can be evaluated. Without this understanding, it is difficult to consider usability during software development or perform appropriate software usability evaluation. Because of that, we will also proceed with a qualitative evaluation through empathy mapping [15]. We intend this technique to aid in decision making, exploring the user attitudes and behaviors, and reveal any holes in existing user needs.

Second stage: Delphi consensus

A Delphi consensus is a structured process used to evaluate expert opinions on health and medical topics. It uses a series of questionnaires that are iterated until a consensus is reached. Although it does not rely on statistical power but on group dynamic to reach a consensus among experts, some specialists' features are desirable as education and field of expertise, accumulated experience, and willingness to engage in the research, in addition to a recommended sample size of between 5 and 20 experts in the Delphi panel. This method was chosen as the most suitable research method to address the research objective, as the results of the previous literature review study will inform the initial statements for the first round of the research [16].

Throughout all the three rounds, respondents will be allowed to elaborate on their decisions and recommend additional or alternative domains and measurement instruments. Participants who did not complete one of the three rounds will be excluded from further participation.

Experts who agree to participate will receive a personal email invitation containing an anonymous web link to the first Delphi round. In this round, participants will be asked to indicate whether every proposed domain was important for the outcome measurement of RD web portals' quality attributes, with three response options (‘yes’, ‘no’ and ‘this is not my area of expertise’). If the reply is affirmative, the respondent will be asked to indicate whether the measurement instruments proposed are suitable for the concerned domain (‘yes’, ‘no’ and ‘no opinion’). Thus, the first round will aim to identify potentially suitable measurement instruments for the RD web portals' quality attributes. Hence, experts will not be asked to consider a preference for a particular measurement instrument until the second round but rather were asked to indicate whether a proposed instrument would be suitable for RD web portals.

Based on the consensus obtained in the first round, we intend to verify, in the second round, if the same instruments are applicable and would cover beyond their proposed scope of minimal attributes for international RD portals web [17]. Thus, the identification of the core domains will be carried out in the second round. To narrow down the selection of key domains, we will rank the domains that reached consensus in the first-round ascending by the percentage of 'Yes' responses. Regarding the domains for which there was no consensus on the level of the measurement instrument, participants will be asked to indicate their preferences, placing the proposed instruments in order of preference (first placeismost preferred, last is least preferred). Finally, the third round will enclose questions to help clarify the last issues regarding overlap between selected attributes presented at the RARAS Portal.

Third Stage: eService Quality

A web portal is also responsible for many consultations of medical and health information every day. Most of its users only analyze the information on the first ten sites retrieved in a search [18]. In this sense, understanding the critical factors to improve a website's traffic through Search Engine Optimization (SEO) is essential to assess the

UX and the adhesion and engagement of new users, which can be boosted by the reach and quality of a website [19]. Even if the concept of UX is very broad and complex, a good UX results from the obtained evidence, mostly qualitative. One such evidence is electronic service quality (e-SQ) monitoring.

The e-SQ is defined as the extent to which services based on web technology facilitate effective and efficient online communications, purchases and delivery of products or services. Its concept includes five dimensions: reliability, assurance, tangibles, empathy, and responsiveness. In terms of attributes, this corresponds to technical adequacy, content, security, communication, prestige, ease of use, ease of learning, memorability, layout, graphics, system availability, speed, accessibility, navigation, reliability, accuracy, privacy, contact information, online help, responsiveness, sustainability and currency [18]. As indicated, many of these e-service quality dimensions and attributes can also be applied to usability and UX, measured by stages 1 and 2, respectively.

Thus, one part of e-SQ is planning and optimizing web projects. However, it also means monitoring website performances. For performance assessment, we choose off-the-page tools that check single performance indicators and especially the visibility rank of hosted websites represents a very effective approach. These SEO tools (described in section 3.3), will provide digital marketing metrics like the number of total organic and their goal completions via organic traffic, the bounce rate of top landing pages, top exit pages, target keywords and their organic ranking, mobile usability, and crawled errors under search console [20]. To find out the engagement interest and adoption of our portal from the perspective of users, a questionnaire survey will be conducted. The questionnaire survey will aim to find out the opinions, attitudes, and satisfaction of users with the selected e-services provided by the portal and measure the lead conversion rate.

3.3. Instruments and tools

REDCap is a metadata-driven application built at Vanderbilt University in 2004 to enhance clinical research. The software is free and widely used by the scientific community to collect and manage research data. It enables classical and translational clinical research, basic science research, and general surveys, providing researchers with a tool for the design and development of data collection instruments in a flexible way [21]. For the survey portion of this study, several decisions have been made to ensure that data collection is carried out ethically. When participants enroll in the survey portion of the study, they will have an opportunity to take as much time as they need to read an electronic study information letter and ask questions of the research team before beginning the survey. In this sense, the REDCap modules of alerts, data quality, and electronic consent (e-consent) should be used.

The voluntary nature of the study will be communicated in this letter. Once participants have begun to fill in the survey, they can decide to stop at any point without penalty. Participant responses to the survey will be collected via an online survey platform. All data in the online survey are stored on a secure server at the study site, enhancing participant data security. Regarding the specialist panels portion of the study, informed consent will be obtained prior to the first-round beginning.

For the first stage to assess the impact of the portal on healthcare professionals and organizations, we propose using Computer System Usability Questionnaire (CSUQ). CSUQ was validated with 825 employees who worked at nine IBM development sites [22]. Also, for assessing the portal usability from the technical perspective we will use the adapted model proposed by Yoshiura [2]. This model describes opportunities for developing and implementing new observatories or for the adequacy of existing Health Observatories through components based on information technology multi-layer architecture [23]. The starting point for the elaboration of the script of questions for the second stage will be a review of the literature on the minimum set of data and information [24] and the FAIR (Findability, Accessibility, Interoperability, and Reuse) principles of digital assets [25]. For the second phase of this stage, a set of preliminary portals will be presented, and finally, for the third phase, our portal will be submitted for expert evaluation.

Finally, for the third stage, monitoring tools such as Google Analytics and Hotjar will be used. These tools may help web designers to better understand how users behave on their websites, such as how they interact with a product or feature. The tools are also useful for detecting bugs and discovering usability issues. For instance, opportunities for improvements can arise by analyzing quantitative data from Google Analytics, combined with

qualitative data from Hotjar [26]. An e-SQ questionnaire based on Ssemugabi [27] will also be available for voluntary participation and will be present in the outreach campaign in non-participating institutions.

3.4. Data Analysis Pipeline

Computing the RARAS Portal's efficiency is essential to minimize the risk that the user does not return to the service and experience good navigation on the website. Regarding the first stage of Section 3.2, the questionnaires contain closed questions with possible answers as strongly disagree; disagree; neutral; agree; totally agree. Although qualitative, each response will be assigned to a quantity according to the participant's level of satisfaction (0 to 4). Therefore, statistics over the contentment of the first stage can be computed for each one of the categories: purpose, interface, usability, content, and communicational aspects. Then, several metrics can be calculated from the rate of each answered question.

One important metric is computed by the two-way analysis of variance (ANOVA). Unlike the classical one-way metric, the two-factor statistics can help the technical team evaluate average grades over each group of questions and categories, i.e., two independent variables. The two-way ANOVA allows us to understand the variance of average grades within and between each question category, i.e., two independent variables. The analysis of the statistical metric will allow the technical team to understand and further investigate the quality of the RARAS Portal based on the initial value of the F-test [28].

The same methodology will be applied for each round of the Delphi study with the assignment of quantitative points such as totally agree (4) when there is a consensus. Another important test to evaluate users' experience surveys is the student's t-Test [29], which can evaluate the responses of different types of users (medical staff and general users of the website) or over different periods. Furthermore, it is essential to calculate the standard deviation (std) for each one of answered questions in the usability analysis. This standard deviation will allow us to understand the divergence between user experience, which can be further evaluated according to the results of the Delphi study, the exploitation of users' Hotjar heatmap, and Google Analytics.

For stage 3, some of the evaluated metrics obtained by Google Analytics and Hotjar will be the number of clicks on a single page [30] as well as the heat map of a page, the percentage of usage on a page, the amount of traffic and their source (social media, google, among others), time of response of the webpage, cursor distance of different tasks [31]. All metrics will compose a dashboard to help the information technology team in the continuous improvements of the RARAS Portal even after the first two stages, usability and Delphi study.

3.5. General Evaluation Framework: RE-AIM

The RE-AIM model has been applied at various stages of evaluative research. Its application has helped many researchers and managers in the planning and evaluating programs, both at the individual (target population) and organizational (program provider) levels, thus seeking to reduce the gaps between research and practice and maximize the impact of public health interventions. The model is composed of five dimensions: Reach (number, proportion, and representativeness of people who could or want to participate in an intervention); Effectiveness (the impact that a given intervention has on outcomes, including negative effects); Adoption (number, proportion, and representativeness of organizations and environments that are willing to adopt it); Implementation (fidelity and consistency to the intervention protocol); and Maintenance (long-term effects of a program at the individual level and institutionalization of the intervention at the organizational level) [32].

The results of the usability, consensus building, and service quality stages will be organized into RE-AIM dimensions. Reach indicators will include lead conversion rate, participant characteristics, and focus group participation rates. Effectiveness will include results of consensus on the presence of attributes and mechanisms capable of making the RARAS Portal properly locatable and accessible, capable of interoperating with external agents and being reused when requested. Qualitative feedback obtained through empathy mapping of the resources and delivery potentials that the portal has will be used as indicators of Adoption. For a better understanding of this dimension, keywords, traffic objectives, and heat maps will also be considered.

Implementation indicators will include reporting of technical difficulties, the number of days of activity recorded, and participants' perceptions of the portal. Maintenance was divided into individual and organizational. The individual maintenance indicators included quantitative and qualitative results on the usability of each monitor. Experts' perceptions of the intervention will indicate potential organizational maintenance.

4. Related Work

We hope that the systematic development methods and the validation process of the RARAS Portal allow the success of the technological tool developed and reproduce a scientific character to the development process, differentiating it from other existing health sites. In summary, the improvement carried out during the validation of RARAS can contribute to the dissemination of knowledge in the area and include, based on scientific knowledge and clinical experts, offering clear, attractive and accessible information for the population. Therefore, we hope that the RARAS Portal will become a widespread, useful and reliable source of health information, especially for RD patients and professionals, in a quality interactive environment. Figure 1 presents the interaction between the protocol stages and the RE-AIM framework dimensions and levels.

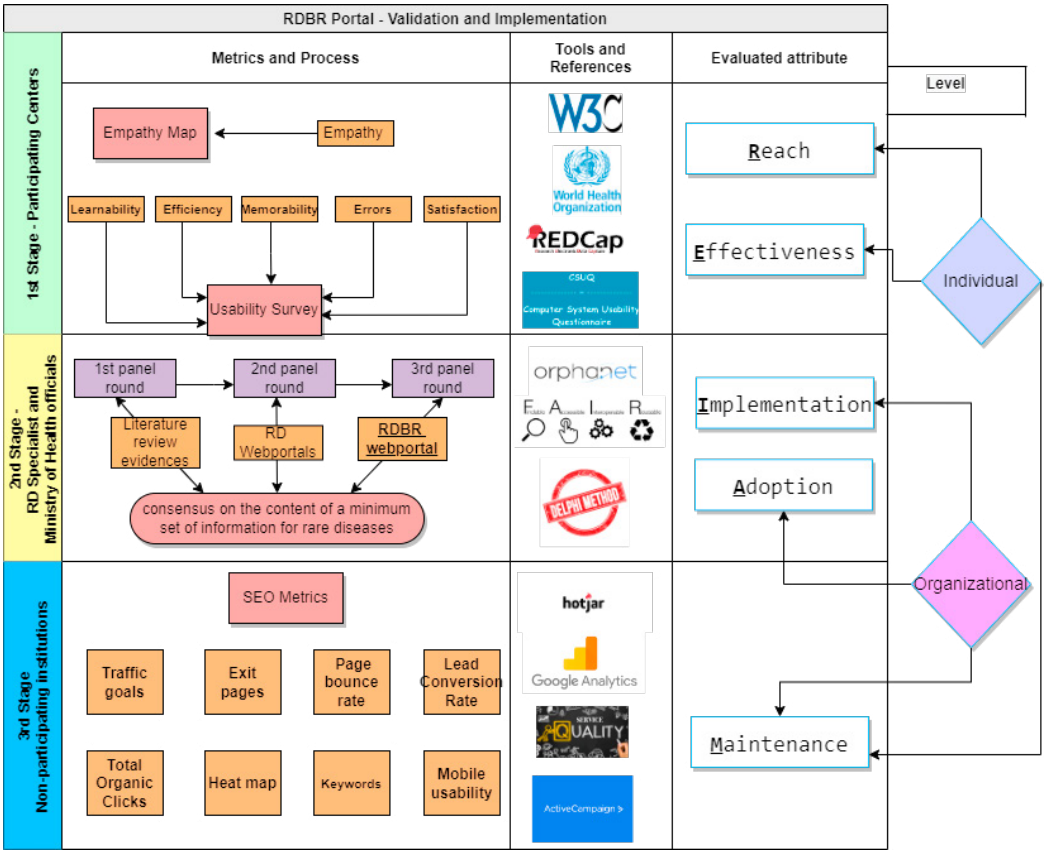

Fig. 1. Validation and Implementation process of the RARAS Portal

The results may be used to guide a broad understanding of the aspects involved in the process and gaps in the implementation of health portals. This understanding can improve their use and adoption and then support better planning and dissemination of RD situations at the national level according to each region's particularity.

Furthermore, the information gathered in this study can provide subsidies for better decision-making in the area of RD and also for planning and creating health policies.

Our proposal has some limitations: Service quality for websites is not a fully defined construct and there is still uncertainty in defining and interpreting its meaning, mainly because there are various types of sites. As such, there is no established conceptual model for developing and evaluating the service quality of websites in general. Besides that, our evaluation analyses just a determined period, it's desirable to understand how the portal scalability and maintenance work for a long time.

The RE-AIM framework can be used to understand how technology can increase user engagement on the RARAS Portal, identifying what stage of the implementation process the various digital technologies are currently at. It can also highlight areas where more research may be needed or processes in place to move from research to implementation.

5. Final considerations

The protocol proposed in this work may result in the first Brazilian portal of centralized and reliable information on RD. To the best of our knowledge, no previous studies have been made to comprehensively model and evaluate the e-service quality, usability, and user experience of RD web portals in a consolidated manner.

Therefore, a research gap exists in determining components of integrated e-service quality, usability, and user experience evaluation model in general, and for RD web portals, in particular. We also expect to evaluate and provide a web portal as easy to use, where the main focus is usability, and enjoyable to use, with the main focus on UX. In addition, users of the RARAS Portal need to get validated content and the required reliable online services without doing exhaustive searches or visiting multiple sources, with the main focus on e-service quality.

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References

[1] Rodrigues, R. J., & Gattini, C. H. (2017). “National Health Information Systems and Health Observatories.” In *Global Health Informatics* (pp. 14-49). Academic Press.

[2] Yoshiura, V. T. (2020). “Desenvolvimento de um modelo de observatório de saúde baseado na web semântica: o caso da rede de atenção psicossocial” (Doctoral dissertation, Universidade de São Paulo).

[3] World Health Organization. (2016). “Guide for the establishment of health observatories.” Available at: https://apps.who.int/iris/handle/10665/246123,%20last%20accessed%202022/06/30

[4] Alves, D., Yamada, D. B., Bernardi, F. A., Carvalho, I., Colombo Filho, M. E., Neiva, M. B., ... & Félix, T. M. (2021). “Mapping, infrastructure, and data analysis for the Brazilian Network of Rare Diseases: protocol for the RARASnet Observational Cohort Study.*” JMIR Research Protocols*, **10(1),** e24826.

[5] Gattini, C. H. (2009). “Implementing National Health Observatories: operational approach and strategic recommendations.” *Implementing National Health Observatories: operational approach and strategic recommendations.*

[6] Pereira, B. D. S., & Tomasi, E. (2016). “Instrumento de apoio à gestão regional de saúde para monitoramento de indicadores de saúde.” *Epidemiologia e Serviços de Saúde*, **25**, 411-418.

[7] Brasil. Portaria nº 199, de 30 de Janeiro de 2014, Ministério da Saúde. Available at: https://bvsms.saude.gov.br/bvs/saudelegis/gm/2014/prt0199_30_01_2014.html, last accessed 2022/02/16.

[8] Félix, T. M., de Oliveira, B. M., Artifon, M., Carvalho, I., Bernardi, F. A., Schwartz, I. V., ... & Alves, D. (2022). “Epidemiology of rare diseases in Brazil: protocol of the Brazilian Rare Diseases Network (RARAS-BRDN).” *Orphanet Journal of Rare Diseases*, **17(1)**, 1-13.

[9] Yamada, D. B., Bernardi, F. A., Neiva, M. B., Lima, V. C., Vinci, A. L. T., de Oliveira, B. M., ... & Alves, D. (2022). “National Network for Rare Diseases in Brazil: The Computational Infrastructure and Preliminary Results.” In *International Conference on Computational Science* (pp. 43-49). Springer, Cham.

[10] Weinreich, S. S., Mangon, R., Sikkens, J. J., Teeuw, M. E., & Cornel, M. C. (2008). "Orphanet: a European database for rare diseases." *Nederlands tijdschrift voor geneeskunde*, ***152*(9),** 518-519.

[11] de la Paz, M. P. "Improved Diagnosis and Care for Rare Diseases through Implementation of Precision Public Health Framework." *Rare Diseases Epidemiology: Update and Overview*, **55**.

[12] Nguengang Wakap, S., Lambert, D. M., Olry, A., Rodwell, C., Gueydan, C., Lanneau, V., ... & Rath, A. (2020). "Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database." *European Journal of Human Genetics*, **28(2)**, 165-173.

[13] Turinsky, A. L., Choufani, S., Lu, K., Liu, D., Mashouri, P., Min, D., ... & Brudno, M. (2020). EpigenCentral: Portal for DNA methylation data analysis and classification in rare diseases. *Human Mutation*, ***41*(10)**, 1722-1733.

[14] Nielsen, J. (2012). "Usability 101: Introduction to usability." NNGroup. Available at: https://www.nngroup.com/articles/usability-101-introduction-to-usability/

[15] Nielsen, J. (2012). "Empathy Mapping: The First Step in Design Thinking." NNGroup. Available at: https://www.nngroup.com/articles/usability-101-introduction-to-usability/

[16] Haughey, D. (2010). Delphi technique a step-by-step guide. *Project Samart. co. uk*.

[17] Domensino, A. F., Winkens, I., van Haastregt, J., van Bennekom, C. A., & van Heugten, C. M. (2020). "Defining the content of a minimal dataset for acquired brain injury using a Delphi procedure." *Health and quality of life outcomes*, ***18*(1)**, 1-10.

[18] Rayess, H. M., Gupta, A., Nissan, M., Carron, M. A., & Zuliani, G. F. (2017). Search engine optimization: an analysis of rhinoplasty web sites. *Facial Plastic Surgery*, ***33*(06)**, 665-669.

[19] Pilarcikova, K., Rusnak, P., Rabcan, J., & Kostolny, J. (2019, November). User experience in the development of the education system. In *2019 17th International Conference on Emerging eLearning Technologies and Applications (ICETA)* (pp. 626-632). IEEE.

[20] Lewoniewski, W., Härting, R. C., Węcel, K., Reichstein, C., & Abramowicz, W. (2018, October). "Application of SEO metrics to determine the quality of Wikipedia articles and their sources." In *International Conference on Information and Software Technologies* (pp. 139-152). Springer, Cham.

[21] Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). "Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support." *Journal of biomedical informatics*, ***42*(2)**, 377-381.

[22] Lewis, J. R. (1995). "IBM computer usability satisfaction questionnaires: psychometric evaluation and instructions for use." *International Journal of Human-Computer Interaction*, ***7*(1),** 57-78.

[23] Yoshiura, V. T., Yamada, D. B., Pellison, F. C., De Lima, I. B., Damian, I. P. M., Rijo, R. P. C. L., ... & Alves, D. (2018). "Towards a health observatory conceptual model based on the semantic web." *Procedia computer science*, ***138***, 131-136.

[24] Bernardi, F. A., Yamada, D. B., de Oliveira, B. M., Lima, V. C., Félix, T. M., & Alves, D. (2022). "The minimum dataset for rare diseases in Brazil: a systematic review protocol." *Procedia Computer Science*, ***196***, 439-444.

[25] Lamprecht, A. L., Garcia, L., Kuzak, M., Martinez, C., Arcila, R., Martin Del Pico, E., ... & Capella-Gutierrez, S. (2020). "Towards FAIR principles for research software." *Data Science*, ***3*(1),** 37-59.

[26] Kierkegaard, E. (2021). "Optimizing the sign-up flow for a fintech company using Google Analytics, Hotjar and A/B testing."

[27] Ssemugabi, S. (2019). "Development and Validation of an Integrated Model for Evaluating E-Service Quality, Usability and User Experience (E-SQUUX) of Web-Based Applications in the Context of a University Web Portal." *Unpublished PhD thesis*.

[28] Armstrong, R. A., Eperjesi, F., & Gilmartin, B. (2002). "The application of analysis of variance (ANOVA) to different experimental designs in optometry." *Ophthalmic and Physiological Optics*, ***22*(3)**, 248-256.

[29] Mishra, P., Singh, U., Pandey, C. M., Mishra, P., & Pandey, G. (2019). "Application of student's t-test, analysis of variance, and covariance." *Annals of cardiac anaesthesia*, ***22*(4)**, 407.

[30] Ferreira, J. M., Acuña, S. T., Dieste, O., Vegas, S., Santos, A., Rodríguez, F., & Juristo, N. (2020). "Impact of usability mechanisms: An experiment on efficiency, effectiveness and user satisfaction." *Information and Software Technology*, ***117***, 106195.

[31] Harrati, N., Bouchrika, I., Tari, A., & Ladjailia, A. (2016). "Exploring user satisfaction for e-learning systems via usage-based metrics and system usability scale analysis." *Computers in Human Behavior*, ***61***, 463-471