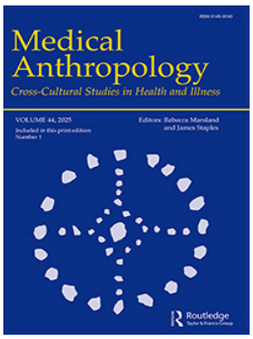

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Testing Ecology: Breast and Gynecological Cancer Predisposition Tests and the National Healthcare System in Spain

Violeta Argudo-Portal [a,b]

[a]Department of Social Anthropology, University of Barcelona, Barcelona, Spain; [b]Institute for Public Goods and Policies, Spanish Research Council, Madrid, Spain

ABSTRACT

This research asks what is being put to the test by breast and gynecological cancer predisposition testing in Spain beyond genes or cancer. By combining document analysis and fieldwork with national healthcare professionals and drawing on the anthropology and sociology of testing, I examine how the molecular relations of these tests extend to the political economy of the national healthcare system. I show how the capacity of these tests to produce a low-risk collective has paradoxical consequences for the political economy of the national healthcare system, unsettling professionals' concerns and spotlighting what is prioritized in personalized medicine strategies.

RESUMEN

Esta investigación,desarrollada en el contexto español, se pregunta qué se pone a prueba con los test de predisposición al cáncer de mama y -ginecológico más allá de los genes o el cáncer. Combinando el análisis documental y el trabajo de campo con profesionales del Sistema Nacional de Salud e inspirándome en la antropología y sociología de los test, exploro cómo las relaciones moleculares se extienden a la economía política del sistema sanitario. Muestro cómo la capacidad de estos test para producir un colectivo de bajo riesgo tiene consecuencias paradójicas en relación con la economía política sanitaria, inquieta al personal médico y pone en el punto de mira qué se prioriza en las estrategias de medicina personalizada.

KEYWORDS

Anthropology of testing; cancer predisposition; national healthcare systems; personalized medicine; political economy; risk stratification; Spain

> More "molecularization" may lead to less diagnostic and prognostic certainty. The uncertainty resulting from increasingly sophisticated tests leaves, in turn, more room for practices and meanings to be shaped locally. (Löwy and Gaudillière 2008:318)

In January 2024, the online press in Spain posted a news article from the EFE Agency, without authorship, with the following headline: *El 20 percent del cáncer de mama es heredado y los expertos recomiendan hacerse el test genético* ("20 percent of breast cancer is hereditary and experts recommend taking the genetic test"). The article's visual companions included colorful anatomic illustrations of breasts and archive images of test tubes. After two years of qualitative fieldwork in Spain around breast and gynecological cancer predisposition tests and talking with national healthcare professionals about the increase in ads for private hospitals offering cancer-risk genetic tests, I was shocked and intrigued by this news article promoting almost the opposite of what I had gathered during fieldwork. The first unclear aspect of the headline was whom the recommendation was targeting. Was it for diagnosed patients or anyone wanting to estimate their cancer risk? This productive ambivalence – common in

CONTACT Violeta Argudo-Portal apvioletas@gmail.com Department of Social Anthropology, University of Barcelona, Montalegre 6, Barcelona 08001, Spain.

This article has been corrected with minor changes. These changes do not impact the academic content of the article.

the genomics labs' online marketing narrative – is replicated in the headline's hook. The article's body text begins by adjusting the percentage used in the headline, noting that while the hereditary component is estimated to account for 20 percent of ovarian cancer cases, hereditary breast cancer makes up around 5–10 percent of cases, which is the agreed upon percentage for the hereditary component of cancer. Then, the article quotes an oncologist who explains that the test is recommended for those diagnosed with breast cancer who meet the criteria established by the 2020 clinical guidelines in hereditary breast and ovarian cancer of the Spanish Society of Medical Oncology (Redondo et al. 2021): patients diagnosed at a young age, those whose breast cancer is associated with other tumors, diagnosed patients with a male relative with breast cancer, or triple-negative cases in women under 50 or 60 years old without family antecedents. This recommendation aims to promote diagnosed patients' access to genomics-targeted therapies and restrict these tests' use only to patients who fulfill the guidelines' characteristics and not for everyone.

The article's take-home message is that genetic tests ultimately aim to help reduce the number of tests conducted at the population level and move toward surveillance and treatment based on risk estimates. Toward the end, the voices of other professionals are incorporated in a few sentences, as if it were a minor matter, highlighting the need to ensure that all hospitals and regions have access to the same tests, which is not the case now, to avoid increasing healthcare inequity in the country. Overall, the article offers a hodgepodge of professional takes on the topic while erasing the context and avoiding uneasy questions, all under a problematic headline. Yet, this is the kind of take on the topic – similar to many other pieces reporting on healthcare technologies – that a considerable part of the Spanish population can access through their phones while riding a bus or lying on the sofa. In addition, such news pieces illustrate that cancer serves as a spearhead when it comes to the transformations of healthcare models. Underlying the piece is a silent proposal to transition toward risk estimates as prescribers of preventive surveillance to make the national healthcare system more cost-effective while promoting a paradoxical de-medicalization discourse. This proposal moves forward the technoscientific and political framework of personalized or precision medicine despite the lack of consensus on this approach among professionals in the Spanish national healthcare system, as I will show. Let's first place these tests in context.

Spain has a national healthcare system that provides universal coverage for Spanish citizens and residents with a regularized status, covering 47,755,450 inhabitants (Informe ANUAL 2023), and anyone residing in the country has the right to essential health protection and services. The regulation of genetic tests is based on the 2007 Biomedicine Law. Genetic tests are allowed for research and therapeutic purposes if requested by a *certified professional* and if genetic counseling is offered before and after the test. However, the law does not consider commercial medical testing. And what a "certified professional" means in practice is unclear, considering that the medical specialty in clinical genetics is not recognized in Spain. Thus, while non-medical direct-to-consumer tests are prohibited, medical genetic tests in the private sector remain in a gray area (Cabezas-López 2019). Since around 2017, this situation enabled different commercial genomic labs – which until then had found their main niche in assisted reproduction testing – to offer testing kits for breast, gynecological, and colorectal cancer predisposition based on next-generation sequencing of multi-gene panels. In recent years, these tests have been increasingly included in private healthcare services as a consumer product, mirroring the US model. More broadly, a strong bifurcation exists between private hospitals and the Spanish National Healthcare System's approach toward these tests and cancer predisposition risk models. Private healthcare clinics are increasingly offering breast and gynecological cancer predisposition genetic tests, while doctors and geneticists in the national healthcare system advocate for restrictive use. In this context, throughout the article, drawing on institutional and professional documents, field notes, and interview transcripts with healthcare professionals in the Spanish national healthcare system, I analyze a complex web of testing scenarios surrounding predisposition testing for breast and gynecological cancer in Spain. I argue that these tests not only involve the actual genes and variants being tested but also serve to unsettle professionals, healthcare models, technocentric narratives, biological determinism, epistemic absences, and precision medicine assumptions. Overall, what is prioritized in the reorganization of the national healthcare system is put to the test.

In this research, acknowledging the multiple social, cultural, economic, and political effects of testing, I put into practice recent analytical proposals in the anthropology and sociology of testing. Anthropologists Street and Kelly (2021) argue that due to the multiple purposes for which medical tests can be used, the anthropology of medical testing should not be subsumed into the field of anthropology and sociology of diagnosis. Medical testing transcends diagnosis, and as such, they propose an anthropology of testing that contributes to comparative discussions and attends to "what tests and testing do in and to social and medical worlds" (Street and Kelly 2021:3). In a similar vein, science and technology studies scholars Marres and Stark (2020:430) propose a new sociology of testing which argues that tests "should be evaluated not only based on their validity or by what they resolve but equally by what they generate," and that, "more important than the test results is what results from the test." Following such analytical observations and acknowledging that almost any test generates additional testing situations and is part of an "ecology of testing" that needs to be examined (Marres and Stark 2020), this article explores what is being tested – beyond genes or cancer itself – by breast and gynecological predisposition tests in Spain.

First, I introduce how medical anthropologists have pioneered the study of predisposition genetic testing and the figure of the predisposed individual, noting that in this article, I shift the focus from the individual body to questions concerning the body of the national healthcare system. After presenting the study methodology and data, drawing on anthropology and sociology of testing, the analysis unpacks three interconnected areas put to the test by cancer predisposition testing in Spain: 1) Testing, ¿Café para todas?, testing the interactions of the private and public healthcare, 2) Testing genomics, testing the understanding and interpretation of genomic tests results, 3) Testing the national healthcare system, testing the reorganization of the healthcare system concerning precision medicine initiatives. This ecology of testing shows how the production of *low-risk collectives* through cancer risk stratification based on predisposition testing can have paradoxical consequences in relation to the political economy of the Spanish healthcare system, simultaneously serving to promote biomedicalization and de-biomedicalizing initiatives. In this work, I stress the need to attend to the political stakes of cancer epistemics (Bhangu et al. 2024) and its consequences on cancer research, healthcare, and risk perceptions. I focus on what can be learned about what these tests put to the test to think about medicine, genomics, and national healthcare systems transformations.

Three decades of genetic testing for cancer predisposition

Three decades have passed since the mathematician and geneticist Mary-Claire King presented a genomics statistical study at the 1990 meeting of the American Society of Human Genetics, establishing links between early-onset breast cancer and mutations in the BRCA1 gene, showing that breast cancer could be inherited. Six years later, in 1996, the company Myriad Genetics Inc. started offering commercial testing for hereditary breast and ovarian cancer susceptibility in the United States. Since then, discussions, calculations, patent filings, tests, and experiences around breast and ovarian hereditary cancer risk have populated the biomedical and social sciences literature. In biomedicine, recent publications illustrate efforts to assess the clinical utility of genetic tests for breast and ovarian cancer predisposition (Lee et al. 2019; Yoshida et al. 2021), and what genomic data actionability should mean in practice remains under discussion even in the well-studied case of BRCA1 and BRCA2 (Lucci-Cordisco et al. 2022). Scholarly discussions also illustrate the difficulties in classifying some gene variants as "truly pathogenic." The literature comprises 20 years of ongoing updates and disputes regarding the analysis and associations around cancer risk estimates (Turnbull et al. 2018).

In the social sciences, medical anthropologists pioneered the study of genetic testing (Nelkin 1996; Rapp 1999) and the understanding of genes as "embodied risk" (Lock 2011; Lock et al. 2007), setting a precedent for a growing body of qualitative research exploring the rise of "proto-illness" (Gillespie 2015), "patients-in-waiting" (Timmermans and Buchbinder 2010), and the entrepreneurial patient (Dickenson et al. 2018; Tutton and Prainsack 2011). In the case of cancer, scholars have paid attention

to the daily experiences of patients who inhabit the everyday clinical genomics nexus. They have studied patients' relations to immunotherapy tissue economies (Llewellyn 2022) or advocacy for access to targeted therapies (Kerr et al. 2021) and how breast cancer patients' experience is shaped by the "diagnostic layering" generated through the classification of breast cancer subtypes based on genomic techniques and its effects on treatment selection (Ross et al. 2021). They have explored experiences of genetic risk as a form of chronicity when testing positive for Lynch syndrome (Heinsen et al. 2022). Predisposition testing has also generated inquiries on the overlaps between cancer genetics, ancestry, and colonial histories of migration (Gibbon 2013). The "predisposed individual" figure has been central in all these works.

Genetic predisposition and susceptibility discourses have led anthropologists and historians of biomedicine to track the transformations from the nineteenth-century notion of *diathesis* to refer to an individual's constitutional fragility that makes them vulnerable to disease to the contemporary embodied genetic predisposition. Löwy and Gaudillière (2008) note that while *diathesis* refers to a vague, broad notion of a fragile body without much specificity, contemporary risk as a predisposed condition stems from statistical measures. The source of such potential fragility can be located at the molecular level, and medical professionals and healthcare systems are expected to manage such a condition through individual engagement with self-transformation. The individual experience has had a strong presence in medical anthropologists' and sociologists' work, mirroring the effect of biomedical risk individualization and giving rise to crucial research on genetics, identities, and biosocialities (Gibbon and Novas 2008).

Although anthropology has addressed an extensive range of topics around cancers, multi-level approaches that consider national healthcare models' transformations and healthcare professionals' hesitations about the effects of predisposition testing not only in the individual physical body but also in the body of universal national healthcare remain scarce. Here, I analyze breast and gynecological predisposition testing in Spain, considering that "molecular relations extend outside of the organic realm and create interconnections with landscapes, production, and consumption, requiring us to tie the history of technoscience with the political economy" (Murphy 2008:697). I aim to add the standpoint of professionals working in the Spanish national healthcare system and consider how they relate to the tests and genomics, and how molecular relations extend to the political economy of the national healthcare system in Spain. For this inquiry, we must first go back two decades when, in the context of the first inquiries on cancer genetic predisposition amidst the hype of BRCA1 and BRCA2 tests, Lock (1998: 7) published a piece on breast cancer and genomics with a warning that proved prescient:

> Although genetic testing permits us to speculate with more precision than was previously the case about who may be struck with misfortune, a characteristic feature of divination nevertheless remains, namely that in seeking to avoid misfortune, we create new ambiguities and uncertainties.

As Lock (1998) warned, genomic knowledge has not reduced uncertainties and ambiguities around cancer. Instead, as scholars have noted in different locations, uncertainty has become part of cancer in many senses. Offersen et al. (2018) define cancer as uncertain, ambiguous, and having unstable boundaries. Through a study of cancer mythologies in a suburban Danish middle-class community, they illustrate how knowledge production around cancer has not decreased uncertainty. Arteaga Pérez's (2021) ethnography on "learning to see cancer" points out how researchers manage uncertainty in developing experimental models in cancer studies and how cancer research is partially built on uncertainty. Similarly, Kerr et al. (2019) explore how professionals deal with uncertainty and expectations in translating genomic research to the clinic, while Hunleth and Steinmetz (2022) identify uncertainty as key to navigating breast cancer screening and follow-up practices in rural Missouri and its relevance regarding the "logic of choice" (Mol 2008). Thus, uncertainty – a recurrent topic in recent anthropological and sociological studies of cancer – affects both patients and medical professionals, despite and sometimes because of the implementation of new technologies around cancer, such as testing for cancer predisposition and risk assessment. What is certain is that predisposition testing is

unsettling genomics and national healthcare in ways that require anthropologists' attention. Here, I trace some of the uncertainties, ambivalences, and tensions generated by the possibility of testing non-diagnosed individuals and populations for breast and gynecological cancer predisposition from the perspective of professionals working in the Spanish national healthcare system. As such, I move the focus from the predisposed individual body to the national healthcare body.

The study

This research stems from a larger interdisciplinary project on how different genetic tests deploy forms of anticipation.[1] For this article, I draw on materials from a case study on cancer predisposition testing for breast and ovarian cancer in Spain. For the study, I analyzed institutional and professional policy documents, protocols, and guides on breast and ovarian cancer to grasp the presence, absence, consensus, and concerns regarding genetic predisposition testing. Document analysis of professional guides and position pieces was selected as they offer a window to the negotiation between policy, legislation, scientific knowledge, and the clinical and market spheres. These documents also allow me to situate predisposition testing in the ecology of testing situations and conduct a relational approach (Menéndez 2009).

In addition to document analysis, between 2021 and 2022, I conducted two fieldwork visits to two Spanish commercial genomics labs offering cancer predisposition genetic tests; I interviewed their personnel and analyzed their websites and test flyers. Both commercial labs are companies registered in Spain, located in three different regions of the country; one is part of a bigger Spanish private healthcare group (Commercial Lab 1) in which two of the research directors were interviewed on their cancer predisposition testing kits and their breast cancer risk stratification tool. The other is a start-up derived from a public university (Commercial Lab 2), and one of the CEOs was interviewed. My empirical materials also include 10 semi-structured interviews carried out between 2021 and 2023 with professionals from the Spanish public healthcare system involved in breast and ovarian cancer. These genetic counselors, screening specialists, and oncologists working in hereditary cancer units represent a workforce that, as Manderson (2022) has noted, still has little presence in anthropological writings. Standpoints of professionals working in the public healthcare system and practitioners' guidelines form the backbone of my analysis.

The Research Ethics Committee of the Spanish Research Council gave ethical clearance for this research. All interviewees' names are pseudonyms, and the names of private commercial labs where fieldwork visits were held remain anonymous. References to public institutions and politicians' appearances retain their original names.

The testing ecology

Marres and Stark (2020:428) note, "If we study these diverse forms of testing in isolation from one another, we are unlikely to understand how society is transformed by means of testing." This section unpacks how attending to what predisposition tests put to the test enables us to account for the effects of these technologies and the ecology of testing situations that challenge the Spanish national healthcare system and, in turn, healthcare organization and health meanings.

Testing ¿café para todas?

In private hospitals in Spain, flyers offer tests with the imperative of anticipating cancer. In one, eucalyptus-like leaves run along a woman's right shoulder, up to her neck, and into the bun where her hair is tied.[2] We can only see her torso and facial profile; her left hand rests on her shoulder, and she is gazing toward the horizon. This illustration adorns one of the many brochures used by private hospitals and clinics in Spain to advertise genetic testing to predict breast and ovarian cancer risk. This one comes from a leading private hospital in Spain owned by the German group Fresenius, which

leads private healthcare services in Europe. The illustration uses the chromatic range of the hospital's logo, green and coral, and includes a box with the text: "Anticipate the possibility of developing breast or ovarian cancer." If not for this text box, the illustration – which leads the viewer to gaze at the horizon along with the woman – could be from a perfume ad. The test advertised analyses 18 genes linked to breast, ovarian, and endometrium cancer, referred to as the BRCA + 16 genes, which are considered to increase cancer risk. The cost of these tests ranges from 490 to 1,200 euros depending on the private healthcare provider; users can receive a discount by booking them online. This flyer defines the potential test user as follows:

> Men or women with a history of breast cancer, women with previous ovarian cancer, women with cancer in the family, and, in patients known to have this type of tumor, those wishing to find out whether the tumor is hereditary. *Genetic testing can also help women over 30 with no history of cancer but who want to know their genetic risk of cancer so they can make an informed decision on their prevention and screening options.* (Emphasis added by the author)

At first, the flyer demarcates potential test users in connection to a known family or personal medical history of cancer. However, it ends up including women over 30 who want to know their cancer risk to make future decisions, which are usually connected to the financialization of fertility (Lafuente-Funes 2024; Van de Wiel 2020). Therefore, the flyer unfolds the anticipation techniques and politics of temporality characteristic of biomedical settings (Adams et al. 2009), that is, anticipatory or preventive biomedicalization (Clarke et al. 2010). They offer the test to any woman over 30 years old aiming to become an entrepreneurial proto-patient. The flyer can be found in Spanish and English; by contrast, the national healthcare system provides flyers in Spanish and the country's co-official languages but never in English. Thus, the flyer also targets newcomers, probably high-income migrants ("digital nomads")[3] working from Spain for international companies.

Meanwhile, the national health system protocols for breast and ovarian cancer establish that predisposition genetic testing should be used only in a few cases, and age, family history, ancestry with founder mutations, or hormone receptor status must be considered before offering a test. Testing beyond familial history has started to be considered only based on tumor sequencing results, and a professional effort is being made to differentiate between familial cancer and hereditary cancer to illustrate that not all familiar aggregation is linked to an inherited condition. Indeed, familial aggregation is usually formed by shared exposure to different carcinogens, which requires, for instance, attending to habits or geographic pathology to understand "exposed biologies" (Wahlberg 2018). In the effort to make this differentiation between familial cancer and hereditary cancer, the doctors interviewed aim to stress that familial aggregation should not be reduced to heredity.

According to Dr. Mar, an oncologist coordinating the national unit of gynecological hereditary cancer, "Most cancer causes are external, but it is easier to think they come from within. After all, we know that only 5–10 percent of cancers are hereditary." As such, this test at the population level could be defined as an *anticipatory technology of exceptionality*. The tests are designed to anticipate something exceptional: cancer genetic predisposition, and where anticipation as a temporal "affective state" that mandates action and optimization is put into play (Adams et al. 2009). Indeed, the national healthcare professionals I interviewed treat the tests as such, as an *anticipatory technology of exceptionality*, whose results rarely are actionable. They dispute predisposition genetic tests as *café para todos*[4] when offered at the population level. Dr. Lucía, gynecological cancer oncologist and breast pathology specialist, explained to me:

> It seems like some people expect that we will start testing everyone. The problem with *café para todos* is that you then have to commit to an interpretation for each person tested, and we can end up having to interpret results with variants of uncertain significance. And what do you do with all those patients [for whom] you cannot offer a clear interpretation of the test? If you are testing someone, you need to be able *to offer a resolution to the test results*. Conducting tests just because you can do it makes no sense.

For Dr. Lucía, it is essential to point out that having access to the technological possibilities of performing a test is not the same as having the right to conduct it. Indeed, deciding what to do with

these possibilities is a political decision. Moreover, the healthcare professionals I interviewed approached the uncertain predictive value of predisposition risk assessments with caution at both the individual and population levels. Their prudence stems not only from the uncertainties around extant individual risk estimates and the limitations of scaling them up to the population level but also from these tests' connection to a critical aspect professionals have been wary of since 2014: the over-sized risk perception of the hereditary component as a cause of cancer in the Spanish population.

In 2021, the Spanish Association Against Cancer published the results of its survey, which collected Spanish citizens' perceptions of cancer. According to the survey, cancer and degenerative conditions remain the most feared diseases with which to be diagnosed. The survey also asked questions about the causes of cancer and found that in the last decade, the percentage of people who believe that hereditary factors play a significant role has increased. The survey report notes: "It is noteworthy that the perception of the hereditary component in the last 10 years has almost doubled to 60 percent of people who place it first" (Oncobarómetro 2021:34–35, my translation). The hereditary component has thus replaced smoking as the most critical perceived cause of cancer. In many ways, these results confirmed a concern already expressed by cancer screening professionals a few years earlier regarding the over-sized risk perception regarding the hereditary component of cancer. This concern led the Spanish Network of Cancer Screening to publish in 2014 a consensus document pointing out the need to work toward "a more realistic perception of the risk posed by the presence of family history" (Ascunze Elizaga et al. 2014:11). This document established as a key objective of the Cancer Screening Network for everyone to understand that a positive test indicates the inheritance of a susceptibility – a risk probability – not a cancer. Such an apparent easy distinction was also made when talking with the research director of a commercial lab offering breast cancer predisposition tests, "here the concept of diagnosis must be taken out of our minds; these are probabilities" (Commercial Lab 1, 2022). However, as risk scholars have shown, such an apparently straightforward distinction is not easy to draw in the lived experience (Douglas 1990).

This rising visibility of and public concern over the hereditary component of cancer and professionals' worries regarding the excessive importance given to cancer predisposition risk cannot be detached from the ecology of practices, markets, hopes, and hypes that sustain the political epistemics of cancer research. Reflecting a worldwide prioritization of risk individualization and the dominance and absence of different types of "carcinogenic accountabilities" (Bhangu et al. 2024) or "chemical regimes of living" (Murphy 2008),[5] and growing technoscientific promises. Within this ecology, we can observe in Spain how commercial testing in the private sector has been gaining traction since 2017, with private healthcare clinics offering breast and gynecological predisposition cancer testing as an anticipatory tool for any woman over 30. Meanwhile, Spanish national healthcare professionals keep showing their concerns about oversize risk perception around hereditary cancer and oppose an approach in predisposition testing that calls for "café para todas," as noted during the interviews and professional consensus. All this in a country with restrictive legislation around DTC tests (direct to consumer), but that leaves medical genetic testing in private healthcare in a gray area.

In 2019, the Spanish Association of Human Genetics (Pàmpols Ros et al. 2019) published a position piece in which a critical stance is taken regarding the commercialization of healthcare propelled by the expansion of DTC testing and its impact on the doctor-patient relation, the relations between consumers and the healthcare system, and the genetization of health.[6] However, this statement is less straightforward than the one published that same year by the Royal College of General Practitioners and The British Society for Genetic Medicine (2019), warning practitioners and calling for caution about the increase in inquiries due to DTC, noting not to take these test results or reports at face value and consider that NHS costs of accommodating test results in the NHS system coming from DTC companies.

Spain's private and public healthcare sectors' interactions around breast and gynecological cancer predisposition testing remain ambivalent due to a lack of official data on testing by the private healthcare sector and its effects on the national healthcare system, as the phenomenon is still in its first stages. When I asked the interviewees if commercial test results were landing in the national

healthcare system, they generally responded that they had encountered a few cases but that inquiries from commercial testing were not common in their daily work (yet). It is yet to be seen if Spain might be in an incipient stage of what has already unfolded in the UK, where the NHS reported increased demand for genomic services due to direct-to-consumer testing (National Health Service England 2022). Alternatively, if not that many people opt for predisposition testing in Spain or if there is an increasing bifurcation and lack of connected vessels between those paying for these tests in private clinics and the national healthcare system. In the next section, I argue that while the marketization and offer of predisposition tests in private healthcare clinics in Spain are increasingly visible and follow an already well-studied biomedicalization approach, the national healthcare professionals are immersed in a practice of prudent genomics that typically goes unnoticed and unexplored. I show how not only is the tension between private and public healthcare approaches tested, but health genetization and genomics uncertainties are also tested.

Testing genomics

In December 2022, I visited the oncology department of a public hospital well-known for its genomics lab to interview Dr. Gregorio, a breast cancer surgeon who became a breast cancer genetic counselor two decades ago after training in the United States. His office was in a cubicle inside the genomics lab. We could see the lab technicians processing samples, and they could see us sitting there. After half an hour of talking about cancer genetic predisposition, I showed him some Spanish commercial lab websites promoting their cancer predisposition/susceptibility tests with flyers like the one described in the previous section and asked what he thought. He began to shake his head disapprovingly, put the tablet aside, and noted:

> Until some time ago, I would say to a patient, "Look, since you are a BRCA1 carrier, you have up to an 80 percent chance of having breast cancer during your lifetime," and I would remain so calm. Now I say, "Look, at the moment, with the data I have, I can tell you that the risk is this, but it is very possible that I will know more in the future and then adjust it [the risk score] more." In the beginning, with predisposition gene testing, we only analyzed people who had many cases in their family or were (diagnosed) at very young ages, and of course, the risk was very high. We have now seen many cases and families, and we can provide a more accurate risk. However, we must be very honest with what we tell the patient and let them know that this information gets updated day by day. Otherwise, we are confusing patients. Certainty is not there, at least not yet.

In this excerpt, Dr. Gregorio's initial response to the cancer predisposition tests offered by labs and private hospitals was to put the results and interpretation to the test. He recognized how more knowledge about genetic predisposition and risk model calculations has challenged the excitement and conclusions reached at the beginning of the millennium around predisposition genes. More experience around predisposition genetic testing with a broader pool of individuals has allowed researchers and doctors to assess the predictive value of genomic data and the probabilistic calculations in constant reformulation, leading him to shift his way of communicating breast cancer genetic test results and risk estimates. He insists on leaving the meaning of the test results open to reformulation. Dr.Gregorio's recalibration of his way of understanding and communicating genomics and relating to the results represents another test outcome.

His shift can be situated in genomics' general trend toward welcoming and recognizing uncertainty. The variants of unknown significance are an explicit example of accommodating uncertainty in contemporary genomics. A publication in the *European Journal of Medical Genetics* notes:

> One of the main factors influencing the clinical utility of genetic tests for cancer predisposition is the ability to provide actionable classifications (i.e. pathogenic or benign). However, a large fraction of the variants identified in cancer predisposing genes (CPGs) are of uncertain significance (VUS), and cannot be used for clinical purposes either to identify individuals at risk or to drive treatment. (Lucci-Cordisco et al. 2022:1)

Incorporating the "uncertain significance" into the contemporary genomics vocabulary illustrates a bifurcation between commercial labs' quest to expand the panel of genes as if testing more genes was

a market differential that improved their tests. At the same time, professional and scholarly consensus keeps growing around lowering the expectations of how extended a panel can be and what a predisposition test can offer to a proto-patient. Dr. Mar, the oncologist in charge of the national unit of hereditary breast and ovarian cancer, also illustrates a cautious approach toward the use of predisposition testing:

> It is important for us to nuance big slogans around predisposition testing because if the test is negative, it does not mean that you won't have cancer; it is just saying that you have tested negative regarding the selected genes that are known to be linked to hereditary cancer, that is all. That is why those tests without context have no meaning at all. If you only have that information [the test result], it is meaningless. We only use those types of tests in very few cases in which we have already done a family history follow-up, and even in those cases, we are cautious as many external factors also affect familial aggregation.

Throughout my interviews with cancer healthcare professionals, genomics counselors, and researchers in the national healthcare system, I observed that when I brought up the issue of cancer predisposition tests, the interviewees commonly responded by expressing their will to work toward undoing decades of geno-determinism and recognizing uncertainty as an integral part of contemporary genomics rather than promulgating the value of these tests beyond diagnosed patients. For Dr. Gregorio, a cancer genetics counselor, "Socially, it is like genetics results cannot be disputed, but any test has to be interpreted, and depending on that interpretation, many things can vary; tests can be questioned and reviewed, and they should be." Genomics uncertainties then unsettle the biomedical regime by making doctors and patients unlearn old ways of presenting medical results as definitive.

Therefore, conflicting logics coexist. Private healthcare in Spain has increasingly incorporated into its portfolio cancer predisposition tests as anticipatory consumer products for anyone older than 30 if they can afford them, as if such tests could offer some medical resolution to anyone anxious about genetic cancer risk. Simultaneously, I found that the professionals interviewed engaged in what Reardon (2022):228) calls "thoughtful genomics," which recognizes "that this new domain of technoscience is not a panacea capable of revolutionizing medicine in all cases and places. Instead, its tools and diagnostic operate and are effective in particular cases and places." In the case of predisposition testing, for the professionals interviewed, the genetic tests serve as a tool to target therapy for diagnosed patients or to intensify follow-up procedures for very few healthy, predisposed patients. However, how to adjust such follow-up remains under discussion in most cases. As Nelson et al. (2013:406) observed, predisposition testing does not fit the actionability regime, under which test results serve "to point medicine at" at the clinical level. Only in very few cases can predisposition testing, as an *anticipatory technology of exceptionality* or stratification tool, mobilize such actionability as, for instance, genetic testing of tumors of sporadic cancers (non-heritable mutations) does by enabling targeting treatment or orienting cancer management. Thus, beyond the cases of diagnosed patients for whom the tumor can be tested, their comments for the general population tend to downplay the relevance of the hereditary component and genomics, delegitimize testing outside the national healthcare system guidelines, and avoid accepting the test results in isolation or without considering their openness to reinterpretation.

The practitioners interviewed practice "thoughtful genomics" by acknowledging that predisposition testing offers minimal clinical value for patients without a diagnosis and highlighting how rapidly genetic classifications can shift, underscoring the field's instability. Consequently, the widespread use of predisposition testing challenges the boundaries of oncologists' competencies and training while requiring asking if a test that does not offer a diagnosis can be considered a medical test with the consequences this would have legislation-wise. In this vein, discourses that fit "thoughtful genomics" are not innocent narratives but critical points to explore negotiations in the field, where responsibilities are located, and how usefulness in cancer care is understood. Following the ecology of testing discussed above that illustrates paradoxical stances, in the next section, I close the analysis by unpacking how predisposition testing challenges the national healthcare system and requires reflecting

on the transformations ignited by so-called personalized/precision medicine as a tool for optimizing some national healthcare systems.

Testing the national healthcare system

Spain's healthcare system is similar to that of the Nordic countries, which Böhm et al. (2013) define as a "national health service" with state regulation, financing, and provision. For some time now, in the Nordic countries, personalized medicine has gained some publicity in the national level discourse, spurring scholarly research on how personalized medicine was presented as both a healthcare and economic model (Gjødsbøl et al. 2021; Hoeyer 2019; Tarkkala et al. 2019). In Spain, precision medicine and personalized medicine have not gained the same recognition at the national level (yet) and continue to be greeted with caution by most professionals. They are worried that these changes would propel increasing healthcare access inequity among various regions or between urban and rural areas while only prioritizing funding technology-based medicine. However, in the middle of the COVID-19 syndemic, in September 2020, the Spanish government approved a budget of 25.8 million euros to set up a "Personalized Precision Medicine Strategy," to which 51.5 more million were added in 2021: a total of 77,3 million to fund the set-up of the strategy. To put this in context, in 2022, health spending in Spain amounted to 92,072 million euros, 6.8 percent of gross domestic product (GDP), 14.1 percent of the spending covers primary healthcare with 11,911 million euros, with a 4.2 percent increase from the year before (Ministerio de Sanidad 2024). Then, even in the year with the highest expenditure on primary healthcare, it cannot compare with the ongoing funds directed to a blurry and highly technocratic "personalized precision medicine strategy."

Under this situation, in January of 2024, Congress took up a discussion around this strategy. Rafa Cofiño, a retired primary care physician and representative of a moderate left-wing electoral coalition (Sumar Party), declared that "precision and personalized medicine was already invented, and it was called primary and community healthcare." To support his argument, Cofiño narrated in Congress the story of a community nurse and family doctor's home visit from getting out of their car to arriving at the patient's apartment, their walk through the neighborhood park, attending to the kinds of shops that are open, the aroma of food or lack of it in the building stairs. They entered the home and met the patient's daughter, an exhausted caretaker of her elderly mom and her kids; the nurse observed that the patient sleeps in a high old bed, making it difficult for the patient to move, and so on. With this example, Cofiño argued that we can recall a healthcare longitudinal approach, cordiality, differential diagnosis, improved pharmacological decisions, and the social context – all of which should be part of what we understand as personalized and precision medicine and what the national healthcare system should work toward – stressing that health care quality cannot be understood only through technology innovation lenses. This critical stance opposed the two big parties in the country (PSOE, a center-left party in the government during the approval and development of the strategy, and PP, a conservative party) that have shown their support for promoting a "personalized precision medicine" initiative that revolves around a technocratic innovation discourse. Such an intervention sums up a considerable part of a decade of discussions between public health and technocratic personalized medicine, as well as recent scholarly analyses on what is prioritized in personalized medicine and healthcare inequalities and social justice (Galasso 2024; Green et al. 2023).

The personalized precision medicine strategy is generating a discussion of what kind of healthcare system we want and what needs to be valued. After all, the Spanish healthcare system has become more precarious since the 2008 crisis due to austerity measures and other political decisions, and discussions around the transformation of the national healthcare system have been avoided or postponed. Martín Zurro (2022), a primary healthcare doctor, notes that the COVID-19 syndemic finally destroyed an already deteriorated healthcare system due to a lack of political will and an ongoing model that had not been renovated or reviewed since its institution in 1986 with the General Health Law. Currently, half of the doctors in the national healthcare system are employed under temporary contracts,[7] blankets and free water are not always available in hospital rooms, and primary healthcare services are

swamped. However, as with many other things, cancer remains an exception, and oncology is one of the few areas in which personalized and precision medicine initiatives are being implemented, mainly targeting treatment based on tumor genomic testing or the use of advanced therapies.

In this context, breast and gynecological predisposition testing for non-diagnosed patients challenges the dysfunctionalities of, concerns about, and ways of relating to a highly precarious national healthcare system on the verge of collapse. Technological and commercial predictive promises spurred by private healthcare products co-habit with national healthcare professionals' precautionary principles toward genetic tests, a general population ennui after witnessing the decay of the Spanish national healthcare system, and the open question of which healthcare model Spain wants to move toward. This situation requires keeping close to the basic but crucial questions posed by the anthropology of testing regarding "the work tests are being asked to do, for whom, by whom, and to what specific ends" (Street and Kelly 2021:10).

For example, MyPeBS is a study that compares the clinical and economic aspects of standard breast cancer screening strategies based on national guidelines with personalized screening based on risk stratification estimates (using risk scores and polymorphisms). The study includes women between 40 and 70 years old and excludes women already diagnosed or classified as predisposed to very high risk. Spain, Belgium, France, Israel, Italy, and the UK are participating in the study. Following the risk stratification, each group has a different temporal screening window: the low-risk group has mammography every four years, the average-risk group every two years, the high-risk group annually, and the very high-risk group has annual mammography and MRI. In this context, predisposition tests engender risk individualization while producing populations through ordering group stratification.[8] The logic behind risk-based screening is to reduce and adjust surveillance based on risk estimates to reduce the number of tests carried out, considering that only 5–10 percent of cancers have a hereditary component and not all are very high risk. Risk stratification is expected to reduce the number of tests carried out at the population level and help reduce some drawbacks of standard screening models, such as the high number of false positives, overdiagnosis, and overtreatment. Thus, genetic testing helps put standard breast cancer screening to the test and serves as a tool to reduce the use of other tests.

In the social science literature on predisposition testing, the protagonist tends to be the predisposed or high-risk individuals and their experiences. However, when talking about the use of predisposition testing at the population level with Dr. Juana, a doctor specializing in breast cancer screening, she noted:

> It is difficult to explain to a patient that has a higher risk [of cancer], but the problem for me, the real problem regarding these tests or the personalization of screening, is to approach low-risk patients – what do you say? Look, you do not need to screen yourself every two years; you should screen yourself every four years. This is tolerated in a worse manner than increasing surveillance. You can see how *they look at you, thinking you are sparing a service just to save money for the system*. We saw this when we increased time intervals for mammography and pap smears a few years ago. *People assume that the surveillance will increase when we talk about personalized screening, including genetic data, but it might not*. Indeed, it will decrease as almost everyone is low-risk. (Emphasis added by the author)

She sees a clear message that precision medicine is cost-effective because it provides the tools to reduce biomedical surveillance. Dr. Juana's concerns revolve around how a generalization of predisposition testing might challenge the public's imaginaries of personalized medicine, which tends to be assumed to equal an increase in healthcare tests and services when citizens' uneasiness with increasing standard screening intervals has not been resolved yet. For her, high-risk individuals due to hereditary causes are not a matter of concern; they make up a small percentage of people, and a well-established professional consensus exists regarding follow-ups for such proto-patients. What worries her is the lack of evidence to move forward with individual or population risk models and these tests seem to be following a path toward becoming population tests, or what in the interviews has been summed up using the Spanish expression "café para todos." This has given rise to an uneasy subject for the national healthcare system: the *low-risk collective*, resistant

to increasing time intervals between screenings or follow-ups. After all, they have come to know cancer according to the logic of "the sooner, the better," which became part of public health initiatives to highlight the relevance of standard screening. Biomedical surveillance has become a synonym for good care, and its reduction is approached with suspicion or mistrust. While the predisposed individual has helped to analyze the biomedicalization of our contemporaneity, the *low-risk collective* poses unanswered questions in the medical realm, but also, I would say, in the social sciences regarding the challenges of studying de-medicalization in high-income countries in relation to national healthcare system transformations.

As noted by Dr. Juana, breaking the long-standing inertia of increasing surveillance to provide good care is a current challenge for cancer professionals. Adjusting incorporated temporalities around cancer surveillance is a complex and ongoing task. During our interview, she explained how, in Spain, it is increasingly common to find women who do not trust the increased intervals between surveillance tests for the prevention of gynecological cancer and who, if they can afford it, pay for the tests in private hospitals during annual checkups, rather than following the screening guidelines, generating tests duplications.

> You find women who, even if they should be doing a mammogram every two years, they do it annually. The year that we do not schedule [national healthcare], they do it in a private hospital, with all the implications that these practices have for patients and the national healthcare system. We have to deal with these duplications and difficulty assessing protocols if only some commit to the national guidelines, which include not going to a private hospital for double checkups. And the same happens for pap smears. We try to reduce surveillance, false positives, and unnecessary medicalization and increase surveillance intervals, but who follows such a timeline? (Dr. Juana, cancer screening specialist)

Drawing on her experience with patients' reluctance to increase screening intervals after years of trying to de-escalate medicalization, Dr. Juana alerts the national healthcare system's lack of tools and workforce to deal with a *low-risk collective* produced by risk stratifications based on predisposition testing (which underplays other carcinogenic causes and whose risk models are not strong enough). Considering the ecology in which these tests take place, hereditary syndromes are a minority, and professionals are already concerned about genomics uncertainties, over-sized hereditary risk perceptions, over-diagnosis, over-treatment, and iatrogenic effects spurred by intensive surveillance cancer risk stratification is presented as paradoxical at this point. The stances at play require first more attention to how women already relate to and act upon the national healthcare system's increase in testing intervals for mammograms and pap smears, that is, to the ecology of testing situations from which predisposition genetic testing cannot be isolated.

For some time, genetic predictive tests aimed to produce predisposed individuals, with a subsequent increase of surveillance in contexts such as the United States. Attending to what such tests might be asked to do in other contexts and healthcare models is crucial. I have observed in the Spanish context how those same tools are now being considered to simultaneously produce a *low-risk collective*, thereby reverting biomedicalization while relieving national healthcare of what is considered over-surveillance (costs). Personalized precision medicine initiatives aim to put these tests to work to make the national healthcare system more cost-effective. For personalized precision medicine strategies, cancer is also an "economic disorder" (Burke and Mathews 2017) and is treated as such. Thus, personalized medicine initiatives at the population level are presented as key to increasing the cost-efficacy of flooded national healthcare systems like the Spanish one while putting to the test discussions on cancer early-detection strategies, de-medicalization under biomedical regimes, and redistribution of health services.

The ecology of testing presented aims to open a discussion on the reorganization of healthcare provision, particularly in countries with national universal coverage and calls for exploring the twofold role of these tests for biomedicalization and healthcare cost optimization, with the potential of spurring ambivalent modes of de-biomedicalization in decaying national healthcare systems.

Conclusion

This work offers a practical example of what an anthropology of testing that goes beyond medical diagnostics and attends to what tests generate in different social orders and what they are asked to do can offer. Genetic predisposition testing thus cannot be isolated from a broader ecology of medical, economic, and political testing. Attention to such testing ecology has allowed me to identify critical biopolitical questions. The materials presented in this article, based in a country with a national healthcare system with universal coverage, offer crucial insights into what the tests are asked to do for the national healthcare system. Exploring predisposition testing beyond the individual and physical body, I grasp the clash between commercial or market interests and the national healthcare system's caution. More importantly, it allows us to account for the professionals' critical stances on the general use of these tests as sources of information for anticipatory practices and the paradoxical role these tests can play for the national healthcare system. Drawing on a relational approach to breast and gynecological cancer predisposition tests, I have shown that these tests mainly can produce a *low-risk collective* (as hereditary cancer is exceptional), which unsettles doctors and the national healthcare system by posing unresolved questions on healthcare management of cancer risk probabilities and cancer screening. Predisposition testing puts to the test the relations configured by biotechnological markets and molecular biomedicine that sustain contemporary cancer epistemics, which are producing a particular type of cancer epistemics in which genetic predisposition keeps gaining public visibility over other carcinogen causes such as environmental toxicity or its links to occupational health (Hunsmann et al. 2023).

Following up on the ecology of testing situations provoked by these tests, I have noted how molecular relations extend to the political economy of the Spanish national healthcare system. Beyond that which has been widely documented on the individualization of risk through the molecular gaze and the figure of the predisposed individual, my observations based on policy documents and interviews point to predisposition tests as a tool for improving the cost-effectiveness of cancer surveillance for national healthcare systems. This involves not only the *optimization of the self* – as in the private hospital flyer quoted above and as observed by different scholars in the United States over the last two decades (Clarke et al. 2010; Hogle 2005) – but also, in this case, the *optimization of the national healthcare system*. Predisposition testing for risk stratification is expected to reduce unnecessary surveillance and optimize the national healthcare system by reducing the number of tests and interventions to the low-risk collective. The ecology of testing explored fleshes out at least three paradoxical stances at play around biomedicalization: 1) the promotion of these tests as self-optimization by private healthcare; 2) doctors working in the national healthcare system concerns on an already over-sized cancer risk perception linked to hereditary causes and overdiagnosis; 3) precision medicine initiatives for which cancer risk stratification is presented as crucial for a more cost-effective and optimized national healthcare system, for such a strategy of paradoxical "de-biomedicalization" a low-risk collective has to be produced. Finally, this article reveals national healthcare professionals' difficulties in making patients relate to de-biomedicalization in some stances as a "logic of care" (Mol 2008) and not just a form of economization, particularly in contexts of decaying national healthcare systems, such as the Spanish one. This research identifies that further inquiries are needed on the public approach to decreasing screening time intervals, professionals' ways of discouraging buying in commercial predisposition testing in the private healthcare circuits or explaining extending screening intervals, whether health professionals fail to communicate the benefits of de-escalating some biomedical interventions, and if it is not only a matter of citizens' mistrust in the economization of the national healthcare system.

Medical anthropologists have proven well-equipped to address biomedicalization and techno-centric strategies. Still, this study points to the pending work needed to tackle the ways in which de-biomedicalization might take shape in unexpected forms at the intersections of economic optimization, biomedical interventions, national healthcare systems transformations, and some professionals' aim to practice an "otherwise" biomedicine (Povinelli 2012) to reduce over-diagnosis and iatrogenic effects. With this work, I am calling for a collective reflection on the

methodological, conceptual, and analytical tools we can deploy to engage with the challenges spurred by paradoxical instances in which different modes of biomedicalization and de-biomedicalization are entangled. In short, this research has shown that while cancer predisposition testing has mainly been analyzed as a biomedicalizing tool for self-optimization and surveillance increase for the predisposed individual, these tests might play less expected roles in decaying national healthcare systems through the production of low-risk collectives which would require our close attention.

Notes

1. The project IfGene (PIs: Mauro Turrini and Rubén Blanco) delves into the relationships between genomics and the future by focusing on the medical domain. The project is based in Spain and focuses on the Spanish context. However, it also establishes a dialogue and comparative analysis with collaborators in France, Denmark, and the state of Telangana (India). It aims to analyze different areas of genetic testing for healthy and "at-risk" people to explore the anticipation of the future and highlight the global chains that operate through various modalities, both material and symbolic, around the spread of genetic testing for humans and cognate species.
2. The flyer referred in the text can be accessed from: https://www.quironsalud.com/malaga/es/cartera-servicios/genetica/pruebas-geneticas/test-genetico-cancer-mama-ovario.ficheros/1142654-Flyer%201_A5percent20Cancer%20mama%20y%20ovario%20QS%20AF.pdf. [Accessed 04 December 2024]
3. See Mancinelli (2020) for an ethnographic overview on "digital nomads."
4. *Café para todos*, literally "coffee for everyone," is an expression in Spain that means offering equal treatment to all parties involved in an issue to please (or displease) everyone equally. People began using this expression in the late 70s as Spain moved from a dictatorship to a democracy. One of the great debates about the new system involved the formation of a centralist or federalist state since certain regions demanded greater autonomy. The supposedly "neutral" solution entailed offering autonomy to all regions, which Minister Manuel Clavero Arévalo phrased as "café para todos," which subsequently became a popular expression in Spanish politics and beyond.
5. Michelle Murphy (2008:698) notes "the chemical regime of living, then, is less about harnessing life to profit as in the bioeconomy, than it is about contestations over making legible the distributions of molecular harm and precarious life as effects of a complex political economy." Murphy notion of "chemical regime of living" draws on Collier and Lakoff (2005):23) notion of "regimes of living," "refer to a tentative and situated configuration of normative, technical, and political elements that are brought into alignment in situations that present ethical problems-that is, situations in which the question of how to live is at stake." Murphy offers another turn into this notion by giving emphasis on political economy, governmentality, and epistemology regarding molecular relations. That is why I bring Murphy notion of "chemical regime of living" regarding the effects of what we have called elsewhere "the political stakes of cancer epistemics" (Bhangu et al. 2024).
6. I refer to genetization ("genetización" in Spanish) as how healthcare professionals express their concerns about genetics' preponderance in medicine and the public's understanding of disease. This term has also been used in the social sciences to refer to a biomedical and technoscientific tendency to define health issues as genetic problems isolated from other causes or relational approaches.
7. For an overview of updated and visual data on the Spanish National Healthcare System, see "Radiografía de la Sanidad en España:" https://www.rtve.es/noticias/radiografia-sanidad-espana/
8. See Vogt et al. (2019) analysis of three studies that warn on how big data screening can increase overdiagnosis, and their discussion on the challenges posed by risk stratification more broadly.

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Notes on contributor

Violeta Argudo-Portal studied social anthropology and globalization studies in Barcelona and New York. She holds a PhD in Science and Technology Studies (Universitat Autònoma de Barcelona) with a thesis on biobanking practices in Spain and their role in the contemporary biomedical supply chain. Violeta's scholarly work intersects social anthropology, science and technology studies, feminist thought, and public policy. Her research examines how biomedical knowledge, products, services, and technologies are organized, produced, and distributed.

ORCID

Violeta Argudo-Portal http://orcid.org/0000-0002-6057-2559

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