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CHAPTER 6

DESIGN AND DIGITAL CURATION FOR A VIRTUAL SPACE THE VISUALLY IMPAIRED*

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ABSTRACT

The chapter presents the digital curation process of the pilot project “I remembered you” through which a network of volunteers responsible for the organization, reading and production of audios for people with and without visual disabilities, especially for the elderly, established during and after the pandemic to alleviate states of loneliness and provide people with visual disabilities access to stories, poems, among other contributions from the group of volunteer readers. The aim is to promote citizenship and the constitution of the autonomy of the public served from the theoretical and aesthetic concepts, the awakening of recollections and memories that help blind people to elaborate mental images and assist them in the processes of expanding the repertoire knowledge, social integration, improvement of

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the quality of life and well-being, meeting the scope of inclusive design and design with social responsibility.

Keywords: Inclusive Design, accessibility, visual impairment, digital platform, pandemic and post-pandemic.

RESUMEN

El capítulo presenta el proceso de curación digital del proyecto piloto “Me acordé de ti” a través del cual se estableció una red de voluntarios responsables de la organización, lectura y producción de audios para personas con y sin discapacidad visual, especialmente para ancianos, durante y después de la pandemia para paliar estados de soledad y brindar a las personas con discapacidad visual el acceso a cuentos, poemas, entre otros aportes del grupo de lectores voluntarios. El objetivo es promover la ciudadanía y la constitución de la autonomía del público atendido a partir de los conceptos teóricos y estéticos, del despertar de recuerdos y memorias que ayuden a las personas ciegas a elaborar imágenes mentales y las asistan en los procesos de ampliación del repertorio de conocimiento, integración social, mejora de la calidad de vida y bienestar, atendiendo el alcance del design inclusivo y del design con responsabilidad social.

Palabras clave: Design Inclusivo, accesibilidad, discapacidad visual, plataforma digital, pandemia y postpandemia.

1 INTRODUCTION

This article presents a research project that brings together the contemporary relations of Design, resuming its guiding principles, expressed from actions related to social responsibility and citizenship, its effective contribution through the existing social problems in the country, which are especially addressed in the sphere of inclusive and accessible design, with priority being given to improving the quality of life and well-being of individuals.

The results of the research carried out indicated the need to establish the group of blind and low vision elderly people as a priority, due to the vulnerability and fragility inherent to these elderly people, especially in the face of loneliness, an issue identified by them as one of the most serious problems. to be faced.

Faced with the situation of social isolation imposed by the SARS - Covid-19 pandemic, this feeling of loneliness is aggravated. This fact leads us to the need to develop practices related to the universe of inclusive and accessible design, guided by a theoretical body that enables an effective system for communication, interaction and integration in a solidarity network for the elderly with visual impairments, providing an effective relationship between the university and society based on the scientific knowledge developed.

In view of these aspects, we will deal in this project with issues related to visual impairment, to Design in the inclusive and accessible social sphere, as well as to the elderly, loneliness or state of loneliness, mental images in visual impairment that are made possible by orality and sound, the role of readers¹ and the process applied. These aspects, added to the theoretical framework, have, among the main authors: Acosta (2016), Amiralian (1997, 2004, 2009), Bomfim (2003), Bonsiepe (1993, 2011), Frascara (2011), Gibson (1962, 1966, 1979), Guimarães (2020), Maldonado (2012), Manzini (2015), Margolin (2006), Margolin and Margolin (2006), Moura *et al.* (2021), Papanek (1971, 1995), Rancière (2009), Redig (1978), Sacks (1995, 1997, 2010), Portugal (2013, 2021) and Vygotsky (1991, 2009), which constitute the framework for the development of this research project.

1 Readers are people who read texts and information from different natures allowing blind people or people with severe low vision to be “Ledores.”

The central questions of this research are related to the autonomy of the individual, to social integration, to improving the quality of life and well-being of the elderly with accessibility, to people with visual impairments, and, given the scope of inclusive design, they are also directed to elderly people without visual impairment (seers).

Our main objective is the creation, systematization and implementation through the development of a digital platform for management, collection and communication for interaction in a collaborative and solidary network of readers and listeners, aiming at strengthening self-esteem and motivation to promote autonomy and integration. of elderly people with visual impairments.

To meet the objectives, both general and specific, of this research project, we adopted the qualitative method with bibliographic, documentary and field research approaches associated with collaborative and participatory processes with the group served and involving evaluation, validation and improvements in processes developed.

2 WHY THIS PROJECT

By adapting to the countless contemporary cultural, social and technological innovations and dialoguing with different fields of research, design is re-signified and goes through increasingly alternative paths to the initial concepts that associated it solely with industrial production. This project addresses a reflection on the performance of human-centered design and some of its developments such as co-creation and other perspectives of action, supported by an argument built from the discourse of contemporary design scholars. In it, we reflect on the role of design in social contexts, especially in an action in which the subjects participating in the research become co-responsible for the results obtained.

Visual impairment is characterized by the decrease, loss or absence of visual acuity or visual field. These two ophthalmic scales concern the ability or inability to see at a distance (visual acuity) and the amplitude of the area reached by vision (visual field).

The most recent survey on disability in Brazil was carried out

by the Brazilian Institute of Geography and Statistics (IBGE, 2010), being reiterated and published by the Brazilian Council of Ophthalmology (CBO, 2019), and points out that the number of citizens diagnosed with visual impairment has exceeded the mark of 6.5 million people, with 6 million people with low vision and 500 thousand people who are blind.

According to Ottaiano, Ávila, Umbelino and Tuleb (2019), data based on the world population in 2016 show an increase in the number of blind people in the elderly population (over 60 years old) as a result of longer life. More than 82% of all blind people in the world are over 50 years old, despite the high percentage, this group represents 19% of the world population. According to the IBGE (2019), the elderly population should double in Brazil by the year 2042, compared to 2017, when the country had 28 million elderly people, or 13.5% of the total population. In ten years, it will reach 38.5 million (17.4% of the total population).

Faced with this reality and reflecting on the basic principles of design, we are concerned in the search for solutions and contributions to improve the quality of life and well-being of people with visual impairments. And, in recent years, we have dedicated ourselves to the study and research related to the ways in which design contributes to people with visual impairments, which is often referred to as social design.

The question of social or social responsibility, or even inclusive and accessible design, has been on the agenda of several design theorists and professionals in recent decades, resuming a thought that was constituted from the 1930s with the Movement of the League of Physically Disabled in New York, being expanded in the 1950s with the Barrier Free Environments Movement of World War II veterans with disabilities and followed in the 1960s with the organization of the Movement for the Rights of Persons with Disabilities, led by Ed Roberts in the USA.

Driven by practices and applications of design research with humanistic approaches, movements, debates and actions on the performance of design as an instrument of social responsibility emerged between the 1960s and 1980s, among these movements we highlight the Scandinavian socioeconomic policies that took place in the 1960s. 1960 in Sweden, which formalized the concept of “a society for all”, referring

mainly to issues related to accessibility, a proposal that expanded worldwide when recommended by the Stockholm Declaration, approved on May 9, 2004, by the General Assembly Ordinary of the European Institute for Inclusive Design, where it was defined, on that occasion, that the built environment, everyday objects, services, culture and information must be accessible, usable by all in society and sensitive to the evolution of human diversity (EIDD, 2004).

Facts that were reflected in the production of Victor Papanek's texts with the social theme in design or in the design acting in social changes or, still, the thought of design for society. Papanek (1971) questions, provokes and calls on designers to become aware of their role related to the social and the sensitive.

These issues are reverberated in the area of design after the attack on the Twin Towers, in the USA, in 2001, with publications that discuss the role of the designer as a citizen. Steven Heller (2003) points out the need for a critical posture in the attitude of designers in their professional performance and also as citizens, recalling Milton Glaser who stated: "Good design is a good citizenship", that is, making a good design is a matter fundamental and indispensable for society and culture; in this case, he refers to good design as an indispensable obligation that adds value to society, expands cultural and social dynamics, and that is why design and citizenship must go hand in hand. "Designers have to be good citizens and participate in building government and society. As designers, we can use our particular talents and skills to encourage others to take action and participate." (McCoy, 2003, p. 15)

In 2004, Sylvia and Victor Margolin published articles in which they discussed and proposed a model for the social practice of design. And they remember that, after Papanek's call, many designers started to act and develop design programs for "social needs, needs of developing countries, special needs of the elderly, the poor and people with physical disabilities" (Margolin, & Margolin, 2004, p. 43). However, they emphasize that there are numerous theoretical and practical models (methods, processes, management, marketing, semiotics, consumption) for market design, but no model for the needs and social practice of design, which includes knowledge about the structures, methods and goals of social design. And they also point out that no attention has been paid to changes in the education of designers, especially with

regard to the development of projects for needy populations.

It becomes evident, both in the authors discussed here and in the basic precepts of design, that the main focus of this area is the human being, however, when we look more closely at this relationship, we realize that when idealizing a project, many designers take into account the profile of a standardized man, defined by homogenized statistical data that do not reflect reality and do not consider the singularities that involve people today.

In this way, we believe that the great challenge of contemporary design is to be developed in a sphere that understands the complexity and diversity of people who live the reality of our time and, therefore, agreeing with the arguments of the authors that we will present in this reflection, we consider that The search for a real improvement in the quality of life is configured as one of the aspects encompassed by contemporary design, finding solutions to current social problems, in which one of the most prominent and also complex aspects is inclusion, especially in these times. of social isolation in the face of the Covid-19 pandemic.

In this reflection, we consider human-centered design as a type of contemporary action that promotes the participation of subjects, in which part of the design stages is delegated to non-designers. In this way of designing, it is up to the professional to mediate the interactions necessary for the process, an act that, according to Manzini (2015), represents the end of the imposing strategic position acquired by designers since the industrial age, granting autonomy to the subjects involved in the process. Thus, relevant points already raised by Bonsiepe (2011) are recovered, who argues, based on his solid professional experience, that autonomous production is an alternative to heteronomy and a restorative action, which implies the formulation of more humanist projects.

Contemporary Design goes beyond the new features of form, materialities and immaterialities and the development of new methods that lead to multidimensional features. There is a growing aspect that occurs through services and the search for solutions that can be found in the universe of the sensitive, and these in turn can collaborate for the political and social action of designers.

We live in an environment populated by visual, sound and spatial stimuli, with an excess of information and the imposition of frenetic and accelerated rhythms that can suppress our sensitivity and the ability to perceive and exercise empathy, alterity and dialogue with the other. Studying and analyzing contemporary issues associated with the universe of design, we focus on the possibilities of the exercise and the needs of the contribution of this area to the human being, subject to the changes of our time and our society and we ask ourselves about how to contribute effectively to seek the much desired and talked about quality of life and well-being. One of the paths that are presented is the performance of design beyond materialities, in a universe of the sensitive.

The research project, now presented in this article, “I remembered you Design and Inclusion (in and after) a pandemic with accessibility for elderly people with visual impairments” is based on the development of previous research and research in progress on design and inclusion.

When we had intense contact with the reality of visually impaired people - blind and with low vision - we were faced with the seriousness of the problem caused by loneliness, especially among the elderly. The results of the semi-structured interviews carried out in the field research process showed that the elderly were unanimous in indicating that the biggest problem they face is loneliness².

Loneliness or exclusion from activities with family, friends or in public spaces, usually happens because most cases of low vision or absolute blindness come from causes acquired with age or, especially, due to accidents at work or, and diseases resulting from aging.

Most diseases that cause visual impairments affect the elderly. In the adult population, some of the major causes of blindness are: cataract, glaucoma, diabetic retinopathy, age-related macular degeneration, trachoma and corneal opacities, but the relevance of refractive errors in eye health conditions cannot be disregarded (...). For every blind person, there are, on average, 3.4 people with low vision (...) Studies show that more

² A state of loneliness is considered as a passing situation in which a person finds himself in a period or phase determined by various circumstances in life.

than 90% of visual impairment in the world is located in developing countries. (CBO, 2019, p. 24).

In social isolation, the feeling of loneliness gets worse and adds to the insecurity and awareness of our fragility and finitude, as we are all at the mercy of a moment to another of being affected by a serious illness that can lead to death or to treatments and invasive procedures.

Also, if contact with other people is not feasible during the pandemic, whether inside homes or in public spaces, one way to reduce the feeling of loneliness is to bring the voice of another common person (not famous people) through. at regular intervals, to those who are in a state of solitude. And what better way to take someone else's voice if not literature in its various genres (narrative, lyrical, dramatic) and also music, life stories, memories, remembrances?

Given this situation, this project aims to address the problem of loneliness or the state of loneliness that affects many people who are in social isolation, working for inclusion and accessibility through design from actions that generate the social integration of the individual from the stimulus and expansion of the perceptual, aesthetic, sensitive, imagery and cognitive repertoire, making it possible to strengthen self-esteem with a view to building autonomy, dignity and, consequently, citizenship.

The social innovation involved in the project will be based on the expected results and occurs especially because there is little bibliographic production with cases and Brazilian reality aimed at people with visual impairments.

3 METHODOLOGY

To meet the objectives, we adopted the qualitative method with bibliographic, documentary and field research approaches, associated with collaborative and participatory processes of the group served and involving evaluation, validation and improvements in the developed processes.

We will take as a basis the Social Model of Design Practice

developed by Margolin (2004), which can be applied with the collaboration of different professionals, be them from health, education, or public administration. Margolin (2004, pp.45-46) points out that the participation of processes and projects involving teams of human services and designers is still open to be explored and that there are two main reasons for the fact that there is no greater support for social design: the absence of a program of education and training in design schools and the absence of research demonstrating how a designer can contribute for the human well-being.

The proposed Margolin model involves 6 stages, namely: 1. Commitment; 2. Evaluation; 3. Planning; 4. Implementation; 5. Estimate; 6. Finalization. Our details involve the following sub-stages: 1.1 Listening to learn about the problem and reality of people served (target audience); 1.2 Involvement in order to search for a joint solution (co-creation, participation, diffuse and specialist design); 2.1 Examine and promote interaction; 2.2 Analyze and understand the problem; 2.3 Generate a list of needs; 3.1 Prioritize urgencies; 3.2 Promote brainstorming in search of the solution; 3.3 Develop a list of goals and objectives for each one involved in the process; 4.1 Intervene according to goals and goals defined in the planning; 5.1 Evaluate by means of interviews with the public served and validate the process and 6.1 Evaluate the dynamics and the general process. Produce and publish scientific papers, chapters and books about results obtained.

4 PILOT PROJECT I REMEMBERED YOU

The Covid-19 pandemic is undoubtedly a huge challenge for all people in the world. However, the impact comes in different ways and degrees.

In the development of these researches and in the application of projects with groups and institutions of the elderly and blind, it was identified that the great and main problem that affects these elderly, blind or low vision people is loneliness.

Faced with the constitution of a theoretical body and the development of practices related to the universe of inclusive and accessible design in contemporary times, we began to question ourselves what our role was and how we could contribute to people

in general, but with accessibility for those with visual impairments, in the situation of social isolation imposed by the SARS - Covid-19 pandemic. After all, what were we designers doing for the audience we worked with to reduce this feeling of loneliness during quarantine?

Digital curation refers to new practices and methodologies of access, information retrieval and dissemination of digital collections among users, using, for this, methodologies that facilitate the extraction, manipulation and validation of the data obtained, according to the curator of the British Library, Aquiles Alencar Brayner (2017).

And thus, the project entitled I remembered you was born. The purpose of this project is to be inclusive, that is, for all people who are or feel lonely or in a state of loneliness in this pandemic, of any age, and also, accessible to people, elderly or not, with visual impairments, regardless of age, city or location they are in, but as long as they have access to a mobile phone with WhatsApp.

The main objective is to create a network of people who, through their voice and message, awaken feelings of empathy, welcome, comfort and hope to other people in a state of loneliness during the pandemic. To meet this objective, we created a network made up of volunteer mediators/organizers, readers/readers and listeners.

Participants in the Remembered You project are volunteers who work in the organization and mediation group, in the group of readers who, together, serve a network of listeners (individual people, local agents who work with other small groups or communities and institutions for the elderly, youth and children with or without disabilities). This network of listeners was formed with the indications of the project's volunteers and will be expanded through a public relations action.

This is an emergency action to meet the needs of people who feel lonely and isolated, but the project foresees several other more complex actions in the short, medium and long term.

Associating language, orality, literature and other artistic or popular expressions via oral manifestation and bringing together a group of volunteers to be readers forming a network with other people, individually, collectively or institutionally, elderly people with or without visual impairment, we laid the foundation for our inclusive

and accessible design project.

However, the application of the pilot project showed us two extremes. On the one hand, the effectiveness with the positive responses of the listeners served, on the other hand, indicated the pressing need for a broader and deeper systematization to achieve greater effectiveness and better dynamics by expanding accessibility.

The unfolding and expansion of the pilot project “I remembered you” is presented in this research project that is established from the need to involve not only the pandemic period, but also the post-pandemic period, and a systematization via the development of a digital platform for management, communication and interaction.

4.1 Target audience

Elderly, adults and children in isolation during the pandemic, accessible to people with visual impairments (blind and low vision).

4.1.1 Reminder of You working process

The process takes place as follows:

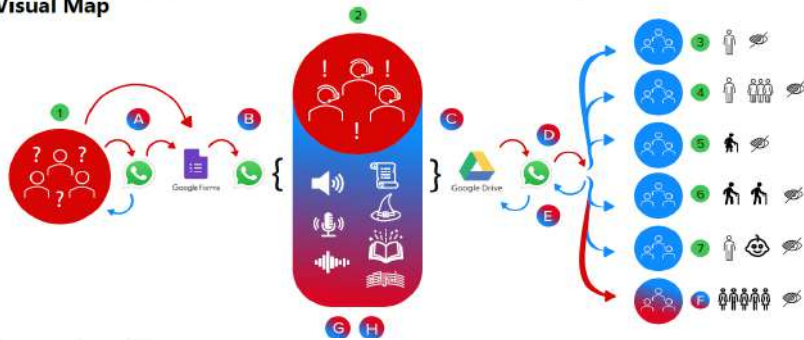
Volunteer participants, whether management or readers, fill out the registration form and confirm that they agree with the Term of Assignment of Use of Audiovisual Resources. After the validation of each volunteer's registration, he is added to a group in which he must send the audios that will be saved in the cloud, cataloged in categories, verified and, later, directed to the listeners; we currently have ninety-three volunteer readers and eighteen volunteers in the organization.

Blind and low vision listeners are registered in WhatsApp groups and receive eight audios per week. Listeners are divided into categories: individuals, groups and institutions. Currently, we have 678 registered listeners, of which around 550 are assisted in institutions that support people with visual impairments, one of which is a long-stay institution for the elderly, located in the state of São Paulo and Minas Gerais. The other 128 listeners are distributed in groups with people of different ages, sighted, blind and with low vision, from different locations in the Brazilian regions.

The multidisciplinary team was made up of professionals from different areas, designers, illustrators, pedagogues, musicians, programmers and professionals of Letters, led by researchers Mônica Moura, MárcioGuimarães and Cristina Portugal, all designers and PhDs in Design. There are still eighteen people in the organization/mediation. So far, 567 audios have been collected, including tales, poetry, songs, memory reports, among others.

Figure 1: Reading Guide for the Visual Map of the I remembered of you Project

**I remembered You
Project Organization
Visual Map**



**I remembered You
Visual Map**

Colors:

- Organization
- Volunteers
- Listeners
- Whatsapp Group

Symbols:

- Incidence of the Blind/Low vision
- Individuals
- Groups
- Small /medium-sized Institutions
- Large Institutions
- Children's Institutions
- New Institutions

Organization:

- A** A service to volunteers
Responsible: Valéria
- B** Inserting contacts to the Group
Responsible: Maria Alice
- C** Audio selection and documentation
Responsible: Iana, Márcio, Mônica, Cristina, José and Tetê.
- D** Sending Audios
Responsible: Mônica and Cristina
- E** Collection of testimonials/feedbacks
Responsible: Valéria
- F** Contact with Institutions (Expansion)
Responsible: Márcia
- G** Txtual revision
Responsible: Márcia
- H** Coordination and Project (Registration and Notices)
Responsible: Cristina, Márcio e Mônica.

Whatsapp Groups:

- 1** Pre-Volunteers with doubts
- 2** Registered Volunteers (Forms)
- 3** Individuals
- 4** Sharing Agents
- 5** Small /medium-sized Institutions
- 6** Large Institutions
- 7** Children's Institutions



Source: prepared by the authors (2020).

For Volunteers

The volunteer will receive a link for each record. Accessing the link, it will fill with the personal data and must agree with the Term of Assignment to Use Audiovisual Resources and, then, click in SEND.

After validating the record of each volunteer, this one will be added in a group for sending messages using WhatsApp.

In this new group, volunteers must send the audios that will be stored on the Cloud, cataloged, verified and later, directed for the listeners;

The volunteer will receive a PDF file with a suggestion about how the recording must be made, the presentation, Project name, type of message, text, poem, tale, and ... the farewell, in order to standardize the approach of audio for this project;

Audios must have a minimum time of two minutes and, at most, 15 minutes. Content may be constituted by histories, tales, stories, music, poems, legends, memories and personal reports of memory (from their Family, their friends or fictional);

The proposal is to have one audio per week for each volunteer, but volunteers are free to send as much as they want;

If some external interference happens, such as noise covering the voice of volunteers, we will indicate (privately), the need of redoing the audio after verification;

The initial group of volunteers will remain active to answer questions and exchange experiences. If there is feedback from any listener or group of listeners, we will also post it in the volunteers group.

For listeners

Listeners will receive an invitation to receive audios. They will have access to one audio per week.

For institutions

The volunteer who assumed the role of public relations (PR)

in the project "I Remembered You" will have to collect the indications of institutions from the other volunteers and, also, make a survey to organize a database of institutions to be served;

The contact with institutions will occur by email from the project (projetoembreidevoce@gmail.com) or WhatsApp to collect the contact data in order to send the form to be filled out;

If the institution agrees to participate, the person responsible for the institution receives a link to access a Google form, which must be filled and, after this stage, the institution's mobile number will be added to start receiving a message once a week during three months. After this period, we will carry out an evaluation of the project. We will adjust according to the needs of each institution. At first we will be able to increase the number of times of sending messages, for example, two days, then three, until reaching a daily message;

The RP monitors the answers of institutions' messages and informs the organizing group in order to send the messages and, subsequently, if institutions ask for message themes or types (poetry, short story, story, music, legend, personal or collective memory report).

Team of Project I remembered you

The multidisciplinary team was made up of professionals from different areas, designers, illustrators, pedagogues, musicians, programmers and professionals of Letters, led by Researchers Monica Moura, MárcioGuimarães and Cristina Portugal, all of them designers and doctors in Design. It also has ten people in the organization / mediation; 69 volunteers so far and 300 audios, among tales, poetry, music, etc. recorded and stored for distribution. The audios will be made available weekly to listeners in individual groups, agents of small groups and institutions, the latter being divided into institutions for adults and for children

The innovation involved in the project will take place based on the expected results and occurs especially because there is little bibliographic production with cases and Brazilian reality for people with visual impairments.

And, finally, it is expected to create a digital platform, from the

studies, analyzes, evaluations and surveys carried out, the planning and execution of the beta version of the digital platform for managing communication, collection and distribution of content for the visually impaired ones, including and also targeting visionary people, since accessible and inclusive projects must meet and provide comfort to everyone. Also, it is expected that the results obtained will contribute to the creation of autonomy and, consequently, the well-being and improvement of the quality of life of the individuals participating in the research.

5 CONCLUSION

From the pilot project “I remembered you” and for its deepening, the need was perceived in terms of the search for solutions to create information and communication management systems that are currently inserted in an environment of permanent challenge and that requires updating and development of new forms of presentation, in addition to the traditional ones, in order to make them understandable and usable by people with visual impairments. In this sense, this project searches for new models, new methods and new approaches for developing virtual spaces via digital platforms to reduce the state of loneliness in which these people find themselves, which can provide meaningful information and create pleasant experiences, moreover, as mentioned earlier, to expand the repertoire of information, as well as the aesthetic and the sensitiveness to stimulate mental images, memories and memories, aiming to strengthen self-esteem and to promote motivation for the construction of autonomy and, consequently the inclusion of blind people in society, with low vision and the elderly, but including sighted elderly people.

The digital curation of this project started from the definition of activities involved in data management, from the planning of their creation to the development of the audio storage system and its distribution.

Starting from an online meeting with the main stakeholders, the volunteers were selected and registered for producing the audios. Then, the group of listeners and institutions was selected, in order to have a database of those involved in the project.

The digital curation also included the management of data sets –audios, volunteers, listeners—so that they data can be accessed and searched in order to be ready and continuously interpreted. Digital curation extends beyond the control of the repository that files the data. Attention is needed in managing the entire life cycle of digital material.

As for the development of the digital platform, the aim is to create a space that facilitates the reception and distribution of content. The strategic, methodological resources and technologies involved in digital curation practices can facilitate access to data (audio), as well as their archiving and distribution, by improving the quality of these data, their research context and checking the received audio quality. In this way, the curator can ensure that this data is valid as records, so that the data can be used immediately as it is being distributed as shown in the project's Visual Map Reading Guide and in the future, through the digital platform. In addition, it is worth noting that using patterns across different datasets can create more opportunities for cross-sectional searches and collaboration.

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CHAPTER 6

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