Proposal of Model for Curation Digital Objects of an Oncology Research Center

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Abstract. This article presents a proposal model for curation of digital objects from an oncology research center in Santa Catarina State. This is an exploratory research with a qualitative approach, in which the technical procedure of case study was used. From the case study it was possible to know the digital objects that make up the informational context, and the actions taken of digital curation in the studied cancer research center. The basal phases that make up the proposed model were extracted from the literature. As a result of it, there is a model proposal to support the preservation, maintenance, access optimization, use, reuse, and the promotion of added value to the digital objects of the studied cancer research center.

Keywords: Digital curation · Oncology research center · Digital objects

1 Introduction

In the Health area, the preservation of digital information for future generations becomes essential given the growing emergence of new diseases, as well as the resurgence of others. As for example in the specialty of oncology, based on data published by the Institute José Alencar Gomes da Silva, also known as the INCA, it was estimated for the 2018–2019 biennium the occurrence of 600,000 new cases of cancer annually [1].

These estimates reinforce the need and urgency to propose new cancer prevention and control actions in Brazil. It requires further research to find the cause and cure of cancer, for which patient records and existing studies are excellent sources of information to support it.

Access to this digital information to ensure further research in the future will only be possible through preservationist actions.

In this projection, digital curation is inserted as a solution for the preservation of these digital objects, aiming at their access and reuse in new long-term research.

Based on this, a proposal for a digital object curation model of a cancer research center in the state of Santa Catarina was developed in this article. Its objective is to support active management, access optimization, use and reuse, and promote the value addition of the digital objects of this research center.

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1.1 Search of Problemam

With the arrival of the 21st century, the development of information and communication technologies (ICT) has brought significant changes in all segments of society.

In the Health area, for example, these changes brought innovations, such as the Telehealth Brazil Networks Program, the expansion of the implementation of the Electronic Patient Record (PEP), among other services and processes related to Information Management in the administrative sectors of these units. Services and processes which helped with culmination in the significant increase in the birth of digital information.

In this context, the problem arises in relation to Digital Preservation and Curation, because this digital collection of varied nature (textual and multimedia digital objects) needs to be organized, stored, made available for access (current and future), reused in new consultations and/or subsequent research, and as an element "[…] supporting the functions and activities of people, groups and institutions" [2].

It is generally agreed that this type of information support requires theoretical and practical knowledge to perform maintenance. It requires them due to the physical fragility and obsolescence of hardware, software, file formats (extensions), and storage media that are necessary for the correct maintenance, interpretation, and visualization of the bits that form a digital object [2–4].

The Digital Curatorship, besides being concerned with digital preservation, is concerned with the active management of digital objects throughout the life cycle, so that they remain continuously accessible, can be retrieved when necessary, and with aggregation of data value of these digital objects (in the sense of generating new sources of information and knowledge) [5–7].

From this perspective, considering the scope of health: where digital objects are of great value for the development of society and characterized by a complex scenario of diversified nature, in which there are textual and multimedia digital objects (image, video and audio), consisting of structures (structured, semi-structured and unstructured), with different metadata and interoperability standards, protected by medical confidentiality, which access is allowed by classifying the content of the information recorded, and may be restricted or free, as established by Law Access to Information, the various resolutions of the Federal Council of Medicine (CFM), the Brazilian Constitution and the Civil Code. The guiding question to be answered in this study is: How to make digital objects available from oncology Research Centers with a view to its maintenance and subsequent access and reuse in new research?

2 Digital Curation: Concepts and Definitions

Digital curation involves maintaining, preserving, and adding value to research data throughout its life cycle. Active management of this data reduces threats to their long-term value and mitigates the risks of digital obsolescence. In addition to reducing duplication of effort in research data creation, digital curation reinforces the long-term value of existing data by making it available for reuse in high quality new research [8].

Abbot [9], from a broader perspective, defines the concept of Digital curation as a set that brings together all the activities involved in data management, from planning its

creation—when systems are designed—to digitization (dealing with analog materials), selecting formats and documentation, and ensuring that such data is available and suitable for future discovery and reuse. Digital curation also includes managing large data sets for everyday use, ensuring, for example, that they can be accessed, read and interpreted continuously.

Higgins [7] assures that the focus of digital curation is to manage the entire life cycle of digital materials, so that it remains continuously accessible and can be retrieved by those who need it.

Sayão and Sales [5] draw attention to value addition and data reuse. They define that digital curation ensures the sustainability of data for the future, while it gives immediate value to data for its creators and its users. Strategic, methodological resources, and technologies involved in digital curation practices facilitate persistent access to reliable digital data by improving the quality of that data. Its research context and authenticity are checked. In this way, the curation helps to ensure that this data is valid as archival records, meaning that it can be used in future as legal evidence. The use of common standards across different data sets, provided by digital curation, creates more opportunities for cross-sectional and collaborative searches. From a financial perspective, data sharing, reuse, opportunities for further analysis, and other benefits, value and protect the initial investment in data collection.

In the last decade, Digital curation has emerged as a new broad-spectrum practice and research area that dialogues with several disciplines and practitioners of varying categories. The Digital curator combines technologies and good practices of archiving, digital preservation, and reliable digital repositories with the management of scientific data. This combination gives rise to a new area of research, full of practical and theoretical gaps to be addressed, preferably oriented by a multidisciplinary approach [5, 10].

For the purposes of this study, we considered the concepts of digital curation presented by Abbot [9] and Sayão and Sales [5]. The first one for addressing the digital management and preservation of digital objects. The second one for focusing on value addition through the use and reuse of these digital objects by the community of users. It should be noted that previous studies do not give due importance to the power that the community of users has in adding value to digital objects.

3 Curation Lifecycle Model

The literature presents a range of life cycle models to systematize the application of digital curation activities, being the Digital Curation Center - DCC [8] life cycle model the most known and applied in Digital Curation projects. DCC [8] provides a digital curation life cycle model, it reflects a high-level view of the stages needed for the successful curation and data preservation process that begins at the conceptualization or data receipt stage in the repository.

Sayão and Sales [5] explain that the model proposed by the DCC is oriented towards planning curation activities in organizations or consortiums. It helps to ensure that all steps of the cycle will be fulfilled. However, it does not imply that all organizations must complete the cycle from the first stage. The operationalization of the stages will depend on the actual needs of each organization.

The key elements of the model are: data, digital objects, and databases. At the core of the curator's life cycle is data - which is any information encoded in binary format [8].

The model that can be seen in Fig. 1 presents three types of actions that should be applied during the Digital Curation process, that is, actions for the whole life cycle. Those include description and representation of information, preservation planning, participation and monitoring, and curation and preservation. Sequential actions include conceptualization, creation and/or receipt, evaluation and selection, archiving, preservation, storage, access, use and reuse, and transformation actions. Finally, occasional actions include elimination, reevaluation, and migration. The model designed by DCC provides a collective view of the set of functions required for curation and data preservation. In addition to defining roles, responsibilities, and concepts, it introduces the standardization infrastructure and technologies that must be implemented [5].

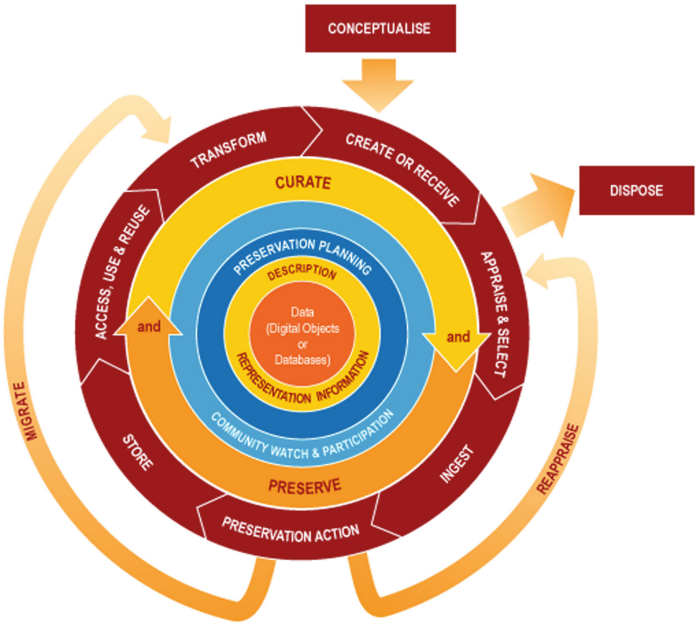

Fig. 1. Curation lifecycle model from Digital Curation Center – DCC.

4 Digital Objects in Health

For this proposal, it will be considered the concept of digital object proposed by Yamaoka and Gauthier [11] based on Ludwig [12], due to its broad scope of conceptual scope - as shown in the concept map expressed in Fig. 2.

Thus, digital object means any information object of any type and format expressed in digital form. Which, as Thibodeau [13] assures, inherits properties of three layers:

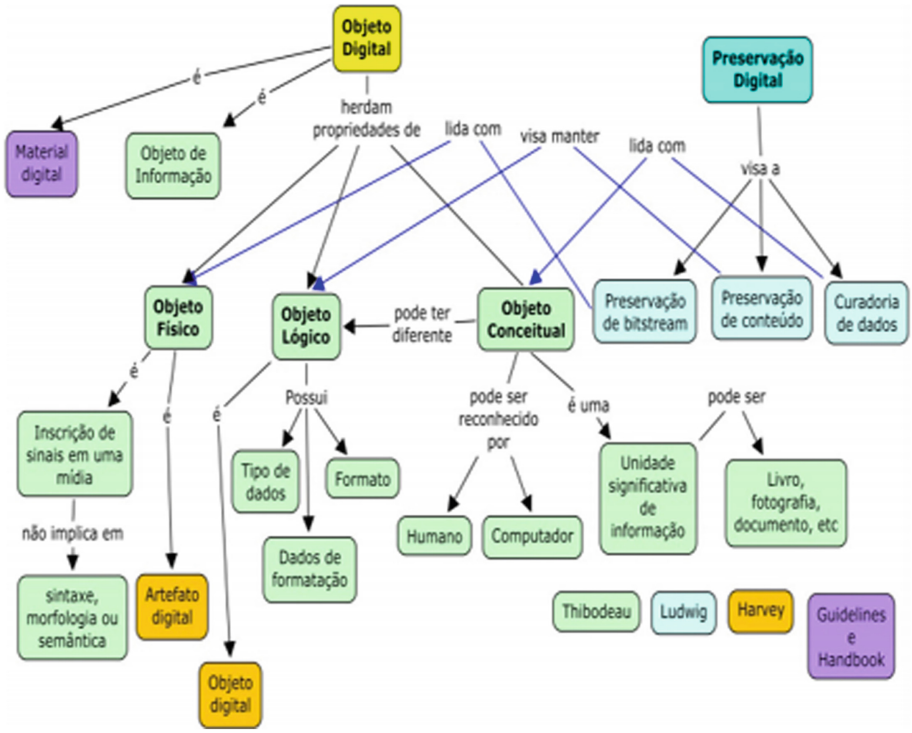

Fig. 2. Conceptual map of a digital object based on the model of Thibodeau [13] and other authors. **Source:** Yamaoka and Gauthier [11] based on Ludwig [12].

physical object, logical object, and conceptual object. The digital object deals with the physical object and the conceptual object. It aims to maintain the logical object.

In the physical object layer, the digital object is simply an inscription of signals in a midst. Not implying syntax, morphology, or semantics. The physical object is also called a digital artifact by Harvey [14]. At the logical object layer, the digital object is recognized and processed by software. Grammar does not interfere, and the format, formatting data, and code (ASCII) data types of the object are recognized by application software.

Harvey [14] calls the logical object a digital object. In the conceptual object layer, the digital object can be recognized and understood by humans or computers. It is a significant unit of information. It can be a book, a map, a photograph, a memo, and so on. Coding in the conceptual object may differ from the logical object, and this has implications for its preservation. Digital preservation aims at bitstream preservation, content preservation, and data curation [12].

Based on the case study conducted at a Santa Catarina cancer research center, the following digital objects in health were identified as:

– Electronic Patient Record (PEP): This is a unique document, consisting of textual properties (identification forms, prescriptions, examination requests, etc.) and multimedia (examinations in image and video format), multifunctional (generated and used for various purposes) and multi professional (registered and consulted by a multidisciplinary team) [15, 16].
– Primary studies: These are medical studies that correspond to original investigations. They constitute the majority of publications found in medical journals and are classified as: Case report; Case Studies and Controls, Case Detection - Screening, Cohort Study, and Randomized Controlled Trial [17].
– Secondary studies: seek to draw conclusions from primary studies with a brief record of findings that are common to them. These studies correspond to: Reviews, Systematic Reviews, Meta-Analysis, Guidelines, Decision Analysis, and Economic Analysis [17].
– Scientific publications: include articles, thesis, dissertations, and reports (estimates of new cancer cases, tumors with higher incidence rate, distribution of incidence by geographic region, and deaths by cancer types for a given period).

5 Methodology

This is an exploratory research with a qualitative approach, applied in nature and in which the technical case study procedure was used.

This case study was conducted at a Santa Catarina cancer research center in April 2019, after being approved by the ethics committee and signed by its participants, in a Clear and Informed Consent Form (ICF).

It aimed to know the digital objects and their characteristics, and finally the digital curation actions undertaken in this place.

The concept of digital object adopted in this research was proposed by Yamaoka and Gauthier [11], as described in the literature review, in the section that deals with digital objects. The choice for this concept is justified by the broad conceptual scope.

As for the digital objects belonging to the center studied, the research identified the following: Patient's electronic records, Primary studies, secondary studies and the scientific publications.

Regarding the actions taken at the center studied regarding digital curation, the research found the use of backups, the implementation of the electronic medical record via TASY system and the use of PACS software for automated treatment of image and video exams.

It should be noted that these initiatives do not ensure the maintenance, long preservation and value addition of these digital objects.

In this sense, a model proposal for digital curation of digital objects is presented, based on the Digital Curation Center (DCC) life cycle model adapted to the reality of the cancer research center studied, aiming at preservation, maintenance and value aggregation of these digital objects.

6 Model Proposal for Curating Digital Objects from an Oncology Research Center at Santa Catarina

Based on the theoretical framework presented, this paper presents a proposal for a generic model to curate digital objects from cancer research centers. This proposal will be developed based on the life cycle model proposed by the Digital Curation Center [8]. It is aimed to ensure the active management, preservation, and value addition of digital objects from cancer research centers.

To do so, the basic phases that constitute the present proposal will be presented. Figure 3 presents a macro view of these phases, followed by their description.

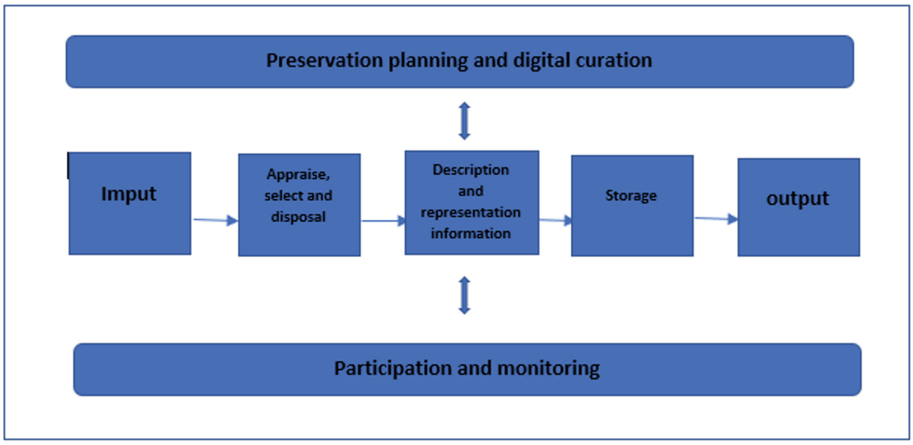

Fig. 3. Flow of the macro phases that make up the model proposal. **Source:** Prepared by the authors.

As already mentioned, this proposal aims to ensure the active management, preservation and value addition of the following digital objects of the studied center: electronic patient record (PEP), primary and secondary studies, and scientific publications.

Therefore, guidelines are proposed regarding the implementation of a curated project for these types of digital objects: textual and multimedia, structured, semi-structured, and unstructured. They have different metadata and interoperability standards. They are protected by medical confidentiality, whose access is allowed, based on a set of laws.

This model proposal has the function of systematizing the digital curation process, assisting the curator in a practical way in the administrative processes and management of digital objects, as well as in the selection. In the selection he will decide for the preservation, or not, of a certain object and its digital transformation (giving rise to new digital objects from the original).

It should be clarified that the following phases must be employed and strictly adhered to in order to ensure the authenticity, reliability, integrity, and usability of the digital object [19].

a) Input

In the model proposed for cancer research centers, the curator may be an IT professional, librarian, or archivist. Digital objects are understood as any information object of any typology and format expressed in digital form that inherits properties of the object layers: physical, logical and conceptual [7–9, 18].

The digital objects dealt here are: electronic patient record (PEP), primary and secondary studies, and scientific publications.

In the input phase, the curator conceptualizes the digital object received or created in order to identify what type of object it is. The professional designs and plans digital object creation. It includes capture methods and storage options. Issues such as intellectual property, embargoes and restrictions, funding, responsibilities, specific research objectives, capture and calibration tools should be recorded [5].

It should be noted that the receipt will happen in accordance with the policy, rules, administrative acts, and other regulations established by the maintaining center. This information is recorded to characterize authorship (intellectual property), typology, access, embargoes and restrictions, funding, responsibilities, specific objectives, appropriate metadata for curation and preservation, capture tools, and calibration.

After the conceptualization, whether the digital object is received or created, the curator prepares the digital object to enter the CD cycle. The curator assigns to it administrative, descriptive, structural, technical, and preservation metadata.

In the case of self-archiving, the author plays the role of curator and inserts the metadata - obeying the policies, rules, administrative acts, and other regulations established by the maintaining center.

The input phase steps are shown in Fig. 4.

b) Appraise, selection and disposal

Once conceptualized, the curator evaluates the digital object received applying sound selection criteria set out in established policies, guidelines or legal requirements by the cancer research center. Based on these criteria, the curator decides whether the object will be selected or not for long term preservation. Digital objects that have not been selected for long-term preservation will be discarded or relocated to a file or other custodian. In some cases, depending on the nature of the digital object, legislation may indicate safe destruction (Fig. 5).

c) Description and representation of information

Once selected the digital objects that will be part of the curation process, they will receive appropriate technical treatment. It will be assigned administrative, technical, structural, and preservation metadata according to the appropriate standards. In the research, it was found that the chosen center uses the following metadata and interoperability standards: ICD 10, SUS Table, DICOM Standard, HL7, openEHR, EAD, Dublin Core and Z39.87.

The description and thematic representation of the information contained in the digital object can be done through the AACR2 (Anglo-American Cataloguing Rules), RDA (Resource Description and Access), DDC (Dewey Decimal Classification) or UDC (Universal Decimal Classification) - based on the policies of the digital objects holding units of the studied center. In the case of electronic medical records, the technical treatment of the data is done using the tools provided by the Philips Tasy system itself. The same

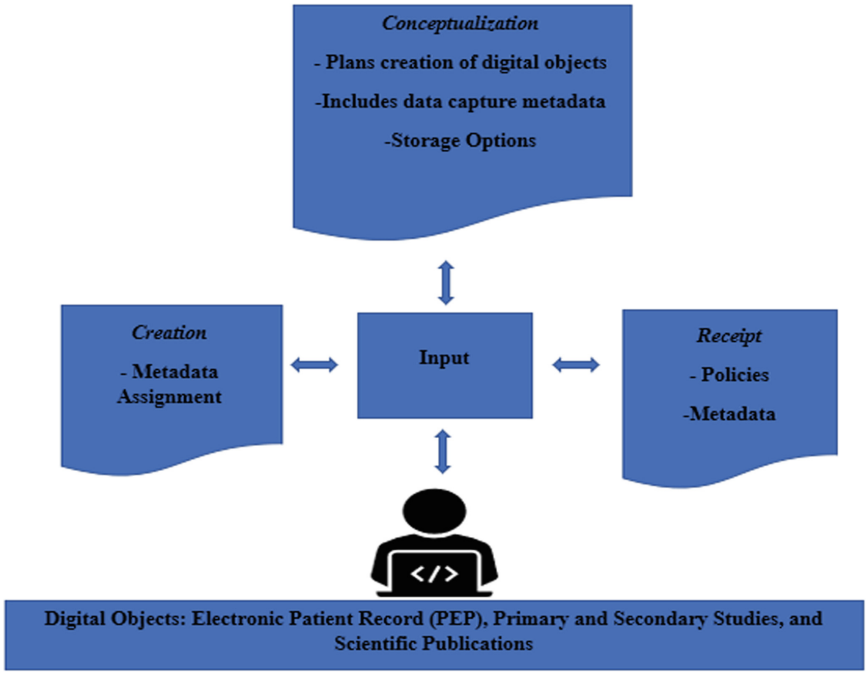

Fig. 4. Input phase steps. **Source:** Prepared by the authors.

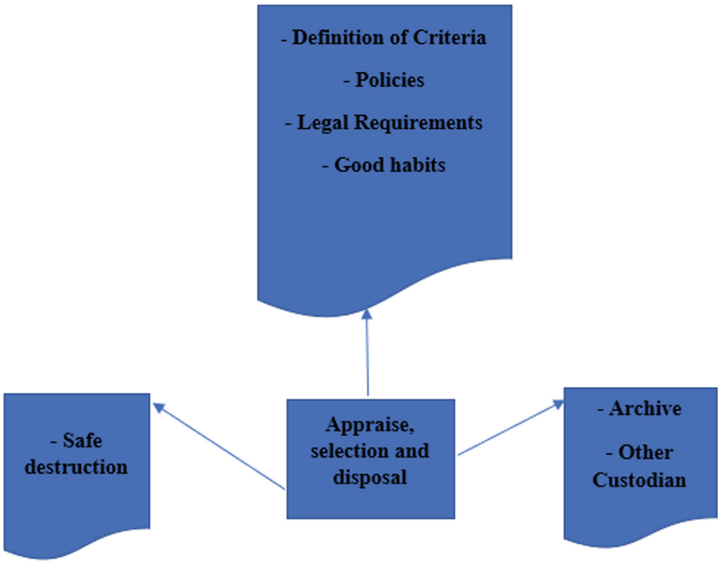

Fig. 5. Appraise, selection and disposal. **Source:** Prepared by the authors.

is applied for imaging and video examinations through the Communication and Image Archiving System (PACS) system by the radiology sector (Fig. 6).

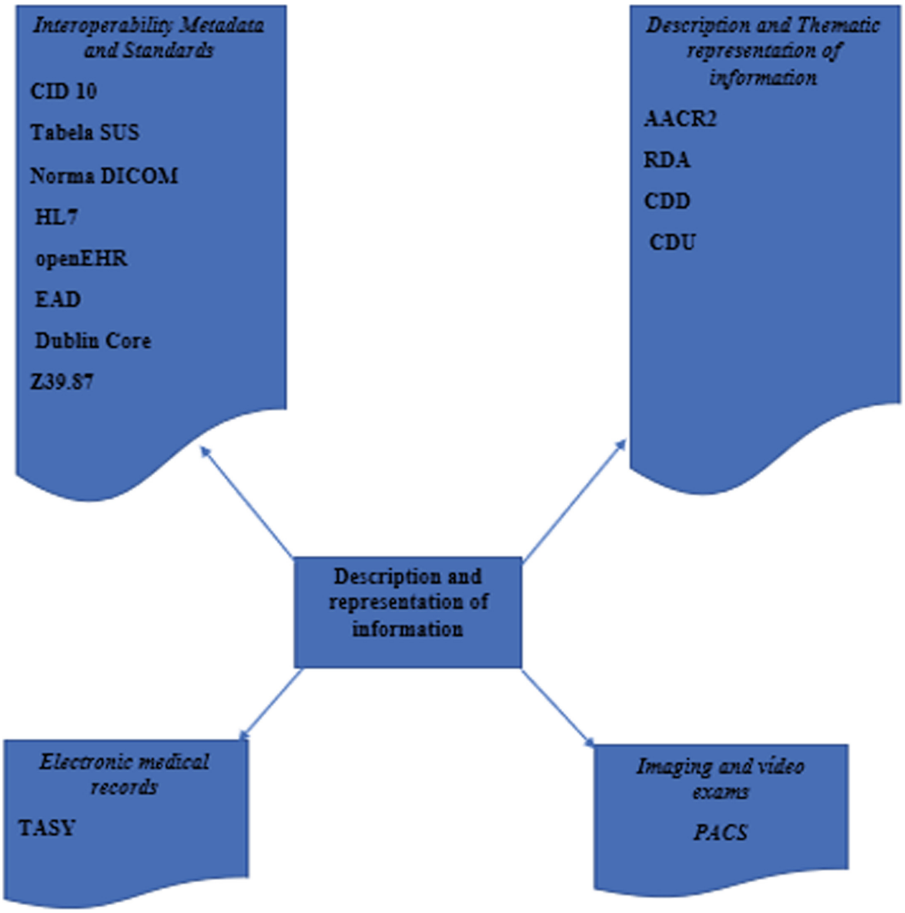

Fig. 6. Description and representation of information. **Source:** Prepared by the authors.

d) Storage

At the end of the technical processing phase of digital objects, they will be ready to be stored in databases, institutional repositories, and other digital platforms to be found by users in need - which in this case are: doctors, nurses, nursing technicians, pharmacists, nutritionists, social workers, cancer patients, family members, and other employees of the study center. They will be able to be found in the present and in the future, regardless of the format or current technology.

Storage in repositories should be based on preservation and access policies. Preservation in these environments can be accomplished through backup, metadata use, and preservation strategies: migration, emulation, refresh, encapsulation, and technology

preservation, and adherence to the requirements set out in the Open Archival Information System (OAIS) protocol reference model. The OAIS reference model became in 2003 an international standard, ISO 14721: 2003, with the objective of establishing an archiving system information through a schema order to preserve these and make them available to a designated community [20].

Elements must be stored in preservation formats in storages with their metadata. Preservation storage should be performed on a separate infrastructure from web servers for user access as shown in Table 1 [20].

Table 1. Definitions of file formats for preservation and access. Source: Siebra et al. [20].

Tipo	Formato	Base
Portable Document Format Archives (PDF/A)		
Texto (preservação)	PDF/A-1	ISO 19005-1:2005
	PDF/A-2	ISO 19005-2:2011
	PDF/A-3	ISO 19005-3:2012
Texto (acesso)	Portable Document Format (PDF)	Adobe Systems Incorporated
Imagem (preservação)	Tagged Image File Format (TIFF)	Adobe Systems Incorporated
	TIFF, Revision 6.0 and earlier	
	TIFF Uncompressed File with Exif Metadata	
Imagem (acesso)	JPEG file with Exif metadata	ISO/IEC 10918
		ISO/IEC 14495
Áudio (preservação)	Broadcast WAVE file, version 1, with LPCM encoded audio	EBU Tech 3285 - Specification of the Broadcast Wave Format (BWF) - Version 1 - second edition (2001)
	Broadcast WAVE file, version 2, with LPCM encoded audio	
Áudio (acesso)	MP3 (MPEG Layer III audio encoding)	MPEG-1: 11172-3
		MPEG-2: 13818-3
Video (preservação)	MP4 File Format	ISO/IEC 14496-14:2003
	MPEG-4 file format, version 2 (sem compactação)	
Video (acesso)	MPEG-4 com compactação	ISO/IEC 14496-2:2004

e) Output

At this stage, it deals with issues related to access, use and reuse of digital objects. In this sense, products and services are developed to promote digital objects submitted to the curation process. It includes: repositories, databases, digital object access products,

search and retrieval services. In the design of these digital informational environments, it is recommended to consider the main attributes of Information Findability (AEI) established by Vechiato [21], namely: Navigational Taxonomies, Folksonomies, Computer Mediation, Affordances, Information Discovery, Accessibility and Usability, Mediation, Mediation of subjects, Intentionality, Mobility, Convergence, and Ubiquity. They are recommended in order to optimize access and use of information. Still in this phase, it includes the participation of the user community. They can access through the internet the contents of digital objects already archived, produce new content from them, as well as provide information about a certain digital object - aiming to enrich this resource through its context and its domain information. The platform will record community interactions with digital objects and the effects of this interaction. This registration can help to adapt the way resources are made available to users, as well as the arrangement of objects in the repository or system through the principles of Information Architecture. It is possible to use ontologies to link a document to related ones through their entities. Its purpose is to reference other objects of the same subject, and, thus, keep the user informed of the interrelationship of these objects in order to indicate the contributions and projection for new research. All this interaction of users will be recorded in the system, accessed, used, and reused in order to contribute to the process of planning their digital preservation. It can be considered the transformation or reevaluation of a digital object.

It is noteworthy that their access, use, and reuse will occur through rules of access restrictions, copyright, and rules for data dissemination and sharing. It should be noted that digital objects from an oncology research center carry a range of sensitive information protected by medical confidentiality. It has restricted access by others, as set forth in the law of access to information, in several resolutions of the Federal Council of Medicine (CFM), in the Brazilian constitution and in the Brazilian civil code.

f) Participation and monitoring

In this phase the user community is assisted, as well as the activities that take place under them. All interaction will be mapped through statistical reports to investigate if reuse of "cured" digital objects is happening and at what level it is happening. That is, it will be identified if cured digital objects are resulting in new research, new procedures and the impact of this on cancer treatment (based on data presented in previous years reports on the evolution of this disease).

At this phase, is also noticed the evolution of technological tools, social media, and applications. Also, it is noticed how they can contribute to leverage the process of adding value to cured digital objects of the center (Fig. 7).

g) Preservation planning and digital curation

This phase includes activities that permeate the entire digital curation lifecycle on an ongoing basis. At this stage, the physical structure necessary to support such a project is dimensioned, from the present moment to a temporal projection date. Here it is analyzed storage data servers, servers, and other physical components needed to achieve the desired goal in this project. An analysis of the archives typology is performed and the formats for their access and their preservation are defined, as shown in Table 1. Based on this, the preservation strategies are timely, security measures are established, and finally,

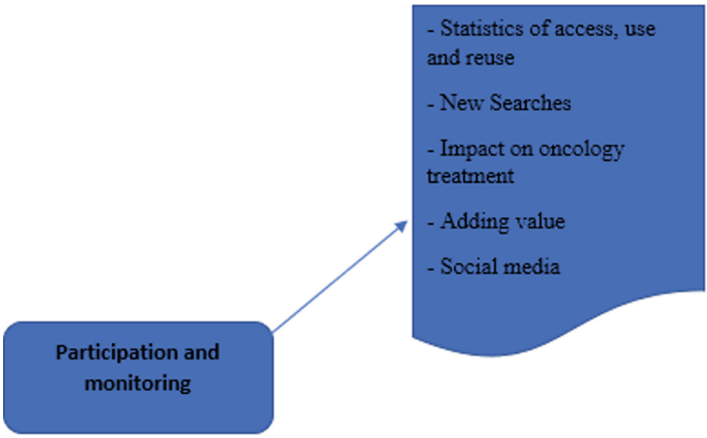

Fig. 7. Participation and monitoring. **Source:** Prepared by the authors.

people are assigned responsible for the custody and actions that ensure the full exercise of the digital curation process for the digital objects of the research center. For each of these planning steps, a checklist will be developed as a quality tool to ensure that tasks are performed as scheduled.

This phase also focuses on transformation and reevaluation activities. Based on the access and use and reuse of digital objects, a certain digital object is forwarded to the selection and evaluation stage. It is forwarded for further consideration and decision as to whether discard it or not. In other cases, it may be recommended to transform the digital object, that is, create others from the original to meet new demands.

7 Conclusion

The development of this model proposal for the digital curation of digital objects of an oncology research center was motivated thinking about allowing the access, use and reuse of information from the center afterwards. It is believed that the development of this framework will support health researchers in tracking, controlling, and decreasing the number of new cancer cases. That said, as it is a proposal, it is recommended as future work, the application of this in a unit of cancer research to investigate their adherence to the processes of preservation, maintenance, and value addition of digital objects. Also, focusing on investigate the impact there of figures presented in the INCA reports on cancer in the coming years.

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