

## Article

# “Not Storing the Samples It’s Certainly Not a Good Service for Patients”: Constructing the Biobank as a Health Place

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**Abstract:** Biobanks have been established from the beginning of the millennium as relevant infrastructures to support biomedical research. These repositories have also transformed the paradigm of collecting and storing samples and associated clinical data, moving these practices from the healthcare services and research laboratories to dedicated services. In Portugal, the establishment of biobanks is happening in the absence of a specific legal framework, turning it difficult to fully understand the scope of their action. This ethnographic research explored how establishing a biobank challenges the dynamics between healthcare and biomedical research. The ethnography intended to follow the path of biological samples from the hospital, where they were collected, to the biobank in a research institute, where they were stored. Findings suggest that although the nature of the biobank’s technical work seemed to inscribe it as a research-oriented setting, the biobank’s daily work was performed through symbolic action in the logic of care. Biobank staff constantly recalled the human nature of the samples, and they built complex illness narratives of each sample, promoting a connection with the absent donor. These practices were crucial to constructing the biobank as a health place, one that was designed to be life-saving in the near future.

**Keywords:** biobank; health; human biological samples; biomedical research; ethnography; caring practices; illness narratives; Portugal (study context)



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## 1. Introduction

This article explores the construction of a biobank as a health place. Biobanks, for the collection and storage of biological samples associated with clinical data, have played a major role in the last decades in supporting the development of biomedical research. Moving forward to a post-Human Genome Project Era, laboratory medicine and biomedical research are now focused on genetics and genomics. This turn into genomics was accompanied by the dissemination of large samples as a way of acquiring statistical significance [1], reflecting medicine’s biology-centered approach. Conducting such massive research projects implied the study of a large number of samples and clinical data. Biobanks are crucial for this task, providing storage facilities that enable gathering a significant number of samples and their maintenance for long periods of time. Although medical and biomedical research already have a long tradition of samples and data collection from the beginning of the century, currently, these infrastructures have scaled in number and dimension. The size is actually one of the major differences from the previous repositories used by individual doctors and small research teams, which have led to debates over ethical, legal, and social issues [1].

Biobanks collect a wide range of samples such as blood, tissues removed in surgeries or biopsies, saliva, hair, teeth, and feces, among others, and these would be, in most of the cases, given by donors voluntarily<sup>1</sup> aiming to contribute for the advancement of biomedical research. Regardless of their health status, every person could be a biobank donor with

different attributes or functions. Biobanks store these large amounts of medical information and biological samples collected in healthcare services to be used in biomedical research. These two contexts—healthcare services and research laboratories—have a significant role in determining the chain of procedures through which samples are collected and organized.

Different countries have been setting up their biobanks differently. From national to local initiatives, biobanks vary in size, shape, and in their governance models [2].

In Portugal, biobanking activities are starting to be established and finding their way into the context of scientific research; however, they are quite under-covered. In fact, the existence of biobanks remains unknown to most medical practitioners and researchers. Currently, the existing biobank initiatives are fragmented and do not correspond to any organized strategy at the local or national levels. Even in institutions that host biobanks, these are more of a project from a small team or group of medical doctors or researchers than an institutional enterprise [3]. Without a dedicated legal framework, biobanks are emerging in hospitals, research institutes, and universities. However, it is not yet entirely clear which characteristics they should have: how do biobanks operate, or under which jurisdiction should they be placed? The latter is key to understanding aspects that may influence the organization model, the funding programs, and the rules that apply to biobanks. Biobanks are often found in a vacuum, making it more difficult to delimit their nature, attributions, or potential. Most of them are organized within a research framework, being settled as research services. Nevertheless, the dependence on healthcare services and the fact that many biobanks were created at hospitals by medical doctors blurs the picture of how these actors and institutions interact when it comes to organizing a biobank.

This research aimed to explore the organization of work in a biobank and to comprehend how it was constructed as infrastructure at the intersection of Health and Science. In the first instance, the rise of biomedicine and its research techniques are discussed, explaining how it enabled the establishment of biobanks. Then, the development of biobanks in Portugal is presented to frame the challenges and the questions posed by this research, reflecting on the role of medical doctors and life-sciences researchers in such an effort. The results are presented reflecting on three main findings: (i) how the work in the biobank makes use of medical categories to organize biological samples and data; (ii) how samples are constructed by a human and what this definition implies in working at the biobank; (iii) how the production of illness narratives based on biological samples contributes to producing practices of care in the context of the biobank. To conclude, these practices are discussed as being crucial to constructing the biobank as a health place.

### *1.1. Setting the Scene for the Emergence of Biobanks for Health and Biomedical Research*

Medicine has always made use of bodies and body parts for studying, teaching, and research. However, in recent decades there has been an increasing need to draw on large sets of human biological samples and produce data in a systematic way to cope with the growing needs of biomedical research.

In order to understand these changes, it might be worth reflecting on the work of Clarke et al. [4]. The authors argued that the turn into biomedicine and biomedicalization was due to a number of transformations that have marked the way of performing, learning, and presenting medicine. In the name of health, life has become an object and an end in itself [4,5]. These transformations were connected mostly to technological developments, such as the appearance of powerful computers and informatics. Computer technology has facilitated the collection and the use of larger amounts of data and the refinement of statistics applied to life sciences. Although these changes began to insinuate themselves after World War II, it is possible to recognize several initiatives of considerable scales, such as the Framingham Heart Study<sup>2</sup> in the United States or the Varmland Health Survey<sup>3</sup>, which took place in Sweden. It was at the end of the 20th century that this way of investigating and producing medical-scientific knowledge gained greater visibility through the Human Genome Project. For this reason, it was after this moment that the appearance of more and larger repositories of biological samples to support the intensification of this form of

research was rendered more evident. Current research uses large amounts of systematic information, aggregated in databases, as a way to ensure the robustness of scientific evidence in biomedicine and requires an increased storage capacity, both samples and information, requiring technological devices that allow accessing and managing these data [1]. Moreover, it stresses the biological understanding of the disease processes by applying the logic of biology to medical research.

However, the approximation of Medicine to Biology, which had already been hinting since the beginning of the 19th century, had become more evident through the sharing of the laboratory [6]. In this line, Jewson [7] noted that people were no longer the object of medicine; however, the human body has maintained its value as a resource for developing medical knowledge. The influence of Biology progressively extends to language and the way of investigating the body [8]. Against this backdrop, the use of data science becomes more recurrent, as biology has also come to incorporate an important strand of biostatistics and bioinformatics [9]. Statistics as a source of scientific knowledge had already been used in medicine since the early 18th century by collecting information about the state of populations [10,11]. This was even more pronounced in the transition to biomedicine, which brought with it the normality of the body based on statistics. Statistics are produced by comparison with the population considered healthy [11], becoming criteria for defining disease status [12]. The *medical gaze* [13] is now transformed, in the words of Rose [14], into a *molecular gaze*. As noted by Sharp [15], the increased claims for body parts by biomedical researchers contribute to the fragmentation of the medicalized body and, at the same time, promote their commodification. Thus, body parts, namely human biological samples, are still quite useful for the study of physiology and cellular mechanisms, helping to understand disease in biomedical research. The body is, in this paradigm, seen as a complex organization of molecules to be studied. In some cases, genetic testing (both in clinical contexts and self-performed, e.g., direct-to-consumer tests) is defining new ways of dealing with one's body and disease [16], reconstructing self-identity [17], and even mediating the relationship between the nation state and citizens [18–20].

Another important transformation of medical research within this period, signaled by Rose [14], was the emergence of non-medical research professionals conducting research in life sciences. This approach to the life sciences implied an integration of knowledge from other scientific areas and the incorporation of research practices that were not so common in medical practice until then. In this line, the crescent specialization of biobanks is seen by the construction of a specific body of knowledge reflected in scientific articles dedicated to the topic, a scientific journal dedicated to biobanks, and best practices in samples' preservation is a recurring theme at biobanks conferences.

This changing paradigm of biomedical research set the scene for the emergence of greater repositories of samples and clinical data. Biobanks such as deCODE in Iceland and the UK Biobank in the United Kingdom were two big biobanks storing millions of biological samples and clinical data. The appearance of networks such as BBMRI-ERIC (*Biobanking and Biomolecular Resources Research Infrastructure—European Research Infrastructure Consortium*) at the European level that gathers biobanks from all over Europe are also signals of the recent developments in this field.

### 1.2. The Emergence of Portuguese Biobanks

In Portugal, biobanks are in their early stages. In 2021, there were 16 initiatives: some of them were already in place, and others were just an intention to open a biobank in the near future. Organizing a biobank demands a wide range of resources alongside institutional support. Nevertheless, the low level of recognition of biobanks within the scientific community makes biobanks to be projected by small teams of researchers or medical doctors that mobilize their own resources to organize their own biobanks. Although the growth of initiatives possibly points to a crescent recognition, the existent biobanks are still underused by researchers. In many cases, there is no solid institutional support or a strategic mission that informs the constitution of a new biobank. The absence of a legal

framework or a national strategy for biobanks is also problematic—not only because their scope of action is unclear but also because it limits their development. Since biobanks are neither a research project nor a research institution, nor are they considered a health service, they cannot benefit from grants or apply for the more common funding opportunities in the field of healthcare [3]. The lack of specific funding has been seen as a lack of investment in health research. To date, there are some fragmented strategies to stimulate healthcare research, but there has never been a true scientific health research policy in Portugal [21].

In the last 30 years, health research in Portugal has had an impulse through the establishment of relevant research institutions that try to settle upon the intersection of medicine and fundamental research. However, this is a recent and circumscribed phenomenon, and its impact is not yet visible in the biobanks landscape. The investment in health research is poor, with the Health Authorities recognizing the low level of interest in health research [22]. This opened the way for life sciences researchers to develop their research in the health domain. In 2010, it was already clear that doctoral and post-doctoral scholarships in the field of medical and health sciences have come to value mainly biomedical research, where there is no involvement of patients [23].

The management of the biobank itself demands knowledge of laboratory procedures and is mainly carried out by technicians with training in life sciences, and not so much by doctors since many of them do not have the knowledge to operate at this level. This fact is noteworthy since if, on the one hand, doctors seem to be increasingly distant from laboratory research, on the other hand, they still hold leadership positions in these infrastructures [3].

Doctors are still indispensable when it comes to collecting samples through the recruitment of donors. Additionally, considering the legal framework into force that might relate to collecting samples for research [24], only medical doctors could request samples to be used in clinical research. Medical doctors still have a relevant presence in Portuguese society, and they are considered authorities when it comes to health matters [25]. Interestingly, this fact is in line with the expectations of Portuguese citizens reported by Gaskell et al. [26], where 45% place the physician as being an adequate person responsible for protecting the public interest in this field (the highest value of the 27 countries surveyed), followed by researchers (13.2%).

In 2018, there was an attempt to produce an updated legal framework for biomedical research<sup>4</sup>, where biobanks could be included and where the most relevant funding agency in Portugal excluded biobanks from its scope of activities, pushing biobanks to the jurisdiction of health authorities. The bill did not come into force; however, these discussions among the possible authorities in charge of biobanks illustrate how difficult it has been to define the domain to which biobanks belong.

Despite these difficulties, some biobank projects have succeeded. However, the heterogeneous nature of local and national-level initiatives, and the profusion of actors with changing roles and interests, make it difficult to understand what the biobank attributions are.

## 2. Materials and Methods

This article reports findings from an ethnographic study [27] performed in a biobank. Latour's advice to follow the actors [28] was considered in order to clarify the workflow of a biobank and the relationships it generates between different social actors. This ethnography was based on the premise of following the samples' trajectory from their collection to storage and their distribution to researchers. Following the samples' path allowed for data collection to focus on the interactions, connections, and relationships that are created and sustained by the biobank activities. As a method, ethnography demands observing and being present (or co-present [29]) to go beyond an immediate observation of practices and to uncover their meanings and how they interrelate.

Observing the biobank daily routine implied spending around two years in the biobank context. Observations made during this fieldwork were systematically registered in a fieldwork diary, which was the main source of data production.

Other researchers used the ethnographic method to study biobanks, such as Argudo-Portal and Domènech in Spain [30]; Stiefel in France [31]; or Stephens, Atkinson, and Glasner in the United Kingdom [32]. Although there are differences in their goals and approaches, their work led to relevant conclusions regarding the biobank's work organization or the way biobanks are organized in wider networks, affirming ethnography as a relevant methodology for the study of biobanks.

The particular biobank where this research was carried out was integrated into a healthcare university campus, sharing the space of a medical university and a university hospital. The biobank was located in a room of one of the leading Portuguese biomedical research institutes. The biobank is conceptualized as a facility of the research institute, and its activities took place across different rooms of the research institute building—the harvesting room, where donors came to give samples; the paper data storage room; and the storage facility. Moreover, part of the facilities needed for the daily work of the biobank were shared with the research units of the institute, such as the washing room, flow cytometry, or the histology laboratory.

Medical doctors and basic researchers shared laboratory spaces within the research institute, and many sample collections were medical doctors' responsibility—these doctors were both medical practitioners and researchers. This biobank stored a diverse range of samples from blood, hair, saliva, aqueous humor, bone, and tumors, among others.

In an exploratory stage of research, the biobank was presented as being organized and dependent on healthcare, despite its location in the research institute. This was made clear by the biobank technical director and the head of the biobank, who was a medical doctor at that time. This idea was embodied in the collection of biological samples in the health services, in the medical responsibility for the biobank, and in the initiation of new collections by doctors. Hence, based on this assumption, it was expected that entering the field would be difficult and experience a possible resistance, as described by ethnographic studies in healthcare settings in Portugal (see, for example, [33,34]). The reality turned out to be different with a very welcoming and straightforward start of the fieldwork in the biobank space, which contributes to a deeper reflection and problematization of the biobank as a "healthcare service".

The permanent staff of the biobank was two biochemists and one clinical analyst technician. Biobank technicians spent an important part of their day going to the university hospital to bring samples to be stored in the biobank. This movement was also a symbolic one when bringing the samples to the biobank; samples were disconnected from the healthcare setting and could be integrated into the biobank circuits. Notwithstanding, the biobank was not totally connected or totally separated from these two worlds of scientific research and healthcare. The daily routine of the biobank staff demanded long hours in the biobank designated space where the storage unit was located. This space comprises a laboratory bench area for preparing samples and an office-like area with computers. It also includes the already mentioned storage space where the freezers were isolated from the other spaces with a false wall and door, the isolated area where procedures considered cleaner were performed (for instance, Peripheral Blood Mononuclear Cells isolation) with specific technical equipment as a laminar flow cabinet.

In this space, contrasting with the colors of the cryogenic tube caps—even considered *photogenic* (fieldnotes)—the biobank atmosphere related to the laboratory idea: an image of brightness, extreme asepsis, and free of contaminants. Despite some minor differences, the biobank was not that different from other laboratory spaces within the research institute, where it was integrated.

The data were generated by setting up the biobank as a place for observation for two years, from 2016 to 2018, considering periods of intermittent observation that allowed

them to go from the circumscribed shared space of the biobank to other settings where the biobank technicians developed their activities.

Being at the biobank included the observation of daily routine, including activities such as seminars, conferences, and presentations in health events, among others. It also included being present on biobank open days, when biobank technicians collect samples in public and private institutions in order to recruit donors to obtain control samples for research. This allowed the construction of a place of observation that was not confined to the biobank site. Although other spaces might have been chosen for setting the fieldwork, the biobank was supposed to be referential in the process of sample transformation [35,36] and might eventually be defined as an obligatory passage point [37] in sample trajectory.

The ethnography was preceded by a set of 17 exploratory interviews with biobank coordinators that allowed tracing the map of Portuguese biobanks. The data presented here also refer, when relevant, to the data collected at that stage.

Fieldnotes were the main source of data, reporting not only the daily life in the biobank but also including data generated by watching TV programs, checking the biobank's Facebook profile and posts, news (published mostly on the web), and biobank-produced documents such as posters and leaflets. During fieldwork, interviews were carried out with different actors working closely with the biobank, such as nurses, researchers, scientific committee members, biobank directors, and the former director.

The study was granted authorization by the biobank direction. All actors involved have expressed their consent. The research project was explained to all interviewees, and permission to record and use anonymized data in the dissemination of research results was requested. All the interviews were recorded and transcribed verbatim. Only one interviewee did not allow to record the interview, although they gave permission to use the data. All the material was gathered in MaxQDA version 12 software, enabling a systematic data analysis by themes. All the quotations cited in the text were translated from Portuguese to English by the author.

The next section reports the findings of the research, drawing upon the generated data: fieldnotes and interviews—making use of some illustrative quotes brought directly from the fieldwork diary and the interviews conducted during the fieldwork.

### 3. Results

#### 3.1. A Medical Framework to Classify Samples

Biobank staff was responsible for the organization and storage of samples. In this regard, classifications recurring to health and illness frameworks were common and central to the work organization. Other management decisions, such as the ones concerning the quality of the samples, the samples to be discarded due to technical conditions, or decisions about sample viability, only depend on the biobank staff's judgment. Samples could, for example, be labeled as infected, diseased, or healthy.

Biological samples were classified according to the part of the body from which they are taken: a bladder, a kidney, a testicle, a carotid artery, a synovial membrane, even if the sample is only part of these organs or anatomical structures. In other cases, they are DNA, RNA, tumors, and cells, according to their typology. These simple classifications reveal different classification systems—some favoring body anatomy, more frequently used in the healthcare sphere, while others are more commonly used in the laboratory sphere. The imposition of reasonably stabilized classification grids also rendered the donor's body into a sample object, which is simpler and easier to manage.

In the day-to-day work, questions about the nature of the samples arise: alive, dead, animal, human, healthy, sick, infected, or not infected are classifications that arise with a certain regularity and that are determinant in or determined by the daily practices of the Biobank. These classifications are, for the most part, changeable and not always obvious. Their complexity is, in many cases, interconnected with essential categories such as dead/living, mortal/immortal, animal/human, or even infected/non-infected, stable/unstable, visible/invisible, healthy/sick. These sets, which apparently constitute

opposites, are commonly used in day-to-day life, and throughout the ethnographic observation, it became more evident that they were not necessarily configured as opposing poles but could even coexist in the same sample or in the same reality. This complexity of classifications and articulations also refers to the symbolic domain of the body, to a set of other possibilities that are being created through the biological samples [5,38]. Sometimes the classification of biological samples is clearly determined by the donor; sometimes, it is determined by the analysis of the biological sample itself and its use.

Infected and non-infected is an obvious example of categorization of biological samples, determined a priori by the infected or non-infected status of the donor and imply the medical definition of infection. The classification regarding the infection of the sample is perhaps one of the most obvious and has a direct impact on the processing of biological samples at the Biobank. This classification precedes the entry of the biological sample into the Biobank and is determined by the patient's laboratory tests and then conveyed by the physician. An infected sample designates, in a very general way, samples that may carry in themselves the potential of infecting laboratory technicians in their manipulation, which may lead to the contraction of a certain disease. Thus, biological samples from patients with HIV and hepatitis are considered in this group of infected biological samples. This classification does not depend on systematic verification. Some health services tend to have more patients with these pathologies and are more easily identified; therefore, the biological samples are identified as such. However, in case these pathologies are unknown, the sample is not classified as infected. Therefore, the infection status of the biological sample is not always known to the techniques at the time of entry into the biobank.

On these occasions, the work of the Biobank is completely determined by the categorization attributed in the clinical context to the biological samples. In these circumstances, the encounter with the physician is determinant in the definition of these categories [39,40]. Infection is not macroscopically visible and is not always implicated in disease pathology; therefore, it is necessary to rely on the assessment that is performed in a medical context, admitting that it is not always possible to be in possession of such knowledge.

The contact with biological products, either by spilling fluids or by cutting with the same blade that has already been used in the manipulation of biological material, exposes the Biobank staff to risk, bringing them momentarily closer to the patient's bodily reality.

Another essential category in everyday life is whether the sample is precisely "healthy or diseased". Although this category refers primarily to the status of the donor, it is commonly used to refer to biological samples—a healthy sample is a frequent terminology.

In the health care context, only samples from patients are collected, whereas on days organized by the Biobank, samples are collected from *healthy* people. This option is often called into question as the health status of the healthy is often corrupted with various pathologies.

*"We ask the responsible researcher what kind of control he wants, and they give us the criteria of what is healthy for them. Usually, the ones that are healthy are the ones that don't have the disease under study." Biobank technician, Fieldnotes.*

The categorization of healthy or sick seems to refer more to the comparative function that certain biological samples may play in scientific research. Moreover, underlying this classification is the place where the biological sample is collected. If the sample is collected in health care units, it is considered a patient sample, and it is included in collections dedicated to certain projects. If, on the contrary, the biological sample is collected as part of an action for the dissemination and promotion of the Biobank, as happens in the aforementioned open days, that sample is considered healthy. Moreover, it sometimes happens that the declaration of healthy is contradictory to what is considered "healthy" at the laboratory level, reminding us that there are several ways to materialize the disease [41].

*"Look, it was a sample that came supposedly from a healthy control and when I went to do the cell count, there were almost none. That person couldn't be healthy." Fieldnotes.*

The healthy and diseased category is often decided a priori, usually not depending on a laboratory analysis for diagnosis or for assignment of such category. Thus, donors who come into contact with the Biobank on open days are naturally integrated into the sample collection of “healthy controls”. There is no prerequisite in this case except wanting to donate the biological sample. Various categories are assigned using a medical classification system, which often includes the samples in collections with the name of the pathology “they carry”. The medical categories are then transported to the laboratory, and there is not necessarily an immediate or direct correspondence in the classification that is assigned in the Biobank. It should also be added that these categories are not necessarily stable, being regularly redefined in the process of laboratory treatment of the biological samples. Even if the sample is subject to unforeseen conditions, it may still meet the criteria to be used in another way.

Even technical procedures carry medical categories. For example, the implemented system of color classification, with the goal of quickly identifying to which biobank collection a particular sample belongs when opening the freezers. The colored caps of cryogenic tubes indicate, e.g., red for cardiac pathology, black for cirrhosis, transparent for healthy donors, orange for tumors, etc. This is also referred to by Palmer [42] as a way of objectification; it was crystallized in the idea expressed by a journalist who visited the biobank in the news headline “In the biobank, diseases have the colors of the rainbow” (published on 14th October 2017, in a widely read Portuguese newspaper). The metaphor continued throughout the text, enforcing the idea of the absence of the donor and the diseases as being relevant subjects. These classifications enabled a link between health and illness context; additionally, they reduced the multidimensional aspects of the ill-health status of the donor.

The categorization of biological samples often carries the categories assigned to donors, such as infected or non-infected. In other cases, the classifications assigned to the donor and to the sample may be dependent or independent, displaying the donor and sample against each other in the coincidence or mismatch of the categories assigned. Medical categories are thus essential to classify and organize not only samples but to define the work in the biobank.

### 3.2. *Constructing Biological Samples Identities as Being Human*

The collection of samples to the biobank regularly encompasses three moments—harvesting, storing, and distributing the samples to biomedical research—around which the biobanking activities are organized. The identity of samples is therefore constructed while they are progressing through this path. The construction of the samples’ identity was a constant process of negotiation, and biobank technicians played a relevant role in performing this negotiation in different situations.

The sample collection was additionally accompanied by a collection of lifestyle and clinical data. Usually, medical doctors collect clinical data during medical appointments or pre-surgery procedures. Then, the biobank technicians would pick the samples and clinical data survey, and the informed consent form at the hospital. The biobank staff was rarely responsible for the data and sample collection. They were, in all circumstances, responsible for managing data and samples in the biobank space. When the samples entered the biobank, they needed to be organized and added to the computer system. Both data and samples were collected together, although they entered two different sectors in the biobank software, and the connection between the donor and the samples started to disappear.

Although the linkage between samples and the donor could be replaced, it was partially destroyed at the moment biobank staff entered sample data and donor data into the software. Additionally, pseudonymization was another essential process to silence the connection between donor and data (sample and personal/lifestyle information). The link could only be restored in case the donor asks for withdrawal or if researchers need more data and the donor has consented to be recontacted in this regard. Right before they were no longer identifiable, biobank technicians have the last opportunity to connect the



sample to the donor they did not meet, avoiding immediately transforming the sample into an object. Right before they were no longer identifiable, biobank technicians have the last opportunity to connect the sample to the donor they did not meet or had any other previous have not met, then refusing immediately transform the sample into an object.

*During a technical procedure of processing samples, one technician says to another: “This cannot be like that, please cover the “ruizinho” [allusion to the donor’s real name] otherwise he will get a cold.” Fieldnotes.*

Not only does the origin of the biological sample seem to be difficult to forget [42], but also the links to the original donor should not be forgotten, although the process of pseudonymization is about to happen. In all the cases, samples were considered to be objects but from a special kind:

*“I do think it is humanization in the sense of transformation that sample in a human thing”. Senior Researcher, interview.*

After samples were processed and stored in the biobank were mentioned as *work material* for researchers. Furthermore, from this moment on, sample management entered a field ruled by principal investigators and medical doctors. Researchers and medical doctors were the ones deciding in which collection the samples were going to be included, in what research they were going to be used and with which researcher samples could be shared, and under which specific conditions. While the Portuguese Legal Framework [24] defines donors as the owners of the biological material, they were no longer responsible for the usage of the sample after they entered the biobanking circuits (unless they desired to withdraw the sample and data). Giving back the property of the samples was also something recalling for the donor—and was not only because it is enforced by law to obtain donor informed consent but also because it was embedded in technician discourses as being the natural and obvious thing to do.

To classify the tissue and cell status, biobank technicians evaluate whether the cells are viable or non-viable and which biological samples could be considered alive or dead. These classifications enable the decision about the quality of samples, type of storage, or type of laboratory analyses that could be performed. The classification relies exclusively on biological material analysis and works apart from donor status. Therefore, biological samples and donors could have different classifications, somewhat ensuring their separation as different entities.

The transformation of samples into human objects was particularly evident when denying samples of possible animal nature. This issue was central in the negotiations of samples’ humanness. In some particular cases, such as the case of feces-microbiome preservation, the boundary between two categories was made clear, however allowing the combination of both natures in one entity at the same time.

*“The problem is that microbiome has human and microbial material, that’s why we need to ask two different entities for allowing us to store feces.” Biobank technical supervisor, fieldnotes.*

Metzler and Webster [43] mentioned the tendency to consider these entities as human subjects even though their boundaries could be difficult to be considered an asset. If in the precise situation of the microbiome, the boundaries seemed clear, usually they appeared blurred, and the human nature of samples prevails. The boundary was made obvious when the biobank workers were confronted with certain questions about the nature of the samples stored in the biobank.

*“Here we only have human samples. The closest we have to animal samples are the tumors that we insert in rats and when they grow, they are removed [and kept in the biobank]. But this is still considered as human tissue.—Explained the biobank supervisor to a technician from another biobank who went for a visit.” Fieldnotes.*

The boundary between animal and human was again repositioned, though denying the possibility of mixing the natures of the samples again. The boundary was not that

clear, but biobank-involved professionals tried, consistently, in diverse moments, to assure the biological samples were human. These biological samples seem to be what Douglas called “a matter out of place” [44]. In this sense, they should be forced to integrate a manageable and already existing category of objects and beings that perfectly fit the previous categorization in action. Therefore, not only the former categories were conserved, but they also enabled the removal of the particular legislation, which provided specific rules to store animal samples. Here, the legal framework does not consider both natures and to what extent these samples should be incorporated into different categories [45].

In addition to the constant denial of a possible animal identity of the samples or avoiding deleting the linkage between the original donor and the biological sample, there were other strategies powered in the daily routine work contributing to setting this human identity.

### 3.3. Crafting Illness Narratives

The biobank technicians’ efforts to defend biological samples stored in the biobank as being human are a result of pushing boundaries that maintain the control and the management rules of the biobank.

Moreover, samples were observed mostly as scientific objects when the link between the sample and other personal data was hidden in order to preserve the donor’s identity. Nevertheless, other links are to be created and told.

Kopytoff [46] and Daston [47] suggested that objects could have different biographies, depending on a variety of circumstances, from the object owner’s relationship with the object to the cultural setting or the time when it was produced. Similarly, samples also could have their own biography, and biobank workers were involved in their crafting while they processed and stored samples. Samples in themselves were enough to say something about their own trajectory. The sample’s appearance could reflect the status of the disease at a given moment. They settled the link between the sample and the donor’s disease status. Lawrence [48] described how body parts transformed into relics are embedded in spiritual auras that were passed from the saint to the body part. Here, the donor gives the sample; there is no knowledge or little knowledge about the donor. Thus, she provides the sample with the disease or healthy status, and then all storytelling must be made.

*“For example, this sample, it’s not the worst sample at all, but we can see that the patient has been through chemotherapy or radiotherapy [holding a blood tube and looking carefully searching for details]. I could be wrong, but it should be something like that.”*  
Biobank technician, Fieldnotes.

In line with Mol [41], this could be another picture of how the disease could be perceived or, in her words, how the disease is enacted. The biological samples enable the construction and projection of the patient disease trajectory. When the biobank staff receives samples from the same donor at different time points, which they call follow-up samples, the narratives turn into more complex stories.

*“In other cases, we have samples from a patient, and we are receiving samples and one day we realize that we are not having samples anymore from that donor and usually is not because he decided to stop giving samples, usually it’s because he died . . . ”* Biobank technician, fieldnotes.

The narration is assisted by the biological properties of biological samples in conjunction with personal experiences. Moreover, the biobank staff tended to connect with their own experiences of life, health, and illness, creating a sense of identification with patient trajectory.

*“By the time of my first pregnancy, we were collecting samples for a study with neurotumors and neurological diseases in a pediatrics study. Sometimes I substituted the researcher in duty, doing the medical surveys to parents. I could not remember if the question was there or if it was something that parents mention spontaneously, but I remember so many parents mentioned the labor duration or situations that happen during*

*labor . . . I started to put all pieces together and started wondering . . . how it is going to be my labor and how it could influence my child health. It was such a hard time.” Biobank technician, Fieldnotes.*

This contact between biobank staff and donors, especially patients, was rare. When other professionals, such as medical doctors or nurses, collaborate with the biobank in samples or data collection and establish their narratives around the donors’ experiences, they often use this contact with the patient in the narrative construction.

*“I remember exactly the person [donor]. When I start entering the data [on the computer] “Oh, this one”—because I have the social-demographic data and the profession and helps me to remember. And also, because I’m going there requesting the consent form, after I do the follow up. Then I know who they are and sometimes it’s such a pity because some of them died and I really remember them, young people, and makes me wonder . . . ” Nurse—researcher, interview.*

The narrative inquiry has a long tradition of exploring illness in social sciences [49]. Usually, the narratives are produced by patients but also by health professionals, namely medical doctors, in order to better comprehend the patient’s suffering or experience [46]. Here, instead, the biobank staff constructed narratives for their own purposes of making sense of their work in a wider context of health and illness.

### 3.4. Taking Care of Biological Samples

By entering the categories of human beings, occasionally with a story, the biological samples were then in place of being cared for. Not only biobank staff but other actors involved as medical doctors or researchers acknowledged that humanness in samples should be recalled and have implications when it comes to research. The implications were mainly related to the research practice.

*“So, when we use that sample [referring to a human sample] we have the responsibility and an ethical duty of be sure what we are going to do justify the usage of that sample. We are not going to try things because we think that the research project would be more interesting.” Senior researcher, interview.*

Furthermore, not conducting research with the samples collected was considered non-ethical concerning the donor. In this regard, the samples could not be envisaged as simply as objects collected and stored to be used in the distant future. Additionally, sample discard was strongly discouraged since it would incur a disrespectful practice to the donors who were promised that research would be conducted with their samples. Dignity extended from the human beings to their body parts, as suggested by Palmer [42], reinforcing once again the humanness of biological samples.

In all the aforementioned situations, the concerns about research in biological samples were not orientated specifically to the biological samples but devoted to concerns related to their human nature and the original donors.

In other cases, caring practices only gained shape when the donor was not considered. In the creation of cell lines from a human skin sample, for example, the donor themselves were rarely mentioned. In contradiction to this absence, the samples were compared to babies with some of the features regularly attributed to human babies—such as vulnerability or the need to be nourished and cared for.

*“Have you seen them? Our babies? We are creating primary cell lines! And until now they are resisting!*

*I must change the substrate. I am afraid they die before we finish [the cell line]. The substrate is their food, it has all the nutrients they need. They are still very sensitive; the substrate has antibiotics to prevent infection.” Biobank technician, Fieldnotes.*

In the biobank’s open days, the practice of care expanded outside the biobank’s more confined space. The space had to be adapted in order to be functional for the activities

they were about to perform, which is usually the sample collection from donors. The outside space was, in fact, more permeable to be changed. Dealing with donors required efforts to transform the space into a comfortable environment, which often included a good-tempered conversation and a jar with sweeties over the table, while donors fulfilled the informed consent and the medical questionnaire. Additionally, transform a regular office room into a waiting room, or transform a shared open space in a health fair into a semi-private space for the samples' collection procedure:

*We went for a biobank open day. All the time the space has to be organized in order to be functional for the blood collection procedure and for the fulfilment of the medical questionnaire.*

*"I am going to take these chairs out of the room [said one of the biobank technicians to the other]. Doing this, the donors could wait here comfortably, and it will be look more as a waiting room." Fieldnotes.*

In making these space arrangements, biobank technicians organized the space in a way that automatically helped establish the link with healthcare. The created space was closer to a medical doctor's office or a clinic: as the space would be more appropriate for welcoming donors when organized in such a manner. The connection to healthcare was made clearer when a medical doctor highlighted how not collecting samples could even be considered poor-quality healthcare:

*"Not storing the samples it's certainly not a good service for patients." Medical doctor, fieldnotes.*

Moreover, the recurrent motto in biobank posters and leaflets had an inscribed symbolic meaning. "Help us to save lives" or "finding cures" was recurrent and inscribed in what seems to entail an economy of hope [50,51] that both serve donors as the biobank staff. Particularly, it re-inscribes the work performed in the biobank in the logic of healthcare.

#### 4. Discussion

When biological samples leave healthcare services, they enter the biobank where they are reorganized accordingly to medical classifications or alternatively with categories only attributed in the context of care (as infected).

In this context, samples are transformed into objects of scientific work for the future use of researchers. Nevertheless, despite being considered objects of scientific knowledge, their nature is constantly reconstructed through the work performed in the biobank. The biological samples' identities were not given only based on the assumption the donor was a human being, but they were elaborated recurring to other strategies that enable to consolidate the humanness in biological samples.

Denying animality could be seen as a way to render samples to normal objects, avoiding their troublesome nature [43,52,53], as well as the management of complex issues such as different legal frameworks or laboratory protocols. The constant negotiation of their nature, especially the denial of their possible animal features, was integrated into a set of efforts to restore humanness in biological samples [43]. In a context where the biological sample was often reduced to the sample itself plus the associated diagnosis, considering other aspects was a work of restitution of the social context of the donors, their living conditions, or social relationships [54].

By taking care of biological samples, biobank technicians enforced the importance of the biological samples' humanness. The caring relationship established could invoke an asymmetric relationship where donors are no longer allowed to enter [51]. However, the complete absence of the donor is, in fact, somehow compensated when caring for the samples is into place during work as a reminder of the donor's gift.

In order to construct these narratives, it was needed to recall some information about the patient or the patient trajectory. In this biobank context, sample biographies were mostly based on building up on health and illness experiences. The illness narratives generally used to confer coherence to illness experiences by individuals or health professionals [49,55] were used here with a similar goal by the biobank technicians. The biological sample was a

connecting link to a donor; however, the narrative might probably be different from the one donor could tell. Then, recognizing the original donor narrative was not the intention. The aim was instead to promote a sense of identification and empathy with the absent donors.

Therefore, they were able to resignify the biological samples' trajectories while they developed meaningful work practices. Crafting narratives could also be a way of contesting the dehumanization created by biomedicine during the process of objectifying the body through its continuous fragmentation into biological samples [15]. This contestation could even be amplified if it is taken into consideration that the work in the biobank is invisible and usually could not be clearer objectified. In this kind of work, where tasks performed could be reduced to the processing and storage of simple samples, operational work [31] has relatively lower importance when compared to scientific work. The bonds and the emotional and affective relationships emerging in daily work [56] were essential in rescuing the humanness in biological samples. This also strengthens the inscription of the biobank as a healthcare space.

In addition to the rescue of biological samples' humanness, it is important to highlight the role of experiences of health and illness. These experiences work as background, fluid, and changeable, according to the actors' voices that are in action. However, what reunites these different voices is somehow the human features attributed by the biobank technicians. Frequently used *health, diseased, ill, and healthy donors and patients* are a necessary vocabulary to characterize biological samples. In this sense, health and illness references acted as a layout for sample classification, the motivation of technicians to take care of the samples, and the narrative's construction. Thus, the symbolic language associated with health and illness added a reminder that these activities were intended to result in better human wellness and health.

In shaping the biological samples as things in human objects, the biobank staff allow themselves to portray the biobank as a healthcare space and intrinsically entangled in healthcare system provision. Although French, Miller, and Axler [57] already evidenced the biobank as part of healthcare within an entrepreneurial approach, here, neither the hospital nor the biobank was integrated into such orientation. The biobank is thus connected to healthcare through caring practices of the human biological samples and employing medical categories in samples' classification. These enable the construction of health and illness referential where the biobank develops part of its activities and to what it refers in terms of symbolic practices.

## 5. Conclusions

This article discussed how the biobank is transformed into a health place, established at the marginal space between science and health.

This entails a reflection regarding the emergence of new professionals in the health field; as the context of healthcare changes, new practices of care develop. However, it seems that the biobank's role is far from healthcare provision, the symbolic action points in the opposite direction.

The work of biobank technicians plays a relevant role in recreating the human identities of samples; however, this identity creation is not a barrier to performing the biobank work but enables it. In addition, the practices of taking care of samples were significant and contributed to transforming daily work into meaningful practices of caring oriented for the benefit of humanity. It is noteworthy that the exploration of other biobanks contexts without such a strong relationship with healthcare services, as the one portrayed in this study, could lead to different conclusions.

However, there are questions that deserve further exploration. When considering the biobank as a healthcare support infrastructure, it is also needed to explore the emergence of new voices and actors in this field. What are their action possibilities, which role they perform, how they interact with the other professionals, and which knowledge is constructed in their practices? Conducting this is essential to address new challenges that are set in the healthcare landscape.

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## Notes

- <sup>1</sup> Although the term *donor* is not consensual among the social sciences literature about biobanking, here it was chosen as it was the term commonly used by the biobank where the research was conducted. At this stage, in this particular biobank, the options regarding participation of the people entrusting their samples to the biobank, is limited not fulfilling the criteria to be considered research participants.
- <sup>2</sup> The Framingham Heart Study is still active, and more information could be consulted at: <https://www.framinghamheartstudy.org> (accessed on 16 December 2020).
- <sup>3</sup> The Varmland Health Survey could be consulted at: <https://snd.gu.se/en/catalogue/study/ext0169> (accessed on 16 December 2020).
- <sup>4</sup> This legal project was proposed in 2018 in the Portuguese Parliament but has not been voted. More information about this proposal could be consulted here: <https://www.parlamento.pt/ActividadeParlamentar/Paginas/DetalheIniciativa.aspx?BID=42877> (accessed on 9 June 2022) (text available only in Portuguese).

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