



The political stakes of cancer epistemics

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ABSTRACT

We demonstrate a *transnationally situated dialogue* as a method to bring ethnographic and historical research in Brazil, East Africa (Kenya, Tanzania and Uganda), India, Russia and Spain into conversation to show three cancer epistemics sites (research, detection, and care access) where the politics of cancer epistemics are at play. First, in the field of research, we show how certain ways of knowing, and certain questions about and interests in cancer, are privileged over others. Using examples from Spain and East Africa, we highlight how a shift towards microbiological and high-technology research has outpriced many more locally grounded research agendas, ignoring questions of industrial and capital accountability in cancer aetiology. Second, we look at ways of making cancer visible, how knowledge is mobilised in cancer detection and screening, where and for whom. We discuss the increased individualisation of risk which is reframing cancer surveillance and therapeutic agendas. Using examples from India, Spain and Brazil, we demonstrate how the epistemics of cancer detection generate discourses of blame and responsibility at the individual level and accentuate existing inequities whilst simultaneously absorbing patients and their families into complex networks of surveillance. Lastly, we examine how the epistemics of cancer implicate the very possibilities of accessing cancer care, shaping care pathways and possibilities for patients. With ethnographic examples from India, Russia and Brazil, we demonstrate how an orientation towards the individual shifts attention away from the commercialisation of healthcare and dominance of logics of profit in therapeutics. Throughout the paper, we point towards what is holding these cancer discourses together and grapple with how the politics of cancer epistemics are at play across the globe, even if they appear to be taking many different forms. Our approach highlights how practices are mirrored in the framing, implementation, detection and care of cancer with far-reaching effects.

1. Introduction

In the last two decades, scholars have highlighted the social, political, and cultural lives of cancer across the world through explorations of patient experience and hospital ethnographies, among others (e.g., Banerjee, 2020; Jain, 2013; Livingston, 2012; Van Hollen, 2022; Wailoo, 2010). Their writings have contributed to our understanding of how cancer is lived, experienced, and addressed globally. These social scientific investigations of cancer also resulted in the creation of collective projects and networks encompassing different geographies. In 2022, an

international group of social science researchers working on cancer formed the Political Stakes of Cancer Network – which seeks to ask questions about the relationships between science, society and power in cancer worlds across the globe. This paper is born out of a series of conversations in the Network, particularly around how political contexts, both local and global, have shaped the nature and form of cancer research, epistemics, therapeutics, and care. It brings together historical and ethnographic research in Brazil (Araújo Neto), East Africa (Kenya, Tanzania and Uganda) (Cochrane), India (Bhangu & Surawy-Stepney), Russia (Denisova) and Spain (Argudo-Portal), developing a

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methodological approach, a *transnationally situated dialogue*, to draw out themes common to our diverse projects to analyse cancer epistemics. In this article, we utilise this approach to put into practice a form of polyphonic writing, drawing out the resonances in cancer epistemics and its formations across the world. This *transnationally situated dialogue* led us to understand that the knowledge about cancer as a disease and its causes is increasingly individualised and obfuscates the role played by capital, state, industrial and post-industrial factors, and other such macro forces which are recrafting the milieus that contribute to cancer incidence and prevalence.

In our investigation of the political stakes of cancer epistemics, we approach the political as multi-layered. It pivots around the power relations between individuals, societies, structures, and systems. We lean on scholarship in science and technology studies (STS) and social anthropology to recognise the political as intimately related to structures and systems of power in which power produces knowledge and vice-versa - asking what relations of power are at play in cancer epistemics (Foucault, 1980; Rabinow, 1991). We interrogate the “mutually constitutive relationships between scientific orderings of the world and other orderings, such as those entailed [... in] projects of development or state building” (Street, 2014, p. 12) and study epistemic formations, including how technologies require forms of political life and operate in specific sociotechnical systems (Winner, 1980), how different epistemics are intertwined with values, beliefs and expectations (Daston, 1995), and how these define scientific facts, technological artefacts, evidence and data (Latour, 1987). As we attend to these forms of the political accompanying scientific and medical projects, we also draw attention to the silences in cancer epistemics. Discussing the social and political stakes of cancer epistemics, therefore, involves taking power and the moral as constitutive elements of knowledge, not hidden factors. From data production to care practices, defining what can and cannot be approached by health professionals, policymakers, technicians, advocates, and patients, we encounter social and political stakes across the cancer continuum, from the individualisation of risk to the challenges of accessing care.

This expansive continuum from cancer research to detection to care has led us to ask the question of cancer epistemics, i.e., how do we know cancer, towards STS scholarship on the production of knowledge and scientific facts. We attend to the forms of writing and discourses in which scientific objects are produced, reified, and circulated (Rheinberger, 1997). These writing practices and discourses constitute ‘experimental systems’ that shape how we understand the world scientifically and carry within them the coda that we act upon. By studying the experimental systems of cancer, we analyse the knowledge of cancer, the production of this knowledge and its circulations, and interrogate the questions which are posed, the answers which are sought and the framing of the problems inherent in the disease of cancer. We argue that these shape both what we know about cancer and what is collectively done about it. Embedded in experimental systems are politics of visibility and invisibility. While certain elements are brought into sharper relief such as the links between cancer and genetics, other links such as the identification of carcinogenic substances and their exact contribution to different cancers, remain under-explored. The unknown and hidden nature of the aetiologies and causalities of cancer shape not only how cancer is understood as a disease but also how we address it.

In this paper, we show three sites (research, detection, and care access) where the politics of cancer epistemics are at play and have a significant impact. We adopt a division that follows the continuum from research to care, or from definitions of disease entities to patients’ experience as Rosenberg (2002) put it, whilst recognising that the relations between these analytical sites are non-linear and intertwined. In the field of research, we show how certain ways of knowing, and certain questions about and interests in cancer, are privileged over others. Using examples from Spain and East Africa, we highlight how a shift towards microbiological and high-technology research has outpriced many more locally grounded research agendas - both within European contexts, but

also very significantly within the global south. Equally, these shifts in research foreground the development of high-cost therapies, supported largely by pharmaceutical agendas whilst ignoring questions of industrial and capital accountability in cancer aetiology. Second, we look at ways of making cancer visible, of detecting cancer, wherein we ask what forms of knowledge are mobilised in cancer detection and screening, where and for whom. Using examples from India, Spain and Brazil, we highlight the increased individualisation of risk and ask how the politics of epistemics frame cancer detection practices, our therapeutic agendas, interventions and detection. Lastly, we examine how the epistemics of cancer implicate the very possibilities of accessing cancer care. Drawing on ethnographic materials from India, Russia and Brazil, we reflect on how different capacities and facilities for knowing and understanding cancer shape care pathways and possibilities for patients. This is not just a question of access to the most advanced equipment but can also reflect difficulties in gaining access to even the basic therapeutics employed therein. Throughout the paper, we point towards what is holding these cancer discourses together: how we over-invest in certain ways of knowing cancer and ignore others. We grapple with how the politics of cancer epistemics are at play across the globe in the formation, framing and implementation of cancer research, detection and care. With a wide range of ethnographic examples, we show that the way we think about cancer and the knowledge formations we build around it have far-reaching effects. The comparative lens of the paper highlights how these effects are mirrored across countries, even if they appear to be taking many different forms.

2. Methods

The paper brings together research data from six different ethnographic and historical research projects in Brazil, East Africa (Kenya, Tanzania and Uganda), India, Russia and Spain into conversation. These studies were conducted between 2015 and 2023. Data collection was based on qualitative methods (oral history, document analysis, interviews, and ethnographic observations), backwards grouped and discussed for reflexive thematic analysis (Braun et al., 2019). The projects this paper draws on include: first, a historical and STS analysis of conceptual changes, policies, and practices of cancer care and prevention in Brazil, focusing on incorporating new technologies and the role played by social inequalities in the organisation of care. Herein Araújo Neto participated in a project that conducted ethnographic and oral history research in Rio De Janeiro, including 50 semi-structured interviews with patients (breast and cervical cancer), health professionals, technicians and health managers in the Brazilian National Cancer Institute (INCA) alongside archival and documentary analysis between 2015 and 2023. The second project is a historical and anthropological project examining cancer research and data production in Africa over the last century. In this study, Cochrane conducted multi-sited ethnographic fieldwork in 2022 at 5 cancer registries in East Africa (Kenya, Tanzania and Uganda) and 72 semi-structured interviews with registry staff alongside archival and documentary research on cancer registry reports. The third project is an ethnographic study into the emergence of the National Cancer Grid, a new cancer care formation in eastern India and the lived experiences of cancer patients in the region by Bhangu. This involved one year of ethnographic observations in 2021–2022 at a cancer hospital recorded via fieldwork diaries and 150 semi-structured interviews with cancer patients, family members, medical and paramedical staff and social workers. The fourth project is an ethnographic study into the circulations of morphine in north Indian cancer care. In this project, Surawy-Stepney conducted observations in a large cancer hospital alongside 24 semi-structured interviews, including staff at the cancer centre, oncologists, government regulators, palliative care specialists and pharmaceutical representatives in 2019–2020. The fifth project is a study of cancer care infrastructures and the role of private clinics in patient navigation in Russia wherein Denisova conducted a qualitative study of 3 private clinics in 2 large cities, 27 semi-structured interviews

with clinical staff, patients, physicians and healthcare experts at partner organisations, and analysed digital materials related to the work of these clinics in 2021 and 2022. The sixth and last project this paper is based on is an interdisciplinary social science research project addressing policy, legal, and anthropological issues on predisposition genetic testing for gynaecological cancer in Spain. In her work, Argudo-Portal conducted case studies of 2 commercial and 2 public genomics labs and 12 semi-structured interviews with gynaecological cancer predisposition professionals of the Spanish National Healthcare System, including oncologists and geneticists and learned on fieldwork observations between 2021 and 2023. The authors conducted data collection and translated it into English when needed for the paper; none of the projects relied on translators. We provide a more detailed overview of the research materials, language and coding methodologies in [Appendix 1](#). For all studies, ethical clearances of local institutions were obtained, and the written or oral informed consent from research participants was secured.

The authors are all members of the Political Stakes of Cancer Network and have met virtually each month since June 2022 to discuss their projects' insights and writing. Inspired by feminist scholars' call for "situated knowledge" ([Haraway, 1988](#)), we developed a methodology of analysis, one which we refer to as a *transnationally situated dialogue*. By articulating a dialogue between the projects' research data, we bring insights from our distinct research locations after sieving through our fieldnotes, interview transcripts and diaries for utterances, themes and notes around the epistemics of cancer in different parts of the world. In this, we interrogate the political stakes of cancer epistemics: how knowledge of cancer is produced, reified, and circulated, and the links it establishes or fails to with cancer treatments and therapies in each location where we have conducted our research. Throughout our reflexive thematic analysis, we observed that the responses of our interlocutors and documental materials around how we know cancer are largely organised based on their positionalities and expertise. For some, these emerge as questions of knowledge (research), for others as questions of cancer prevalence and prevention (detection), and for many cancer patients, these are questions of access to care and therapeutics (care access). As such, these three sites (research, detection and care access) operate as the coda of political stakes of cancer epistemics and structure the paper.

In drawing together six different social scientific investigations on cancer from a multiplicity of locations, our paper identifies resonances and similarities in the political stakes of cancer epistemics across the globe. To retain this density and multiplicity of thought and analysis, we engaged in an exercise in polyphonic writing whereby each author contributed to the writing of this paper and assessed whether its arguments were supported by their individual research data in addition to engaging with the social sciences studies on cancer literature. This situated and reflexive methodology, developed over the course of numerous discussions and deliberations around the projects' data, helps us draw attention to the resonances and coherences in cancer care projects globally. We deem our methodology of a *transnationally situated dialogue*, which moves from specific and situated contexts towards a global evaluation of the current moment in cancer epistemics, as productive for investigating the increased emphasis on genetics, lifestyle and habits and the confluence of health care efforts with moral projects and to illuminate the role of capital, state, industrial and post-industrial factors.

3. Epistemics of cancer research and carcinogenic accountability

This section explores how contemporary cancer research articulates a particular way of thinking and producing knowledge about cancer, generating numerous concerns for professionals and communities across the globe regarding the questions and people that cancer research today leaves unattended. The politics of cancer epistemics and research have

gone through numerous shifts and continuities since the late 19th century. From the contributions of pathology to framing the cancer schemata ([Löwy, 2010](#)) to multi-centred genomic platforms ([Keating and Cambrosio, 2012](#)), research has had many different positions in the social responses to cancer. One could trace back the contemporary configurations of cancer epistemics to the second half of the twentieth century ([Gaudillière, 2006](#)) when two shifts occurred: from clinical medicine to biomedicine and an increased emphasis on micro- and molecular biology. This started to drive what ought to be known about cancer, under a biomedical platform oriented by molecular and genetic analysis ([Keating and Cambrosio, 2004](#)). These shifts created grounds for new forms of cancer knowledge, promoting multicentric research centres, standardising data production and analysis, and increasing transnational networks of research and clinical practice guidelines while remaining focused on individual cancer presentations ([Cambrosio et al., 2006](#)). Cancer epistemics have since moved towards research about individuals with cancer highly detached from their contexts, social, political and personal, and focuses instead on the individual (biological) body. With this increased emphasis on the individual and interior biological body, research and healthcare projects emerge as moral projects focusing on human behaviour and life-style factors. This form of knowledge about cancer and its causes draws attention to individual acts and actions and obfuscates the role played by capital, state, industrial, and post-industrial factors, and other macro, infrastructural and social forces that shape our social, political, environmental and ecological landscapes and contribute to cancer incidence and prevalence. Like Amy Moran-Thomas in her work on diabetes, we argue here that we must pay attention to "all that is muted when researchers focus on cells and molecules alone" (2019, p. 196).

With individual's biological bodies in the spotlight, contemporary cancer research's focus on lifestyle and habits heightens the individualisation of risk, and produces a convergence between risk, prevention, and the disease itself ([Aronowitz, 2015](#)). This tendency for risk individualisation which began in the 1980s, when discourses and initiatives around the personalization of breast screening programs in Europe emerged, has continued and strengthened in the contemporary boom of studies and publications around polygenic risk scores that identify individuals at risk of developing cancer ([Xin et al., 2023](#)). In places such as India, this convergence has led to increased spatial extensions of medical efforts into local worlds through medical camps and screening efforts to capture cancer ([Banerjee, 2020](#); [Van Hollen, 2022](#)). These have also altered notions of pathology, as Bhangu discovered, to include those deemed "at-risk," "pre-cancerous," and "pre-malignant" within the ambit of cancer detection and care thus, temporally advancing this risk individualisation and situating cancer knowledge production "before" cancer. As cancer is geneticised and molecularized, cancer research shifts further and further away from exploring environmental and ecological links, such as between certain cancers and viruses.

In East Africa, for example, where Denisova undertook research, there was a surge of interest in the environmental and social causes of cancer from the 1950s until the late 1970s. This research agenda was driven by the significant influence of geographical pathology as a key epistemic framework for understanding and investigating cancer at the time. Championed by some of the biggest names in the field, from Pierre Denoix to Richard Doll, geographical pathology sought to advance our knowledge of the causes of cancer by studying and comparing populations living in different geographical circumstances and exposed to widely varying nutritional, social, economic and environmental factors ([Cochrane and Reubi, 2023](#); [Fraser, 2020](#)). The voracious scientific interest in geographical pathology as a research method to understand cancer resulted in numerous, highly funded and complex research projects into cancer in Africa, from studies on Burkitt's Lymphoma to research on liver cancer. However, a gradual move towards molecular interests in cancer meant that by the 1990s geographical pathology lost traction as a research method globally, and with it the broader focus on environmental causes of cancer.

This shift in research toward a molecular study of cancer is a worldwide established phenomenon, as has been identified by Pereira Cabral et al. (2018) in a bibliometric and network analysis of the global cancer research landscape between 2012 and 2017. Their study provides relevant insights into the ways in which cancer research operates as a political project and unpacks what is known about cancer today. If we delve into what kinds of cancer research is encouraged, the authors identify a rise in the number of publications on cell biology, increasing 564% from 2012 to 2016. Their bibliometric analysis results align with the cancer research highlights identified by the European Association for Cancer Research (2022), and the ‘hot topics’ listed by the American Association for Cancer Research (2022). The highlighted research areas by both scientific and professional associations can be summarised in three big streams: molecular tumour ecosystems (Schwaiger-Haber et al., 2023), immunotherapy (Hodi et al., 2021), and genome-wide mapping (Ganini et al., 2021). All these streams, considered ground-breaking in cancer research, illustrate a cell biology-centric approach, driven by genomics with an emphasis on tumour ecosystems and profiling - highlighting what is considered worth knowing about cancer today. As these inquiries lead and dominate contemporary cancer research, all other epistemic concerns about cancer are left behind including calls to understand the social determinants of cancer, the “causes of causes” (Marmot, 2015).

These epistemic practices have come to permeate research cultures across the world. For Gregoria, a retired geneticist in her 80s who still goes to a public hospital-based lab three days a week in Barcelona (Spain), a lab in which Argudo-Portal conducted her ethnographic research, there is no doubt that research technologies are influencing forms of cancer research and technical arrangements are defining what is to be known and understood about cancer.

“They [labs/institutions] invest in machines that are so expensive that, of course, they must make a return on it. The investment in these modern machines requires leads to research that is too far from any clinical utility. Such research might be valuable in the future; now, it is too uncertain, and we are not ready to interpret it. With this, I want to say that maybe we should be doing something else [other kinds of research]. Instead of sequencing more and more just because now we can do it faster. We should stop and ask: who is leading the work, the machine or the researcher?” (Barcelona, Spain, April 2022)

Gregoria’s sharp comment must be situated in the experimental, biomedical and technoscientific ecosystem in which genomics live nowadays, between next-generation sequencing, whole exome profiling expectations, and a growing number of uncertainties around genomics, its clinical utility, and the viability to travel to the clinical bedside (Kuijper et al., 2023). Gregoria’s question brings the effects of a scientific and commercial context in which genome and exome sequencing technologies are becoming faster and leading the arrangement of some research questions and not others. Gregoria expresses a need to step back, get perspective, and acknowledge the entanglement between cancer technologies and research agendas. She also reveals the “seamless web” in which she feels trapped that produces scientific knowledge where the distinctions between technology and knowledge production are elusive and tend to fade. The conditions of possibility of these next-generation sequencing technologies promote a genomic approach to understanding cancer accentuating a molecularization of life (Kay, 1992), and that, as Gregoria notes, is not giving much room for other types of inquiries or concerns.

Such comments reveal that cancer research cannot be detached from the epistemic structures and technologies that produce it. While data produced by sequencing technologies are becoming the norm, they require numerous experts to interpret and multidisciplinary efforts to evaluate and consider their clinical utility. Genomic data sourcing inertia clashes with the scarcity of professionals trained to interpret such data, and even when available, they lack time for more training to catch

up with the latest developments as Argudo-Portal observed through her research in Spain. The push for high-tech forms of biomedical research has significant effects on professional communities and healthcare infrastructures, while leaving unattended the exploration of low-tech research questions that would, in turn, generate other forms of knowledge about cancer. They also create prohibitively expensive research agendas that are inaccessible to many across the globe.

Within the east and southern African context, this has marginalised local researchers and left a significant lacuna for research into low-tech, low-cost solutions for cancer therapeutics. Researchers from South Africa complained to Cochrane that the fascination in the global north for high-tech, high-cost therapeutic solutions meant that African oncologists and cancer centres often had to rely on old and frequently outdated technologies because newer technologies were not reachable for them. Not infrequently these pressures have resulted in health practitioners innovating and improvising cheaper and often more locally effective and patient responsive solutions (see for example Livingston, 2012). Nonetheless, researchers complained that there was a lack of interest in, and therefore funding for, new research into advancing old or creating new, cheaper and locally more applicable cancer technologies. The result of this is an ever-growing gap between cancer therapeutics available to patients in the global north and those in the global south coupled with a stagnation in the production of cheaper and more simple technologies - perpetuating a global research environment that does not cater to the lived experiences on the ground for many of the world’s most vulnerable cancer patients.

It is clear that one of the key things a politics of cancer epistemics requires of us is to carefully question from where and by whom cancer research agendas are being set especially as concerns around these questions echoed in all our fieldwork locations. As Mala, a research coordinator in India recounted to Bhangu, “We are included in all major epidemiological studies but always as data points, never the ones setting the research agendas or questions.” In Delhi, Dr. Hina, a senior global health expert described another challenge:

“When [Country A] wants to send India aid and wants to develop a new health project, it is a lot of work. From their side, they may want to try out a new drug or want access to patient databases and their industry actors may have their own goals, but we have to explain to them that our government officials aren’t going to support projects in which we are only test cases as India has its own agendas.” (Delhi, India, April 2023).

At levels of governance, international relations, and capital, thus, the decision making is not rooted in therapeutic goals, environmental aetiologies, or cancer care. Instead, we observe operating at national and international levels, health agendas collapsed into economic and trade interests, nationalistic desires, and disputed grounds of global relations, all the while clinicians in India and East Africa struggle to care for a growing number of cancer cases.

This global setting of the research agendas becomes clearly evident in the east and southern African context. In the 1950s–1970s, as mentioned above, research funding flowed into projects on liver cancer and Burkitt’s Lymphoma in order to find concrete evidence for oncogenic viruses. As these interests waned in the 1980s and ‘90s, funding for cancer research dramatically decreased. By the late 1980s, however, the identification of a correlation between HIV/AIDS and Kaposi’s Sarcoma (KS), meant that there was plenty of funding available for research projects focused primarily on KS. Other cancers, however, were severely neglected. Historically, most of the cancer research taking place in the region has been primarily funded by outside donors and funders who have thereby largely shaped the cancer research agenda. In recent years, pharmaceutical interests, in particular, have had significant sway – with these efforts being largely oriented towards new therapeutic technologies and drugs, and not into identifying complex aetiologies of cancer. The potential environmental causes of cancer, or even more murkily, the industrial or chemical causes, are barely studied. As Noemi Toussignant

has put it, Africa, and African bodies continue to be exposed to “literally poisonous global capital” (2018, p. 2) - yet within “chronically underfunded” (ibid) scientific landscapes, overworked research scientists do not find the time or the financial support to undertake research projects that could begin to examine and expose some of these environmental, industrial or chemical carcinogens. Dr Mathew Mwangi, an otolaryngologist in Kenya, articulated some of these frustrations in an interview with Cochrane. Interested in trying to unpack why so many Kenyans suffer from nasopharyngeal carcinomas, Mwangi complained that his heavy workload doing vital clinical work in a country with very few specialised clinicians, meant that he never found the time, or the funding, to follow his research interests. These sentiments, of not having the time or the funding to do aetiological cancer research, were expressed by oncologists and pathologists across Kenya, Uganda, and Tanzania in private interviews with Cochrane. For example, Felicity Akello, a pathologist in Kampala, Uganda, complained that there was far too little time for research, “we could do so much more, but there is no time,” she said. Or Dr Markus Baya, an oncologist in Mwanza, Tanzania, who felt that “we should be focusing more on research, because oncology in our area is such a grey zone [but] we have so many patients,” so the focus of their work is too practical. “Treating patients takes priority,” he said, “so research is side-lined.”

In our works, we have observed how professionals express their concerns regarding the difficulties of exploring less molecularized research questions, setting their own cancer research agendas, or lacking resources and time to do research on top of their clinical workload. These concerns around cancer research speak about other possible cancer epistemics as well as the research that is missing. We have also observed how the current epistemic orientation and inequalities sustain a form of research that gives little room to any form of what we term *carcinogenic accountability* due to the lack of research into environmental and industrial carcinogenic infiltrations. The concept of carcinogenic accountability calls into question who is being held accountable for carcinogenesis, and where funding flows and research agendas are being oriented towards. Time and time again, there have been efforts in the social sciences to delineate the murky links between industrial and corporate interests and the prevalence and incidence of cancers (Carson, 1962; Jain, 2013; Larrea-Killinger et al., 2017; Tousignant, 2018). This quieter but significant body of scholarship has argued that self-serving financial logics are so deeply embedded in our social worlds that they produce the grounds for carcinogenic infiltrations in the present and in our futures and when forced to contend with the realities of cancer, these logics further, rather than oppose, more corporatized solutions. Therefore, the relevance of carcinogenic infiltrations and questions of broader carcinogenic accountability are not unknown, but rather significantly under researched.

While the funding for scientific investigations into carcinogenic accountability remains insignificant, communities across the globe are calling upon their governments to investigate industrial and capital driven carcinogenic links. In 2020, the Marsabit county in northern Kenya, for example, lobbied the government to undertake an investigation into what they perceived to be unusually high cancer incidences in the region. They believed that drilling for oil in the 1980s had left poisonous chemicals in the ground water and hoped to show that this was causing a rise in cancer cases (The Star, 2021; interview with Cochrane). The evidence that was gathered for the lawsuit was inconclusive and the case was dropped, however, the desire of the county to ascertain carcinogenic accountability was nonetheless articulated and expressed. Such citizen mobilisations have also been noted by Ruth Prince in Western Kenya where ordinary Kenyans are increasingly worried about the environmental toxicity and pesticides they are exposed to, and express concerns about the potential carcinogenic substances in their food (Geissler and Prince, 2020; Prince, 2021). Similarly, in Spain, epidemiologists have called for more research on the links between proximity to open pit mines and cancer incidence in the south of the country (Fernández-Navarro et al., 2012). Yet despite people’s

serious concerns, little research has been done into the potential toxicity of their environment or food. These epistemics frequently run along racialised lines within which “death and dismemberment of nonwhite people [has] come to seem ordinary” (ibid. 51) thus marginalising research agendas which would be of importance for nonwhite communities. This produces fields of a type of willful ignorance, which often runs in conjunction with white ignorance (Martín, 2021), in which certain absences and elisions seem to be actively overlooked.

From the particular, genetic technologies in Spain, to the regional, geographical pathology or lack of it in East Africa, to the national and international agendas that are influencing knowledge production in medicine and medical care, we observe in this section how experimental systems and new knowledge forms shape the trajectories of cancer research. Within these trajectories, there are research questions that are never asked, perhaps posed but not explored, studies that remain unfunded, uncondacted, and findings that remain unpublished. Only by understanding the deep-rooted links in the politics of cancer knowledge and cancer epistemics can we begin to understand what we know and not know about cancer and how this produces particular forms of epistemic dominance and absences and generates different types of accountability.

4. Individualisation of risk and socially situated cancer detection

Research around cancer is not the only realm in which cancer epistemics play a defining role. Knowing, seeing or detecting cancer is equally connected to the shape, form and nature of epistemics upon which knowledge is built. These framings significantly impact what medical researchers, practitioners, scientists and even social scientists of cancer attend to (or don’t) in the field. The increased emphasis on cancer genetics, molecular biology and lifestyle risk factors meant that in the realm of cancer detection, how we identify presentations of cancer, we are mainly focused on the individual, and largely ignore the milieus, environments, temporalities, and ecologies in which cancer appears in screening efforts.

This search for the presence or absence of cancer states is accompanied by an apparatus of moral and epistemic infrastructures which take the shape of cancer awareness programmes, screening camps and other clinical and extra-clinical efforts which have come to extend cancer detection to lifestyle choices, genetic histories, individual physiologies, and habits, and thus, reframed prevention and therapeutics of cancer as a matter of individual responsibility. This gives rise to “blame-worthy patients” and loses sight of carcinogenic accountability and ‘blame-worthy’ industries or corporate, state, or capital interests (Moran-Thomas, 2019, p. 77). Alongside, such efforts conflate practices of care with surveillance, transforming descriptions of cancer screening and detection into sites of epidemiological and oncological capture leading to moral burdens of blame and responsibility to be borne by frontline health care workers, individual patient bodies and their families. For health care institutions and actors, these moral burdens also include debates over resources and the ethics of resource allocations in screening efforts. Yet, none of these discourses recognise the challenges of social inequities, inequalities and disparities within and among national contexts, which makes population-based detection and screening programmes less effective, inadequate or even unfeasible.

While the anchors of how cancer is known and made visible are similar in India, Spain, and Brazil, the configurations of these markers are specific. In each location, they draw attention to the desires and anxieties embedded in cancer detection projects. They also highlight the fractured cancer epistemics that underlie cancer research and public health efforts. Another common element in the stories of cancer detection in the fieldsites analysed in this article is entanglement between cancer detection strategies and moral orders. We understand moral order as a set of established values, sentiments and social norms that have power over collective and individual action. Even though moral

orders are situated and change considerably in geographical terms, they play a fundamental role in how people make sense of illness and health across the globe. Even further, moral orders are intertwined with material conditions, such as inequality in accessing care, which means that while cancer is individualised, the burden of its detection and of its address falls unequally. Like the women's groups in Spain who Argudo-Portal studies, Cecilia van Hollen's work in southern India has also emphasised the particular ways in which cancer awareness and screening efforts reinforce middle-class sentiments and moralities around women's bodies, sexualities and motherhood (Van Hollen, 2023).

Such individualising and "blame-worthy patients" approaches have been persistent in the history of screening in the twentieth century, despite the propositions of broader socially aware programs. In 1963, the WHO produced its first expert report on cancer control, which indicated general criteria for screening and detection programs and highlighted problems that ended up becoming recurrent topics on this matter, such as the feasibility of incorporating high-technology tests in mass programs and the creation of decentralised detection centres and health services, separate from hospital-based approaches, among other aspects (WHO Expert Committee on Cancer Control & World Health Organization, 1963). A vital element for differentiating screening from mass examination campaigns was the role played by health education in making regular testing a routine. Education would convince the public of the relevance of regular cancer tests since "examinations should be based on persuasion, not compulsion" (WHO Expert Committee on Cancer Control & World Health Organization, 1963, p. 6). However, the imperative of technological innovation and the incorporation of new diagnostic tests in public health services created a landscape of controversies over what would be the "right tool for the job" (Clarke and Fujimura, 1992) in cancer screening. This mobilised disputes over moral values, scientific evidence, public policy and management (Aronowitz, 1995). The definition of gold standard screening procedures often focuses on each technique's detection efficacy, obfuscating the place of social realities in screening, such as follow-up measures and environmental risk factors. In countries with large populations, such as India and Brazil, the challenges with technological solutions led to a debate on whether screening would be a feasible strategy (Boyes, 1985). In this paper, as we think through our diverse observations around cancer detection and screening efforts, we advocate for addressing these long standing debates by beginning with *socially situated detection* strategies, emulating the idea of screening and detection as more than technological or mass examination programs, and recognising the ongoing efforts in preventing cancer.

In eastern India, for example, where doctors remain crippled by vast patient volumes and are unable to shift their attention to research, Bhangu observed medical teams devise action-oriented research studies which incorporate cancer screening with awareness programmes in public health interventions. In order to spread awareness in local communities, these medical teams operate screening clinics. In these, they begin with awareness sessions in which a senior medical or paramedical worker conducts an information session to encourage early detection. Following this, the cancer screening clinic is run and all those who are present are invited to be examined. If a person is identified as "pre-cancerous" during the screening, then hospital employees immediately create a hospital patient ID and a patient file for the person. Alongside, initial medical examinations such as blood tests and punch biopsies are immediately conducted and follow-up appointments for additional tests and consultations in the hospital are also set up thereby creating a seamless continuum from awareness to screening to care. As one doctor explained, "This allows us to do everything at once ... we can spread awareness and if patients are able to come early then we can have better treatment outcomes. Otherwise, we only see late-stage and untreatable cancers." By intertwining medical research and public health efforts, the medical team at this hospital has been successful in securing government funding and support and this has contributed greatly in making early

detection programmes feasible.

To combat resource poverty and strengthen early cancer screening, detection and education, doctors in southern and eastern India have begun training Accredited Social Health Activists or ASHAs, India's frontline healthcare volunteers who are a significantly cheaper and much more readily available workforce than trained medical personnel. ASHAs are asked to make a distinction between normal and not-normal or abnormal oral cavities, breasts and cervix. They are not required in these encounters to diagnose cancer but rather to identify those who may require expert attention. They also teach women to self-examine breasts and watch for signs of cervical changes, thereby recruiting women in cancer screening efforts and training them to partake in cancer surveillance. If they notice any altered signs, women are asked to approach their ASHA. If the ASHA confirms an abnormality in any of these locations (oral cavities, breasts, and cervix) then they accompany the person to the nearest primary health centre or cancer hospital. This detection technique has proved to be very effective in early diagnosis and therapeutics in several Indian states (Tamil Nadu, Assam, Bihar and Uttarakhand) (Bhatla et al., 2021; Khapre et al., 2022). By mobilising territory-based interventions and social participation similar to "bare-foot doctors" in China and "community health agents" in Brazil, ASHA's approach situates screening in primary health care, differing from the traditional secondary health care structure of detection centres or regular examinations and yet, the effort remains in individualising cancer and its detection.

The results of these screening and public health programmes have been palpable in Assam, India, as Annie, a radiology technician who has worked in the hospital for more than a decade described, "The Screening teams are doing a lot of good work ... I have started seeing Stage 1 and 2 cancers for the first time in so many years of working here". Such success has come about as screening and detection efforts lean on face-to-face relationships between ASHA workers and the local communities and intertwine techniques of care, attention and capture. However, two challenges remain: first, such research efforts are rooted within individualised approaches to cancer and do not advance carcinogenic accountability in cancer epistemics for which we have argued in the section above. Second, as they do not lie within the technological and molecular research paradigms of cancer, these low-tech imaginations of cancer screening face several challenges. Despite being very effective as a screening technique, this training of ASHAs and awareness sessions among the general public is seen as too expensive by the local governments, and even Dr. Sumitra, the doctor leading this research effort in Assam, shared, "Cancer is there and we are being able to catch it ... In a population of 45,000, we got around 160 suspected and 31 cancer cases. I am explaining to myself that we are helping but we are using such vast resources."

The stabilisation of associations between "cutting edge science" or "best therapeutic options" and the use of the latest technologies and innovations runs so deep that Dr. Sumitra, whose project costs USD 122,000, deems it expensive even though it leads screening efforts in entire districts. In a span of three years, the project has screened an area of 600,000 people, led cancer awareness drives, generated employment and trained healthcare personnel. At the same time, the host institution of this research study has spent USD 1.2 million to get a new Linear Accelerator (LINAC) machine which can treat at most 30 patients a day (10,950 individuals per year, 32,850 in three years by working on all days, including Sundays and holidays). We, the authors, recognise that these false financial equivalences which are crafted based on a purely economic instrumentality - as this paragraph does - have played a truly detrimental role in health care in general, and in the field of cancer care in particular. However, it is remarkably distressing to encounter that these calculations, of the number of cancer cases prevented (as people screened) and the number of cancer patients treated (as lives saved), have now also become the modes of evaluation by frontline healthcare workers and researchers, even as they struggle to negotiate and win research awards and government support. This has twofold effects: first,

we observe in the examples of Gregoria in Spain and Sumitra in India a confusion about the stakes and purpose of their work and its significance for our collective knowledge of cancer, and second, we face an ever-widening fracture between the molecular, genetic and technology-centric efforts in cancer research and the demands of cancer care, as moral and epistemic projects, in public health and clinical encounters.

Comparing Eastern India's approach to screening to Spain's approach, one can see that individualisation performs differently in different contexts, despite traversing the same moral and epistemic landscape where narratives of vigilance and being "on-time" or early are commonplace (Henderson, 2022). In India, cancer screening efforts have temporally extended to include those deemed "at-risk" and involved women in the surveillance of their bodies. In Spain, these temporal narratives and individualised vigilance have engendered how we know cancer and identify potential patients, particularly by asking them to watch and screen for cancer "on time" to avoid late detection. Such public health messaging in Spain has led to cancer screening and gynaecological checkups becoming one of the critical forms by which women relate with and know cancer. In such a context, cancer detection and getting to know cancer cannot be detached. These narratives also reveal how temporally sensitive screening and tests are viewed as the best (and almost only) way to address cancer. If cancer is known by screening tests that detect it on time, then such external tests become the protagonists of the proto-cancer ecosystem and drive the ways of understanding what matters. These different performances of individualisation indicate that socially oriented detection does not mean excluding surveillance – a constitutive part of screening – but making it aware of the social conditions of detecting cancer and not reducing it to tests and self-awareness. Individualised restrictive approaches have implications beyond the materiality of care, also affecting the way people make sense of it.

In Spain, these temporally sensitive cancer detection efforts and the emphasis on individual responsibility led to grounds of friction between women's groups and public healthcare systems. With the recent introduction of austerity measures in the public healthcare system, a debate has surfaced on the growing time intervals between mammograms and the increase in time durations from annual check-ups to every three or five years for gynaecological pap smears. In public discourses and online forums, Argudo-Portal observed women show confusion around these changing policies and contest the time intervals. They have demanded more transparent explanations from the national healthcare system for what they consider to be long intervals between screenings and tests. In April 2023, a Spanish journalist posted on Twitter questioning the change in policy not to include women below 40 years of age in breast cancer screening. The journalist asked, "Don't women under 40 have cancer?" This post reached 120 likes and gathered a thread of around 30 responses in which the responders shared their incredulity around the durational changes in gynaecological check-ups in their regions from once every year to once every two or even five years after being schooled for years about catching cancer "on-time." They recognised the healthcare economization strategies leading this change but cited the cancer awareness programmes to which they had been subjected for years that emphasised regular, and on-time screenings. The debate over resources was viewed as a justification of neglect and an embracing of policies which are willing to put lives at risk. Only two respondents noted a need to evaluate the harms of these tests and drew attention to mammography, asking about the need and suitability of such regularised testing.

In Brazil, social inequalities in health affect directly how people access cancer detection services and how they make sense of screening as a health intervention, formulating contested perspectives around cancer care. Since the 1980s, an unsolvable controversy persists around the initial age for breast examination and the technique which should be employed. As a country with continental dimensions and severe inequality, the challenges for medical systems and breast cancer detection are further confounded. On the one hand, middle-class women in urban areas use the private system, which promotes mammography as

the right tool for the job through clinical protocols and public campaigns. For those who can afford health insurance, cancer diagnostics and prevention is a technology-intensive and temporally-sensitive issue that they approach with mammograms and regular and frequent appointments with their doctor (Teixeira and Araújo Neto, 2020). On the other hand, poorer and countryside women comprising most of the Brazilian population, use the public health system, which has several problems in organising screening programs and following up on detected tumours, despite the integrated network of services and the universality of care. For these women, breast cancer screening depends on clinical examination by overwhelmed health workers and an opportunistic use of poorly distributed mammograms. This divided system of cancer detection translates into values and sentiments about state actions, considered ineffective and not sensible about people's suffering and privileging bureaucratic reasoning (Araújo Neto, 2022). These configurations also reveal a persistence of the metaphors of resources, again appearing as a feature of public health decision-making of vital importance, governing where, when and whose lives are privileged and where, when and whose lives are left to bear the burden.

In India, Spain, and Brazil, cancer detection epistemics and strategies are transversed by surveillance practices, moral orders, and uneven social realities and are marked in cancer research by individualising approaches. This has shifted the responsibility of detecting and addressing cancer onto the public and medical personnel in each country, who we find struggling with the temporal imperatives of being "on time" to detect cancer.

5. Knowing and accessing cancer care

As we discuss the politics of cancer epistemics and how these influence its research and detection, another key component in this story is that of care. The questions posed in research agendas around cancer care can equally address or obfuscate the reasons particular therapeutics may be lacking or hard to access. Research does not simply guide what we know about the disease, but also how medicine attends to it and how those afflicted with cancer come to know and seek care for it. For in no part of the world is access to cancer care a simple matter. Even when care is available, the *longue durée* of treatment complicates the relationship between knowledge, treatment, and the attempts and practices of care.

There are several key points to address here. As we have shown throughout the paper, the growing technological focus of cancer research can result in the development of knowledge and therapeutics increasingly distant from - and ill suited to - the sites of cancer care delivery. But important too are the limits of patient understanding of both the science and practices of cancer which influence decision making among patients and their families (how patients themselves know cancer and access treatment). Likewise, how distinctions between public and private forms of healthcare shape what is and isn't rendered knowable about cancer therapeutics and access. Utilising examples from India (Surawy-Stepney), Russia (Denisova), and Brazil (Araújo Neto), this section attends to these concerns – to what patients know about cancer and how they act in the face of cancer based on this knowledge. The arguments in this section of the paper therefore seek to demonstrate the gap between our modes of knowledge generation around cancer, and the realities of cancer care, and to foreground a *careful cancer therapeutics*, one in which we begin with the concerns of those who bear the brunt of the cancer experience, the patients and their care providers.

As Surawy-Stepney demonstrates, it is not only a debate over highly advanced and expensive equipment or over resource allocations in cancer detection and care which are impacted by the particular epistemics we have described. Instead, such challenges are also encountered with routine medical objects that are abundant and cheap. Even today, morphine, an inexpensive and critical drug in cancer pain management, is difficult to access in many parts of the globe. India is a prime example. Its paucity in these settings is a problem that is widely even if

imprecisely known, spurring the questions: what is limiting its use in these locations? Why do doctors and other healthcare professionals refrain from giving this drug to their patients? Research has focussed largely on public hospitals and has spawned tables of discrete explanatory variables: a lack of ‘training and awareness’ of healthcare workers, ‘cultural attitudes’, ‘fear of diversion’ and so forth, ranked according to the frequency by which they are cited (see for example, the ‘Progress in ensuring adequate access to internationally controlled substances for medical and scientific purposes’ report produced by the [International Narcotics Control Board, 2018](#)). Implicit within studies on this phenomenon has typically been the assumption that it is the role of public healthcare to deliver these drugs, and that individual factors (lack of training, ‘cultural’ attitudes and so forth) underlie a hesitance to do so.

While evidence around morphine use acknowledges healthcare systems as a factor in the ‘rational’ distribution of opioid analgesics, the assumption that public healthcare *should* provide these drugs leaves unaddressed the systems and logics of private companies – corporate hospitals, pharmaceutical companies and so forth – that ensure a wider commercialised healthcare environment hostile to such ‘non-curative’ care. As Surawy-Stepney learnt, particularly in a country such as India that has undergone economic ‘liberalisation,’ the imperative for financial profit resonates throughout the healthcare system. Pharmaceutical companies do not wish to produce a drug so heavily and punitively monitored and often refine morphine stocks further into codeine. Corporate hospitals extend ‘curative’ forms of treatment until late stages of disease, and, amidst a highly competitive and insecure financial backdrop, move away from any therapeutic such as morphine that has the potential for reputational damage.

Now, research into cancer pain and its therapeutics has the potential to move beyond a focus on individual ‘attitudes’ and ‘training’, and suggestions that in public healthcare institutions strong opioid analgesics are ‘culturally’ rendered undesirable and subsequently withheld. Such research orders interventions at the level of individual practitioners, while obfuscating the links between the types of cancer pain relief that are available and the commercialised healthcare environments that limit the ways in which they are imagined, distributed, and consumed. The availability and uptake of medical technologies involved in care (as much as those involved in detection) are thus also shaped by the questions we ask about the disease and its treatment.

Just as cancer epistemics suture research programmes to the design and implementation of care plans, so too does knowledge of cancer become braided with knowledge of care infrastructures for those who seek to access them. The stakes of cancer ‘knowledge’ are perhaps highest around those experiencing the disease or its symptoms. As scholars studying in India ([Banerjee, 2020](#)) and Senegal ([Tousignant, 2023](#)) have shown, questions of knowledge transmission, disclosure or concealment, are essential for both clinical and familial caregivers. These scholars have focussed largely on cancer knowledge as it operates around diagnosis and prognosis. But it is also vital as a question of access. To know cancer often demands an understanding of how cancer care is organised and provided, knowledge that is not easily obtained.

In Russia, Denisova observed that when cancer is suspected, patients often face multiple obstacles in attempts to get adequate treatment. Even as they desire care, for these people, cancer becomes the issue of understanding ambiguous healthcare infrastructures and learning how to navigate them. While cancer patients in Russia are entitled to free healthcare, in practice they encounter multiple access barriers, delays and discontinuities. These contradictions and ambiguities have led [Denisova et al. \(2024\)](#) to characterise cancer care infrastructure as ‘swampy’; simultaneously embodying both the neoliberal principles of the marketization ushered in the 1990s and early 2000s, yet maintaining the legacies of direct state interventionism, inherited from the Soviet centralised healthcare system and reinforced in the last decade.

These contradictory health care policies have resulted in an ambiguous infrastructure: it is not clear upon what kind of rules it functions or how to navigate it. Denisova’s research participants highlighted the

individuating circumstances under which they attempt to access care. In these processes, patients often ‘disappear’, ‘get lost’, and even ‘give up on treatment completely’ – as if they were getting swamped by the healthcare infrastructure in attempts to traverse it. When asked to locate major disruptions at particular levels of healthcare infrastructure, these research participants were often puzzled and hesitant to do so. For them, the malfunction was a characteristic of the whole infrastructure, rather than its specific elements. It thus becomes impossible to disassemble this swampy state as it consists of entangled obstacles that accumulate through a patient’s journey. Patients trying to get diagnosed end up in a diagnostic loop; getting an appointment or referral takes weeks or months, medical tests lose their ‘expiration date’. By the time patients arrive at an oncology hospital if they do at all, they have already lost a lot of time and resources. Even once successfully admitted, new infrastructural obstacles await them; treatment can be inadequate due to the bureaucratization of care and medicine procurement, appointments brief and with changing physicians, and advanced technologies can be absent.

The unknowability of navigating this swamp-like space is so acute that it has given birth to new arrangements. Some cancer patients seek support from private clinics, because they provide them with a form of navigation service. The private clinics studied by Denisova offer patients a second medical opinion, speed up the diagnostic process, and refer patients to trusted physicians, including those working in public hospitals. These clinics not only provide patients with medical care but also share informal knowledge about how ambiguous cancer infrastructure operates. Consequently, access to these clinics can open up new opportunities (for those who can afford it) to learn about cancer therapeutics and access – knowledge otherwise unavailable in public healthcare. In such circumstances, knowing cancer translates into knowing how to access cancer care. As the oncologist at one private clinic explained:

No one talks to the patients [at public hospitals], no one explains what is happening and what will happen after the surgery. This is not because doctors are bad, this is not true at all. It’s just the system! An oncologist at a hospital has 10–15 minutes for an appointment and sees 60 people a day. In this sweatshop system, there is absolutely no way to build any kind of interaction with the patient, any kind of mutual understanding. (Online interview, Russia, August 2022)

But it is not just the murky infrastructures of multiple competing healthcare systems that implicates patient knowledge of cancer. In Brazil for example, the realities of accessing early cancer detection services are marked by moral and political stratifiers and gradients of inequity for patients. Everyday interactions of patients and their significant others with cancer detection and care pathways are embedded in social, moral and political knowledges that have radically impacted how patients know and approach cancer care. In Brazil, such stratified burdens are strongest among poor black women in the slums of major cities, people with limited access to health care and who suffer a variety of oppressions during clinical encounters. The difficulty begins even before having access to primary care, as shown by [Gregg \(2011\)](#) in her ethnography on cervical cancer among women of Recife, a major Northeastern capital city. She demonstrates how the framing of cervical cancer as a “disease of the sexual pervert,” and “of whores,” causes women to hesitate in seeking health services such as pap smears and attending general gynaecological examinations. In his fieldwork, Araújo Netohas also seen situations where the pathologization of sexuality and the stigmas of cervical cancer were key factors for women not engaging with screening and detection programs. Soraya, a middle-aged woman from Rio de Janeiro, commented on the fact she had never had a pap smear before presenting signs and symptoms of a gynaecological issue – she was diagnosed with cervical cancer. When asked why she had never undergone a preventive test, she said that she was embarrassed by the idea of a health professional seeing her naked and touching her body, and that she resisted a lot during the examination. After the

embarrassment, came guilt for never undergoing screening tests, “I felt like ... kind of sloppy. I was afraid and ashamed.” Soraya’s experience with cervical cancer highlights the moral aspects of screening, the individualisation of risk, and fears and concerns about clinical encounters. But most significantly, the limits of health communication and protocols around screening tests.

As such, in the politics of knowing cancer and accessing care, patient activism and advocacy play a fundamental role (Banerjee, 2020; Kehr et al., 2023). Patient activism strives to ensure that most patients get to know their diagnosis and treatment options and that access to such knowledge itself is part of good care. In countries where universal healthcare coverage is guaranteed by constitutions but is hindered by multiple inequalities and lack of resources, interest groups engage in efforts to raise patient awareness about their rights to free and timely healthcare. In Brazil, as Araújo Netohas observed, activist and advocacy organisations pressurise public health institutions and the legal system to provide better access to cancer care (Travassos et al., 2006). One such case of a successful advocacy intervention was the implementation of the thirty-day law which ensures individuals suspected of having cancer receive a diagnosis within 30 days of their initial appointment. Nevertheless, the everyday reality of the healthcare system reveals situations where this law is not consistently applied, with few patients aware of how to access care they are entitled to. Similar to the Brazilian context, Russian cancer care regulations are often inconsistently applied in practice and patient organisations play an active role in informing cancer patients about their rights, advising them on how to communicate these rights to doctors and healthcare authorities (Temina et al., 2023), and by doing so, improving access not only ‘on paper’ but ensuring that this right can be mobilised in constraining healthcare environments.

In knowing cancer, patients and their families face a series of challenges. They must traverse cancer as a problem of navigating murky medical infrastructures, negotiate between available resources and care options, navigate opaque healthcare systems, face the public/private imbalances, and as the ethnographic examples above highlight, mobilise, form collectives and struggle through law and political means to be granted support. Such forms of knowing cancer are often missing from research agendas and demonstrate the multiple ways in which lived realities of the epistemics of cancer are bound up with the politics of accessing cancer care.

6. Conclusion

By engaging with a polyphonic exercise that draws on materials from Brazil, India, East Africa, Russia and Spain, we have developed a transnationally situated dialogue that unpacks the political and social stakes of cancer epistemics. Throughout the paper, we have illustrated the distributed character of cancer epistemics at regional, national, and international levels and how such epistemics are articulated in practice in cancer research, detection, and care. From across fieldsites, we have discussed what kind of cancer research is being developed, what forms of knowledge and knowing are being produced and what is unknown or ignored.

Our work highlights how cancer epistemics is currently driven as a research endeavour favouring the molecular level of disease over environmental aetiologies and therapeutic challenges. As we have shown, it is an endeavour that raises professionals’ concerns in different parts of the world regarding the questions being ruled out due to the molecular and technology-centric paradigm that drives cancer research. We also argue that this firm orientation has resulted in a cancer epistemics which ignores what we have termed *carcinogenic accountability*. In an era marked by “the fallout of Western industrial orders,” which produces “landscapes of exposure,” we emphasise the need for research which identifies and measures links between cancer-inducing social, economic, environmental, industrial and political conditions, and the forms of social life in which these are rooted. (Masco, 2020; Tousignant, 2018).

This includes identifying who and how certain groups are benefited and at what costs. Currently, carcinogenic accountability hones in on the individual and individual lifestyles choices and practices. This individualisation, however, obfuscates the enormous carcinogenic production of global industrial capital, a production which often most severely affects countries in the global south. As the examples from East Africa show, this epistemic imbalance is further entrenched by the question of who does the research (and who pays for it), with East African researchers, who might want to explore more structural and infrastructural aetiologies of cancer, not getting the financial support or time to shift the orientation of global research agendas in favour of local concerns.

We have also observed how the epistemic orders of individualisation and technologised “cutting-edge” detection neglect highly effective and technologically simple approaches. As outlined in India, an emphasis on ‘cutting-edge’ detection can mean that highly effective, technologically simple, (hu)manpower based solutions such as the roving health workers are not given credence and support. We argue that the epistemics of cancer detection obfuscates certain forms of knowledge since the current epistemic order has embraced logics of individualisation of risk and detection efforts. Drawing on researchers, patients and families, healthcare volunteers, or public health initiatives in different parts of the world, we indicate the relevance of *socially situated detection* programmes and strategies that incorporate social determinants of cancer and consider the social, economic, and political factors that impact us collectively and frequently underlie this disease prevalence in populations. Through this we show how cancer detection is critical in producing ways of knowing and making cancer visible in particular ways.

We suggest, however, that cancer epistemics not only deeply impact medical research and practice, but also are an important dimension of patient experience. To show this, we draw attention to an additional cancer epistemics – the ways in which patients themselves know cancer through murky and iniquitous healthcare messaging and cancer detection programmes, swampy infrastructures and inaccessible pain medications. Here, we examine the burden on afflicted patients, their family members and frontline healthcare workers who lack the necessary knowledge to navigate treatment and care of a life altering disease like cancer. In the current, ever-changing economies and stakes of cancer knowledge, it is not simply the cancer care practitioners but those afflicted with cancer who face the brunt of cancer’s unknowability. This includes, as the paper has demonstrated, a wide spectrum of realities from what we know about cancer, how we detect cancer, and how we organise therapeutics of cancer, to even questions around where and how one should seek the necessary care. Cancer epistemics are therefore not only polyphonic in their global distribution, but also at the various levels at which they operate - from research, to medical practice, to patient experience. The social and political stakes of cancer epistemics brought about from our transnationally situated dialogue show the need to generate new epistemics of cancer so other forms of *carcinogenic accountability* can be forged, where *socially situated detection*, and *careful cancer therapeutics* can be pursued.

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Ethical statement

All projects included in this paper received ethics clearance from the corresponding institutions.

CRedit authorship contribution statement

Shagufta Bhangu: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Violeta Argudo-Portal:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Luiz Alves Araújo Neto:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Thandeka Cochrane:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Masha Denisova:** Writing – review & editing, Writing – original

draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Nickolas Surawy-Stepney:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

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Appendix 1. Research methodologies and materials

Geographical region	Researchers	Period	Research sites	Research materials	Analysis technique
Brazil	Araujo Neto in collaboration with Luiz Teixeira, Carlos Barradas, Keila Carnavalli, Vanessa Nolasco, and Rosilene Gomes	Between 2015 and 2023	Three qualitative research projects in Rio de Janeiro, including Brazilian National Cancer Institute	Historical work: document analysis and archival work; Ethnographic work: oral history interviews (n = 50) and observations Language: Portuguese	Serial history and conceptual history methods; narrative interview analysis
East and Southern Africa	Cochrane in collaboration with registrars from the African Cancer Registry Network	Between February–December 2022	Multi-sited ethnographic fieldwork at Cancer Registries: two in Kenya, two in Tanzania, one in Uganda and one in Zimbabwe	Ethnographic observations and interviews (n = 72). Language: English	Ethnographic fieldwork journaling; thematic analysis of interviews and observations
Eastern India	Bhangu Member of tGrid Oncology: Remaking Cancer Care in India led by Carlo Caduff (Fieldwork conducted independently by Bhangu)	October 2021–October 2022	Primarily: Cancer Hospital in Southern Assam. Also accompanied medical and social worker teams from the hospital in screening and prevention efforts, palliative home care visits, bereavement visits in the surrounding region.	1 year of ethnographic fieldwork including participant observation in hospital research and patient care efforts recorded via fieldwork diaries and journals; 150 recorded in-depth, semi-structured interviews with cancer patients, family members, medical and paramedical staff and social workers. Language: Bengali and English	Ethnographic data analysis via semiotic, linguistic and phenomenological methods.
Northern India	Surawy-Stepney Member of the Grid Oncology Project: Remaking Cancer Care in India led by Carlo Caduff.	In 2019 and 2020 (each of four months' duration)	Ethnographic fieldwork at a cancer centre	Ethnographic observations, semi-structured interviews (n = 24), document analysis. Language: English	Iterative approach to data analysis; thematic analysis of research materials
Russia	Denisova in collaboration with Prof. Klasien Horstman and Assistant Prof. Olga Zvonareva (Fieldwork conducted independently by Denisova)	Between 2021 and 2022	Qualitative study of three private clinics in two Russian large cities	Semi-structured interviews (n = 27), situational observations, analysis of digital materials related to the private clinics' work. Language: Russian	Iterative approach to data analysis; thematic analysis of research materials
Spain	Argudo-Portal Member of Ifgene Project led by Mauro Turrini and Ruben Blanco (Fieldwork conducted independently by Argudo-Portal)	Between 2021 and 2023	Case study of two Spanish commercial genomics labs and two hospital genomics labs within the Spanish national healthcare system.	Policy document analysis; qualitative fieldwork observations; and in-depth semi-structured interviews (n = 12). Language: Spanish and Catalan	Iterative approach to data analysis; content and thematic analysis of research materials

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