# Among White Coats: Politics and Practices of the Ethnographies of Biomedicine and STEM

**Edited by Cinzia Greco** 

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#### Introduction: Conducting ethnography among white coats

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"la realtà bisogna guardarla e non capirla, al fine di capirla meglio" [You need to observe reality without understanding it, in order to understand it better] Carlo Ginzburg

This phrase comes from an interview with the historian Carlo Ginzburg (Adamo 2022) in which he discusses his essay collection *Wooden Eyes* (2001), a translation from the Italian *Occhiacci di legno*, which, Ginzburg explains, is a reference to Carlo Collodi's *Pinocchio*. 'Wooden eyes, why are you looking at me?' is what Geppetto says when he is working on giving shape to the Pinocchio puppet and feels observed by an almost human entity that is not yet human. The title and the collection are a reminder of the power and destabilising role of a different and unexpected gaze. A new, unexpected and sometimes unwanted look is the subject of this book. *Among white coats* is a book about ethnography, about the importance and difficulty of observing reality and writing about it with a fresh look. This volume focuses on a specific type of ethnography, the one conducted among STEMM<sup>2</sup> scientists and medical professionals by ethnographers who bring to the field a different scientific background, that of the social

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<sup>&</sup>lt;sup>2</sup> STEMM indicates the combination of the more commonly used acronym STEM – Science, Technology, Engineering and Mathematics, and of the additional 'M' of Medicine. In this book we shift between STEMM to indicate the whole range of disciplines the ethnography of which we discuss, and 'STEM' and 'biomedicine' when focusing specifically on the sub-disciplinary distinction between the ethnography of science and the ethnography of biomedicine.

sciences, and who look at these medical-scientific contexts with a new eye. Our wooden eyes move in contexts that are often difficult to access and in which we might not always be fully welcome, and our presence there is shaped by asymmetries of power and prestige, which also inform our subsequent analyses. These asymmetries are at the heart of the experiences presented in the book. To anchor the following chapters in the wider questions of ethnographic practice, in the rest of this section, I present a brief analysis of ethnography and its evolution over the last few decades, with a particular focus on STEMM and biomedical contexts.

The etymology of 'ethnography' shows its definition as the writing (*graphia*) about peoples (*ethnos*). Ethnographers and historians have claimed authors such as Tacitus (e.g. Robben and Sluka 2015) and Ibn Khaldun (e.g. Hymes 1996) as early writers who have described the culture and the habits of groups of people. In more recent times, Bronislaw Malinowski's work (1922) among Trobrianders has been presented as a codification of ethnographic practice.<sup>3</sup> Three key aspects of the classical formulations of ethnography are of interest for this book. First, ethnography as 'writing of peoples' has for a long time been applied to 'remote' or at least 'other' peoples: anthropology has been interested with the populations of what more recently has been defined as the 'Global South' or 'global majority'. Second, ethnography in Malinowski's codification of Malinowski's fieldwork diaries (1967) revealed the author's challenges and prejudices in entering a social group as a foreigner<sup>4</sup>, and classic texts of ethnography such as Geertz's analysis of cockfighting in Bali (1972) describe the early days of being ignored in a new field. The issue of access and of the positionality in this sense have been particularly important to ethnography, even before an explicit discussion about this aspect

<sup>&</sup>lt;sup>3</sup> As in all histories, the actual record is more complex – Malinowski's codification is indebted for example to the earlier development of ethnology as a separate discipline in 18<sup>th</sup> Century German writing (cf. Vermeulen 2015), and other authors such as Frank Cushing could be credited for anticipating some of the methodological innovations that are routinely attributed to Malinowski (cf. Ugwu 2017).

<sup>&</sup>lt;sup>4</sup> In his diaries, Malinowski also focuses on the difficulty of finding a stable job in the academy. The professional situation of academics has certainly changed from the early twentieth century to today, but it remains characterized by profound precariousness which affects the type of research carried out and the knowledge produced. This aspect runs through many of the contributions present here, demonstrating that professional precariousness trickles in multiple directions, shaping non only our lives precarious, but also the outcomes of our work.

started to develop. Third, the history of ethnography is strictly intertwined with colonialism. The opportunities, funding and demand for traditional ethnographic research were strongly tied with European colonialism, and the aims of producing knowledge about populations that were to be subject to political domination and economic exploitation.

While initiatives to separate the production of knowledge from its practical and theoretical colonial links have gained momentum in the last few years (e.g. Mignolo and Walsh 2018; Meghji 2021), anthropology (and the ethnographic method with it) has seen discussions about the need to decolonise the discipline at a much earlier stage. This does not mean that anthropology (or ethnography) has completed the decolonisation process, but rather that, as a discipline with particularly strong colonial links, it was forced earlier to confront its role within colonialism. The critiques within the discipline started in the 1960s, and found a developed formulation in edited volumes in the 1970s, including Anthropology and the Colonial Encounter (Asad 1973a) and The Politics of Anthropology (Huizer and Mannheim 1979). From the analyses of the time, it is clear that it was the success of the political movements of decolonisation that brought anthropologists to address the colonial links of the discipline. In both volumes the focus was on anti-imperialism and the need to redefine anthropology beyond political neutrality. Asad (1973b) linked the criticism of colonialism specifically to the critique of 'objectivity' and functionalism in anthropology, while Huizer and Mannheim's edited volume (1979) included invitations to direct ethnographic inquiry upwards, although the focus was on financial elites and the funders of ethnographic research (Nash 1979; Mamak 1979). The decolonising turn in anthropology is not, however, the only attempt to review the political and epistemological positions of the social sciences. In the contexts explored in this book, the epistemological innovations introduced by feminism in science are particularly relevant, among these stand out the 'standpoint theory' formulated by Sandra Harding (1992) and Donna Haraway's (1991) concept of 'situated knowledge', developed in reference to Harding.<sup>5</sup> According to Harding, the knowledge of a subject cannot be separated from their position and

knowledge produced by different perspectives (standpoints) enables the production of a more objective knowledge by considering the viewpoints and experiences of groups marginalized in

<sup>&</sup>lt;sup>5</sup> Garland-Thomson (2002) reshapes the standpoint theory trough the concept of 'sit point theory', which considers the possibility of thinking, feeling and analysing the world from a different position, that includes the experiences of disability, as a valid way of understanding reality.

reference to gender, race, and class. This approach includes data and perspectives that are typically excluded from scientific analysis. However, Haraway criticises Harding's approach, arguing that this approach does not eliminate the claim to objectivity, but merely relocates it to a different position. Haraway does not support relativism either, as she believes that it is based on an equally abstract claim to a vision from nowhere. Instead, the theory of situated knowledge is based on the idea that every perspective is partial, fluid, and contradictory. In this sense, simply shifting one's point of view is not enough; what is necessary is to establish connections between different perspectives, each of which is recognised as situated.

The encounter between the reflections on decolonisation and those based on standpoint and situated knowledge theory has resulted in the most common contemporary reflections about power in ethnography. Applying to the typical cases in which the ethnographer is in a position of power and/or prestige in relation to the ethnographees, such reflections highlight the need to put forward the perspectives, voices and interests of the ethnographees and aim to make ethnography a practice that can contribute to emancipation (e.g. Madison 2012; Muhammad et al. 2014; Bhopal and Deuchar 2016).

In the last decades, a series of changes and developments have extended and redefined the remit of ethnographic studies. Firstly, anthropology has widened its areas of activity exploring topics such as science and especially medicine – both of which are well-represented in this book. Asad (1973b) explicitly linked the specialisation of anthropology in new fields to decolonisation and the reduced demand for colonial anthropology.<sup>6</sup> In addition to this, the traditional focus of anthropology on 'remote' and rural populations has been redefined. Books such as *Un ethnologue dans le metro* (Augé 1986) have theorised the role of ethnographic practices in understanding the society close to the ethnographer, an approach that has been developed through the idea of anthropology at home, that is, an anthropological approach that applies

<sup>&</sup>lt;sup>6</sup> It is important to note, however, that the extension of anthropology into other fields does not represent an immediate abandonment of a colonial approach, which often persists in more surreptitious forms. In the case of medical anthropology, for example, the role of the anthropologist in medical contexts has initially been seen as that of a cultural mediator and translator to bring patients from other cultures closer to the most effective biomedical therapies (cf. Baer et al. 2013).

ethnographic tools to geographically and culturally close contexts<sup>7</sup>. Ethnographic methods, however, are not only the prerogative of anthropology, but have spread across most social science disciplines (and beyond). While sociologists have been early adopters, with the Chicago School of Sociology as a point of reference for an ethnographic tradition focused on urban areas and already developed in the early 20<sup>th</sup> Century (cf. Jones 2010), other disciplines such as geography, education or gender studies now also produce a significant volume of quality research based on ethnographies. STS (Science and Technology Studies/Science, Technology and Society) as a discipline has started taking up ethnography early in its development, with a particular focus on laboratories and laboratory studies (but see Hess 2001, who notes that, even in early STS ethnographies, laboratories were not the only object of study). Laboratory ethnographies have been identified as central to build central STS topics such as the practices in building scientific knowledge and the management of scientific controversies (Knorr Cetina 1995; Stephens and Lewis 2017). Among laboratory ethnographies, one of the most influential has been the 1979 book by Bruno Latour and Steve Woolgar, Laboratory life: The social construction of scientific facts, based on two years of observation in a US neuro-endocrinology laboratory. As the title itself illustrates, Latour and Woolgar question scientific objectivity and show how scientific facts are the process of negotiations, collaborations and approximations, as it happens for other aspects of social life. However, another aspect characterised this approach, the fact that the ethnographic attention was directed to a previously poorly explored place:

Whereas we now have fairly detailed knowledge of the myths and circumcision rituals of exotic tribes, we remain relatively ignorant of the details of equivalent activity among tribes of scientists, whose work is commonly heralded as having startling or, at least, extremely significant effects on our civilisation (p. 17)

Over the last forty years, there has been an increase of ethnographic research in the laboratory among scientists, in hospital wards among doctors and nurses and in other areas of society which, to quote Latour and Woolgar, have 'significant effects on our civilization'.

<sup>&</sup>lt;sup>7</sup> For an exhaustive examination of anthropology at home see Peirano 1998.

STEMM disciplines themselves have started to use some ethnographic methods, such as indept interviews. Nursing is a discipline in which an ethnographic approach – ethnonursing – started developing in the 1960s in order to provide 'culturally congruent' care to specific groups of patients (Molloy et al. 2015). Ethnonursing relied on conceptualisations of both ethnography and culture that have since been criticised, but, beyond the specific approach, ethnographic methods are part of the toolkit of nursing research. In addition to this, there are specific traditions such as the dual training in anthropology and medicine (cf. e.g. Holmes 2023) and in particular in anthropology and public health (cf. e.g. McClure and Kuhlmann 2022), not to speak of relatively common career paths in which initial training in STEMM branches off towards social sciences applied to STEMM. However, this wider spreading of ethnographic methods in technical-scientific contexts has not completely eliminated some deep-rooted ideas about scientific practice, as supposedly pure and objective. STEMM disciplines are still seen as capable of producing a more reliable account of a reality that exists independently of the methodological and ideological tools used to research it.

#### 1.1 The benefits and the challenges of studying-up

This extension of the scope of ethnography has undoubtedly changed the practice itself. As a result, what was initially the 'writing of peoples' is now a much more diverse practice, embracing social domains well beyond those initially explored with ethnographic methods. The consequence is that, as long as positionality assumptions continue to reflect the traditional domains of ethnography, there is little systematised understanding of the issues and challenges ethnographers can face nowadays. Some further developments in ethnography are worth discussing briefly here. First, the discursive turn (Clifford and Marcus 1986) has further questioned the objectivity claims of traditional ethnography, calling attention to ethnographic writing and discourse as an integral part of the construction of knowledge. The discursive turn is intimately linked to the transformations brought about by post-modernism. In the field of social sciences, a post-modernist approach has paved the way for redefinitions of the relationship between reality and the tools to describe it. Writing ceases to be a linear and reliable transposition of observation but becomes a practice to be analysed, to be wary of, and to innovate and revitalise. In a word, it is the linearity of ethnographic practice that is

problematised. Another fundamental element that has been redefined since the 2000s is that of 'field' (Faubion and Marcus 2009). Another assumption of traditional ethnography, along with remoteness, was conceiving the field as a delimitated, small-sized and self-contained area typically a village – where the ethnographer could spend some time observing the salient elements of this unusual reality. The innovations of ethnography have changed the nature of fieldwork and introduced multi-sited (Marcus 1995) approaches and cases in which the field cannot be circumscribed at all. The introduction and extension of the Internet have further modified the idea of fieldwork so much so that it has been necessary to introduce the subcategory of digital ethnography, which is focused not on material but on virtual places, including social media. While the initial formulations of digital ethnography have looked at online spaces as constituting a self-contained social dimension, more recent approaches have looked at the continuity between off- and online and the materiality of getting online (e.g. Przybylski 2020), with approaches such as 'hashtag ethnography' (Bonilla and Rosa 2015) looking at the exchanges between social media and wider social events. The fragmentation of the concept of field, the birth of new fields, virtual and material, and the new relationships between digital and material reality make it necessary to rethink ethnographic practice. Typical places of the ethnography of STEMM, such as laboratories or hospitals, multiply the presence of the ethnographers. They are not only physical but also virtual places - e.g. websites and social media accounts - and taking into account the multiple events on real and virtual terrains often includes new skills and new theoretical approaches. Accelerated by the Covid-19 pandemic and the resulting lockdowns, these mutations pose further questions regarding positionality, epistemology and methodology. A very recent development has been the patchwork ethnography approach (Günel et al. 2020). The authors of the manifesto have observed how considering ethnography solely as a long-term, full-time and away-from-home endeavour is not feasible for precarious and disabled ethnographers, nor for ethnographers with care responsibilities. They have therefore observed how much of contemporary observations involves short-term visits or by a combination of 'field time' and 'house time'. This also changes the concept of 'presence on the ground', which now mixes a presence in physical places and virtual forums with repercussions that are mostly unexplored.

While these efforts in discussing the changes in ethnographic practice and offering a deeper analysis of this method have greatly influenced and improved ethnographic approach, there is still the tendency to reproduce some assumptions linked to its colonial past. Among these legacies, there is an interest in social sciences that focus on the experiences of disadvantaged and marginalised social groups. Simultaneously to the decolonisation of anthropology, there have been calls to change the direction in which anthropology orients its eyes and 'studying up'. Laura Nader (1974) was among the first to express the urgency for anthropologists to change their perspective and object of study. She asks: '[w]hat if, in reinventing anthropology, anthropologists were to study the colonisers rather than the colonised, the culture of power rather than the culture of the powerless, the culture of affluence rather than the culture of poverty?' (p. 289).

In the fifty years since Nader wrote this, anthropology and the social sciences have extended their scope of interest to the upper classes with prestige, power and influence. Between the 1980s and 1990s, the French couple of sociologists Michel Pinçon and Monique Pinçon-Charlot were among the first to establish a long-standing project to study the aristocracy and the great bourgeoisie from an ethnographic point of view. They also discussed the methodological and professional difficulties in tackling this object of study (cf. among others Pinçon and Pinçon-Charlot 1997). The couple underlined the difficulties of accessing specific contexts and the fact that the innovative nature of their approach was not always well received by other sociologists. If sociologists who occupy stable professional positions and enjoy a certain notoriety find themselves in difficulty, we can imagine that the situation becomes more complicated for young researchers who are in a more precarious position, both on a professional and personal level.

These difficulties are little explored in manuals and methodology courses, since, as mentioned, most of the political methodology of ethnography is concerned with how to take into account the power advantage that ethnographers have over the people they observe, assuming that the ethnographer is usually in a position of power.

However, studying up opens the way to new and partially unexplored challenges for researchers, for which classical ethnographic approaches have few solutions to offer. Remaining in the French context, Nicolas Jounin (2014) discusses the difficulties of his sociology students from more modest social classes in conducting ethnographic research in an affluent Parisian neighbourhood. Another example is Souleles' (2018) honest recollection of his experience of conducting fieldwork among private equity investors. The researcher states that traditional anthropological methods are 'put on a pedestal' (p. 53) even when they are not

helpful in investigating new contexts and answering new research questions. Furthermore, studying up opens up new difficulties that traditional ethnographic accounts often ignore. These include the risk of micro-aggressions and emotional stress, which frequently result from encounters with members of more prestigious and influential social spheres.

#### 1.2 Asymmetries, Knowledge, and Prestige

Conducting ethnography in scientific and biomedical contexts represents a very specific kind of studying up. It has to do with power, but not necessarily the difference in power that Nader identified when inviting ethnographers to explore the administrations and the companies shaping the US society. This kind of ethnography can include differences of class, but STEMM professionals can also be internally stratified, and not all of them hold higher class positions than the ethnographers. In STEMM fields the ethnographer is confronted with an epistemic asymmetry. STEMM disciplines have claims to the capacity to produce objective knowledge that is often applicable to 'real world' problems and has the potential to benefit society. More importantly, the same disciplines attract substantial social recognition and prestige despite raising worries about anti-scientific attitudes among a part of the population. Ethnography, on the other hand, as the social sciences from which it originates, is characterised by more limited claims to the production of valid knowledge, and, while it can benefit from the general prestige attributed to codified knowledge and to academic positions (when the ethnographer is an academic), it receives less legitimation and prestige from the society as a whole. It might receive even less recognition from people with a STEMM background, given the opposition between the traditional paradigms attributed to 'hard' and 'soft' sciences<sup>8</sup>. In this sense, the discussions about the risks of objectification in ethnography, that is, the risk that the voices of the other participants might disappear in an analysis that only follows the point of view of the ethnographer, apply less when the study is directed towards types of STEMM knowledge characterised by far more developed (and, for most people, more convincing) forms of

 $<sup>^{8}</sup>$  'Hard' and 'soft' are used here between quotation marks, as they suggest a hierarchy between the two groups of disciplines, rather than looking more specifically at their epistemic and social differences – cf. Shapin 2022, and Greco's chapter in this volume.

objectification. Pierce (1995) and Gusterson (1997) have explicitly theorised (and Gusterson has criticised) the use of traditional ethnographic objectification and exoticisation to fill the gap in prestige between ethnographers and specific elites when they are the subject of ethnographic study. While none of the chapters collected in this book have followed this approach, the aim of this book is to bring forward the reflections on the need to account for the power asymmetries that characterise the ethnography of STEMM contexts.

This issue is probably familiar to some degree to most ethnographers who have worked on STEM and/or medical contexts, and appears often in the background of ethnographic publications on these topics. However, there is a lack of systematic and critical work on what conducting ethnography in biomedicine and STEM entails. The ethnographic study of STEMM contexts was already well-established in the 1970s, but, as mentioned, the transformations in ethnography that developed in general anthropology mostly assumed that ethnographers held more prestige than ethnographies. This assumption delayed the introduction of new approaches mindful of power relations to the ethnography of STEM and biomedicine. Despite the wealth of ethnographic studies that have since developed on STEMM contexts, systematic analyses of the specific challenges of doing ethnography in these areas have been relatively rare and often confined to the methods sections of books and articles of ethnographers working on the sectors (e.g. Gusterson 1997; Williams 2018). In STS in particular, after early reflections on the impossibility of remaining neutral in the study of scientific controversies (Scott et al. 1990), examinations of the changing nature of ethnography have been linked to the expansion of online ethnography (Beaulieu 2010; Beaulieu and Estalella 2012). Reflections on the power asymmetries between social scientists and STEM researchers have emerged particularly in reference to a series of interdisciplinary collaborations marked by challenges (Rabinow and Stavrianakis 2013; Viseu 2014; Stavrianakis 2015; Leighton and Roberts 2020). The point is not that collaborations between ethnographers and STEMM are necessarily challenging - the two chapters focused on collaboration in this book (by Monteiro and colleagues, and by Aparicio de Narváez) discuss ways of working together that were mostly successful. Rather, such collaborations represent a moment that can highlight the asymmetries characterising encounters between different disciplines. An issue frequently mentioned in previous literature on challenging collaborations is that social scientists are called to fulfil essential but limited roles, such as advising on the ethics or providing a translation of the findings for the lay public. This contrasts with the social scientists' vocation to discuss the wider social process of production of knowledge, from which they are often excluded either because they are not considered legitimated to discuss such aspects, or because they would be legitimated only by adhering fully to STEMM norms. In this book, we aim to discuss how such assumptions about the capacity to produce knowledge apply to formalised collaborations, but also to a wider range of encounters between ethnographers and STEMM.

The difficulties of studying up and collaborating in STEMM and biomedical contexts may emerge with force when researchers need to negotiate access to the fieldwork. How can we justify the presence of an ethnographer in a hospital ward, in a laboratory or another place of this kind? How can we explain the subject of our research and methodology to scientists who may not be familiar with the methods and findings of the social sciences? The desire to study a medical topic from a social perspective can arouse amazement in medical personnel, whose agreement is necessary to access the field (cf. Derbez 2010). The analysis of these difficulties is often under-explored in the methodological chapters of published ethnographies. On the other hand, discussions about the same difficulties often enliven conversations on the sidelines of seminars and conferences. These discussions may also have a more central role in the debate among social scientists, with a growing number of panels and workshops addressing this topic (cf. Prainsack et al. 2010). These discussions are essential and welcome and can be of help, especially to early career researchers and PhD students, who can benefit from advice and ideas that can facilitate access and contacts. Accessing the field, however, is a pragmatic, a methodological, as well as a theoretic aspect of the ethnographic work. The places that can be accessed, along with those restricted are integral to ethnographic results and shape the kind of knowledge produced. Power relations, a theme central to this book, also influence this access. By focusing on the ethnography of STEMM, we intend to show the different ways in which relations of power can influence the production of knowledge – firstly, disparities in prestige between ethnography and STEMM disciplines, but also differences of power within the STEMM field. These include asymmetries along West/non-West and North/South axis, and asymmetries linked to gender, class, race/ethnicity, age etc. Studying such asymmetries in STEM and biomedicine goes beyond the simpler assumption of ethnographers representing the powerful side because of prestige, disciplinary role, and often geographic background, class and ethnicity. It further allows us to systematise the debates around the need to recognise gender, race, nationality, seniority, and other asymmetries of power within STEM, biomedicine and the social study of such fields.

This book collects critical examinations of the politics, positionality and epistemological and methodological facets of doing ethnography in a number of locales across the globe and in fields including computer science, astronomy, mining, biology, and medicine.

#### 1.3 The contents of this book

Among white coats is not a handbook. Across the chapters, readers will certainly find practical and methodological-epistemological insights on how to conduct ethnographies in STEMM settings. The book further offers a plurality of points of view across the different contributions in terms of geographic origin, career stage, disciplines and areas of specialisation, and approaches to specific aspects of ethnography. However, the primary aim of the book is to discuss more in-depth the politics, positionality and epistemology of doing ethnography in STEMM settings. In *Among white coats* we do not aim to present a systematised and prescriptive set of methodological steps and the experiences of the field. While reading this book can offer helpful insights for social sciences that are about to start their fieldwork, the contributions also illustrate the tensions that can arise when ethnographers work in STEMM sectors and with STEMM scientists, tensions that can be fomented by the different configurations of prestige, epistemological legitimacy and power.

The relation the ethnographer can have with the other actors in the field is one of the *fils rouges* of the book. The initial project was indeed driven by the need to analyse the asymmetry of prestige that ethnographic disciplines and researchers encounter when studying STEMM disciplines, researchers and institutions. However, the contributions collected for this book show further complexities. While most contributions focus on the asymmetries between ethnographers and STEMM, several chapters also discuss how positionality can be a complex and shifting concept. Ludwig's chapter on medicine in prison examines the relations between the ethnographer, the medical personnel, the guards and the detainees. In the chapter on mining in Brazil by Monteiro and colleagues, the ethnographer is located among other STEMM and non-STEMM professionals, local authorities, mining organisations, and the miners themselves. Finally, Pushkar's chapter is written from the point of view of a physician-ethnographer who studied the activism of medical personnel in the British National Healthcare System (NHS). In addition, STEMM professionals obviously hold unequal roles within their institutions and

wider scientific fields and are subject to higher regulation and governmental instances. Moreover gender, age, ethnicity and class further stratify the relations between ethnographers and ethnographees within STEMM professions. Several chapters also present a more finegrained analysis of differences and asymmetries. The geographic origin of the ethnographer and the migration movements that characterise the academic experience of many early career scholars is also present in some of the contributions. Greco discusses her position as a Southern Italian doing fieldwork in the UK and France, and Weidner discusses how her Turkish background was a marker when studying the field of supercomputing. The geographical origin of the ethnographer can also complexify the Global North/Global South and West/the rest divides. Uzelac shows how, as Serbian ethnographer working in a Serbian astronomy institution while affiliated with a Canadian university, she was expected to act as an ambassador for Serbian science in the 'West'. Graber further analyses his experience of studying Cuban biomedical institutions while affiliated with a French institution.

The volume aims to present the variety of experiences of researchers who move among white coats, their difficulties, and the inventiveness and resourcefulness necessary to continue to produce ethnographic knowledge. One of the inspirations for the book title comes from Sylvie Fainzang's (2015) description of her discomfort in wearing a white coat during her fieldwork in a hospital, as this simple garment could alter the nature of her presence (on this, see also Rehsmann in this book). Many of the ethnographies presented here were conducted among white coats, and this title captures the symbolic power of this garment and its ability to modify identities and spaces.

The individual chapters in this book are organised in three sections, which reflect both methodological and practical issues of the ethnographies of STEM and medicine, and epistemological and political questions linked to such ethnographies. The volume captures a wide breadth of ethnographic case studies conducted by scholars at different stages of their careers, with a variety of geographical backgrounds, and working across different settings and regions of the world, demonstrating the unfoldment of overlapping concerns in unique ways. *Among white coats* is a systematic and critical examination on the politics and epistemology of doing ethnography in biomedicine and STEM, adding to the extensive production of studies based on the ethnography of medicine and ethnography of science, as well to the ongoing debate on the foundation of ethnography. The volume is geared towards academics and research

students from different disciplinary backgrounds. The volume enriches previous analyses of how ethnographers should reflect on their positionalities in their research and writing, and in this sense it offers a reflexive guide to think through the political and practical aspects of ethnographic practice.

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The first section, 'Positionalities', explores different issues about the role the ethnographers can take in a STEMM field. This includes obviously the profile of a social scientist, more or less knowledgeable about and more or less outsider to the studied discipline. But it further involves the social positionality brought by the ethnicity, background, gender and class of the ethnographer. Moreover, the different actors in the field have their own positionalities, and ethnographers need to locate themselves both in relation to the field itself and in relation to the different actors they encounter. This includes the complexity of doing research from and/or on 'Global North' or the 'Western world' (cf. Williams 2018) and the complexity of what it means being a 'native' or 'non-native' ethnographer, for example when a 'non-Western' ethnographer does 'ethnography at home' while working for a 'Western' university. Further, the section explores the complexity of analysing and using biomedical knowledge from the standpoint of the ethnographer, and on the multiple duties of doing ethnography in contexts of domination. Uzun Weidner's chapter explores the transnational profile of both STEM professionals and the ethnographer herself in a study of supercomputer research. With a disciplinary field that is concentrated in the Global North but diverse in terms of geographic origins of the actors, Uzun Weidner analyses the positionalities deriving from this situation, and how these intersected her own positionality as a woman from the Global South, affiliated with a Global North university. Pushkar's chapter on the other hand discusses the positionalities deriving from a dual role. Being both an anthropologist and a physician, Pushkar found himself as a 'double native' (not

only working close to home, but also within his own field of employment) by doing research in the NHS. Along with the complexity of understanding and disentangling such positionalities, his chapter addresses specifically the political questions of studying a sector under attack, mediating between the political ideals brought by the ethnographer and those held by the ethnographees. If Pushkar's chapter looks at the positionality of the dual role, **Greco**'s chapter is a study of the positionality of a non-physician anthropologist studying the biomedical field across the UK, France and Italy. Greco's chapter is an analysis of the dilemma between acquiring the knowledge and the point of view of the field, and keeping the critical point of view of the external social scientist. Further, her chapter looks at how such dilemma can vary in different national contexts, interacting with the ethnographer's own background. Mirjana **Uzelac** explores again the geographic complexity of positionality in her ethnography of astronomy. Serbian-born and affiliated with a Canadian university, Uzelac studied a Serbian astronomy institution. In the chapter she shows how she was both 'at home', and called by the local actors to represent Serbian science in the 'Western' context she is affiliated with.

The second section of the volume, 'Collaborations', examines the complexity of collaborations between ethnographers and STEMM disciplines. The section problematises ostensibly fixed and hierarchical disciplinary categories, attending to ideas around the co-production of research agenda and rethinking disciplinary boundaries (cf. Viseu 2014; Leighton and Roberts 2020). The section examines how such collaborations require not only complex translation from one discipline to another, but also the need to learn to observe processes that are not obvious even when one is physically present. Further, the contributions to the section explore the conflicts that emerge around the legitimacy and the roles of the ethnographers and of the other actors, the boundaries of each actor's competence, and the ownership of the knowledge produced. Monteiro and colleagues offer a reflection on how interdisciplinary collaborations are positioned in relation to other actors. Reflecting on a multidisciplinary workshop project on mining in Brazil, they discuss not only the interactions between social and STEM disciplines, but also how in an applied context these relate to different stakeholders in the mining sector strictly speaking. Through these reflections they suggest a potential to redefine the concept of co-production. The chapter of Alberto Aparicio de Narváez looks at a linked issue: how ethnographers can find place in collaborations within the framework of social responsibility. Starting from his ethnography of a xenobiology group, he discusses the spaces and the limits that such collaborations entail for ethnographers, as often diverging ideas about social relevance, about the social more largely, and its role in STEM, come into relation.

The third section '*Domination and access to the field*' is occupied with themes of access to highly securitised places and the production of subjectivities including that of the ethnographer in the field. The contributions explore both the issues of accessing fields that are secretive or accessible only through agreements that limit the use of the data produced, and the ways in which knowledge is hidden and dissimulated in biomedicine and STEM. Further, the

contributions discuss the decisions that ethnographers need to take in relation to their standpoint and identity, particularly in reference to the different prestige of the disciplines involved, but also in contexts characterised for example by medical authority, or when dealing with prisons. The first chapter of the section, by Ariel Ludwig, shows the triangulations of the positionality of the ethnographer by analysing her ethnography of medicine in prison. She explores the loyalty dilemmas of working with health professionals in the coercive context of imprisonment, and being in a position of power towards the prisoners but subordination in relation to the medical professionals and corrections staff, and analyses further a context in which not only the initial access but the continued work is subject to the conditions of the institution. Violeta Argudo-Portal discusses another kind of high-security field, analysing her ethnography of biobanks. Looking at the often unwritten parts of ethnographic experience, she discusses the multiple negotiations to access sites (and to present data when confidentiality agreement are involved) and how the positionality of the ethnographer continuously influences the kind of position available and negotiable within the field. Julia **Rehsmann** approaches the issue of access through the prism of expertise. She compares her two ethnographic studies of transplant medicine and palliative care to highlight both different positionalities she took (clearly distinct from the medical personnel in the first case, more participant in the second) and how this further relates to varieties of expertise among the medical professionals themselves, with the distinction between specialist and inter-disciplinary knowledge. The last chapter of the book, by Nils Graber, returns to questions of geography and explicit politics with an analysis of his ethnography of biotechnology and biomedicine in Cuba. His chapter discusses both the political stakes of a sector that is a national priority, and the differential access offered by medical diplomacy and by engagement with everyday biomedicine.

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**Part I: Positionalities** 

### Positionality in STEM Ethnographies: "Where are you Really From?"

Nil Uzun Weidner<sup>1</sup>

#### **2.1 Introduction**

I was going to be a "sociologist of science and technology:" Geographically unmarked, a knowledge worker of a global sort, making universal theoretical claims about technoscientific fields. Early in my academic career, after years of working within and on Middle East studies, I was advised halfway into my Ph.D. to become a sociologist of "something," like sports, medicine, or science. As someone outside of Euro-American circles, being without any specific geographical preoccupations was not necessarily considered the ideologically right thing to do but a professionally strategic one. Doing so would increase my chances of getting a job in Europe or North America instead of navigating the job market as an "area" expert, a native insider frequently invited to inform and *lecture* about where I am from but expected never to overstay her welcome. I had not thought about that advice until I ended up researching the fastest computers and the geopolitics around them for my doctoral dissertation. In addition to supercomputing being a fascinating and timely topic, I was also intrigued by the promises of a global field, not having to put the location of my research on the titles of publications, not enacting any spatial markers of my identity, and not working as a native insider of a specific locality. After years of work on the politics of scholarly knowledge production in area studies, not having geographical referents but only disclaimers in my work would be a scholarly mobility move for me from the periphery to the center, according to that reasoning. My impression from rigorously reading the methodological discussions within STS was that I

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would be primarily preoccupied with aspects of my identity other than location, mainly being a social scientist outsider and a woman in a male-dominated STEM field. This was the idea in 2016 before officially beginning my fieldwork on the global competition for the fastest computers until I realized that I, and many of my interlocutors, never had the privilege to leave behind where we are (really) from.

The fastest computers today are known as supercomputers. There is no one clearly set definition of what a supercomputer is, but it is the speed that makes them super. Speed is equal to power for supercomputers, which outperform the storage capacity and processing speed of personal computers by multiple orders of magnitude. They are compared to football fields in size and described as the world's most powerful and fastest computers at any given time. Twice a year, a list known as the "Top500" ranks the world's fastest 500 supercomputers and the nation-states in which they operate (https://www.top500.org/). Initially funded and developed for military interests, supercomputers are designed, built, and operated for large-scale simulations and the analysis of complex systems. They are a crucial element of scientific computing, from medical imaging, genome sequencing, and molecular dynamics to nuclear weapons research, climate modeling, and astrophysical simulations. For the geopolitical prestige and power supercomputers symbolize, governments invest hundreds of millions of dollars in supercomputing research every year, and the leading universities and research centers building and hosting these machines compete fiercely for a position on the Top500 list. In addition to their role in nuclear weaponry and data processing, the competitive logic of the Top500 organizes the global political relations around supercomputing, which brings forth military and national security-related issues, dual-use concerns, export control regulations, and broader geopolitical power dynamics regarding this technoscientific field. Given this setup, multiple intersecting positionalities of ethnographic researchers, scientists<sup>2</sup>, and engineers working in this field, mainly where they are *from*, become more difficult to ignore empirically and methodologically.

<sup>&</sup>lt;sup>2</sup> In this chapter, I use the terms "researcher" to refer to the ethnographer studying technoscientific fields and "scientist" to the actors within those fields who have been my interlocutors. While many different actors within these fields can also take multiple roles, such as policymakers, politicians, administrators, industry representatives, etc., this chapter focuses on the encounters of the ones with explicit scientific functions.

Positionality in qualitative research refers to the premise that all knowledge is situated, that is, "all knowledge is produced in specific circumstances and that those circumstances shape it in some way" (Rose 1997, p. 305). To unravel the partiality of the knowledge produced, it is crucial to take the different positions of the researcher into account in terms of where she is situated within the multiple, intersecting, and complex social and historical relations of power (Collins 2015). These biographical and historical positions of the researcher directly impact the research process, for example, by granting particular insights to some groups of researchers easier than others and by mediating the response of the ones being researched through the presence of the researcher (England 1994, p. 248). In that sense, the idea of positionality addresses the role of the multiple, intersecting social positions of the researcher and the researched, such as race, ethnicity, religion, gender, sexual orientation, and class, on the research processes and scholarly knowledge production.

In the context of STS, positionality, as an extension of reflexivity, that is to reflect and inquire into the conditions and multiple positions of the inquiry (Ashmore 2015), has occupied a relatively central place, particularly around the idea of social constructedness of (scientific) knowledge. In many cases, these methodological discussions expand on the role of multiple perspectives of the research subjects in technoscientific research processes, as well as the assumable universality of scientific knowledge they produce (Law 2004). For example, questioning the idea of objective scientific truth as a direct representation of reality out there, seminal works in STS have directed our attention to practices and relations through and within which scientific knowledge (and to some extent objectivity) is embodied, produced, mediated, claimed, and enacted by multiplicities of human and nonhuman actors (Haraway 1988; Harding 1986; Latour 1987; Mole 2001). However, there have not been substantial critical discussions about who the researchers and the scientists they study are and how we can methodologically navigate the encounters among them and theoretically make sense of the historical global inequalities that undergird their positionalities.

In this chapter, I make a case for attending such positionalities within a global context to bring depth to the ethnographic analysis of technoscientific fields. I argue that paying attention to the historical power dynamics of (global) positionalities of the actors within technoscientific fields,

as well as the researchers studying them, and how they understand, navigate with, negotiate, or disregard their situatedness, reveal additional empirical dimensions and complicate the understanding and strategies of "studying down, up, sideways, and through" (Williams 2018, p. 201). To do that, I reflect on my multi-sited ethnographic fieldwork (Marcus 1995, 1998) of global connections (Burawoy et al. 2000; Tsing 2005) within supercomputing as a global technoscientific field and my experience as a female sociologist from the Global South affiliated with an institute in the US, studying a male-dominated field and casting my ethnographic gaze upon the Global North. I discuss the role of the (global) positionality of researchers and scientists through three different kinds of encounters with the question of "Where are you from?" to exemplify the different ways within which where one is from impacts the research process.

#### 2.2 Positionality: Global, local, unequal

More than half of the doctoral degrees in computer sciences are awarded to "foreign-born" individuals in the US, and one-third of the science and engineering workforce in the US and UK are foreign-born researchers (HESA 2021; NCSES 2023; NSB 2020; Royal Society 2016). Yet the works dealing with the global positionalities of both foreign and non-foreign-born scientists are very limited. For example, Pereira (2019) shows a lack of attention to positionality despite the growing attention to social structural inequalities in STS research,<sup>3</sup> especially in "feminist, black, and postcolonial scholarship on science," which affirms that "knowledge producers are inescapably embodied creatures. . . [where] this embodiment makes a difference to how others perceive their epistemic and professional capacity" (p. 339). As a result of the dominant imaginary of the most authoritative knowledge producer as a white, middle-class, Western male, as evidenced in these studies, Pereira argues that the different intersecting axes of a scientist's positionality never take center stage but remain an extra, external, or a specific issue, a spin-off, sub-topic or an add-on, particularly in the context of boundary work, that is the sets of practices and performances marking what is and is not science (pp. 356-357). In addition, the positionality of the Northern/Western/Euro-American

<sup>&</sup>lt;sup>3</sup> See Hess et.al. (2016) for a review of such works.

researcher is rarely discussed within its historical and institutional context in relation to the global hierarchies of technoscientific knowledge production. Rather, the idea of "global positionality" either assumes fully mobile disembodied scientists as universal actors above all spatial concerns or, in more critical accounts, geographical situatedness becomes a relevant factor only in the cases from the global south or elsewhere where they serve as complementaries, coloring and spicing up the implied Euro-American universalities.<sup>4</sup>

Yet, all knowledge, artifacts, and people circulate globally, albeit within a hierarchy. Scientists and ethnographers studying them alike move in between nations and participate in global technoscientific fields. They collaborate and compete with their geographically marked positionalities and sometimes conflicting national and institutional identities. While not all scientists are equally mobile (Appelt et al. 2015), the internationalization of sciences varies across countries (Royal Society 2016), and geopolitics have different degrees of impact on different technoscientific fields, power dynamics in between different global positionalities of the actors still remain an important but understudied topic in STS. There is also a tendency in the ethnographic accounts of scientific fields to stabilize, fix, and take national and geographic categories for granted. Even though the topics of "internationalization of science," "globalization of science," and "scientific mobility" have been widely discussed (e.g., Franzoni et al. 2012), in many cases, scientists are assigned nationality or belonging by institutional affiliation at best (e.g., "German scientists") or assumed to be unmarked white Euro-Americans at worst. Their situated agencies within global hierarchies vanish behind the confines of nationstate-centric approaches, sometimes to the extent that they appear as disembodied knowledge producers synonymous with the nation-states they operate within, representing national institutional cultures. The same assumptions also hold for the ethnographer researchers who study them. Even methodological discussions on "studying up" within technoscientific fields

<sup>&</sup>lt;sup>4</sup> For example, even the review of Hess et al. 2016 of works tackling "structural inequality as global position" begins with "[s]ince 2000 STS research has increasingly paid attention to science, technology, and power on the global south" (p. 330). The primary reflex of thinking about "global" is "global south." There is indeed relatively less attention paid to the cases outside of the Euro-American context in STS. Still, the idea of a global that only concerns the global south is problematic.

predominantly formulate power relations between the ethnographer and the interlocutors regarding disciplinary differences, expertise, or gender relations.

For technoscientific fields like supercomputing, where geopolitics has a central role, actors' perceived and performed race, nationality, or ethnicity and markers of "foreignness" become more prominent and operational in everyday interactions and scientific practices. For example, they conduct research outside their countries of belonging where they might or might not nationally identify with their institutional affiliations. Given the geopolitical context of their fields, they might be considered a "threat" in the public imagination, and their access might be constrained due to propriety or security reasons. In a broader sense, they might be hastily grouped within the historical categories of "others" with accompanying stereotypical assumptions. Different global positions of foreignness intersecting with identity markers, such as race, sex, gender, ability, and class, affect their scientific activities, career choices, mobility, and affective responses to and broader understanding of the scientific field.

My idea of "global" in what constitutes global positionalities within technoscientific fields is rooted in the way it is formulated in global sociology discussions to describe always-already interconnected, spatially expansive, historically situated social relations (Bhambra 2013; Burawoy 2009; Go and Lawson 2017). These connections and "the things being connected are not 'things' in the sense of essences, but fluid entities constituted by the connections in the first place" (Go 2016, p. 118). This formulation of "global" does not lend itself to the idea of frictionless globalization of constant flux, movements, and all-encompassing mobilities of peoples and things. Instead, it directs to how connections are historically built and operationalized to constrain and enable the movement of groups of people and material entities and, in return, transform what they connect. While the concept of "transnational" can be understood as "what happens at borders as knowledge moves across them," "global" points to "social interconnections and interdependencies at a scale beyond national borders." (Krige 2022, p. 2 – emphases in original). Therefore, the global positionality of scientists refers to how they are situated within these connections across and beyond nation-states shaped by the power dynamics of colonialism, imperialism, and globalization. Within the global technoscientific fields, movements, circulations, and connections of actors are enabled, fostered, constrained, limited, and prohibited in line with their positionalities. As the notion of "global" encompasses all things being connected no matter how asymmetrical they are, global positionality is not an exclusive feature of the situatedness of anyone associated, one way or another, with a non-Euro-American geographical location. As opposed to the common reflex in STS to summon "global" as a descriptor of "Elsewhere" (Trouillot 2002)<sup>5</sup>, either by adding "alternatives" to the Euro-American empirical cases and concepts or extending them outwards to the "global" ones, the idea of global positionality I use here builds on a relational understanding of subjecthood where the power dynamics within global positionalities reveal themselves through connections or, in more interactional terms, encounters. I trace global positionalities operationalized within asymmetrical interpersonal relations where they can work as the primary marker of one's identity or be rendered invisible. As such, I call for the ethnographic reflexivity of global positionality (and its co-constitutive role in uneven connections) of not only "foreign-born" scientists but also Euro-American scientists and science studies researchers.

This call for reflexivity results from my experience in the field during the initial phase of my research. Since I heard about supercomputers for the first time, the topic has consistently proven to be a fertile, compelling, and highly relevant case for my area of interest in global politics of technoscientific knowledge production. The tight-knit relationship between geopolitical motivations and supercomputers, particularly the military origins of the development of computing technologies, and the increasingly widespread visibility of global technology competitions made it attractive for me to focus on and explore the field. After years of working on the politics of scholarly knowledge production in Middle East area studies, I also considered this as an opportunity to finally be able to work as a geographically unmarked researcher, a sociologist of science, whose work would attract more intellectually deeper engagements in disciplinary discussions, for example during sociology conferences in the US, beyond comments like "that is interesting" or "I did not know that about the Middle East." The gripping geopolitical discussions about the fastest computers in the world that involved export restrictions and espionage accusations and the grandiose media framing of supercomputer speed with powerful imaginaries kept sparking my interest to research supercomputing formally. I was excited about studying the macro-institutional entanglements of global politics

<sup>&</sup>lt;sup>5</sup> See Hofmänner (2020) for a critical discussion of this concept in relation to STS.

and technoscience. This study would hopefully grant me as a geographically unmarked sociologist within the global division of academic knowledge production (Baber 2003).

#### 2.3 "Where are you from?"

During the initial period of my fieldwork, graduate student networks, and friends as gatekeepers allowed me to connect with people I talked to more affectionately and build trust to conduct life story interviews. My subjectivity and positionality were less of an explicit discussion since we already knew each other or connected through common friends within these networks. This introduction to the supercomputing field also afforded me overcoming partially the burdens of "studying up," such as access to interviewees, performing the "knowing expert" subject, or proving myself to the natural scientists as a social scientist. However, these challenges began to appear in my fieldwork after some time, especially when I began more formal expert interviews. They became more pronounced when I reached out to scientists with official administrative roles, where it became almost impossible to get any personal accounts of how these scientists were making sense of political embeddedness beyond the official narratives they embodied. It was during these later stages of my fieldwork, when I extended my networks beyond my personal connections, that I began to observe more the impact of the different ways scientists move with their embodied global positionalities within technoscientific spaces. In that context, I had to reflect on my own ethnographic presence and multi-layered foreignness.

After the initial exploratory phase in the US, which included document collection, site visits, and informal interviews, I officially began my multi-sited fieldwork in early 2018, adding two sites from the UK and Germany and attending international supercomputing conferences in the US and across Europe, two of which the annual Top500 list was announced. International conferences are important sites for ethnographic work to understand a specific profession's complex social organization, practices of knowledge production, and identity formation (Leivestad and Nyqvist 2017). I attended these conferences as a participant observer, engaging with the presenters, asking questions, and having informal discussions with the attendees during the daytime events and additional social excursions.

For one of these conferences, I traveled to Frankfurt, Germany, to attend the International Supercomputing Conference (ISC) High Performance 2018, one of the two leading global supercomputing gatherings where the Top500 list was announced. On the first day of the event, on my way to the conference venue, Frankfurt Messe, the taxi driver, a man in his fifties, looking in the rearview mirror decorated with a blue nazar (evil eye) sticker, asked me, "What it is about this time" referring to the crowd around the convention center, which regularly hosts international trade fairs and congresses. After our brief, casual conversation about the city's traffic during such meetings, he paused for a second and shifted to a more personal gear. "Your German is not bad; where are you coming from," he asked. I told him I traveled from the US, where I have been doing my Ph.D. "But you are not American, are you? Where were you born?" a question I have been asked many times before or in different iterations that reflect different predispositions. I told him I was born and raised in Turkey and moved abroad to study in my early twenties. With a bit of surprise, he responded in Turkish, "You did well; science and education are very important." His "Turkishness" did not surprise me as opposed to his reaction to mine. "Now go there and do us all proud, but never forget where you are from," he sent me off. His emotional remarks would have been just an ordinary encounter for me in Germany since I was often asked similar questions in everyday life. However, I was not expecting to be repeatedly reminded of and forced to come to terms with the role of Turkey in my subjectivity within "global" scientific circles, particularly during the supercomputing conferences and the STS networks in Europe.

On that first day of ISC, I got off the taxi of the Turkish-German driver. I put aside the weight of the responsibility of representing a whole country as an "educated" woman, especially its diaspora in Germany, as much as I could to embark upon my fieldwork. I was excited to do research where I was not a native insider anymore, not geographically marked by the places I study. My research was my rite of passage to become a "sociologist of science and technology," a title devoid of any marks of global positionality that could predispose the reception of my work to the confines of historical spatiotemporal assumptions. At that point, I was planning to socialize with scientists during the session breaks and social events and approach their booths in the exhibition area. But first, I had to get in line to register and get my conference badge that shows my name, the name of my university, and where it is located.

While waiting in line, I ended up talking to a company representative from the US. "University or industry?" he asked. I explained to him that neither, in the sense he was thinking about. I told him that I was a sociologist researching the politics of supercomputing. He asked me where I came from. I relied on the vagueness of his question and his American accent and told him that I actually traveled from the US, where I work. I wanted to keep the focus on him, emphasizing our common denominator of place. He did not take my bait and became even more intrigued to hear about my ethnic origin story. "But where are you from?" he asked. I told him that I was from Turkey, but I had been living in the US for almost ten years by then, insinuating that my Turkishness does not play much into my research, trying to perform my hard-earned status of "just" sociologist of science from nowhere. "Interesting! I have not seen many Turkish people at ISC before," he remarked. Until it was my turn to register and get my badge, our conversation was almost exclusively circled around Turkey and sometimes the broader idea of the Middle East before it was over.

It was not only because "I" was interesting but also because, in a field where geopolitical competition has a significant role, the Orientalist tropes were actively tickling curiosities. The technoscientific resources of the imagined land of Middle East, especially as proxies of military power, were also something the company representative and several others wanted to hear from a first-hand account. For example, on another occasion, a senior engineer from the US whom I approached after his talk started asking me about Turkey and its supercomputing resources. "I did not know Turkey had supercomputers," he said. I told him I knew one but was not very well informed about the government's plans. "Maybe that is why they sent you here," he said with a pesky smile. Whatever aspects of my positionality I strategically presented (a social scientist from a US institution well informed about supercomputing) were dismissed and overshadowed by his image of me, "being sent" to the conference, as a passive, objectified extension of the land, where I was from. These examples were not the only encounters during my fieldwork where Turkey's supercomputing plans, or lack thereof, often got in my way of establishing meaningful connections with people I was not introduced to via my gatekeepers.

#### 2.4 "Where are you really from?"

It is not only the positionality of the researcher that has a significant impact on the ethnographic research. The positionality of the ones being researched, in this case, the scientists in the supercomputing field, also affects the way they navigate their own field of research as well. In several encounters with them, I realized I was not the only one who received questions about where I am from, inquiring into my identity. For example, during a workshop I attended on microaggressions in the scientific workplace organized by the "Women in HPC" group, a software engineer, who is "originally," as she puts it, from a predominantly Muslim country and has been working in the UK for more than ten years, presented her own experiences and observations:

"Where are you from? Where were you born? Where are you really from? Where are you originally from? What is your nationality?" These may sound harmless, but to be honest, it depends on the context of the conversation. Like I attended this conference, someone approached me and asked where I am coming from, and I said I am coming from the UK. The person looked dissatisfied, so another question, "ok, no, where are you originally from." Ok, do you really care, really? Let's talk about something related to the conference. Or "You speak very articulate; your English is really good." I have another one; someone said, "I couldn't guess you are from [her country]." Is this a compliment, or am I too sensitive? Or, like I was talking to a colleague in my own language, someone passed and said, "Oh, you talk faster in your own language." Oh, the other one, I get that a lot, "Why don't you wear a hijab? You are not like other Muslim people". Am I overreacting? You tell me! Another colleague told me, "Oh, I didn't know [her country of origin] had so many women scientists." Another one; there was this NHS staff holding my British passport in her hand. She asked me [talking very slowly and enunciating the words], "What-isyour-nationality?" She was British, so I am not saying she had an accent or anything, but the way she asked me, excuse me, you have my passport in your hand. Another thing I get in the office sometimes: "Oh, please don't do this; it's not the British way." Ok, what's the British way? I still didn't figure out the British way!

Her example has not been the exception, as she also demonstrated in the rest of the workshop with a collection of other narratives of "foreign-born" scientists who were harassed because of their "foreignness" or denied opportunities such as travel visas to attend conferences. These narratives, added to the other accounts I collected, demonstrate how where someone is from impacts not only scientists' daily social interactions but also their scientific practices and how they produce knowledge.

The inquiry of being from "elsewhere" can extend to multiple generations, so much so that non-foreign-born scientists also experience similar issues in the field. One example is from an oral history interview with Cecilia R. Aragon (2021), professor in the Department of Human Centered Design and Engineering, the director of the Human Centered Data Science Lab at the University of Washington in Seattle, US, who published her memoir *Flying Free: My Victory over Fear to Become the First Latina Pilot on the US Aerobatic Team* (2020) among other books in computer science. Aragon recounts writing her memoir:

It turned out that I'd developed terrible fears in childhood that were hindering me in my career in STEM. Actually, I was more afraid of getting a PhD in math or computer science than I was of getting in a small airplane and facing death. How could that be? To understand why, I wrote a memoir called Flying Free: My Victory over Fear to Become the First Latina Pilot on the US Aerobatic Team. This book is about more than flying. It's about overcoming internalized racism and about overcoming terrifying and severe fears of pretty much everything, like a fear of heights, a fear of flying, a fear of speaking in public and so much more. What I learned, which was really interesting, is that many of those fears came from my childhood background and the expectations of teachers. The book details this. Why for a young Latina is it more terrifying to be good at math and science than it is to face death in a small plane?

In the interview, Aragon discusses her life experience impacting her broader career at length, from the encounters in her childhood to the ones in the professional settings. She also gives an example of many incidents "related to being a Latina in a scientific field":

I had an acquaintance who had a Ph.D. in physics, and she worked at a national lab. At one point, I expressed an interest to her in applying to that national lab. At the time, she didn't know my background. She just knew I was a Latina. Her face fell a little and she said, "Well, it's really hard to get a job at this lab." So I said, "I have an undergraduate degree in math from Caltech and a Ph.D. in computer science from Berkeley." I'll never forget how her face changed. I could see that she had a certain impression of me, and it completely changed when she heard about my
degrees. This confirms research about what it means for people of color to have a pedigree, an academic pedigree. If you're a white man, it doesn't really matter what university you get your degree from but, for women or people of color, having degrees in science and math from highly ranked universities improves their career outcomes. It shouldn't be this way, but for me personally, this pedigree was important because it acted as a counterpoint to people's expectations.

Aragon's statements about how she was perceived as not belonging in her field in relation to her "background" demonstrate that scientists navigate technoscientific spaces with their embodied positionalities and situatedness within the intersecting structural inequalities and the positions of privilege. The affective imprints of racist, sexist, and xenophobic encounters in technoscientific fields impact the knowledge they produce and the ways they develop various strategies for accessing resources and negotiating their positions. The citizenship status, ethnicities, passports, and minority/majority positions in a country affect how they engage with scientific practice. But these examples also show the power dynamics within these encounters between the ones who get to question where one is from and decide upon the relevancy of this question. They unravel the obscured hegemonic positionalities of those who are entitled to belong and who are granted the default universal position of a "scientist" pretending to have "no geopolitical determinations" (Spivak 1988, p. 271).

# 2.5 "Almost forgot where you are from"

During ISC 2018 and two other conferences, I carried my participant badge around my neck, clearly stating my institutional affiliation with big letters and making sure people saw it. Yet, my North American university did not shield me from frequently getting asked "where I am really from." My Turkishness took center stage on many occasions, making it difficult to stir the conversation to focus on the interlocutors' experiences. It was about me and *my* relationship with the geopolitics of the field. Being a woman from Turkey, representing a North American institution, and casting my inquiring gaze on the global supercomputing field, a predominantly global northern space, brought significant challenges I was not prepared for during fieldwork. However, the global power dynamics around the inquiry of where I am from did not surface

only as a methodological challenge while researching the supercomputing field. I had to reflect on my origin story, in many cases unexpectedly, within the social scientific field of STS as well.

One such encounter occurred at the beginning of 2019 while attending an academic workshop in Germany to present my research findings right after completing the fieldwork. The workshop, which was in English, was organized by a well-known institution for PhD students who work within an STS perspective. The participants were from universities in Germany and several other northern European institutions. The call for the workshop, the program, and the presentations were mostly about technologies in general, referencing them from a broader, almost universalizing perspective. The arguments, the implied assumptions, and the discussion points were evolving around the all-encompassing notions of digitalization, data, or technology without any historical concerns. If any geographical markers were mentioned, they were either presented as disclaimers or to fulfill the requirements of ethnographic etiquette.

During one of the social gatherings, after two days of getting to know one another and intensely discussing our research topics, we walked past a Turkish restaurant where I commented on the menu. A participant from Germany, who I happened to be walking next to, turned to me and, with a slight surprise on his face, told me, "You are from Turkey! I almost forgot that!" I wanted to dig deeper into his surprise that I was from Turkey and that he almost forgot it. He eventually told us that many people he knew from Turkey or people with similar "*Migrationshintergrund* [immigration background]" at the universities were actually studying migration or integration in Germany: "but I have not seen that many in STS circles," he explained while others were nodding in agreement.<sup>6</sup> It was still unclear what made him forget where I was from, but it was telling that within that crowd, it seemed like only my national identity marker was a matter of active remembering and forgetting (even though I was not the

<sup>&</sup>lt;sup>6</sup> His and also others' subjective experiences reflect what anti-colonial scholars have long been addressing as the uneven material and epistemological conditions of the global division of scholarly labor. One of the main discussions is about how the empirical materials are provided from the peripheries with which theories and concepts are produced at the centers and exported back to the peripheries as universal knowledge (e.g. Hountondji 1990; Zeleza 2006).

only "foreign-born" researcher in that context). As this example makes it clear, it is not only about the impact of where one is from and other markers of difference on the ethnographic and scientific knowledge produced but also who has the power to decide, bring up, or be able to forget about who belongs where and whose "origin" story is deemed relevant or irrelevant. It is about the power dynamics through which identity markers are rendered visible and invisible.

#### **2.6 Conclusion**

Critical ethnographic discussions point to the contextuality, fluidity, and dynamic relationality of one's positionality regarding how researchers perform different, multiple identity markers in different contexts and how positionality is more than a static list of identity markers (Folkes 2022). Researchers take up different roles in different circumstances where they perform and bring forth various aspects of their subjecthood. Some parts of their identities might become relevant in one context, for example, to gain access to research sites and interlocutors, while in another one, the exact identity markers might hinder meaningful outcomes. Methodological discussions offer performative strategies to capitalize on different aspects of positionalities or preventative measures to keep them hidden. They suggest drawing on researchers' visible and invisible ethnographic toolkits (Reyes 2020), given the dynamic contexts in which positionalities are co-constituted with research participants. In this chapter, I demonstrated the power dynamics within these co-constitutive processes in STEM ethnographies by focusing on the making and marking one aspect of researcher and scientist positionalities. I discussed three different types of encounters with the question of "Where are you from?" to address which bodies and scholarly works are localized and spatially marked and which bear the universalist undertones.

One can think of these encounters I discussed as anecdotal cases or just interpersonal curiosities inquiring into one's identity and where they are from. However, many accounts show that this particular question works as more than a naïve curiosity. In most of the situations it surfaces, this inquiry into origin is among the "subtle rhetorical reminders" of out-of-group status (Park 2013), where it operates as part of "foreign-othering" practices, which might even impact academic career decisions (Laufer and Gorup 2019). As sociolinguists argue, this question

"functions as a boundary practice of ritualized othering in everyday interactions" (Bolonyai 2018, p. 271), especially in the context of belonging. Critical race theorists also point at the function of such questioning as "the epistemic violence that irreducibly operates in visual othering" and constructing foreignness in contrast to racializing Europeanness as white (Yue 2000, pp. 177-178). Therefore, it is crucial to consider what it means for researchers studying STEM fields to encounter such questions within those fields and in STS circles as well. The examples I provided here point to the power dynamics within scholarly fields that cannot be explained solely by focusing on interpersonal hierarchies in social interactions. While a proposition of an encompassing methodological framework to overcome the challenges of ethnographic belonging and foreignness in STEM fields is outside the scope of this chapter, one particularly critical insight might be a good place to start thinking about it that neither localities nor subjects and their "foreign others" are ontologically fixed entities, but historically and politically constituted. We need to be wary of who "can operate simply as an individual unencumbered by different elements of 'othering'" and "who cannot, for which it is crucial to keep in mind, not just in STS, that "colonialism and coloniality are still among us" (Prasad 2022).

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# Ethnographers and subjectivity; doctors and comradely critique

Piyush Pushkar<sup>15</sup>

Anthropological and STS scholarship often involves doing research with experts, whether they are recognised as authoritative (such as doctors and scientists) or not (patients and experts-by-experience). Maintaining independent theoretical analyses can present difficulties in these fields, since such experts develop their own analyses, often even using the same words and concepts as social scientists (Mosse 2006). In the relational, embedded work of participant-observation, how can the ethnographer maintain her own authorial voice while remaining faithful to her interlocutors?

In this paper, I review the different techniques that scholars have used to tackle the problem of doing rigorous research that maintains both independence of the scholarly analysis, and also faith to the experiences of research participants. Such strategies have included allowing people to tell their own life story (Nash 1979, 1992), replacing a critical attitude with a reparative one (Fitzgerald 2017), co-opting interlocutors as co-theorists (Miyazaki 2013), and "unwinding" (Riles 2004, p. 394) knowledge practices to reveal occluded blind spots. I argue that all of these strategies share a common theme: using the ethnographer's own subjectivity as a research tool. Although some of the strategies I describe preceded STS and anthropology's now well established interest in entanglement (Barad 2007), they all recognise the complex and relational nature of subjectivity, as well as the way the ethnographer changes during fieldwork. These changes are not just a matter of recorded observations, but actually something more visceral that changes the ethnographer herself. Reflexive recognition of the changes in one's own subjectivity are a useful means of accessing and understanding the communities the ethnographer is observing.

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To elaborate my argument, I briefly recount two vignettes from my own fieldwork with political activists campaigning against cuts and privatisation in the NHS, the UK's public healthcare system. Both stories highlight how reflexive insight regarding the relationship between my positionality, my affect, and my behaviour led to important analytical breakthroughs with my interlocutors, particularly with regard to their own understandings of socialism and political alliances. Mosse (2006) argues that the reflexive labour of ethnographic analysis requires a demarcation of relational space between the ethnographer and the people she is doing research with. He calls this conscious distancing "ethnographic exit" (2006, p. 946). I ask whether and how ethnographic exit was ever possible for me, a triple insider: British, a doctor, and a healthcare activist. For me, what was at stake with any attempt at ethnographic exit was actually one of the subjects of my research: solidarity. Consideration of the costs and benefits of ethnographic exit led me to further reflection on what – and whom – exactly my ethnography was for.

#### 3.1 Subjectivity as ethnographic tool

In this section, I outline two of the strategies anthropologists have used to separate their own analyses from their interlocutors', while maintaining fidelity to them and their experiences. From 1971 onwards, June Nash (1979, 1992) made multiple trips from her academic bases in the USA to Bolivian tin mines, working with a miner and workplace organiser there called Juan Rojas, as well as his family and fellow workers. Her approach was to prioritise their own voices within her work. Her first ethnography from Bolivia, *We Eat the Mines and the Mines Eat Us* (1979), includes long quotations from labourers recounting their own life stories and the history of the mines. Her biography of Juan Rojas, *I Spent my Life in the Mines* (1992), is written almost entirely in the first person, although the narrator of some chapters is a family member, rather than Rojas himself.

The context for Nash's concern with prioritising the voices of the people she studied was one in which anthropology was undergoing a postcolonial reckoning, in which anthropologists such as Diane Lewis were advocating "insider" anthropology (Lewis 1973, p. 586). By this, Lewis meant to refer to the study of people from a particular ethnic or social group by scholars who were members of that same group. She described how the European/American anthropologist studying colonised peoples did not only support and consolidate the colonial power relations that were the research's conditions of possibility. The consciously chosen – where the choice

being referred to was to study people whom the ethnographer considered to be different from themselves - outsider position did not confer the objectivity that researchers assumed. Such claims to objectivity were an epistemological relic of colonial power. Instead, such an outsider position was one position among many, with its advantages and its drawbacks. She felt that the insider anthropologist's voice would be valuable insofar as it had been hitherto silenced or ignored. The exclusion from the academy of these peoples was both a symptom of and a perpetuating factor in their ongoing domination.

She argued that insider anthropology would be more likely (although not guaranteed) to be an activist anthropology that might come closer to meeting the needs of studied peoples rather than the professional interests of academia generally or scholars in particular. Part of the reason that the insider researcher would be more likely to produce activist scholarship of greater use to the people being researched was "because of the greater pressures for accountability that can be brought by a group on one of its own" (Lewis 1973, p. 589). Lewis considered the ongoing relational ties that would mould the ethnographer's questions, analysis and representations to be generative and useful for the production of more impactful scholarly work.

Nash was not an insider; she was not a Bolivian miner. However, she did take anthropology's postcolonial reckoning seriously. Her approach of allowing Rojas and his family to speak for themselves was consciously reparative. She sought to allow previously silenced voices to speak for themselves. And the solidarity that she felt with these families was evident. However, at no point did she consider herself one of them. She recognised that her versions of Rojas and his family's narratives were still, in essence, works of interpretation that required translation, analysis and consideration of how to (re)present her research. Ultimately, the books she wrote were hers, based on research that she did. Her choice to present their voices as first person narratives was not *just* politically reparative. It was an ethnographic analytical choice.

The Introduction to *I Spent my Life in the Mines* describes the research process and Nash's own involvement, as well as acknowledging the multiple translators involved in the work. Each chapter also includes a summary and introduction that is written by Nash herself. Importantly for the argument of this chapter, Nash's chapter introductions discuss her own emotional reactions to the stories that Rojas and his family tell her, and how they changed over time. Her commitment to supporting the workers in their struggle to improve their working conditions and their lives is never in question, and does not change. It is this commitment to their political struggle that leads her to feel frustration and confusion at times. She describes a moment of seeming potential disaster in 1985. Politically, Rojas and his family were worried about a coup by military leader Hugo Banzer if he did not win the upcoming elections. A coup would bring

fears of reprisals against family members for their political activism. Personally, within the family, there were other concerns. One person was already in jail, another was facing a potential jail term, another had deserted the army, Rojas himself had had a recent stroke. In the context of all these qualms, Nash was bemused by the family's meticulous and enthusiastic preparation for the saints' day celebration. When they pulled down an internal wall to make space for the party she describes her ethnographic puzzlement:

Suddenly all my years of practiced cultural relativity fell away, and I felt completely at a loss as to how to deal with their behavior. How could they think about having a fiesta with all these impending disasters? I left for La Paz and then returned to my own home a week short of my planned stay. I realized at an ethnographic level that having the celebration was precisely the thing that made it possible for them to survive the crises they faced every day. Celebrations give meaning and purpose to lives that are subject to threatening circumstances. I knew this, but still I felt the limitations that my own cultural outlook, which strives for order and security, had imbued in me (Nash 1992, p. 15).

It was reflection on her own emotional reaction and its basis in her social background that underlay her analysis. The book allows the reader to more fully understand the meaning and purpose of these celebrations within their lives, and to other contradictions Rojas and his family experience and make sense of. Thus Nash paints a picture of their class consciousness that derives from their own apprehensions of the dynamics of power and their place in it, rather than using the abstractions of social theory as a starting point. It is reflection on her own reactions – how the field changed her - that led her to the importance of the first person narratives in the elaboration of her argument. At the same time, she separated her own voice from theirs with careful use of explanatory notes.

More recently, Latour's *We Have Never Been Modern* (1993) gave a path-breaking analysis that led to a re-evaluation of (especially European and American) science's self-conception, as well as contributing to the development of STS. But in 2004, he famously issued a qualified renunciation of STS's predominant mode of analysis, *critique*. He styled STS's approach to critique, particularly of scientific experts, as a kind of "debunking" (2004, p. 232). Latour's initial aim had been "to emancipate the public from prematurely naturalized objectified facts" (2004, p. 227). But he perceived that contemporary (postmodern) scholarship was denaturalising *everything*, including facticity itself. At the same time, the will to debunk was not sufficiently appreciating which items of study were recognised as facts by scientists themselves,

and which were recognised as difficult points of study that required detailed attention and complex reflection. That is, STS was denaturalising objects that had not yet been naturalised. Moreover, Latour felt that the fanfare associated with such over-zealous debunking was contributing to a widespread lack of faith in science and the proliferation of conspiracy theories. To reorient scholarship away from such debunking of naturalised facts, he suggested that social scientists focused on what they shared with physical scientists: matters of concern rather than matters of fact. From this starting point, social scientists could build an understanding built less on "gotcha" moments and more on nuanced understanding of what exactly physical scientists were up to.

Latour's argument has itself been critiqued, but the paper has been deeply influential. If STS might now characterise itself as "postcritical"(Fitzgerald 2017, p. 183), such an adjective refers to scholars' recognition of scientists' negotiation with and engagement of quandaries in their quests for truth. (However, a cursory glance at the submissions to any academic conference will confirm that the *post*critical attitude is far from universal in sociology and social anthropology.) To facilitate such openness to scientists' uncertainties and ambiguities, Fitzgerald has followed what he calls a "reparative" (2017, p. 17) approach to his study of neuroscientists investigating autism, inspired by Eve Kosofsky Sedgwick (2003). Following Heather Love's (2010) reading of Eve Kosofsky Sedgwick (2003), Fitzgerald's approach to his field is not one of paranoid, hypervigilant debunking, but one of attentiveness, noticing and "being affected" (Love, quoted by Fitzgerald 2017, p. 17).

Importantly, he was led to the reparative approach by his empirical findings. He writes that he came to his project with a naïve hypothesis that his interlocutors would be following a narrowly scientistic approach, consumed by their own hubris and certainty. He admits to even hoping that he, with the help of the "epistemic murk" (2017, p. 9) of the complexities of autism and the components of its diagnosis, would be able to pull the rug out from under scientists' feet and show them up in some way. Instead,

Where I expected simplification, I found complexity; where I expected certainty, I found only ambiguity; where I expected arrogance, I found self-effacement and awkwardness; where I expected optimism and expectation, I found anxiety about the future; where I expected unbending scientism, I found affectively weighted ways of understanding, narrating, and thinking through scientific practice. Most important: where I expected a kind of committedly reductive organic materialism, I found a group of neuroscientists who were intensely aware (far more than I ever was) of the capacious thing they were dealing with, and who were profoundly open to figuring out a mode of scientific practice and experimentation that would remain alive to that complexity (Fitzgerald 2017, p. 17).

Thus he builds a complex argument in which neither he nor the scientists are able to fix down exactly what autism *is*. Instead, he, like the neuroscientists, *traces* autism. Fitzgerald draws on the verb, 'to trace', and the noun, 'a trace'. The verb suggests following, observing and recreating, while the noun suggests the remains of something that is still there, in this case, the ambiguities of an ongoing scientific project. What is important for this chapter is to note not just how Fitzgerald built his argument on his observations of the neuroscientists, but also on his reflections on how they changed him. It is the traces of his own desire to debunk that invigorate his findings, while also shedding light on his authorial independence.

It is this focus on how the subjectivity of the researcher has changed that both Nash and Fitzgerald share. They demonstrate how a key task of fieldwork is to understand how one's own subjectivity can be used as a research tool. Although Nash preceded STS and anthropology's interest in entanglement (e.g. Barad 2007; Tsing 2021), both Nash's and Fitzgerald's approaches demonstrate a keen appreciation of how subjectivities are entangled. It is this entanglement that makes the self such a useful tool in the relational process of fieldwork. Spending time with others changes the fieldworker, and she must remain attentive to the nature of that change, because it reflects not just on who she is or was, but also on the persons and things that changed her. *I have changed because you have changed me*. Therefore I must document how I have changed, to understand how you have changed me, how our interactions have changed us and the world around us.

Such consideration of the way one's subjectivity is changing requires time and space. David Mosse has argued that this space must be consciously demarcated in a process he calls "ethnographic exit" (2006, p. 46). Following years of ethnographic fieldwork on a development project in western India, in which he was himself participating as a development professional, he published a book based some of this work (Mosse 2004). His colleagues did not appreciate the content of his insights. Moreover, they did not just convey their lack of appreciation through debate and dialogue. He was an insider in the development field. Therefore, he had various ties with the people who took issue with the book: relational, ethical, professional. They used all of these ties; they pulled on all the strings they had available to attempt to block the publication of his book. They accused him of being unprofessional and raised official complaints, including directly to his employer, the university. Mosse takes note of the threat to ethnographic knowledge production when interlocutors "attempt to unpack our 'evidence' back into our relationships with them" (2006, p. 64). This is a problem of contemporary fieldwork, in which the researcher – particularly the insider researcher - remains connected to her interlocutors even after the nominal period of fieldwork has ended. The Trobriand Islanders had no means of remonstrance with Malinowski after he had returned to LSE, but Mosse's colleagues could easily communicate with him, his publishers and his employers. Mosse argues that the separation between field and writing desk is a useful, even fundamental one, for ethnographic analysis. Thus he argues that the contemporary ethnographer must find some way to artificially create ethnographic exit, to consciously, at least partially and temporarily, find some way to cut those ties with one's interlocutors. Effectively, he describes relational distance as a crucial component of social analysis.

Clearly, this technique has been fruitful for him. Mosse has published some of the most brilliant anthropological work of the past decades. But what if the kind of ethnographic insight he describes is not possible for an ethnographer more totally ensconced in her field? Or what if she does not *want* to distance herself from her interlocutors? What is at stake in consciously constructing an ethnographic exit? This is the question I wish to hold in mind while recounting two vignettes from my own field. In 2017 I began 13 months of ethnographic fieldwork with political activists in Greater Manchester, campaigning against cuts and privatisation in the National Health Service (NHS), England's public healthcare system (see also Pushkar 2019, 2023; Pushkar and Tomkow 2020). I also interviewed managers and politicians involved in advocating and administering planned reforms. I came into this field as a triple native<sup>16</sup>: British and already living in Manchester, already working in the NHS as a doctor, and already participating in campaigns, albeit much more peripherally than I was able to during the fieldwork itself.

## 3.2 Alan and the example of socialism

One of the groups I spent a lot of time with during fieldwork was Dunning Keep our NHS Public (Dunning KONP). They had weekly protests outside Dunning Hospital, at which they held placards and distributed leaflets. One of the very first times I joined the protest, the Dunning KONP members introduced me to Alan, who ran a separate but related anti-austerity

<sup>&</sup>lt;sup>16</sup> I am inspired by Zaman's (2008) description of himself as a double native. It is my history of activism that adds a third layer of nativity to my positionality.

network in Dunning. Wes, the chair of Dunning KONP, told Alan about my research project. Alan proudly announced to me, "The NHS is an example of socialism. That's why they want to get rid of it." It was the first – but certainly not the last – time that an activist had described the NHS in this way to me. At the time, I did not realise the significance that this interpretation of the meaning of the NHS would have for me or my thesis.

Socialism was something I had been thinking about for some time before meeting Alan. And I continued to think about it afterwards. Indeed, I am still thinking about socialism. A big part of the reason I continued to think about socialism after Alan issued his diagnosis, was that I kept hearing people describing themselves as socialists. "Socialism" is a word that is heard in the UK a lot more now than it was in the 1990s or 2000s. Before and during fieldwork, I read several recent books (e.g. Srnicek and Williams 2015) and articles (e.g. Frase 2011) by self-described socialists, often outlining programmes for how to consummate "real utopias" (Wright 2013, p. 1) and cohering around some kind of anti-capitalist or post-capitalist (Pitts 2017) vision. In my first attempts to make sense of what activists were talking about, rather than fully investigating what NHS activists meant by socialism, I transposed meanings from my reading onto their words. On my part, this led to some feelings of frustration that drove me towards particular modes of analysis.

The activists often spoke about saving or defending the NHS. Their campaigns were mostly *against* the reforms that were being pushed through by Conservative governments.<sup>17</sup> So it seemed to me that they were not pushing positive campaigns *for* something. In my estimation, they were not going far enough. They were not – at least not explicitly – advocating a radical anticapitalist politics. Instead, they were defending something that already existed. I was frustrated and could not get a question out of my mind: is NHS activism conservative? In the absence of relational distance, while spending time with these activists, many of whom I began to consider friends, I did not want the answer to the question to be yes. So I tried to defend their strategy in my own analyses. I tried to find ways to give a negative answer to the question. It was only when I stopped trying to answer this question, and instead asked myself where the question had come from, that I realigned my focus to more fully understand what socialism meant to the activists themselves. That is, reflecting on my positionality and emotional

<sup>&</sup>lt;sup>17</sup> From 2010 to 2015, the Conservatives led the government in coalition with the Liberal Democrat Party. From 2015 to 2017, the Conservatives held a majority and led the government alone. From 2017 to 2019, the Conservatives led the government with the aid of a confidence and supply agreement with the Democratic and Unionist Party. From 2019 onwards, the Conservatives have again held a majority and led the government alone.

reactions led to a more faithful analysis of my interlocutors. I did not have to sacrifice relational ties, but I did need to consider how those ties were influencing my analysis.

Eventually, the argument of my PhD thesis (Pushkar 2021) was built on Alan's idea of the NHS as an example of socialism. But to grasp what Alan meant required me to understand the meanings of the NHS and of socialism to these activists, and how they built those meanings through the narratives they told each other about their memories and their activism. Activists understood the history of the NHS, of neoliberalism, of cuts and privatisation within the contexts of their own life histories. Many of them were in their 50s or 60s; they considered themselves "children of the NHS". They remembered how they had benefited from state welfare, growing up in a society in which state services were one illustration of how members of society took responsibility for one another. Thus they drew on these memories to imagine the NHS as a moral example of "actually existing socialism", by which they meant a realisation of socialist values, "the social fabric", as one activist described socialism. The NHS demonstrated not only how the state ought to intervene to foster a society in which citizens took responsibility for one another, but also demonstrated that the state *could* intervene in such a way. It also provided an icon around which a politics of collective responsibility could coalesce. Just as Alan convened another group that resisted the withdrawal of other public services, the members of Dunning KONP and the other groups I spent time with often campaigned on issues unrelated to health and healthcare.

#### 3.3 Ruth and solidarity

Ruth was one of the activists I spent a significant amount of time with. A colourful character with colourful clothes – and indeed a colourful house famed in the local area for its paintwork - I already who knew she was before fieldwork. My initial impression before fieldwork had been of someone who was eccentric. As I got to know her better, I realised that what initially came across as eccentricity was actually uncommon certainty in her convictions and forthrightness in following them through. If she wore yellow tights and dyed her hair purple it was because she refused to be cowed into conformity by social conventions. If she was loud in meetings, it was because she refused to bow to authority. If she occasionally came across as rude, it was because she valued egalitarian politics more than bourgeois manners. She had grown up in the East End of London in a Jewish, poor, multigenerational household. Although her family were not drawn to left wing politics, Ruth was; she had been involved in socialist organising

for most of her life. Initially this was in Trotskyist groups, around different parts of England and Scotland, often participating in anti-racist struggles that were rooted in workplaces where the majority of the workforce were black and/or Asian. She then left the country for a period, before returning to Manchester to work in health promotion. Within this new role, she became heavily involved in workplace organising in her union, right up until she retired, at which point she focused her activism on campaigning against cuts and privatisation in the NHS.

Over the course of fieldwork, I saw her in various settings: meetings, leafleting, at protests. Sometimes I would drive her to further away protests as I had a car. Considering she was a retired woman with some health problems, it was notable how much she managed to do. She told me that she had "up" periods, doing anything and everything, followed by "down" periods in which she simply had to rest to recuperate energy. I noted that other activists were often advising her to have a break during her active periods.

My early fieldnotes indicate that I was somewhat scared of her. I perceived a slight standoffishness that added to my anxiety. This was quite unlike the warm welcome I had from other activists around Greater Manchester, especially Dunning. I had the impression that she thought I was naïve – a young middle class doctor, new to the nitty-gritty of political activism - and this explained her standoffishness. It was about halfway through fieldwork that I came to find out that her initial standoffishness was not about perceived - or actual - naivety. She revealed to me that she had not *trusted* me at first. This was because of her experience of doctors in her work. In health promotion (in various fields including sexual health and mental health), she recalled that doctors always thought they knew best. The doctors would swan into projects, tell everyone what to do, then disappear and allow the on-the-ground workers to pick up the pieces. But it was her experience of workplace struggles had really affected her view of doctors. She felt the British Medical Association (BMA, the main union for doctors in the UK) – and its members - were willing to say nice words about solidarity. But in reality, the BMA would only get involved in actions with other healthcare professionals if they saw benefit in it for themselves. And even when they did swoop in to join other colleagues, they would disband again as soon as convenient. The solidarity of doctors could not be relied on.

Therefore, she assumed I would do the same. She thought I would come to some meetings, mansplain (or doctorsplain) to everyone what the real problem was and how to address it, then leave. She told me that what changed her mind was that I listened, and then got involved with doing the work. It was through noticing that I would participate in handing out leaflets, attending protests, writing up briefings from meetings, etc., that she came to believe that I was someone who could be trusted as committed to the campaigns she and others were involved in.

What is interesting for this paper is the effect her disclosure had on me. I wanted to prove to her that doctors could be effective socialist comrades and allies. I was not just there for individual gain, nor to impose my hubristic views upon them. Therefore, her intervention renewed my motivation to participate in campaigns. Moreover, I considered myself as participating *as a doctor*. Her explanation of how she saw me was a potent reminder of my positionality and how others would read it. The reminder led me to think more about alliances and coalitions, particularly between different types of workers and activists. In sum, thinking about how spending time with Ruth had changed me was analytically important for my project. The focus on how ties were developing – and could develop – between people from different social groups led me to think more deeply about what role the iconicity of the NHS was playing in new social formations. I added weight to my theorisation of the meaning of the NHS as an "example of socialism". In particular, I became interested in how activists and managers were interpreting the "values" commonly associated with the NHS in different ways, leading to differing political actions, particularly in relation to group formation.

The NHS is commonly understood as universal, free and comprehensive. "Universal" refers to the service being accessible by anyone. "Free" refers to payment having already been made through general taxation. "Comprehensive" refers to all needs being met by the service provided. Of course, the reason activists are campaigning is because they understand recent reforms of the NHS as undermining these values. It was reflection on my relationship with Ruth that led me to devote attention to the ways in which activists were particularly mobilising universality in their campaigns in order to build alliances between various groups affected by austerity. As I argue elsewhere (with Louise Tomkow, forthcoming), talking about universality allowed them to build consciousness of common interests with, for example, forced migrants being denied healthcare. A focus on universality, grounded in the NHS as an example, thus contributed to building ties of solidarity – rather than charity - with other affected people.

### 3.4 The Stakes of Ethnographic Exit

The eventual conclusion of my thesis was that the NHS was an example of socialism. The first vignette showed how reflecting on how and why my own questions were changing helped me to develop this argument. In particular, reflecting on how my self-imposed definitions of socialisms were leading me to analytical dead-ends helped me to refocus on what socialism – and the NHS as an example of socialism – meant to activists, in the context of the political conjuncture of 2017-2018. These insights fed into my thesis's argument that the NHS served as an exemplar of what a socialist society has achieved, and therefore could achieve, and, indeed, ought to achieve.

The second vignette showed how relational ties developed during fieldwork that affected what I did during fieldwork. But these ties also lasted beyond the end of fieldwork and into the writing stage. A second, more speculative conclusion of my thesis was that the NHS could serve as a rallying icon around which a universalistic, solidaristic class consciousness could be built. The fight to protect and improve the NHS – for everyone - was a fight in which we could all see how our interests were aligned as one.

This argument was based on some empirical observations regarding what activists were trying to do. However, my argument was not based on activists' actual achievements. The class composition of the campaigns I spent time with was largely middle class homeowners, either in or retired from professional roles. So where did my hopeful conclusion come from? Perhaps I took Ruth's disclosure as a challenge: how can you make your research useful to the struggle for solidarity and for socialism? I had consciously attempted to achieve ethnographic exit by stopping attending most activist meetings. (Now, almost four years after end of fieldwork, I keep trying to attend again but can't because young families and evening meetings are somewhat incompatible.) But some fields are difficult to escape. Part of the source of the NHS's potency as a potential icon of universalistic solidarity is that it aspires – or used to aspire – to providing healthcare for all. Some of the struggles of NHS activists are precisely around boundary struggles of who *is* and who *ought* to be included within its aspirations to being all-encompassing. But my own access to NHS care has never been in question. Moreover, I am employed as a doctor within the NHS. The NHS is also constantly in the news, even moreso since the start of the Covid-19 pandemic.

Even if I wanted to escape the NHS, I couldn't. What is more, trying to escape would have meant severing ties with the people trying to save it. A full ethnographic exit would have meant giving up on solidarity rather than taking up the challenge of realising it. It was reflecting on my subjectivity – on my desire to please, appease or impress Ruth – that shaped my analysis towards one that did not just focus on solidarity, but *attempted to embody and foster it.* If, as activists contend, the NHS is being destroyed by successive neoliberal governments, "Is it really the task of the humanities to add deconstruction to destruction?" (Latour 2004, p. 225). I wanted to interrogate and interpret the iconicity of the NHS, not to bring "[m]ore iconoclasm to iconoclasm" (Latour 2004:225). If critique might lead to rupture and cleavage within movements, then how might we instead forge a path towards solidarity? As Latour (2004, p. 230)

notes, critique as debunking is easy. On the other hand, solidarity is difficult. Building and maintaining solidarity takes time, effort, work, and is not necessarily valorised within the academy. However, simply talking about solidarity can also be easy, if it just means agreeing with one's interlocutors. But, as DuFord (2022) has recently argued, building and maintaining solidarity is more about recognising and working through conflict than simply agreeing. Hence we return to our initial problem, of how to separate the analysis of the ethnographer from that of the expert interlocutor.

#### 3.5 Comradely critique

If solidarity is what I found to be at stake with a hard ethnographic exit, then how might it be possible to preserve - even protect and cultivate – such solidarity without sacrificing analytical independence? I now turn to Slothuus' (2023) recent conceptualisation of comradely critique. He has drawn up a framework with precisely this concern in mind – of how to point out and highlight points of disagreement with people with whom one might share a great deal of agreement. Slothuus, like Latour (2004), argues that it can be useful to start by highlighting what one shares with the person(s) to be critiqued. For comrades in a political campaign, this could be shared purposes or visions of emancipation, whereas for Latour it was shared matters of concern.

The concerns, purposes and visions of NHS activists were exactly what I set out to interrogate. This is as it should be for ethnographic fieldwork. Commitment to a shared cause is part of what reflexive analysis must call into question. In my case, this questioning was what led to initial frustration with what seemed to be a lack of radicalism amongst activists. However, as my analysis developed and my understanding grew, so did my commitment to a vision I shared with activists, of a society in which the state empowered people to take responsibility for one another through the provision of public services. For Ruth, my participation in campaigns against cuts to these services signalled my commitment and engendered more trust. Years after fieldwork, but in the absence of full ethnographic exit, I continue to write, continue to analyse. Given the public nature of academic publications, writing thus creates further opportunities to signal either: (a) ongoing commitment to a project shared with my interlocutors, as Nash (1979, 1992) did with her work, or (b) something else, as Mosse (2004) did with his work.

Both Mosse (2006) and Slothuus (2023) consider the public nature of academic writing. But they have different target audiences in mind. Mosse is anxious to maintain authorial independence and fidelity to the anthropological form of analysis. When his interlocutors call his insights into question, he considers it an impingement on his analytical freedom, which, of course, it is. Thus ethnographic exit consists in creating a space in which analysis can take place – as far as possible – without consideration of how interlocutors will read it. In short, Mosse writes for an academic audience.

Slothuus's framework goes into some depth that is not necessary for the purposes of this chapter. The key point for my argument is that, for Slothuus, the comradely critic has a responsibility to consider not just how other scholars will read her work, but also how comrades will understand it. This responsibility cuts exactly into the relational space that Mosse argues is necessary to create by ethnographic exit. However, although this responsibility may create restrictions, it also entails opportunities. In my case, I understood and understand my writing to be political interventions that can advance solidaristic relations: between me and Ruth, between scholars and activists, between doctors and other healthcare workers.

#### 3.6 Conclusion

At my PhD viva interview, both examiners looked concerned. The object of their concern – and thus my own - was my own positionality. Had I really, *really*, managed to separate myself, to achieve sufficient analytical distance from my interlocutors? The combination of nerves then and elapsed time since has blurred my memory such that I don't recall what I said. (Analytical distance from the viva has not helped in this respect.) Whatever I said assuaged their concern. At least enough for the purposes of a doctoral examination. Their concerned countenances eventually melted into pleased and reassuring, sympathetic smiles. I passed. But, really, the problem remains. Had I achieved *sufficient* analytical distance?

Sufficient for what? This is the question that haunts any analytical writing based on empirical research. What is it that your distance is supposed to achieve? To what ends are you putting your research? Is convincing two examiners that you have maintained faith to the doctrines of scholarly research enough? Is that the end? What about the possibility of other ends? Not just convincing peer reviewers that your work merits publication in an academic journal. But what about other purposes to which you might want to subject your research? To make some money

from a popular book? Or to further a cause? What if these other purposes are at odds with the doctrines of scholarly research? Where does your commitment lie? Whose side are you on? I have argued that the problem of analytical distance is felt particularly acutely when researching experts. The first part of the paper described a strategy for negotiating the problem of distance: reflecting on changes in one's own subjectivity. Separating the scholar's views from her interlocutors' requires self-reflection on personal change. However, Mosse argued that such deep reflection required relational space: ethnographic exit. In my own case, doing research as a triple insider, the problem of distance was even greater than Mosse's. I struggled to achieve escape from the totalising nature of the NHS. Moreover, I didn't want to. Because what was at stake in ethnographic exit was something I thought my research could contribute to: solidarity with the same people from whom ethnographic exit would have cut me off. Therefore, I wrote – and write – not just about them, but for them.

Writing *for* one's interlocutors is not what all scholars will want to do, nor am I arguing that they ought to. Instead I call for a recognition of the costs and difficulties of ethnographic exit. The breaking of ties with interlocutors may create space for analytical freedom. But, in my case, I have found not only that ethnographic exit was incredibly difficult to realise while living in England and working in the NHS, but that attempting to break off ties with my fellow activists would have represented a sacrifice of the solidarity that I hoped my research might contribute to fostering.

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# Asymmetries of knowledge and asymmetries of power: the lights and shades of anthropology in biomedical context

Cinzia Greco<sup>18</sup>

## 4.1 Introduction

In this chapter, I focus on the asymmetries of knowledge and power between social sciences and biomedicine. These asymmetries can transform ethnography practices in biomedical contexts into an ambiguous experience, with light and shadows that is essential to explore. The imbalances between disciplines are strongly linked to the perception that biomedicine and STEM (Science, technology, engineering, and mathematics) are capable of producing objective, indisputable data that are not influenced by the context generating them. These perceptions around the nature of scientific knowledge open up the question of how social scientists can approach the categories of knowledge produced and used by "hard sciences". While I am aware of the problematic nature of the "textural" (cf. Shapin 2022) dichotomy between "hard" and "soft" sciences, this distinction captures some widespread beliefs,<sup>19</sup> and these adjectives shape ideas and behaviours around different form of knowledge that need to be addressed.

In my case, the need to explore this question arises from my own fieldwork experience. While conducting this multi-sited fieldwork with various actors in biomedical contexts, I started to pay attention to how social scientists move between different regimes of knowledge, such as, in my case, socio-anthropological theoretical paradigms, medical expertise and patients' knowledge. Our

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<sup>19</sup> 'Hard' can be a synonym of difficult, but also durable and strong, while 'soft' is often used as a synonym of easy, malleable or weak. The list of adjectives is taken form Shapin 2022, to which I refer for a cultural and historical analysis of the hard/soft distinction.

positioning regarding these various knowledge systems and how we utilise or reject them affects the knowledge we can produce through our fieldwork and our ethnographic experience.

While I have always favoured an interdisciplinary approach, my discipline of reference is medical anthropology, which has complex relationships with medical sciences. Some anthropologists, particularly in non-US contexts, emphasise the independence of the discipline from medical knowledge, placing it within the broader tradition of cultural anthropology (cf. Fainzang 2000 for an overview of the different positions). Conversely, the US approach often emphasises the connections between anthropology and medicine, stressing that medical anthropology should find ways to collaborate with medical sciences. For this reason, medical anthropology in the US started as an applied discipline, intending to facilitate medical practice and the doctor-patient relationship. In the late 1970s, Arthur Kleinman, a psychiatrist and anthropologist who became a central figure of the discipline, called anthropologists to find a place in clinical practice to facilitate the relationship between doctor and patient. The anthropologist's role, as Kleinman saw it, was that of a translator between the patients' cultural systems (with the assumption that the patient was non-Western) and the cultural system of the medical professionals, intending to increase compliance, that is, convincing the patient to accept the treatment. In this vision, biomedicine is presented as free from power dynamics (see e.g. Kleinman 1985). Critical medical anthropology, starting in the 1980s, introduced a different perspective to the analyse of the power dynamics within biomedicine and between biomedicine and social sciences (cf. Baer et al. 2013).

Medical anthropologists and, more generally, social scientists of medicine today often work in contact with biomedicine, which increasingly presents itself as an objective, solid science based on evidence-based approaches in which randomised clinical trials and statistical demonstrations are used to show incontrovertible truths (cf Lambert 2006). These methods of inquiry are presented as a proof of objectivity and scientific solidity. This idea is encapsulated in the everyday definition of "hard sciences", which are often opposed to the "soft sciences", which include social sciences, historically considered less capable of producing strong and irrefutable knowledge (cf. Shapin 2022). Moreover, starting with the 1980s, biomedicine has become closer, in method and form, to other experimental sciences through the affirmation of Evidence-Based Medicine and its clinical trial data, expressed in an aggregated statistical fashion.

Social scientists often work within medical institutions and collaborate with medical professionals, such as medical doctors, nurses, biostatisticians and other figures. While these collaborations can be fruitful, they can also reveal disciplinary frictions (cf., for example, Bühler 2023 for an analysis of interdisciplinary collaborations during the Covid pandemic). I consider this chapter an opportunity to explore the asymmetries of power generated in the fieldwork by the different prestige attributed to

social sciences and medical sciences. I aim to question the relationship between the knowledge produced and used by medical anthropologists and biomedical knowledge and to analyse how social scientists use, interpret or distance themselves from biomedical knowledge. My argument is that there is an asymmetry in the recognition of the legitimate knowledges that ethnographers and biomedical and STEM ethnographees bring to the field. This means that ethnographies conducted, as in this case, in biomedical settings, involve also a negotiation about how much the ethnographer is legitimated in acquiring and analysing formalised biomedical knowledge, including the medical literature and the concepts developed in such literature.

This chapter is based on my fieldwork experience in three different countries. In the last twelve years, I have explored the representations, the politics and the experiences of doctors and patients in the case of breast (and lung) cancer. From 2012 to 2015, I conducted fieldwork primarily on the relationship between the ill body and aesthetic norms through the study of post-mastectomy reconstruction with a multi-site research in France and Italy. From 2017 to 2020, I conducted fieldwork on the uncertain borders between chronic and terminal in the case of metastatic breast cancer and on the trajectories of patients with breast and lung cancer, with research in the UK. In these years, I have conducted participant observation in medical settings and more than 140 interviews with patients, medical professionals and cancer activists.

Social sciences have an essential role in understanding different healthcare contexts and the experiences of patients. But what do medical professionals think of the presence of social scientists in medical settings? What does it mean for social scientists to move between different regimes of knowledge, including anthropological theoretical paradigms, medical expertise and patients' knowledge? Furthermore, how do power imbalances generated in fieldwork by the varying prestige attributed to social and medical sciences play a role? How does the asymmetry of knowledge impact early career researchers and those of us in precarious positions? In the pages that follow, I will discuss how asymmetries of knowledge can be transformed into asymmetries of power when conducting fieldwork and how different hierarchical positions can reinforce these asymmetries.

Before discussing the impact of these asymmetries of knowledge, it important to deconstruct them and not to fall into the trap of assuming that quantitative, experimental methods can produce stable and irrefutable knowledge. Social sciences and feminist and postcolonial theorists in particular have underlined, '[w]ith respect to gender, race, and much else [...] science is not value-neutral' (Schiebinger 1999, p. 107). The notion of 'standpoint theory' introduced by Harding (1992) aims to

produce a more inclusive and encompassing knowledge by considering marginal groups' experiences and thoughts regarding gender, race, and class. This approach helps us to gather a more comprehensive understanding by taking into account perspectives that are usually left out of scientific research. The notion of 'situated knowledge' introduced by Haraway (1991) is based on the idea of the partial, fluid, and contradictory nature of every point of view. According to Haraway, shifting the point of view is not enough; what is needed is the connection between different visions, each of them being recognised as situated. These theoretical reflections have had an important impact on part of the social sciences, but so far, they have not touched the "hard" sciences and medicine.

In the sections to follow, I begin by examining how biomedical knowledge is conveyed in biomedical literature. After that, I share my personal experiences from fieldwork and provide insights into how the increasing importance of medical knowledge is influencing and transforming the fields of medical anthropology and other social sciences applied to medicine. The first part of this chapter is informed by my experience with historical and documentary research, while the second part is strongly linked to my fieldwork experience.

## 4.2 The provisional status of scientific knowledge

In biomedicine, it is often assumed that medical knowledge is devoid of external influences. It is presented as pure knowledge. However, recent scientific controversies have revealed various impurities that are inherent in medical disciplines. Medical knowledge is often intertwined with local and contextual political, social, and economic factors. The pure/impure dichotomy is a reference to Epstein's concept of 'impure science' (1996). The metaphor of purity is strongly linked the textural dichotomy of hard and soft, and in Epstein's work the idea of purity is used to explore the organisation of clinical trials for AIDS drugs in the 1980s and 1990s. Access criteria for AIDS trials were quite stringent, requiring "pure" subjects with no or limited history of previous treatments. Activists, however, demanded changes that pushed scientific standards to adopt a more pragmatic approach that considered the complex situation of AIDS patients who often had to employ multiple treatments to survive.

The idea of purity is a useful guiding metaphor as it helps to see the entanglements between biomedicine and its social and political context. It is crucial to recognise the impurities inherent in medical knowledge and to consider the external factors influencing it and develop effective strategies to address them. In different moments of my research, when reviewing the vast literature on breast cancer, I came across articles and commentaries discussing the relationship between breast cancer and mental health and well-being. To better frame this discussion, it is essential to mention that between the 1970s and 1990s, the idea that certain personality traits could make people more prone to the development of cancer was deeply embedded in the lay and specialised understanding of cancer. The leading proponent of this idea was the German-born psychologist Hans Eysenck, who worked mainly in the UK. In his study on lung cancer, he went even further by saying that personality can be a more significant risk factor than smoking habits. While his theories have raised some criticism in the past, it was only in 2019 that an inquiry into Eysenck's methodology and results was launched after careful research conducted by British psychologist Pelosi, which disproved Eysenck's results (cf. Pelosi 2019). However, as Pelosi points out, these findings have been widely cited and have had consequences on how the relationship between cancer, mental health and risk factors has been constructed. Echoes of the impact of Eysenck's theory are found, for example, in research that has explored the role of therapy on the survival of patients with breast cancer. David Spiegel, a Stanford University psychiatrist, published a study on the impact of psychosocial intervention on the survival time of patients with metastatic breast cancer in 1989. Eighty-six women were involved for a year in weekly support group therapy with self-hypnosis for pain. As in other clinical trials, patients were divided between the treatment and the control group, and the authors concluded that '[p]atients with metastatic breast cancer randomised to weekly group therapy for a year lived significantly longer than did controls, by an average of nearly 18 months' (Spiegel et al. 1989, p. 890). The article has been cited more than 3000 times in the following years, and contributed to the idea that the psychological attitude of patients with cancer can influence their survival. Almost ten years later, in 1998, other researchers conducted a study in Spain involving the administration of several psychological tests to women with and without a breast cancer diagnosis, affirmed that their 'results support previous studies, and are in accordance with other findings showing that breast cancer patients tend to suppress, inhibit, repress or deny their emotions' (Fernandez-Balestreros et al. 1998, p. 41). The authors in the article refer to Eysenck's and Spiegel's theories to support the validity of their findings.

However, Spiegel's specific results have never been replicated; on the contrary, other researchers have pointed out how possible methodological problems (Fox 1998) in the distributions of patients in the two groups of the trial might have altered the results. Spiegel himself confirmed in 2007 that he was unable to replicate the survival result (cf. Spiegel et al. 2007).

These beliefs around cancer aetiology have influenced the decisions of several medical professionals and patients and have had tangible repercussions on people's lives (cf. Pelosi 2019). Moreover, the relationship between attitude and outcome is so pervasive that even nowadays there are different injunctions to maintain a positive attitude in the face of cancer, as a positive attitude is considered capable of influencing recovery (cf. De Raeve 2003). In the case of breast cancer in particular, various analyses and comments have highlighted the presence of what Barbara Ehrenreich (2001) has defined as the mandatory cheerfulness of breast cancer. That is, the presence of a pervasive rhetoric that pushes patients to face the disease with positivity and optimism. While individual patients can prefer to face cancer in different ways, these beliefs often limit the range of emotions that people are allowed to express, which can be detrimental to their overall well-being.

In the last decades, scrutiny over how medical data are produced and analysed has increased, and medical professionals are invited to evaluate more carefully scientific data and how they can be used in clinical practice. In fact, since the 1990s, a new approach, evidence-based medicine (EBM), which aims to strengthen the empirical foundations of medical practice has gradually established itself. Some of the initiators of EBM in a 2017 article underline how one of the main objectives that they wanted to achieve through the introduction of this approach was to make clinicians understand that 'not all evidence is created equal, and that the practice of medicine should be based on the best available evidence' (Djulbegovic and Guyatt, p. 416). EBM introduces a 'hierarchy of evidence', and clinical randomised trials<sup>20</sup> occupy the most prestigious position in this hierarchy.

Among the innovations introduced in the field of breast cancer following randomised clinical trials, conservative surgery. introduced in the 1980s, represented a significant progress capable of improving the quality of life of many women. Clinical trials conducted in Milan and in the United States between the mid-1970s and early 1980s showed the effectiveness of radiotherapy associated with conservation interventions, which made it possible to avoid mastectomy without affecting survival time. Although the clinical trials in the two countries reached the same conclusion and mark one of the most significant advances in the treatment of breast cancer, the interpretations of the data by the two surgeons leading the clinical trials present some important nuances. For Umberto Veronesi, the Italian

 $<sup>^{20}</sup>$  Randomised clinical trials are prospective studies in which different groups of patients are compared; this means that they look at how a phenomenon will evolve over time in the different groups involved. For example, to understand the impact that a new drug will have on a disease, patients will be divided into different groups; the experimental group will receive the drugs, while a control group will not receive the new drug (usually the people in the control group continue receiving the established treatment). Patients selected based on specific characteristics – state of health, disease progression, etc. – are allocated randomly to the experimental or control group of the trials. This process is considered to reduce bias and offer an objective level of understanding about the effectiveness of drugs and treatments.

surgeon who led the research in Italy, this approach showed the prevalence of a medical approach that is considered relevant not only to the survival of the patients but also to their quality of life. On the other hand, Bernard Fisher, the US doctor in charge of similar trials, attributed the change in approach to Evidence-based medicine and objective tools (cf. Carlson 2003). Bernard Fisher is 'widely credited as the driving force that brought clinical trials and statistical methodology to breast cancer research' (Travis 2005, p. 1637). Fisher's emphasis on presenting conservative surgery as the result of a rigorous application of the scientific method shows how medicine is constructed as a discipline of objectivity, which follows data and facts, not opinions. Samsky (2018, p. 2) notes how 'EBM's emphasis on its own inherent, inarguable truth sometimes makes it seem a historical'. On the contrary, several commentators have underlined how clinical trials, and consequently EBM, are deeply linked to the research and marketing methods of the pharmaceutical industry (Samsky 2018). In this sense, EBM has reduced the subjectivity linked to medical authority but has introduced new actors pharmaceutical companies and national approval agencies, such as British NICE (National Institute for Health and Care Excellence) and the European EMA (European Medicines Agency), whose decision take into account not only the effectiveness of a drug, but also its cost. Taking into account the cost of a treatment influences cancer care, since several treatments are extremely expensive, and in some cases available only to patients willing and able to pay for them privately. These considerations highlight how, despite the claim of objectivity within EBM, decisions about which therapies will be used are not just linked to the result of clinical trials, and that financial analysis can be as important as biostatistical models, especially in a moment of retrenchment of public spending on health. Considering the many factors that can influence medical practice and knowledge is a useful way to deconstruct ideas of objectivity based on the aesthetics of statistics and numbers. They also show us how medical knowledge, although increasingly based on numbers and statistics, is also impure in the sense that new agencies and financial interests determine play a role in orienting medical practice. These considerations bring us to an important question: how should social scientists relate to medical knowledge?

## 4.3 Biomedical knowledge and biomedical language as ambiguous tools

In an article written over twenty-five years ago, in 1999, Browner discusses what she defines as the 'medicalisation of medical anthropology'. According to Browner, this medicalisation is not simply due to the fact that a growing number of anthropologists work in medical facilities, but also to the fact that many anthropologists tend to study 'entities as they are conceptualised by biomedicine' (p.

135) and to use medical categories, such as post-partum depression or premenstrual syndrome, without deconstructing them. The acceptance of a specific language and a certain way of looking at phenomena, according to Browner, may be due to the need to find a common language with medical professionals. But this can stifle the discipline's analytical power and ability to offer a new lens to look at health and sickness. The doubts that Browner presented are echoed by the French anthropologist Sylvie Fainzang (1998, 2010). Fainzang defends the independence of anthropology from biomedicine and underlines how an epistemological and methodological autonomy of the discipline is the necessary prerequisite for it to offer deep and meaningful analyses of the observed phenomena without flattening such analyses on the needs of biomedicine. Fainzang supports this position by using her own research on communication between patients and medical professionals as an example. Fainzang wanted to explore how doctors share information with patients about their health conditions, and she decided to approach the question by rejecting a moral lens, that is, whether this communication was conducted openly and honestly. In the same way, she refused to adopt the perspective of medical professionals, who considered communication with patients as a way to improve compliance and acceptance of the diagnosis. The anthropologist was interested in how communication was managed and what it could reveal about the relationship between patients and doctors. This approach, Fainzang writes, allowed her to show how 'information is not provided to all patients in an identical manner, since it is given in preference to patients belonging to higher social categories, whereas it is more willingly withheld from patients belonging to lower social categories' (Fainzang 2010, p. 46). What Browner and Fainzang show is the usefulness of problematising medical categories. Indeed, deconstructing biomedicine highlights new aspects of medical phenomena, and I followed this approach in my research on metastatic breast cancer. When I started my study of metastatic breast cancer in the UK, I was interested in the transformations that stage of the disease was undergoing, as thanks to new treatments, it is increasingly presented as chronic. At first, I fell into the trap that Browner warns us against: that is, biomedical definitions of chronicity guided me, and I was interested in whether they applied to metastatic breast cancer.

However, my fieldwork research quickly showed the limits of this approach and revealed the need to deconstruct the concept of chronicity. The new approach shifted the focal point of my research: I was not simply interested in understanding whether therapeutic advances were turning metastatic breast cancer into a chronic disease but also how the concept of chronicity was mobilised in biomedicine, what ideas of medical progress could be built by using it. My research revealed that the ubiquity of the term 'chronicity' is combined with the lack of a clear definition of what actually constitutes a chronic condition. Interviews with medical professionals and the analysis of medical literature revealed that different definitions, meanings and values were associated with this term. For instance,

in some cases, both doctors and patients rejected the idea that breast cancer can be classified as a chronic disease. This is because such a definition risked associating the terminal stage of cancer with diseases that are considered more manageable, such as diabetes. However, many of the medical professionals I met presented nuanced accounts of the usefulness of the term chronic. They emphasised that it can be a beneficial term as it highlights the fact that patients with metastatic cancer can live with the disease for several year, with physical and psychological needs that must be taken into account. For some medical professionals, the term chronic was an invitation to preserve the quality of life of patients in the terminal phase of cancer.

However, exploring the uses of the concept of chronicity also led me to critically analyse another trend in the oncological therapeutic landscape, namely the definition of treatments offered to patients as personalised medicine. Personalised medicine offers the promise of treatments that can be tailored to the specific subtype of cancer a patient has, thus offering a better outcome. Several drugs are now described as 'personalised treatments', and each of these drugs can keep the cancer at bay for a few months, or at best, a few years. This new therapeutic arsenal is not eradicating cancer, but it is extending the time patients live with cancer. These treatments are presented as personalised because they respond to specific breast cancer subtypes - hormone positive, HER2 positive and triple negative. Therapeutic success in metastatic breast cancer is redefined not through the elimination of the disease but through the possibility of keeping it at bay for longer periods, as it happens in chronic diseases. In this sense, the increased use of the adjective chronic helps present the new therapeutic approach as a success since even if it is not possible to eradicate cancer, it can be transformed into a manageable and less scary problem, such as diabetes, with which many people they coexist for decades. The concept of chronicity, coupled with the management of cancer that personalised medicine can promise, takes on a new meaning and introduces the expectation that new personalised treatments can not only extend survival times but also improve patients' quality of life. In this way, personalised medicine and the semantic field of personalisation and individualisation benefit from the fact that the concept of chronicity is strongly associated with manageable diseases (Greco 2022).

Deconstructing and de-essentialising biomedical category can sometimes be difficult, especially when this approach is not understood or shared by medical professionals. Some of the oncologists I met during the project on metastatic breast cancer expressed doubts about the design of my research, saying that I was wrongly considering breast cancer to be one disease. In contrast, breast cancer, according to some medical professionals, is actually comprised of different subtypes of cancer. I was interested in exploring the illness as a whole, so to identify the effects that it produces in the lives of the patients dealing with it. It was essential for me to continue to consider 'breast cancer' as a research

object. However, these comments prompted me to explore better how breast cancer subtypes can influence patients' experiences. Looking at the segmentation of breast cancer allowed me to understand that the separating breast cancer into subtypes is not as straightforward as presented by some doctors, and that often patients with a subtype that should benefit from specific drugs see limited results, and more generally have therapeutic experiences that are much more complex. Unpacking medical categories of chronicity and personalised medicine have provided me with the opportunity to explore sense-making practices of medical professionals but has been helpful in understanding the links between pharmaceutical research and clinical practice.

Browner wonders how the medical anthropologist should position themself concerning medical knowledge. Should we come close, learn and absorb medical knowledge as much as we can or, on the contrary, steer away from it? In my approach, the central aspect was not distance but perspective. I have not ignored medical knowledge; I have taken it into account, but I transformed it into an object of research, not a heuristic tool to explore phenomena.

Ignoring biomedical knowledge and biomedical terms would have prevented me from interacting with my interlocutors in the fieldwork. Both medical professionals and patients used medical terms and medical categories to make sense of their different experiences of breast cancer. Understandably, the way in which patients and medical professionals use medical categories is very different. Many patients use medical terms to extend their knowledge about cancer and to be able to communicate not only with medical professionals but also with other patients. In the same way, I used medical knowledge and medical terms as a common language to facilitate my presence in the fieldwork. In this sense, I approached medical categories as boundary objects. Introduced in 1989 by Star and Griesemer, the concept of boundary object includes a variety of material objects – such as field notes, maps, specimens or catalogues – and immaterial ones – such as technologies, ideas or theories – that can be used by different actors, or communities differently and allow for cooperation and collaborations even in the absence of agreement. Boundary objects are flexible, as they can be interpreted differently in different contexts. However, 'their structure is common enough to more than one world to make them recognisable, a means of translation' (p. 393). In this sense, medical categories are useful for analyses, theoretical reflections and even collaborations (as we will see in the following section) situated on the common ground of a medical category which assumes different roles depending on whether it is used in the social sciences or the medical field. However, the plastic and malleable nature of medical categories as boundary objects is not free from asymmetries of power. In fact, in my case, as in others, it is the medical language that becomes common ground. As a social scientist, the language and analytical categories of my disciplines have not been used to build exchanges and collaborations. My desire to use and extend medical categories is linked to my interest

in this scientific tool. Still, it is, at the same time, a necessity that derives from the power that resides in medical language, considered the bearer of objective messages. Hence deconstructing medical language and the inherent power of biomedicine are two inseparable sides of the same coin. In my case, however, medical language was not the only linguistic barrier playing a role, as I discuss in the next paragraph.

## 4.4 When the anthropologist comes from the (internal) South: flipping the ethnographic script

Anthropology is known for studying contexts and countries that differ from the researcher's place of origin. This has resulted mostly in anthropologists from Global North countries and, especially in the past, from middle and upper-class backgrounds, studying Global South countries and contexts of hardship and poverty (cf. Seppilli 2001). This extractive approach has been widely criticised, and since the end of the 1980s, anthropological research conducted in places geographically close has increased; this is often described as 'at home'. However, as Hadolt (1998) underlines, the expression does not simply express the geographical proximity between the researcher and the research context. It implicitly refers to fieldwork conducted in the countries from which the anthropological practice originates, i.e. research in Western, industrial and rich countries. To circumvent the ambiguities in the term 'anthropology at home', Hadolt introduces a distinction between anthropology that looks at the 'differences between' – meaning between different contexts, different countries and different categories.

Meanwhile, an 'anthropology within' aims to complexify heuristic categories by looking at the differences 'within' contexts or countries. This approach has the advantage of presenting a nuanced analysis of categories and contexts. 'Differences between' can connect different entities and categories, while looking at the 'differences within' can help the anthropologist (or, more generally, the social scientist) to de-essentialise and constantly revise the categories used.

These reflections have certainly changed the objectives and methods of the discipline. While fieldwork is often still conceptualised in reductive and exotic terms, anthropological research conducted in Western urban contexts has found legitimacy and anthropologists from working-class backgrounds also do fieldwork in settings and topics in which the asymmetries of power and prestige are reversed. One of these contexts is undoubtedly represented by medical settings.

As mentioned, I started my fieldwork in 2012 as part of my PhD and conducted large portions of the fieldwork in France. Later, in 2017, I started a first post-doc research project in the UK. During the British fieldwork, the country was (and still is) divided by the tensions introduced by the Brexit

referendum, a vote influenced by criticism of freedom of movement, and a willingness to control migrant from the EU entering the UK. I am a woman from Southern Italy, from a working-class family, a first-generation university student and (obviously) the first in my family to obtain a PhD. I am a migrant, coming from a region that is considered similar but with significant differences. The marginal position of Southern Europe in Europe and Southern Italy in Italy has been extensively analysed (I have discussed cancer in Southern Italy in Greco 2016 and my fieldwork in Southern Italy in Greco 2019 and 2023). My being a southern Italian in Europe can be considered an embodiment of theoretical positions and certainly an element that has influenced my experience as a researcher. My migrant status, my gender and my profile as a young researcher working in a "non-scientific" discipline significantly influenced my fieldwork experience and my relationship with the actors I met during fieldwork, in particular with the medical professionals.

As seen in the introduction of this chapter, in the US context, it is more common for the researchers interested in the social aspects of medicine to be themselves medical professionals. Although this dual role is sometimes also covered by European researchers, this expectation is less strong. This is because in some parts of Europe medical anthropology is connected with folklore studies, and it is acceptable for different researchers to study medical problems starting from different experiential and disciplinary backgrounds (cf. Comelles 2002).

However, this can raise some difficulties and friction when conducting research in medical settings and make interdisciplinary collaborations more complex. As mentioned, social scientists often adopt the language of biomedicine to translate our research to medical professionals and prove the validity of the terms described by biomedicine. On several occasions, translation for institutional or pragmatic purposes is often necessary, such as making a project understandable for medical professionals to obtain ethics authorisation or access to fieldwork in biomedical settings.

Several medical professionals asked me if I had a background in medical sciences or related disciplines, and in some cases, the fact that I was not a medical professional was surprising. It was unclear how a social scientist could be interested in cancer. In other cases, the intersection between my disciplinary background and my nationality aroused interest: why was a social scientist interested in breast cancer? What could I say that could be relevant? In my case, the difficulty in finding a common disciplinary language was amplified by the fact that those discussions were also conducted in English or French, both second languages for me. My accent has often been extremely evident during my fieldwork, as it was the element that would immediately identify me as a foreigner, not only in a disciplinary way but also in a more personal biographical way.
My disciplinary and socio-biographical otherness was often used to question my ability to produce meaningful knowledge. In some cases, it was underlined that, as a foreigner, I could not understand the healthcare system of the country where I was working, whether in France or the UK. However, the status of foreigners, both social and disciplinary, has not so just been an obstacle to the possibility of carrying out fieldwork research. Sometimes, this double estrangement allowed me to ask questions regarding basic aspects of oncology and the functioning of the healthcare system with greater freedom, thus using the assumption that there was a thinner common ground between myself and my interlocutors. My marginal status allowed me to question medical categories explicitly or to ask for clarifications on aspects of the medical system that would otherwise be more straightforward for a local researcher. My interviewees were often willing to offer clarification on more complex medical elements during and after the interview. Social and disciplinary distance did not interrupt the conversation, but it certainly changed its terms, and this shift deserves to be considered as a relevant part of my fieldwork experience.

To put it another way, my status as a foreign citizen without a medical background made it possible for me to explore the differences within by drawing on different resources than those that a local researcher with a medical background would have used. The condition of being a foreigner offered me an epistemological freedom that can represent an advantage. On the opposite, being perceived as a foreigner, both culturally and disciplinary, has made in some occasion my access to fieldwork more difficult, as the perceptions of my abilities as a researcher were influenced by my accent and disciplinary background.

My experience in the field has taught me that interdisciplinary dialogues and exchanges are possible. However, such exchanges are often characterised by imbalances of power and prestige. Facing the challenge of being a foreigner twice over, some interactions, particularly with medical professionals, were difficult. In some situations, the distrust towards what I represented, a foreign woman without a biomedical background, was palpable. It is essential to consider these difficulties not as aporias of research that should be ignored; on the contrary, they are an integral part of the process of knowledge production. These asymmetries of prestige and power influence the kind of fieldwork we can conduct, the institutions we can access and the behaviour of our interlocutors. Thus, they directly impact the knowledge we can produce and the different shades and nuances that we can bring forward through our positionality as researchers and as human beings.

# 4.5 Conclusions

Collaborations between social and medical-scientific sciences are common. During the first months of the COVID-19 pandemic in 2020, the partnership between medical and the human and social sciences of medicine intensified. Sociologists, historians, and anthropologists were called upon to offer answers to an unprecedented and dramatic situation of doubt and uncertainty, in which has difficulties and inequalities already at the centre of the interests of the social sciences, have emerged dramatically. Theoretical tools specific to the social sciences have been used to understand the intersection of medical problems with social dynamics. This demonstrates the partiality of medical science, the importance of social sciences, and the need of collaborations between the two disciplines. However, these collaborations can raise tensions and difficulties.

In this chapter, I have tried to tie together various threads that, during my field, have run through my relationship with medical knowledge, medical institutions and medical professionals. One of the aspects that characterises my experience is the asymmetry of power and prestige between the social and medical sciences. This asymmetry permeated the relationship with the actors encountered on the ground, especially the medical professionals, who often questioned the aims and the validity of my research and my ability to study cancer experiences without a medical background. In this context, the study of medical literature proved to be a necessary but insufficient measure to communicate with my interlocutors during the fieldwork.

Studying extensively the medical literature on breast cancer has enabled me to understand important aspects of the work of doctors and the experience of patients. However, the increased knowledge gained in the field of breast cancer in these years of work did not come with the formal medical qualifications of other actors. My expertise was never considered comparable to the scientific knowledge of my interlocutors. The knowledge of the social sciences is considered limited and anecdotal, in a word not objective, since it cannot reveal stable and universal truths. However, one of the objectives of the social sciences is precisely to problematise the very idea of objectivity. In the Prison Notebooks, in the pages dedicated to science, Gramsci (1977, p. 1455) writes: 'It can be argued that it is a mistake to ask science as such the proof of the objectivity of reality: as such objectivity is a conception of the world, a philosophy, and cannot be a scientific fact' [my translation]. The idea of a permanent and shared reality for all individuals is a way of interpreting and constructing the world, not an attribute to be recognised. These epistemological differences discussed in this chapter emerges from the meeting (and clash) of two ways of analysing the world.

The relationship between social and biomedical sciences can be further strongly influenced by various factors such as the gender, ethnicity, and national origin of researchers. These factors can exacerbate the epistemological differences present in humanistic-social and scientific disciplines. This chapter aims to be an opportunity to explore how asymmetries of knowledge can be turned into asymmetries

of power and can impact the knowledge we produce. These reflections represent an attempt to open a new path on lesser-known methodological aspects of social sciences.

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# Being a Native Anthropologist among Scientists

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This chapter examines methodological challenges and peculiarities of doing a laboratory ethnography as a native anthropologist outside of the Global North. As part of my Doctoral thesis at a Canadian university, I performed ethnographic research at the Belgrade Astronomical Observatory (AOB), Serbia, between 2014 and 2018. A native of Belgrade and Serbia, I was therefore a cultural insider, as well as the outsider, due to my affiliation with a Western university and my lack of scientific background. In the chapter, I will highlight methodological complexities created by the specific circumstances of doing native ethnography among local scientists outside of the Western cultural sphere.

Located in a remote area of the Serbian capital, Belgrade Astronomical Observatory (AOB) is the country's leading institute for astronomy and astrophysics. The Observatory is a small institute, employing between 45 and 50 scientists, around half of which are women. Due to the highly specific nature of the informants' occupation, traditional participant observation was not possible (Nader 1974; Gusterson 1997; Stryker and Gonzalez 2014). Instead, I spent my days conversing with researchers, particularly during their free time, which was abundant due to the specific rhythm of research performed at the Observatory.

In the chapter, I will highlight my experience with fieldwork at the Observatory, particularly in terms of positionality and methodological complexities that I faced as a native anthropologist among local scientists.

# 5.1 Background

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Once part of socialist Yugoslavia, Serbia can be defined as a 'post-socialist' country, along with many others in Eastern Europe. 'Post-socialist' is a tired label, and one that has been criticized (Humphrey 2001; Stenning and Hörschelmann 2008; Chari and Verdery 2009; Rogers 2010): the transition to-ward capitalism is supposed to be over, so once-socialist countries should be viewed in the light of neoliberalism. A more recent approach to region describes it in terms of global power relations: nei-ther part of the Global North nor the Global South, post-socialist countries are defined as 'the Global East' (Müller 2020). Serbia occupies a peripheral position in Europe; it is not accepted in the EU and does not belong to the Western cultural sphere. This liminal position between the 'core' and 'periphery' characterizes many aspects of life in Serbia, and it also reflects on local scientific community (Blagojević 2009).

'The West' is a concept that is commonly used in Serbia to denote the Global North. 'The West,' in this understanding, includes Western European countries (not EU – there are EU countries that are not considered to be the West); North America (USA and Canada), Australia and New Zealand. Serbia's attitude towards the West is ambivalent (Volčič 2005), particularly in the light of post-socialist, nationalist shift after the 1990s, but a lot of complexities stem from Serbia's own liminal position on the political, geographical, historical and cultural map of Europe (and the world). It could be said that while some people in Serbia, in general, do not consider themselves to be Westerners, they do not see themselves to be Easterners, either (Bakic-Hayden 1995).

These complexities are well-reflected at the Observatory: scientists working at AOB have a complex attitude towards 'the West'. On the one hand, they insist on their own equality and even brilliance that can match any scientist in the Global North. On the other, they are aware of Western power and Serbia's marginalized position in the scientific community. The West is seen as the judge and Western scientists are the ones that need to be impressed above everyone else, a belief that comes not so much out of admiration for Western scientists themselves, but from understanding of the power imbalance. This is in line with Hwang's (2008) assessment of the power asymmetries that affect scientists in the Global South. All of those things make the West an important factor at AOB in several ways: through possible funds and collaborations coming from the West to the potential harm that can come from the West. These are the same concerns often expressed by scientists in Latin American countries (Ciocca and Delgado 2017; Kreimer 2019), so these problems are not specific to Serbia or post-socialist, Eastern-European context. In my research, 'the West' was a term my interlocutors used often, and a central concept for navigating insiderness and outsiderness I encountered during my research.

#### **5.2** Positionality

During the time of my fieldwork, I was an international doctoral student from a Canadian university. This put me in a peculiar position: as a person from Serbia, I was a native anthropologist; I was also 'studying up' by doing fieldwork among scientists at a research institute. Finally, I was someone perceived as 'coming from the West', and thus experiencing privilege and power that my interlocutors did not possess. This created a complex ethnographic experience, particularly in terms of positionality and uncertainties about the insider/outsider status that I experienced. In the rest of the chapter, I will map these complexities, particularly in terms of doing native anthropology among a group of scientists, and how the issues surrounding positionality inevitably revolved around my role as a communicator between the locals and the centre of power (the West).

There is, of course, a complex question on terminology. Native anthropologist? Insider anthropologist? Many authors (Cerroni-Long 1995; Kuwayama 2004; Meyers 2019; Narayan 1993) debated the complexities and potential pitfalls of different terminologies aimed at labeling anthropologists who perform research in their own cultures, and *of* their own cultures. In my chapter, I opted for 'native anthropologist', primarily because it is the most direct translation of the term primarily used in my own (Serbian) academic tradition (*nativni antropolog*).

In recent years, many authors have highlighted contemporary approaches to the complex, shifting, and context-dependent nature of doing anthropological field work, particularly in terms of power imbalances and positionality (Becker and Aiello 2013; Berger 2015; Pack 2006; Robertson 2008; Williams 2018; Winfield 2021). These questions are made more complex in the case of native/insider anthropology, with a fluid and changeable 'insiderness' and 'outsiderness', 'nativeness' and 'strangeness' (Ceroni-Long 1995; De Andrade 2000; Kuwayama 2004; Merriam and Johnson-Bailey 2001; Narayan 1993; Sharan et al. 2001; Trzeszczyńska 2022; Turgo 2012; Woodward 2008) that the researcher experiences throughout the fieldwork. These changing positions are highly context-dependent, and shift depending on numerous factors, such as the aspects of researchers' identity (race, nationality, gender, etc.), the aspects of their interlocutors' identity, cultural context, situations, existing power imbalances, and so on. It is also important to note that many of these operate under the perceived and not factual basis; for example, a researcher or interlocutor being perceived as belonging to a group, or supporting a specific cause, can have immense influence on field work, regardless of factual circumstances. All of these factors are highly dependent on context and the situations that arise during the field work.

My basic insiderness in the group derived from a shared belonging to Serbian culture, which is implicitly understood not only through national lens but also as ethnic belonging. In this sense, it was closer to what Cerroni-Long (1995) recognized as a status gained through birth (native status), versus one gained throughout life and circumstances (insider status). In the case of the AOB, the main axis in which my experience as a researcher could be analyzed is the intersection between nativeness and insiderness: I was a native anthropologist by the virtue of my nationality and ethnicity, but I was not an insider anthropologist among a group of scientists.

It was also rooted in interlocutors' assumptions and perceptions about myself as a person, which guided their conduct around me: my nationality and ethnic group, gender, sexual orientation and, above all, my level of understanding of local (Serbian) culture. In addition to these factors that have negotiated my insiderness, there were also those that shaped my outsiderness: my affiliation to a Western university and perceived funding from said institution, and my (perceived) lack of scientific background.

I must emphasize that I am not completely an outsider to science, since I studied astrophysics for a few years. However, since I never graduated, it did not 'count' as sufficient scientific background to my interlocutors. In fact, I was advised by the researcher friend who had introduced me to the Observatory not to mention this, to not appear as claiming a space I do not belong to. During my field work, I did mention my studies to several interlocutors, and while they did not react negatively, they did not treat it as relevant: they continued to perceive me as a non-scientist. My own sense of (partial) insiderness to science did not match my interlocutors' perception, and I could never shred the label of an outsider.

I expect that this situation is similar to many researchers performing their research among STEM scientists, unless they have a specific training in said STEM discipline that their interlocutors recognize. This is also something that researchers performing fieldwork among scientists in the Global North would face. Other aspects of superpositionality (Williams 2018) of importance for studying scientists have to take into account complex issues of the ever shifting and negotiated power relations: are we studying up, down and/or through? (Becker and Aiello 2013; Gusterson 1997; Nader 1972) How do we navigate these complex, changing and always re-negotiated relations? These questions are present in anthropological field work regardless of location, and they are particularly present in the case of performing research away from centers of power (Hwang 2008; Williams 2018).

I encountered these complexities vis-à-vis the Global North ("the West") during my research at the Belgrade Astronomical Observatory, and they influenced my insider/outsider status significantly. Before the start of my research, I expected to be accepted as an insider through shared Serbian culture, and as an outsider in science, but the realities of the field work showed that the key tension arose from different ways in which my interlocutors and myself were connected to the West. I expected to be seen as someone 'with links to the West' in terms of my association with a Canadian university, and my (perceived) financial status and funding from said university. This put me in a relative position of power over my local interlocutors. I also expected to have a lower status compared to them in terms of expertise, age and position in the society – most of my interlocutors were older than me, had their PhDs and well-respected, established positions; furthermore, half of them were men. However, an important component of this researcher/interlocutor relationship was scientists' own connection to the West, the one I did not share: their (perceived) belonging to the global scientific community. While my interlocutors admitted, often in frustration, that it is difficult to 'keep track' with Western scientists and to stay relevant in international terms, due to lack of funding and semi-peripheral position of Serbian scientific community. By the virtue of science that they shared with their foreign colleagues, my interlocutors saw themselves as part of the same group as Western scientists – a group I did not and could not belong to. This created a complex positionality on the local-West axis between my interlocutors and myself:

	Me		AOB		
Local	Nationality and ethnicity		Nationality and ethnicity		Funding
West	Institution	Funding	Science	Scientific community	

In the rest of this paper, I will map the key components of my field work that touched upon insider/outsider tensions, often in relation to the local/West axis, as well as expectations that were put on me as a native anthropologist (from a Western institution) researching local science (with links to Western-dominated scientific community).

# 5.3 Access to Field Site

Gaining access to field site is traditionally understood to be easier for native/insider anthropologists: while issues with gaining access as a native anthropologist exist, the existing connections, shared language and culture, understanding of places, people and appropriate conduct – all of this can improve success at accessing the community and its people (De Tona 2006; Gaztambide-Fernández and Howard 2012; Harrington 2003; Kacen and Chaitin 2006; Russell 2005; Turgo 2012). However, it is important to gauge potential differences in access when it comes to research among scientists. For example, even a local person might not have a free and easy access to a scientific research institute. Performing field work at such a place might come with specific requirements that go beyond the well-established rules of everyday conduct in a given culture. Depending on the situation, a foreign

colleague (another scientist) might, under circumstances, have an easier access to the institution than a local non-scientist.

My access to the Observatory did not include these obstacles. I gained access to AOB through personal connections to one of the researchers, who has been my friend for years. While personal acquaintances are not mandatory for gaining access to the Observatory, such approach is seen as 'more natural' and produces more trust. This was enough for everyone, even those who did not know me before. Such a way of gaining access may not look so different to professional networking in the West, but there is an important, unspoken difference: an open, explicit emphasis on informality. The access is gained through a personal connection as a favor that is not expected to be returned; at the same time, the favor carried an unspoken understanding on how it should be honored. These unspoken expectations made an important feature of my stay at the Observatory, and I will come back to them shortly.

The ease of access and informality I experienced are indicative of two important aspects of the life at the Observatory. One, it provides an insight into the manners in which a research institute can utilize culturally specific norms in its operation: the informality goes beyond welcoming visitors to the Observatory and is an important aspect of teamwork and research. Two, and of crucial importance for this paper, it directly shaped my experience during fieldwork and relationship with interlocutors. The informal aspect of my access to the AOB had influenced people's views on me and had provoked trust and enthusiasm among them. It was a *proper* access, the one that signaled a shared understanding on 'how things are done.' It also reaffirmed my insider status in the wider cultural context, although I always kept my status as an outsider in terms of science.

## 5.4 The Expectations

Freely given access did not come with any formal expectations, nor was I obligated to provide any specific favor to people at the Observatory. However, there were unspoken expectations about my conduct, mainly related to the positioning of myself, a Serbian researcher from a Western university, and them, Serbian scientists working in Serbia. The unspoken, and, sometimes, openly stated, understanding of my role was clear. As a Serbian with ties to a Western institution, my role was to give the 'true voice' to Serbian scientists and to show them in a positive light. This 'positive light' meant what my interlocutors understood as an *honest* light: to show that Serbian scientists are capable, civilized

and 'normal,'<sup>22</sup> just like Western scientists. The assumption was that Serbia and Serbian people have such a bad reputation in the West, and that it was important that my research demonstrate that this stereotype was not true.

This was a crucial aspect of my insiderness at the Observatory: I was seen as an insider, a Serbian person who is familiar with the situation concerning the overall socio-political circumstances in the country. This understanding presumed that I knew what to say and how to demonstrate that AOB scientists are worldly people who perform science to international standards and have civilized behaviour and moral code. Even more than this: I was to show the truth of Serbian scientists achieving all of this despite lack of money and resources.

While none of my interlocutors articulated this goal in terms of giving voices to marginalized groups, this approach was firmly rooted in perceived power imbalances. My interlocutors were not particularly familiar with the concepts of identity politics and marginalized identities and positions, so they did not voice their concerns in those words. However, they regularly spoke about their place in the global scientific community and hardships they faced while attempting to do science outside of centers of power, the Global North. While AOB researchers, and Serbian people in general, do not perceive themselves as belonging to the Global South (Bakic-Hayden 1995), they firmly understand that they are not part of the West, either, and they know that they do not possess power and influence awarded to Western scientists.

This created very specific power relations between the interlocutors and me. By the virtue of my connection to a Western university, I was recognized as someone who can spread their – or, depending on the context, our – voice to the world. At the same time, I have to emphasize that I was never pressured into writing about a specific thing or presenting something in a positive way. There was no talk about a *correct* way to present these things. Nevertheless, it was assumed that I was to write about the AOB researchers in a way that would emphasize their truth: as competent researchers whose expertise can match that of the Western scientists, and who battle hardships such as lack of funding and other problems.

I must emphasize here that, for the most part, I understood what was expected of me, and I understood where these fears and expectations were coming from. I understood the fear of being seen as uncivilized and wild; this sort of bad reputation is something that has plagued the country since the 1990s. I must admit a certain degree of pressure that this arrangement had generated. While I always did the

<sup>&</sup>lt;sup>22</sup> References about normality are plentiful and carry a specific meaning.

best efforts to maintain academic integrity, and while I never promised to anyone (including myself<sup>23</sup>) that I would present things in a way that AOB people wanted to be presented, a certain degree of pressure was present. For what is worth, I did view my role as someone giving the voice to this specific group, although not necessarily in a way that the interlocutors themselves expected of me. The fact that these expectations and duties were completely unspoken and assumed as joined understanding did not make the situation easier.

This is particularly true in the case of things the interlocutors did NOT want me to write about. Most of the time, topics that my interlocutors did not want me to mention involved the poor state of the Observatory's building, built in the early 20<sup>th</sup> century, or some of the working practices the interlocutors saw as 'too chaotic'. I was told that it was best not to talk about them in order not to 'embarrass us *out there*.' This approach of cultural intimacy (Herzfeld 1997) was a common occurrence.

There was a common problem with taking photographs, for example. While I was granted the Director's permission to take photographs of AOB's interior and exterior, many of the interlocutors worried about the image this would send to the West. 'Why are you taking pictures of this dirty hallway? Look at that window, it is so old and can't be closed properly!' The reasoning was implied: do not show Westerners that we work in such an old building, with so little resources. This fear about possible portrayal and representation for the Western eyes is very similar to incidents that Verdery (2018) describes in the case of Romania: Romanians are also sensitive about what Westerners think of them and how they are portrayed by researchers (Verdery 2018).

To overcome this obstacle and gain approval for photographing, I shared stories that illustrated similar 'chaotic' occurrences from Canada. For example, I told an anecdote about heating not working in my office at a Canadian university. This story was met with surprise and disbelief; many people could not fathom something like this happening in the West. Upon hearing these explanations, most interlocutors allowed for photographs to be included: the fact that my potential audience knew what it is like to work in an older building was enough to calm people's fears. On more than one occasion, the permission was given with the words: 'you know them better; you know what you are doing.'

## **5.5 Communication Problems**

<sup>&</sup>lt;sup>23</sup> I perceived my work as me presenting my own culture to a different, more powerful culture. There was a pressure and ethics questions posed by me, to myself.

One of the interesting things during my stay at the Observatory was the attitude of AOB scientists towards my research. For the most part, Serbian astronomers do not collaborate with social scientists, and are not forced to negotiate trading zones (Galison 1997) with them. This created certain communication problems. Generally speaking, Serbian STEM scientists rarely have a chance to come in contact with social scientists, the way this is done in Research and Development abroad (Albert et al. 2008; Viseu 2015). Because of this, some researchers at the Observatory assumed (or decided) that my role should be promoting the AOB and Serbian science abroad. On the other hand (or perhaps because of the abovementioned assumption), some researchers assumed a different attitude: they tried to instruct me on how to do my research, or they offered advice on what needs to be done to make my research successful. The advice typically consisted of instructions on how to apply statistics or another scientific research method. Both men and women were the ones offering this type of advice, although men were more numerous. Similarly, when discussing gender in science, I was advised not to talk to individual people, but to trust the statistics.

These attitudes reveal that AOB researchers, at least some of them, felt that their knowledge of natural science(s) could be applied to any sort of research, including humanities. I must emphasize that the advice was offered unprompted, without asking about my research or its goals. Part of this attitude lies in a common sentiment towards social disciplines: a condescending attitude towards anything outside of STEM. However, the eagerness of certain AOB scientists to help with my research by making it 'more properly scientific' also speaks about their ideas of objectivity. This is hardly surprising, coming from STEM researchers, but it makes particular sense in the light of my perceived role at the Observatory: presenting Serbian researchers in a true light. I suspect that these attempts to shape my research were only partially done for condescending reasons: an important aspect of these guidelines was an honest wish to be represented fairly and correctly, and to be given a proper voice. What is interesting to note is that AOB researchers felt comfortable, even authoritative, offering research advice to someone whose results would be disseminated to the Western audience. It demonstrates AOB scientists' confidence in their own worth and knowledge.

Another issue in communication was finding a balance between topics and conversations that my interlocutors wished to emphasize, and those that mattered in the context of anthropological research. This revealed noted differences between expectations posed by my Western institution, and, on the other side, by local priorities. Early on in my research, it became clear that themes that are of interest and importance to my Serbian interlocutors are not necessarily those that my anthropological and/or Canadian (or, more broadly, Western) readers cared about. This had placed me in a precarious position of finding a balance and the best ways to approach my research. I felt, more on one occasion, that I had to juggle all these different things and translate from one "system" to the other.

For example, the question of gender and, more specifically, women in science, was a pressing topic of interest for the Canadian audience. The interest in these themes was apparent in both professional and informal conversations I have had in Canada. This interest is understandable: after all, low number of women in STEM fields is a well-recognized problem (European Commission 2001; National Science Board 2010; UNESCO Institute for Statistics 2020). This issue is often perceived as a global problem to the point of serious inquiries about what, exactly, makes women less interested in STEM fields (Etzkowitz et al. 2000; Ceci et al. 2007; Hill 2010).

This was a topic that my interlocutors, regardless of gender, did not find particularly interesting nor inspiring. It was, at least in part, due to the fact that around half (47%) of scientists working at the Observatory are women. This is in line with a general trend in Serbia: According to UNESCO Institute for Statistics (2020), women make 51.4% of researchers in Serbia. Similar results can be seen in the entire post-socialist and/or post-Soviet sphere (Glover 2005; UNESCO Institute for Statistics 2020): Eastern and Central Europe, Russia and former Soviet republics, as well as Central and South America. These areas are known for gender balance in STEM and consistently have high percentages of women working as scientists and medical doctors. A study conducted by the Institute for Philosophy and Social Theory of the University in Belgrade (2018) cites official Government statistics: 51% of employees in science and development are women, compared to 25% in EU (Delibašić and Fiket 2018), with a note that this number fails to take vertical segregation into account. Due to these circumstances, one of the most pressing topics of interest for my Western audience – women in science – was not something that my Serbian interlocutors, regardless of gender, found interesting at all, since to them, it was a normalized, non-controversial question.

'Doing science in a local way' was another theme I found difficult to discuss. This did not surprise me, but it made my research more challenging. Scientists working at AOB are astrophysicists, engaged in hard science and subscribing to ideas about objectivity and rationality (Fanelli 2010). They do not see their work and the way they approach science to be subjective or different than astrophysics done at other places in the world. 'The only difference is money,' was a common reaction to these questions. While they were quick to point out important power imbalances and hardships that stemmed from lack of funding, my interlocutors insisted that what they do is science, and it is 'universal everywhere'. In other words, they saw themselves engaging in science in exactly the same way as scientists in the Global North, and, for the most part, they felt they rightfully and completely belong to the global scientific community.

The abovementioned issues posed a methodological challenge during my research. My interlocutors found them uninspiring and, for the most part, 'non-issues.' This made it challenging for me to gather material on these topics, which was even more frustrating because I knew how relevant and important

these themes were for my audience. At the same time, this tension revealed a lot about how these factors influence what is considered important in Canadian and/or 'Western' cultural contexts. Finally, it influenced my own approach and my own thoughts about my field work and these specific topics. During the years of my research, I have faced, more than once, a challenge of translating the aim of my research and its importance between Serbian and Canadian/Western audiences. I have done this with various levels of success, and an unexpected result of my research was learning how to do this translation in a way that is understandable to both groups. This is a challenge that I am still perfecting.

#### 5.6 Conclusion: Who Are We, in Relation to the Global North?

As a Serbian anthropologist with ties to a Western institution, my interlocutors expected me to act as an ambassador and promoter of Serbian science. My role was to give a true voice to Serbian scientists and portray them in a positive light: to demonstrate that Serbian scientists are capable, civilized and productive, just like Western scientists. This chapter analyzes specific challenges and ethical questions that I faced: how to position myself and how to perform my ethnographic research.

I do not wish to imply that my experience was universal, or that it is a representative case of studying local scientists as a native anthropologist. However, it can serve as an illustration of the methodological tensions and complexities that may arise in this type of research. Two topics stand out: first, the expectations posed upon the researcher for protecting the community (TallBear 2014), which is a topic not limited to research among scientists; second, a complex relationship with the center of power, in this case, the global scientific community. Since the second topic is of particular importance for researching local science, and since it displays specific forms in the case of a native anthropologist performing said research, it deserves a closer attention.

A key topic that anthropologists performing fieldwork among local scientists need to address is the relationship(s) with the center of power (the Global North), and, in this case, the Global scientific community. This relationship is significant for all parties involved in research: the anthropologist, the interlocutors, the scientific institution, and the local culture as a whole. Examining relationships and complexities that are created and negotiated between the researcher and their interlocutors vis a vis these centers of power is necessary in order to access not only the anthropologist's positionality, but also to reveal important aspects of local scientific practice. The relationship that local scientists have (or do not have) with the Global North and global scientific community largely controlled by the Global North, is crucial for understanding local scientists and their work (Hwang 2008).

How do these issues affect a native anthropologist performing research in a local scientific community? The researcher's link to the center of power is inevitably important, and it will likely influence the way(s) in which they are perceived by the interlocutors. This (perceived or factual) link to the Global North can influence the researcher's insiderness/outsiderness status significantly; is a person with links to a Western institution accepted as 'one of us' by interlocutors? Does a person who live and work in the Global North, who possessed their financial standard and possibly a passport, too, be considered an insider? (Trzeszczyńska 2022; Turgo 2012). These are common issues faced by native anthropologists with 'Western links,' and are not specific for studying scientists.

However, in the case of local scientific community, the interlocutors and their institutions are also agents with links to the Global North, a relationship that needs to be examined during research, and one that can also complicate a native anthropologist's insider status. Namely, local scientists and their institutions are a part of a global scientific community, by the virtue of performing science (at least in the case of institutes that focus on 'mainstream', not to say 'Western' science, as the opposite of those that focus on traditional and local knowledge systems). Scientists outside of the Global North are commonly sidelined and marginalized in the global scientific community, but their work – their science – makes them part of said community, and they may aspire for a recognition and collaboration within this community (Hwang 2008). As a result, local scientists may feel a deep connection with said community, which leads to a complex relationship with the Global North; local scientists may see themselves as belonging to the same group, 'scientific group' as their colleagues from the Global North, or they may aspire to be accepted in that group. A native anthropologist will not be an insider in this group. Their interlocutors will share local culture with the anthropologist, but they might have (or perceive to have) a link to the Global North that the anthropologist does not possess.

If, then, we take (perceived) Western connections to signify power, and local connections lack of power, added complexities are revealed. An anthropologist or another non-STEM researcher cannot claim insiderness to the group of local scientists by the virtue of their lack of knowledge in science. However, local scientists may perceive themselves as members of the same group – 'scientific group' – as Western scientists. Perceived insiderness does not necessarily guarantee true belonging nor power, but it may be instrumental for the ways in which local scientists perceive themselves as insiders closer to their Western colleagues, than to a local anthropologist. And in many ways, they will be correct, since their shared belonging to the global scientific community cannot be ignored. The researcher's task is to carefully focus on these aspects of positionality and power imbalances, in order to assert how they influence not just scientists' work, but also their relationship with the native researcher. In short, an insider anthropologist studying local scientists must also take into account the

fact that local scientists might have a connection to the Global North in the way they themselves do not.

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**Part II: Collaborations** 

# Critical notes on co-production: empirical analyses on the sustainable mining co-design in Northern Brazil.

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#### 6.1 Introduction: Coproducing sustainability?

Facing environmental problems has become an increasingly complex endeavor, provoking demands for transformation in the current ways which science, policymakers, and the public collaborate. Implementing effective environmental policy requires the combined efforts of many disciplines and active interaction with stakeholders (Klenk et al. 2015). Interactive models of research are increasingly being adopted to understand complex environmental issues in recent years, making co-production an important point of intellectual debate and praxis in environmental governance (Lemos et al., 2018; Van der Molen, 2018). The notion of *co-production* has been applied in various disciplinary traditions as one such interactive model to approach the challenge of producing knowledge about sustainability by involving researchers and stakeholders in a process of dialogue, imagination, and collaboration (Lemos and Morehouse 2005).

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In this chapter we reflect on the co-production model in practice through a real-life exercise involving academics, artisanal miners, and civil society stakeholders. We will analyze a co-production workshop on sustainable gold mining conducted in the state of Mato Grosso, in Northern Brazil. Mining is an economic activity with a long history of environmental degradation and social problems in that country (Pfeiffer et al. 1993; do Carmo et al. 2017; Biller 1994; Veado et al. 2006). However, this activity is the economic base of many communities that legally practice artisanal mining in various regions of Brazil. The workshop was a 5-day engagement event held in the city of Peixoto de Azevedo, Mato Grosso State, Brazil. It involved 15 researchers, several local community leaders, artisanal miners and other stakeholders from mining companies and local authorities. The research team included members from various disciplinary backgrounds, including anthropology; geology; geography; economics; geomicrobiology; ecology and biology. This disciplinary diversity added a layer of complexity around establishing dialogue around defining sustainability and planning the workshop, as we will see below. During the event we discussed challenges and possibilities for building more sustainable mining practices in the area, as well as tried to co-produce research questions with these local stakeholders. One of the main challenges was to also understand their ideas of what sustainability is, or could be for their future, and that was what the workshop was built around. For this chapter, we aim to a) report on important lessons learned from the workshop with respect to co-production processes; and b) discuss key potential successes and pitfalls of the engagement exercise. We hope to add knowledge on how productive or not such co-production exercises can be, and hopefully also contribute to the ongoing dialogue on the place of co-production in sustainability research.

The chapter is organized in three main sections, besides the introduction and conclusion. Section 7.2 explores the model of co-production in theory, presenting the main conceptual lenses of the term in the areas of public administration, Science and Technology Studies (STS) and sustainability science. In section 7.3 we present the criticisms and limitations indicated by different authors in their analysis of practical co-production cases involving sustainable science. In section 7.4, we present the data obtained through participant observation in the workshop in the city of Peixoto and discuss the limits and pitfalls of co-production in practice considering the theoretical debates on co-production.

The analyses obtained through the study in the city of Peixoto Azevedo reinforce the importance of debating sustainability in close contact with impacted communities.

Nevertheless, there are local economic and political factors that impact the effectiveness of any co-production exercise, at least in the way that this type of theoretical framework was idealized in the manuals of research incentive programs in the Global North. If co-production must go beyond stakeholder engagement by scientists to the more deliberate design of societal transitions (Wyborn et al. 2019; Miller and Wyborn 2020), it will be necessary to take into account the social hierarchies and power relations that constitute environmental problems and frame certain visions of the future of local communities.

# 6.2 Co-production in theory

The notion of co-production has been applied in different disciplinary traditions, including Public Administration, Science and Technology Studies (STS), and Sustainability Science (Miller and Wyborn, 2020). Researchers, stakeholders<sup>28</sup> and science funding organizations have embraced co-production of knowledge as a framework to understanding and interfering in sustainability problems (Lemos et al. 2018; van der Hel 2016). Although the concept of co-production has become popular, its meaning varies according to who and how the concept is used.

In the STS field, the term co-production has relation to the constructivist notion that science and society mutually construct each other (Jasanoff 2004; Latour 1983; Shapin and Schaffer 1986). More articulately, Shapin and Schaffer (1986, p. 332) offered, in their work *Leviathan and the Air Pump*, a formulation of this idea: "solutions to the problem of knowledge are solutions to the problem of social order". In the field of sustainability science, the term co-production has been widely used by researchers from different areas, stakeholders, and science funding agencies to frame and solve problems involving sustainability issues through participatory mechanisms. In this sense, the idea of "co-designing" the research with stakeholders is proposed as a methodology that requires to create new mechanisms of participation, forms of dialogue and interaction between

<sup>&</sup>lt;sup>28</sup> We follow Lemos et al. (2018, p. 1) and define the term "stakeholder" as "individuals invested in and affected by problems and with whom researchers interact to co-produce knowledge". These include policymakers and decision-makers, public officials, practitioners, community members, resource managers and individuals whose livelihoods are informed by environmental science knowledge.

scientists, engineers, and stakeholders (Wyborn et al. 2019). In this normative proposal of transdisciplinarity, the aim is to create new forms of governance of environmental problems based on the principles of participation, reflexivity and responsibility (Norström et al. 2020).

In this chapter, our use of the term co-production relates to how it has been debated in sustainability science. Wyborn et al. (2019) suggests that co-production provides a means to an end: improving the *usability* of scientific information by those beyond academia who are looking to science for answers to sustainability crises. Creating usable or actionable knowledge, requires careful attention to the design, structure, organization, and dynamics of co-production processes. Therefore, the co-production process requires a long time and the completion of different stages of interaction which requires building trust, engagement, and co-responsibility among participants. According to Mcnie (2008), to co-produce requires process and approaches that can: a) assess user needs; b) translate, communicate, and share knowledge; c) support the production of social capital; d) construct capacity building; e) and requires leadership and organizational design. As stated by Lemos and Morehouse (2005, p. 1), producing usable science requires a broader effort to build "iterativity" that is "to build effective internal and external networks, including the capability to sustain ongoing flows of information and participation between science and decision makers" (Lemos and Morehouse 2005).

In terms of the outcomes of co-production processes, many authors consider that the interactive process can help define questions and relevant forms of argument (Kates et al. 2001); the collaboration of scientists and nonscientists may help to "incorporate values and criteria from both communities" (Cash et al. 2006); can engage multiple producers in a learning process (Cornell et al. 2013); and can achieve new forms of participation involving scientist, engineers and stakeholders in a interdisciplinarity effort that can produce knowledge that is "demonstrably usable." (Lemos and Morehouse 2005).

But co-production has not been without critique. As this literature booms, and calls for participatory, horizontal, and transdisciplinary forms of governance grow, there is still a gap in how such processes are carried out and thought through. Much of the literature is still aspirational or methodological, debating either for the need to conduct co-production or explaining ways to achieve it, without an explanation of how and why such processes sometimes fail (Turnhout et al. 2020). We believe that such discussions are important to both environmental governance and to considerations on how different types of expertise

relate to each other in collaborative practice. Such collaboration, be it inter or transdisciplinary, is laborious and many times difficult to direct in terms of achieving specific desired results. As a praxis, they involve relations of power internally (e.g. between disciplines with disparate epistemological or cognitive authority) and externally (e.g. involving actors and stakeholders with hierarchically different positionalities and access to resources).

In the example of sustainable mining discussed here, we will specifically address and reflect on a first phase of the co-production process as described in the literature: the codesign of problems, questions, and solutions. The co-design phase, according Wyborn (et al. 2019, p. 16), "sets the foundations for the process, and is a critical time for problem framing, relationship building, and the development of expected outcomes and means to realize them". During the 5 days of workshop, we reflected on how we could facilitate social learning about sustainability issues in local communities to start an initial process of co-production. The engagement workshop tried to promote creativity in generating new ideas and reframing problems. Despite these efforts, we observed pitfalls and limitations related to co-production in practice which the literature of co-production just started to understand empirically.

#### 6.3 The critique of co-production

The theoretical and conceptual elaboration of the normative proposal of co-production is found with some frequency in the form of manuals and principles that guide this practice. However, there is a lack of studies that propose evaluations of transdisciplinary research to understand what kind of results are obtained and what are the limits encountered by this model of science production. In this section, we will present some critical aspects of co-production practice to reflect more comprehensively on the mining case study. We will organize the critiques of co-production into three categories: assessment, procedures, and political and social factors.

#### 6.3.1 Assessment

How to assess the standard of co-production impact, particularly the connection between the research method and its social influence, is a first problem of co-production models. Hansson and Polk (2018, p. 2) consider that "while a lot of attention has been given to methods for transdisciplinary research, less attention has been paid to the quality of transdisciplinary research processes", especially, "regarding stakeholder participation, and its influence on the impacts and outcomes that are being evaluated". Following Wiek et al. (2014), Hansson and Polk (2018) argue that there is not enough empirical evidence on which aspects of participation are more beneficial to sustainability research.

Loeffler and Bovaird (2016) argue that it is evident that co-production faces a number of barriers related to the funding of this type of research and the adequacy of the evaluation criteria adopted by funding agencies. The funding and commissioning barriers occur "partly due to the lack of experience in managing systematic co-production approaches" and "difficulties in generating evidence of value created by co-production for people, professionals, funders, and auditors" (Loeffler and Bovaird 2016, p. 1015). The paucity of forms of assessment of co-production outcomes is a critical point because it makes it difficult to understand what is really being achieved in comparison with the traditional modes of science production.

#### 6.3.2 Procedures

Although co-production manuals bring detailed descriptions of how the process should be conducted in practice, some studies have shown that there are many weaknesses and barriers related to procedures. From the empirical analysis of 16 case studies, Lux et al. (2019) indicate that co-production projects fail on four procedural issues: a) in understanding the historical context of a problem, its genesis and earlier developments; b) in staying in relation with the societal problem and understanding the scope of action in societal reality; c) in reviewing the actor composition; d) in discussing not only "*how* to integrate different kinds of knowledge" but also "*which* knowledge to select (or to neglect) in the process of knowledge integration" (Lux et al. 2019, p. 186). The authors argue that co-production needs a reflexive approach, which proactively considers the dynamics of interests and concerns, the roles and responsibilities, the culture of collaboration within a project, and the connectivity with the addressed context of action.

Chilvers and Kearnes (2015) argue that the procedure of co-production needs to be accompanied by a reflection about what is considered as public participation in this process. The authors suggest that the co-production processes could be a form of reconstitution of public engagement in science in responsive knowledge. This means acknowledging and actively attending to the ways in which the production of local knowledges and diverse participatory practices are powerfully co-produced in relation to wider political contexts.

#### 6.3.3 political and social factors

How external political and institutional dynamics affect the diversity of meanings of relevance, credibility and legitimacy of co-production is another critical point in the literature. Goldman et al. (2018) critique a possible political avoidance and isolation of co-production ideas, asking if the co-production of knowledge is a depoliticized "instrumental" use for adaptation. The authors argue that the normative proposal of co-production tends to ignore how knowledge, power, and world-making practices are mutually reinforcing, and rather focuses on isolating the co-production of knowledge. According to Goldman et al. (2018, p. 6):

Many instrumental approaches to the co-production of knowledge fail to account for the various ways in which power differentials are reproduced within these processes and how, in turn, these shape what knowledge is considered authoritative within adaptation decision making. In this way, uncritical applications of co-production can serve to reinforce existing power dynamics.

Reflecting on the power asymmetries, Wyborn et al. (2019, p. 5) consider the risk of producing knowledge that has direct utility "to those currently in power and help to institutionalize particular problem framings, reinforcing the power of policy elites" or "those who have the time and capacity to engage, and thereby marginalizing those with less capacity or alternative perspectives". Lövbrand (2011, p. 235) identifies problems in the utilitarian interpretation of co-production and suggest "to expose and reflect upon the difficulties and potential problems" that may arise in this field. It is important to assess the conditions under which co-production makes sense. Klenk et al. (2015) reflected on power imbalances between technical expertise and local knowledge and point to the 101

important questions of whose knowledge is being co-produce, for which outcomes, to the benefit of whom, and who decides.

Co-production may fail to engage with the root causes of unsustainability (Abson et al. 2017) and certainly can't be seen as a panacea (Bovaird 2007). There are risks and costs for those involved in this type of project (Oliver et al. 2019) and institutional, organizational, and cognitive differences that can produce deviations from the paths preestablished by the co-production guidelines and principles and lead to unexpected results (Polk 2015).

Finally, we need to understand the local relevance of co-production and the real need of communities. Lemos et al. (2018, p. 723) alert that we need "avoid co-production becoming an end in itself, glossing over the very values and goals that often inspire scientists and stakeholders to engage with one another". The authors advise that it is critical to understand how and why co-production works under certain circumstances and emphasize the importance of avoiding highly prescriptive approaches that mostly focus on the process rather than on achieving desired sustainability outcomes. According to the authors, depending on the pressing issues of local communities, "not all co-production leads to inclusion, use, or desirable use and not all knowledge needs to be co-produced" (Lemos et al., 2018, p.723).

The example of trying to co-produce research around sustainability in mining in Brazil will illustrate some of the critical points presented above and demonstrate how coproduction in practice presents various challenges. During our exercise, we faced many of the problems mentioned above: in terms of procedure, the need to better understand power relations and inequities that play a role on the ground were very much a part of the limitations we detected after the fact. This ties in with the problem of properly considering broader political and social asymmetries that impinged on the issue of artisanal gold mining in Northern Mato Grosse state. This made us reflect on our own limitations in setting up and planning for the exercise, but also on what would be accomplishable through it. In terms of assessment, one major issue came to the fore: what was the idea of sustainability at play in terms of assessing debates around sustainable mining? As we will see below, conflicting ideas of sustainability were one of the major challenges we faced in assessing the results we achieved in the workshop.

#### 6.4 Co-producing sustainability? The case of artisanal gold mining in Brazil

In Brazil, artisanal gold mining or "garimpo" is any area where mineral extraction, usually gold, is carried out in small volumes by one person, a cooperative or association. "Garimpeiro" is the individual who works in the "garimpos", mostly poor people who receive a little profit of what they extract. In many cases, the garimpeiros are part of a production scheme of which they are just a form of cheap labor of associations and corporations. Although the practice of mining is permitted by law in Brazil (Law No. 11,685, June 2008), mining is considered illegal when it is practiced in protected areas without the consent of regulatory authorities.

The garimpo of gold in Brazil has been practiced since the 16th century and, since then, it has been generating conflicts between garimpeiros, indigenous communities and regional oligarchies that directly or indirectly control this type of activity (Godfrey 1992). In the 1980s, mining in the region of Serra Pelada, in southern Pará state, became an iconic example of how promises of easy enrichment through gold extraction can result in immense environmental and social tragedy. The area was invaded by thousands of people and the site quickly became the largest open-air mine in the world. The agglomeration of people in poor living conditions resulted in an unprecedented rate of crime and environmental degradation (Monteiro et al. 2010; Cleary and Cleary 1990).

Throughout history, garimpo has become a practice shrouded in suspicion of irregularities and discouraged as a form of development of isolated regions of Brazil. In the last decades, the frequent invasions of indigenous areas by garimpeiros and the use of mercury to mine gold – that contaminates the river water where the gold is extracted – made the term "garimpo" take on a negative connotation in the Brazilian newspapers that reported armed conflicts and massacres in the Amazon region (Modelli 2021).



Fig. 1: The town of Peixoto de Azevedo, Brazil (source: Massaro and de Theije, 2018, p. 620)

The town of Peixoto de Azevedo, Mato Grosso state, is currently prospering from mining but faces an uncertain future. More than 5,000 artisanal miners (garimpeiros, mainly associated with a cooperative) work in this region. Peixoto de Azevedo, a town of 33,000 people, was founded by garimpeiros in the 1970's. Mining represents approximately 60% of the town's economy. The communities, which develop in such areas, experience transient economic benefits from mining, but the long-term implications for social and public health, the availability of land for post-mining uses, and the economic well-being of communities are typically far from sustainable (Massaro and de Theije 2018).

# 6.4.1 Workshop background

The workshop was funded by the project "Implementing sustainability in artisanal and small-scale mining: the case of the Peixoto de Azevedo gold district, northern Brazil"<sup>29</sup>. The project took a place-based approach to understanding mining activities in the Peixoto region, aimed a detailed view of the sustainability challenges faced by miners and local communities. The challenge of this project was to establish the key priorities for achieving a more holistic approach to environmental and mining problems. This involved designing a co-production exercise involving experts and local stakeholders, to promote more participatory practices in mining and natural resource governance. Beyond Peixoto, some 467,500 people throughout Brazil are estimated to be engaged in artisanal and small-scale mining. There are likely many hundreds of thousands more Brazilians whose livelihoods depend on that activity.

As a first step of the project, a network of 15 researchers from the University of Campinas in Brazil and Cardiff University in the UK held a five-day stakeholder engagement workshop in Peixoto de Azevedo from May 20<sup>th</sup> to 24<sup>th</sup>, 2019. The workshop engaged with stakeholders through a series of thematic group discussions interspersed with plenary sessions to allow transdisciplinary aligned ideas to be discussed by as wide a group as possible.

The workshop was organized in five thematic focus groups: (1) Economy, (2) Environment, (3) Education, (4) Geology and (5) Social Action. Each group had at least one mediator to facilitate the discussion and one rapporteur in order that each group had written material and annotations of those discussions for further analysis. The groups were divided based on the expertise of the mediators, and on the work packages previously identified during project development. In the event, some groups were modified in response to attendance and engagement of stakeholders, for example the Education and Social Action groups combined after the first day due to low initial engagement with each group. Similarly, the Geology and Economy groups combined at various points throughout the workshop to capture significant thematic overlaps in the discussions of the two groups.

While each of the thematic groups proceeded in a slightly different manner, the broad structure for these sessions focused around three key questions posed to the stakeholders:

<sup>&</sup>lt;sup>29</sup> Newton Fund – grant number: GCRFNGR2\10458, 2018-2019.

1. What perceptions do the stakeholders have about the present situation in Peixoto de *Azevedo (related to mining)?* 

2. What visions do the stakeholders have for a sustainable future in Peixoto?

3. How can such a future be achieved (research needs)?

One of the major aims of this workshop was to also build a working relationship with stakeholders involved in artisanal and small-scale mining in the region. This was crucial to co-produce a series of research objectives to enable more sustainable mining practices to take place. Stakeholders came from a wide range of backgrounds and included: geologists; anthropologists; ecologists; garimpeiro miners; senior members of garimpeiro cooperatives; a representative from Ministry of Mines and Energy; junior mining companies; local government; social organizations working in favelas; academics from local institutions; representatives of indigenous communities.

# 6.4.2 Co-production dynamics and its limits

While the workshop had many important promises, including the overall idea of coproducing research questions with local stakeholders and the involvement of an interdisciplinary team, the actual putting into practice of the project presented many challenges throughout its dynamic. These include the preparation stage, which happened many months before the actual workshop; the practical workshop dynamics and processes; and the period after the workshop, which was marked by the Covid 19 pandemic. We want to focus here on the first two parts of the process: the preparation stage and the implementation of the workshop. While understanding the aftermath of the workshop would also provide interesting insight, the project was severely disturbed by the pandemic, which limited the continuation of the broader project of continuing our engagement. The research we planned and co-produced was ultimately not implemented, but we did manage to maintain important and close relationships with people involved. This failure is hard to analyze here because of the exceptional nature of the challenge posed by Covid. What we feel can really be further analyzed are the problems we faced

during the preparation and the implementation of the workshop. During the preparation stage, the challenges related to the different knowledge practices and understandings of co-production and sustainability at play in the team. During the implementation stage, the

challenges related more to the issues of problem framing and power relationships. These two factors do not illustrate all the issues that we could reflect on here, but they are important to the broader argument of this chapter: co-production presents limitations which are still poorly understood, and which present a challenge to harnessing its promise. Insofar as framing, one of the more salient issues was: what are the local understandings of a desired sustainable future emerging from the exercise, and how do they relate with the research we were proposing? This can be simplified as a contrast between sciencebased ideas of sustainable future as opposed to locally emerging views of these same futures, which often clashed in the co-production process. Many times, the visions and desired futures at play were radically different and even contradictory to what we were understanding as sustainability. This troubled a debate on sustainability we had developed at the planning stage: we had presented ideas and reflected on alternative paths of economic and social development long before ever setting foot in the city, and had our own, scientifically informed perceptions of the challenges and potential futures which could present viable alternatives for the local population. When faced with their visions and understandings, we were forced to review and reflexively question some of those premises.

In relation to power dynamics, the problem related to how we understood the local stakeholders and their relationships to each other. We had not prepared as well as we could have in terms of mapping power hierarchies and local conflicts which could impinge on the workshop and its results. Because the workshop involved very powerful actors (the miner cooperative; medium and large mining companies; federal and state regulatory agencies; and the mayor's office), which were in the same activity with marginalized stakeholders (miners from different cooperatives; local women; local representatives of civil society organizations; indigenous leaders), such hierarchies impacted in many ways our dynamic, and constrained what could be actually achieved in the process.

# 6.4.2.1 The challenge of interdisciplinary work

The workshop was prepared months in advance, and involved a diverse team of scientists, as mentioned above. Those came from different disciplines and had themselves different perceptions of what sustainability was or could be. One of the preparation activities we did before the workshop was to share those perceptions and knowledges among us, to produce a more common ground to work with, and to understand better the community we were going to visit. At the outset, problems with interdisciplinary work became very apparent, which have already been discussed elsewhere in such initiatives: as with other interdisciplinary projects, in this one there was a latent difficulty in working between disciplines, which was not an issue we reflected on deeply in the duration of the project. Studies of interdisciplinary collaboration, including those we have published before, indicated that issues of epistemic distance and differences which impinge on the work developed, and which are rarely reflected on (McCallin 2006; Monteiro 2018; Monteiro and Keating 2009). In this project the ethnographer (the first author of this chapter) was a member of a larger team but was not conducting ethnography of the project as such, nor was he in a position to introduce this debate to the broader team, given the objectives and coordination of the project mainly by the geologists involved.

One very interesting aspect of these preparation discussions which is illustrative of the issues of interdisciplinarity at play here are the different discussions we ourselves had about what sustainability was and what a post mining future might look like. While geologists were very much attentive to the issue of post mining development and use of industrial facilities (Limpitlaw and Briel 2014; Mborah et al. 2016), other members of the group were not familiar with that discussion. Meanwhile, economists in the team were used to talking about sustainability as it pertains to the 2030 Sustainable Development Goals (Weiland et al. 2021), while for others, like the anthropologist, sustainability was a term to be problematized, insofar as it potentially imposed specific institutionalized views onto local contexts.

Much of our discussion in this planning stage was spent in sharing knowledge about Peixoto and the local reality, as well as sharing our own expertise with each other. One of the members, a geologist, had previous engagement with the city and with miners, and had a research relationship with the miner cooperative. She was instrumental in both bringing us data about the local realities, as well as in organizing the event and inviting the stakeholders. Another part of the work was discussing sustainable futures, which were thought by us before the event as producing a future after mining. This imagination derived from our perceptions that mining was becoming less important economically in that area, and what we could as scientists help find more sustainable economic
alternatives along with local members of the community. As we will see later on, the actual needs and perceptions of the community clashed directly with this idea.

#### 6.4.2.2 Relationships and power dynamics

The dynamic of the debates between the stakeholders and researchers during the workshop varied greatly from group to group. Some groups were able to discuss the questions posed in a more organized or systematic way, while in others there was more listening to reports of stakeholders. Several constraints conditioned the process of coproduction in which the debates took place. Limitation of time for debates; the absence of participants who needed to work and could not attend the meetings every day; participants with a low level of education and illiteracy who did not follow parts of the process that involved reading and writing; difficulties of some participants in expressing themselves publicly; and the inequalities and hierarchies that emerged between public authorities, mining companies, mining unions and garimpeiros.

The workshop had a diverse group from what geologists call the mining ecosystem of Brazil: the artisanal miners and their cooperative representatives (two of them were present in the workshop); medium and small mining companies, who sent representatives; and governmental agents representing regulatory agencies. There was a huge disparity, as mentioned above, in power and access to knowledge: most company representatives and cooperative leaders had formal degrees and access to higher education. They were therefore able to interact with scientists in a very close way, and in some cases (as with the local cooperative in Peixoto) had years of previous contact with researchers.

The government experts also had degrees and would also speak from a place of institutional authority, as well as with the authority of scientific and technical knowledge. Local garimpeiros, one indigenous leaders and other community members were not able to speak with that same authority, and sometimes seemed to be shy about sharing their views. This became apparent as some opinions would be shared informally and not publicly during sessions. These details showed us how there were dynamics at play during the workshop which we were not attentive to during the planning stage and would have needed much more knowledge about local power dynamics and habits.

During the meetings, it was possible to notice that past relationships between stakeholder groups shaped the interactions between individuals participating in the process. Latent

conflicts between some of the stakeholders were detectable through what was said in public during group dynamics, as well as in informal discussions between public sessions or debates. Many of these we were unable to collect as data, as we did not anticipate the workshop to be a data collection moment but an interactive, co-production event. But many of those came up in public discussions, for example when one of the women talked about the pride they had about the garimpeiro identity, which marked the city and its history, as well as how they saw themselves. We had not anticipated the importance of the garimpo as a form of identity but were able to learn a lot during the event. This show once again the enormous potential of such interactions to form relationships and to foster mutual learning, but it was a warning about how we should carefully tread the territory of artisanal mining as much more than work or source of income.

This could also be observed in the way certain terms were used or avoided during debates. For example, the word "contamination" that many used to refer to the polluting use of mercury in mining. Contamination of soil and water with mercury builds a negative meaning related to mining activities in environmentally protected areas in Brazil, which was rejected by some of the participants. Among these areas are, mainly, the indigenous reserves. The sensitive nature of the terms "contamination" and "mercury" caused these terms to be avoided in the meeting. Again, their pride about their activity and their positive view of mining overall was something we learned during out interactions with them, and it ran counter many of the ideas we reflected on during the planning stage, where mercury and contamination were some of the key topics discussed as something to 'overcome' or 'mitigate'.

The rhetorical construction of a positive garimpeiro identity was a factor that marked several of the public speeches and informal conversations during the event. Aside from the women, as mentioned before, there were other moments when miners would question the criminalization of gold mining or of garimpeiros. This criminalization would come up, for example, when we wanted to bring up the issues of use of mercury, the indigenous people or even the urban dynamics of Peixoto. Each of these brought up controversial topics and miners would be very outspoken about defending garimpeiros as honest, working people. Brazil is a hotbed of environmental crimes, which may include illegal logging and illegal mining in indigenous lands, an issue which grows in visibility as the

pressure on indigenous reserves mounts (da Silva et al. 2023; Villén-Pérez et al. 2020, 2022).

Another important element of our interactions which placed limits on how co-production was able to develop was the presence in the workshop of groups whose interests, sometimes conflicting, may have further inhibited some exchanges or manifestations. At times, certain public agents avoided certain subjects in the presence of other authorities; this was either because of the presence of mining companies and cooperatives and arose from a mismatch in terms of how they perceived the importance of sustainability. We came to realize that we were experiencing several latent conflicts between the various groups that has limited the scope of the great economic importance of mining for that region (Brito et al. 2020) and the influence that the companies play in the local public power. The economic and political power of mining greatly affects what is authorized to be said in an open meeting and modulates the discourse and participation of those who have no power or who in some way benefit from mining activities.

The way garimpeiros' cooperatives organize their members and dialogue with them as well as with major companies and governmental entities is a highly relevant element for the social dynamics of the region. Garimpo Cooperatives are an important channel for dialogue between the population (prospectors and families) and public power, exercising an authority that conditions most other economic activities. The way they act is therefore of the greatest relevance for any actions in Peixoto, including research.

Another latent conflict relates to the indigenous people. The indigenous people are potentially involved with several implied conflicts. The history of Peixoto began with the famous gold rush in the 70's. At that time, the *Panará* indigenous people who lived in that region, mainly on the banks of the Peixoto River, were expelled from their lands. Since them, garimpeiros and farms had cut down the forest, polluted and silted up the rivers, especially the North Arm. The Indians saw the effects of disorderly deforestation, cattle ranching and 20 years of gold mining<sup>30</sup>. Despite the past disaster, nowadays some participants of indigenous groups defend the practice of mining in their land by their communities (BBC Brazil 2023). Although this idea does not represent all indigenous

<sup>&</sup>lt;sup>30</sup> Source: <u>https://pib.socioambiental.org/pt/Povo:Panar%C3%A1</u> access: 28 March 2023.

communities in the region, it demonstrates how the economy of gold mining permeates different interests in the region and shapes barriers to plan pathways to sustainability.

The previously mentioned power relations and the latent conflicts and interests influenced the dynamics of the debates during the workshops and influenced the participants' answers to the questions posed to the stakeholders. Such influence can be perceived in the characterization of the problems and their possible solutions, which basically focused on improving the technical and economic conditions of the region to continue the practice of extracting gold. The participants often claimed that sustainability meant better conditions for training specialized labor to work in mining; more data and information to guide and optimize mining prospection and extraction; improved urban infrastructure, less government bureaucracy, more formal education, economic diversification to reduce the dependency of mining, (including the agricultural potential of some areas); the necessity of legalize the activities of small-scale miners; recovery of post-mining areas, improved safety at work.

# 7.4.3 Envisaging sustainable futures for Peixoto

In general, the environmental problems involved and the search for sustainable pathways as part of visions of the future of Peixoto as we had envisaged during the planning stages were put on the back burner. The debates about environmental issues considered the importance of preservation of natural resources, from the rational use and conservation of water and soil to be the most important aspects of sustainability since they will affect directly or indirectly the achievement of other goals. A desire was expressed for the garimpeiros to achieve total substitution of mercury in beneficiation processes as part of a wider theme of remediating environmental liabilities. There was also discussion of ending illegal mining activity and using technological innovation to increase the efficiency of mining and exploration for small-scale miners.

The group suggested that these improvements would require more rigorous and efficient monitoring by mineral resource and environmental inspection bodies. In turn, this would require a step-up in professional education as such bodies are currently under-staffed. These environmental and regulatory improvements would enable diversified economic activity, which could take place in and around recovered mine workings. These discussions also included the idea of teaching sustainability in schools, what seems to be

a way of moving the issue away from the most urgent decisions involving sustainability, attributing concerns about the environment to future generations.

This way of thinking about sustainability issues reinforces current practices of mining that were seen as something which could be improved on and become even more productive. This ran counter to the debates we were having in the preparation stage: those were very focused on the idea of a post-mining moment, where people would have to find alternatives to mining. An illustrative example of this thinking is the proposal of a regional "center [for] jewelry and jewelry design" and the suggestion to identify Peixoto as a 'gold capital' that could promote geo-tourism in the region. It reveals thinking about sustainability and visions of the future that diverged greatly from what the scientific team (both Brazilian and British) had discussed, which involved a movement away from mining as a path towards sustainable futures in the area. In fact, the community made it clear that it *does not want to end mining* because it supports many families and offers employment opportunities and income to the local population. Therefore, it became clear to the scientific team that co-producing sustainability in the region produced results which were not anticipated, nor did they match what we as scientists had envisaged as desirable post mining perspectives.

Despite all the limitations we mentioned, the workshop proved to be a powerful engagement tool, enabling the forging of alliances with local stakeholders (Municipality, mining companies, regulatory agencies, local miners, indigenous leaders). At the same time, it was quickly apparent the limitation of our mapping process regarding local relationships: the role of mining cooperatives and the local inequalities are just two very relevant variables we did not fully anticipate. Their visions of the future were radically different from our a priori perceptions of what sustainable futures should look like for them. The synthesis that we produced from our debates included four topics where the community desired to have more research be performed:

- 1. Diversification of economy, with mining remaining as a strong component
- 2. High quality education and training
- 3. Low environmental impact from mining
- 4. Improved regulatory environment and social justice

This again illustrates how divergent the results of the co-production process were from what we expected to be viable research topics to construe sustainability in Peixoto de Azevedo. The workshop was an intense and rich learning experience, teaching us (scientists) about garimpeiro identity and pride, their history, local conflicts and local understandings of sustainable futures. It showed how limited our perception of the context was, and how much planning we needed to do to fully engage with them. At the same time, it also made clear how these radically different imagined futures might be a challenge for co-production to perform research: their topics and questions of interest were often very divergent from our own expertise; they demanded better infrastructure, access to services (health, education) and saw the workshop as an opportunity to express these wishes. As scientists, there was very little we could do in that respect, and that was made clear to them.

## 6.4 Conclusion

Participating in the building of this co-production was a powerful learning opportunity for everyone involved, showing the limits of how the scientific team interpreted the local context and also the promise of such exercises as tools of engagement with communities and stakeholders. It enabled the forging of relationships, intimacy and trust between local actors and scientists, albeit not in all instances. It brought together different stakeholders which would possibly not meet or interact otherwise, and clearly affected the local relationships. It made more explicit latent conflicts and power dynamics, which can be useful for further engagement efforts.

But the limitations we encountered were also important to reflect on what co-production could be or could achieve: the exercise proved how limitations in the planning stage condition results of the workshop, as in the way many conflicts and elements of history were not anticipated. It showed how these dynamics of inequality and hierarchy condition what can be achieved in such exercises, as they condition how actual conversations can happen during an exercise, how voices can be heard and silenced, and how certain topics bring up disagreements over what the local problems (and their solutions) are.

There were also problems of knowledge that emerged: a central aspect of our experience was the divergent meaning around sustainability that we encountered during the planning stage and during the actual workshop. Different disciplinary traditions envisage very specific understandings of sustainability and this was something that would need further reflection during planning and after. Also, the visions of future sustainability informed by these different scientific traditions are not necessarily aligned with spirations and visions of the future emerging from local stakeholders. These visions may actually sometimes directly contradict each other, as it was made clear in terms of how different actors saw the place of mining in Peixoto's future.

The analysis of the mining case in Peixoto de Azevedo points to the need for broader empirical documentation in co-production processes. This would allow for the redefinition of theoretical and methodological assumptions, based on feedback from specific practices. In the case of mining, it becomes clear how far we are from achieving effective co-production of science and sustainable governance. This holds particularly true when dealing with deeply ingrained local socio-economic models rooted in community history and a complex network of interests within the gold economy.

It's crucial to deepen our understanding of how to produce knowledge and sustainability in socio-historical contexts dominated by extractivism, where social inequalities shape relations between scientific groups and society. An important question to pose is whether co-producing in these cases might mean replicating such inequalities, even if notions like sustainability become part of the vocabulary and guide mining practices. It is in this sense that, as other authors have pointed out (Oliver et al. 2019), co-production could lead to irresponsibilities with stakeholders and become a more sophisticated form of coloniality. These aspects should be part of the evaluation of co-production projects, encompassing the observation of methodologies and practices within this research domain, as well as the resulting outcomes and impacts.

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# Engaging with a xenobiology laboratory as a social scientist: lessons, opportunities, and challenges

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#### 7.1 Introduction

Science and technology's power to shape and reconfigure our lives and the social fabric of modern societies is becoming more and more far-reaching. As a response, science governance frameworks have displayed increasing concern about the need to balance negative outcomes with values shaping "good" societies and worlds we want to live in (Jasanoff and Kim 2015). These frameworks share an inclination for anticipating and preparing for the changes that technologies may bring and extending decision-making beyond scientists and experts (Gibbons et al. 1994; Guston 2014; Schot and Rip 1997; Stilgoe et al. 2013), reflecting a new contract for science and society (Guston 1999). Frameworks of responsible research and innovation (RRI) have gained attention in scholarly and policy circles in the last decade, aiming to ask better questions about the role of science and society and aim for better societal outcomes (de Saille 2015); focused on implementation and policy relevance, with four pillars of anticipation, reflexivity, inclusion and responsiveness, RRI has given notoriety to "responsibility" as a key driver of the right relations between science and society (Stilgoe et al. 2013).

As the focus of this volume makes evident, the laboratory has been highlighted as a site to study the emergence of knowledge and power, together with locally situated visions of what emerging technologies should stand for and hope to achieve (Lucivero et al. 2011). The laboratory constitutes a space where decisions are made and research trajectories can be "modulated" (Fisher et al. 2006). In this chapter I examine the conditions in which social

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scientists may engage with scientists, adding to a body of literature that has aimed to successfully collaborate and pursue interdisciplinary outcomes. I argue that given the power asymmetries and barriers to breaking the boundaries between "two cultures," social scientists should focus as much on "integrating" as on understanding the conditions that restrain the type of research that is produced, including incentives, career pathways, and barriers for its modulation. This account is based on my engagement as an "embedded social scientist" in a xenobiology laboratory, in which the main goal was to understand the visions and imaginaries of this emerging field of synthetic biology, as well as the construction of biocontainment as a form of responsibility (Aparicio 2021). While I lacked an institutional affiliation to the laboratory I studied, that is, being hired by a facility or part of a research project, this allowed me to explore more freely the bridge-building and collaboration that can be sustained between social scientists.

Synthetic biology has provided a fertile ground for social studies of science and experiments in scientific governance (Balmer et al. 2016; Calvert and Martin 2009) as the acceptability of synthetic biology has become an important concern in policy circles (Marris and Calvert 2020). In the emerging field of xenobiology, a subdiscipline of synthetic biology, scientists explore whether the chemical and genetic basis of life could have been different, carving a place in society for novel synthetic organisms (Marliere 2009; Schmidt 2010). The expansion of the genetics of life that xenobiology raises questions about the relationship and duality between the natural and the synthetic, safety and technological design, as well as the management and balance of benefits and hazards that the field entices.

The goal of exploring life at its limits is not recent, as Langdon Winner remarked in 1990: "It now appears possible to renovate the genetic structure of life forms on the planet. But why? In what sense are such projects needed?" (Winner 1990, p. 60). These were among the leading questions that motivated my engagement with a Xenobiology laboratory. This chapter describes the lessons and challenges of a collaboration between the author and xenobiologists to bring new perspectives to the laboratory. First, I provide an overview of the literature on responsible research and innovation, ELSI, and post-ELSI, focusing on integration approaches between scientists, engineers, and social scientists. In the second part of the article, I address lessons, challenges, and recommendations for future engagements between social scientists and xenobiologists. In the last two sections, I delve into two issues I considered worthy of consideration in my engagement: first, access and distribution of the benefits and risks of

xenobiology, including intellectual property and potential users; second, the environmental impacts and toxicity of xenobiology outcomes. I conclude this chapter with a discussion of my engagement and future directions for collaborating in emerging biotechnologies.

## 7.2 Integrating the social scientist

Responsible research and innovation (RRI), as a meta-framework, aims to orchestrate existing mechanisms that broadly address responsibility in science and technology by incorporating societal values into practices of technology development. Responsibility can be understood as a concern with the purposes and motivations for innovation, as well as 'care,' in the sense of science and technology improving society and sharing its benefits equitably. Owen and colleagues (2013, p. 36) define RRI as "a collective commitment of care for the future through responsive stewardship of science and innovation in the present." RRI puts into question longheld roles and duties of actors in knowledge production, as well as the institutions, norms, and policies that sustain knowledge production, or research and development. It is about asking the right questions (e.g., about ownership, purpose, control, participation) and the framing of problems that need addressing. Unlike similar previous governance approaches, RRI focuses on the values that underlie innovation systems, more than assessing the ramifications or implications of particular developments. It favours an expansion of the type of actors involved in science, technology, and innovation activities (Von Schomberg 2013). Furthermore, it concerns the social relevance and framing of problems that are tackled in science, to make science a contributor toward sustainable and more desirable societies, and carry out experimental forms of participation in co-producing knowledge and social order (Stilgoe and Guston 2017). Although RRI frameworks have been integrated into policy circles, especially in the European Union (Zwart et al. 2014), questions remain about the distribution of responsibility among scientific and non-scientific actors, and how scientists interpret policies and programs for the advancement of science.

RRI scholars have highlighted the contrasts between narratives of responsibility and societal goals, with enactments of responsibility in the laboratory, which continues to be relevant for "upstream engagement." As Guston and Stilgoe (2017, p. 864) explain, "we should look not just to the novel activities taking place under this name [of RRI] but also to the ways in which scientists and innovators imagine their own changing responsibilities." For Macnaghten and

colleagues (2005), understanding the imaginaries shaping the development of emerging technologies (e.g., xenobiology) requires interacting and constituting reflexive relationships with scientists in the laboratory.

In the laboratory, questions of responsibility and research agendas are co-produced (Aparicio 2021), and responsibility is framed in "doable terms," addressable as a scientific problem (McCarthy and Kelty 2010). Scientists display their own "bottom-up" practices of responsibility, shaped by RRI and related policies, even if they feel such policies not to be aligned with their daily practices and goals (Glerup et al. 2017). Others have found that scientists' understandings of responsibility differ from those laid out in RRI national policies (Taylor et al. 2023). Nevertheless, focusing on the laboratory as a site where imaginaries are crafted risks obtaining a limited account of the values and visions of society that inform technoscientific development. Innovation and its effects not only are shaped in the laboratory, but in most institutions of society, including users and non-scientific actors. Such inclination to recognize the workings of science in institutions other than the laboratory has been at the core of the co-production literature (Jasanoff 2004).

The recognition of working closer with scientists in the laboratory has been encouraged increasingly in the EU (Rodríguez et al. 2013; Stegmaier 2009) and the UK (Balmer et al. 2016; Macnaghten et al. 2005; Stilgoe et al. 2013). In the US, it was a tenet of Nanotechnology policy, seen at the time as an opportunity to responsibly govern the emergence of a new technology and earn public trust. The 21st Century Nanotechnology Research and Development Act of 2003 introduced a mechanism for integrating social considerations and systematizing the responsiveness of laboratory practices to efforts of engagement with social scientists (Fisher and Mahajan 2006), aimed at influencing the dynamics of science (Rip 2006). The emergence of Nanotechnology also inspired similar approaches based on dialogue with scientists, such as Rosalyn Berne's 2006 book Nanotalk. Integration approaches take a further step, focused on managing the emergence of new technologies in society and the possibility of modulating research outcomes. Among these, sociotechnical integration research (STIR) sought to operationalize the collaboration between social and natural sciences by 'embedding' social scientists in a laboratory for a period of time, where they use a decision protocol (a template for conducting semi-structured interviews and orienting questions) to guide reflection on social and ethical dimensions of research and innovation in real-time (Fisher & Mahajan 2010). This is thought to lead to second-order reflective learning, prompting scientists to reflect on the

system and wider social and ethical dimensions, in addition to the technical aspects of their work (Schuurbiers 2011).

The efforts from social scientists to bring society back into the laboratory, so that practitioners of science and technology embrace reflection about the ramifications of their research, has had as a reference ELSI (an acronym for ethical, legal, and social implications)<sup>32</sup> policies that arose from the Human Genome Project, which allocated three percent of its budget to the study of ethical and social issues, aimed at ensuring that genomic science would be beneficial for society (Watson 1990); ELSI became later adopted in Europe for a variety of new technologies. Nonetheless, some have argued that ELSI failed to influence policy decisions (Fisher 2005), was too close to the funders, losing its capacity for critique (Zwart and Nelis 2009), and has promoted a moral division of labour, in which scientist do the science, and bioethicists look up potential moral issues (Swierstra and Rip 2007). For Hilgartner and colleagues (2017), ELSI constitutes a mode of governance, in which "Bioethics expertise often plays a powerful role in classifying issues as warranting or not warranting deliberation, defining the terms of acceptable debate, and establishing frameworks for evaluation and oversight." (ibid., p. 834). They criticize ELSI practitioners' lack of reflexivity about their own positionality, assuming that biomedical research (and technological change) is beneficial and unaware of its role in constructing publics and reinscribing fact and value distinctions.

Paul Rabinow and Gaymon Bennett (2012) were among the first to embark on what they called a post-ELSI mode of work, to overcome the deficits they perceived in ELSI frameworks. They considered their involvement in the "Human Practices" thrust of the Synthetic Biology Engineering Research Center (SynBERC)<sup>33</sup> an opportunity to undertake an experiment in collaboration. Similar to the criticisms exposed above, the authors sought to rethink ELSI's focus on downstream consequences and its inability to shape its object of study, too adjacent to scientific practice. Furthermore, ELSI takes for granted categories like society, risk assessment, expertise, and implications (Rabinow and Bennett 2012, p. 86), without asking how they come into being. Rather than consequences, Rabinow and Bennett refer to

<sup>&</sup>lt;sup>32</sup> See <u>https://www.genome.gov/Funded-Programs-Projects/ELSI-Research-Program-ethical-legal-social-implications</u> [last visited October 11, 2023]

<sup>&</sup>lt;sup>33</sup> SynBERC was a collaborative effort among several leading academic institutions funded by the National Science Foundation (NSF) in the United States, operating from 2006 to 2016. The national Engineering Biology Research Consortium (EBRC) initiative was launched to continue SynBERC's mission. See <a href="https://ebrc.org/synberc/">https://ebrc.org/synberc/</a> [last visited September 21, 2023]

*ramifications*, which reflect the multiple pathways that science may take, as the result of human choices and value commitments. Their efforts to develop novel "equipment" and experiment in collaboration with scientists at SynBERC were ultimately unsuccessful since the latter were not willing to learn or incorporate novel human practices, or challenge existing institutional structures–choosing instead to adhere to an ELSI, even an *Asilomar* model, as they call it. They attribute such failure to unequal power relations, in particular their lack of power and authority to influence the decisions and actions of scientists and other stakeholders at SynBERC.

Ana Viseu (2015) provided a similar personal reflection on her "failure" to integrate into a nanotechnology facility in the US, in which she focused on developing practices and relations of care. Viseu found through her role as an embedded social scientist, that integration meant not disturbing the work of nanotechnologists, allowing research to continue, while she addressed social and ethical issues, often understood as conducting public outreach. She describes integration as maintaining a divide between facts and values, in which nanoscientists are not willing to question their own assumptions and the implications of their work. Other commentators have found similar issues in their engagements, such as Robert Doubleday. In his integration into a Nanotechnology laboratory in the UK, he found his expected role as a mediator of the public, promoting engagement activities (such as NanoJury UK) that sought to shape nanotechnology as a public object, and a representative of public opinion for nanoscientists (Doubleday 2007).

Over the last decade, calls for rethinking the role of social scientists in have been made exploring new roles between researchers and breaking down disciplinary boundaries (Calvert and Martin 2009; Macnaghten et al. 2005; Stegmaier 2009). In 2012, Balmer and colleagues articulated succinctly a new vision for the integration of social scientists in their laboratory, in their post-ELSI manifesto.<sup>34</sup> Framed as experiments in collaboration, post-ELSI approximations have explored new roles and relations between researchers (Balmer et al. 2016). Such forms of collaboration have the potential to bring novel forms of critique in STS, encouraging open-ended perspectives in an experimental manner, without knowing from the start what the outcome of the collaboration will be (Calvert and Schyfter 2017). Social scientists have tended to have fixed roles, limiting potential aspirations as co-producers of knowledge, visions, and conceptualization of problems (Balmer et al. 2015). These roles that

<sup>&</sup>lt;sup>34</sup> See the post-ELSI manifesto at <u>https://experimentalcollaborations.wordpress.com/2012/07/03/towards-a-</u>manifesto-for-experimental-collaborations-between-social-and-natural-scientists [last visited October 3, 2023]

need rethinking, Balmer and colleagues describe, include being boxed in a position to bring public views to the laboratory (and avoid potential controversy); as "the trickster," using parody and irony to disturb and suggest alternative ways of thinking; and as a "critic," suspicious of new developments in science and technology, to name a few. As social scientists they have had to "play the chameleon" (Balmer et al. 2015, p. 16) and accommodate to different roles according to different expectations, shaped by power dynamics and affective relations. In short, Balmer and colleagues question the instrumentalization of social scientists for delivering public acceptance and meeting requirements from funders.

In order to develop better co-productive collaborative methodologies, they further suggest "five rules of thumb" (Balmer et al. 2016), which I summarize as follows: First, "collective experimentation:" engaging with scientists and engineers in their everyday work, attempting different ways of working together. Second, "taking risks:" the recognition that collaborating involves playfulness and taking risks, calling for different strategies to earn scientists and engineers' attention. Third, "collaborative reflexivity," reflects on the collaboration itself and the dynamics that emerge. Fourth, "opening-up discussions of unshared goals:" negotiate expectations and reach an agreement over what success would look like. Last, "neighbourliness," recognizing and managing differences, acknowledging vulnerabilities, and respecting each other. Altogether, these rules and previous reflections illustrate the difficulties and opportunities that arise in integrating social scientists with scientists and engineers in the name of aligning innovation with societal goals, which require a reconfiguration of power relations and the recognition of social scientists' contributions to science and technology projects.

Nonetheless, criticisms of ELSI and calls for post-ELSI have been taken with a grain of salt, as ELSI has evolved and adjusted to new technologies such as nanotechnology and synthetic biology. Bjørn Myskja and colleagues (2014) call for a recognition of ELSI's maturation, and portray it as more complex than what it is usually described, encompassing a plurality of methodological and theoretical approaches. They suggest that what they call "ELSI 1" has transitioned to "ELSI 2," incorporating many of the critiques and suggestions of post-ELSI proponents, and the label post-ELSI can deny the achievement and progress made in ELSI (or ELSA in Europe) so far.

The study I conducted in a synthetic biology-xenobiology laboratory was not intended to take the shape of an ELSI or post-ELSI mode of collaboration. Aware of the challenges social scientists face in their engagement endeavours, I aimed to understand barriers and constraints for shaping the research agenda of the laboratory, as well as the imaginaries of responsibility and desirable futures attainable through Xenobiology that emerged in the laboratory. In this chapter I provide a reflection of my experience collaborating with researchers in xenobiology, to foster reflection about their responsibilities and prospect of shaping society. In the next section of this chapter, I address the collaboration I undertook (as a social scientist) with researchers in xenobiology, drawing challenges and lessons for introducing reflexivity in the laboratory.

#### 7.3 Lessons and challenges of collaborating with a xenobiology laboratory

In my doctoral research I collaborated with a xenobiology laboratory in order to interrogate their narratives and imaginaries about the relationship between control and safety through biocontainment, the expansion of life in xenobiology, and its ramifications. The research I conducted also entailed 34 interviews with scientists involved in synthetic biology and xenobiology, and attending academic events (i.e., conferences, workshops, seminars) about synthetic biology and xenobiology, such as the second xenobiology conference (XB2) held in Berlin in 2016 from May 24 to 26.<sup>35</sup>

I spent over a year, between 2015 and 2017, as a participant observant in a synthetic biology laboratory located in a world-class university in London, UK, where xenobiology experiments were also conducted and collaborated with xenobiology researchers in Europe and the US. The group consisted of twelve members, including Master's and doctoral students, technicians, post-doctoral researchers, and undergraduate students. In this laboratory, I observed and conducted experiments, and participated in laboratory meetings and social gatherings. Contrary to some of the works I described earlier, my engagement with the synthetic biology laboratory was not part of a funded project and did not involve a contract. I was admitted to the laboratory by the openness of the principal investigator (PI) and their genuine interest in engaging with and learning about responsible research and innovation.

I originally planned to become an active member of the laboratory to co-construct novel narratives and visions about xenobiology, advice strategies for reaching the public, and make

<sup>&</sup>lt;sup>35</sup> The second xenobiology conference website <u>http://xb2berlin.isthmus.fr</u> is no longer active [last visited 12 August 2018].

the laboratory's research more open to critique and feedback. I thought it would be valuable to create a space in the laboratory to formally introduce these questions to the group in the form of a group discussion (similar to a focus group), so was given time in the weekly meetings where I could lead a discussion on topics of my choice. Over the course of a year, I led five discussions with the group, covering relevant topics for Xenobiology using material publicly available, such as films, podcasts, or recent news. For example, in one session we discussed an interview between science journalist Ira Flatow and Dan Mandell about their recent work in developing semi-synthetic organisms (Mandell et al. 2015).<sup>36</sup> In further sessions we discussed the BBSRC's "synthetic biology dialogue"37, scientists' views on synthetic biology implications for biosafety (Dana et al. 2012; Moe-Behrens et al. 2013), news about "animal free milk," (see Levitt 2016) and gene drives pioneer Kevin Esvelt's "scientific philosophy."<sup>38</sup> These sessions aimed to provide further elements to discuss the politics and ethical aspects of the group's ongoing work. They sparked lively discussions with the group which at times could go sideways, hence this took an additional effort for me to situate the conversation back into what could be considered relevant to their own work and Xenobiology as an emerging field. In what follows, based on my fieldwork I highlight a number of challenges and lessons to take

into account when it comes to collaborating with natural scientists and engineers to seed reflection about the outcomes of their research agendas, based on interviews and conversations with xenobiologists, and the study (and effort in engagement) of a xenobiology laboratory as a social scientist.

*Collaboration requires rapport:* an important factor in the success of my collaboration was the level of trust and rapport I was able to build with the PI and members of the laboratory. The PI granted me access to the laboratory and allowed me to reach other members of the laboratory with confidence, giving me a social license to engage with the group. At first, the group was not keen on having a social scientist on board following their steps and asking difficult questions about their decisions, but the approval of the PI proved crucial to earning the group's

<sup>38</sup> See Esvelt's website Sculpting Evolution for the latest version. <u>https://www.sculptingevolution.org</u> [last visited October 12, 2023].

<sup>&</sup>lt;sup>36</sup> Interview for the radio show 'Science Friday' (released January 23, 2015). See

https://www.sciencefriday.com/segments/scientists-engineer-bacteria-with-genetic-kill-switch/ [last visited October 12, 2023]

<sup>&</sup>lt;sup>37</sup> See the Biotechnology and Biological Sciences Research Council's report Synthetic biology: public dialogue. 2010. <u>https://www.ukri.org/publications/synthetic-biology-public-dialogue/</u> [last visited October 12, 2023].

trust. I was fortunate enough to build good relationships with most of the researchers, who were generous in sharing their thoughts and allowing me to observe their experiments, however, were busy most of the time and sometimes difficult to reach.

It has been suggested that the support of scientists can be aided by conducting useful tasks for the laboratory, for example helping with routine activities or bringing useful non-technical knowledge (for example about regulation or public opinion). I conducted tasks that seem routine for scientists, such as making *E. coli* 'competent cells,' cells that can receive a foreign plasmid (a standard procedure of molecular biology). Nevertheless, I noticed that researchers were cautious about letting an outsider (like myself) conduct experiments that could affect the results of their experiments (and their projects). Experiments in xenobiology were very complicated to perform and the researchers I followed spent a considerable amount of time developing novel techniques, which were highly dependent on tacit knowledge.

The reliance of successful collaborations on human factors is important to be considered in frameworks of governance like RRI that aim to operationalize interventions-making them systematic and repeated in different environments (like the STIR approach mentioned above)- or approaches that aim to standardize guidelines regardless of the context in which the collaboration takes place.

*Engagement with an extended range of stakeholders:* Given the awareness of the scientists of the laboratory that the place of biotechnology is increasingly scrutinized, they were interested in conducting meetings with lay people or policymakers. Nevertheless, given the limitations of funding and the scope of my doctoral project, I did not conduct workshops with citizens or other stakeholders. The creation of spaces for interaction is still an area of research in RRI (Stemerding 2019), where meaningful conversations between participants from different backgrounds and purposes can take place, with results that are policy-relevant and taken into account in policy circles. Regardless of the role of scientists in such interactions, it is important that they are receptive to different points of view, question their own research agendas (Stirling et al. 2018), and see consensus not as the end of the interaction–but as workable compromises (Swierstra and Rip 2007).

*Decision-making capacity of junior researchers:* early career researchers, including graduate students and postdoctoral associates, have limited room in defining the scope and goals of their project's outcomes (like publishing articles), or the research agenda of the laboratory. They make choices about entering a laboratory based on limited information that is available when positions are posted. Of course, there is flexibility in defining research outcomes, since

experiments not always work as expected, but projects often must meet results promised to funding bodies. As I explain below, often a constraint for "co-producing" the social and biological goals of xenobiology was that commitments had already been made to funders, and the PI saw little flexibility to change the direction of funded projects (Aparicio 2021).

In some laboratories the PI can be responsible for most of the paperwork involved in writing grants and managing projects, withdrawing future scientists from knowing the political context in which research takes places and funding is allocated. In this regard, graduate education and pathways for early career advancement could offer skillsets and experiences that reach beyond technical training. Increasingly graduate schools are often interdisciplinary and soft-skills training, which could provide a picture of science policy and the complexities and challenges of doing science in a competitive environment. Nevertheless, students should use skills in their own research environments so that these skills are consolidated.

*Cultural and historical knowledge of the life sciences:* discussions with synthetic biologists and xenobiologists could benefit from awareness about historical events in modern science, such as the unfolding of the Asilomar conference of 1975, the development of the Polio vaccine by Jonas Salk (which was not patented), the controversy associated with the patenting of BRCA1 and BRCA2 genes by Myriad Genetics, the legal dispute over ownership rights to foundational patents for CRISPR-Cas9 technology, or the genetically modified foods controversy in Europe in the 1990s, to name a few. Some researchers I interviewed had heard about these and other events, but not with sufficient detail as to have conversations about the governance or political factors involved. For example, Asilomar was described as a successful meeting in which scientists took the initiative to self-regulate (Gisler & Kurath 2011) and lay a successful future for the emerging biotechnology industry.

I suggested to the laboratory group to have a "reading group" about the recent history and governance of biotechnology, and even offered to lend some books, such as Michael Roger's (1977) *Biohazard*, which documents his participation at the Asilomar Conference of 1975. Participants seemed genuinely interested in these topics and willing to learn more, but often used as an excuse being too busy with their research to add an additional layer of readings , not relevant to their day-to-day research. Moreover, introducing these topics in the few spaces I had in the laboratory's weekly meetings was not sufficient to address cases of biotechnology's history with sufficient depth.

The quality of conversations would be improved if there were shared narratives and stories over which to reflect. We often make decisions and define positions on topics based on collective narratives, which must be scrutinized to reflect their biases; for example, the rationale that if the public knew more about science, they would be more receptive to it. A role of social scientists is to introduce such knowledge and awareness to the laboratory, even if they are not scientific matters that will impact day-to-day experiments. Given the limitations in the time and attention of scientists, engagements would be more productive if this knowledge was imparted in other spaces, like undergraduate and graduate education.

Alignment of the scope of the collaboration with social scientists: natural scientists, engineers, and social scientists carry different assumptions and understandings of responsibility in science and ramifications that may need consideration, what Balmer and colleagues (2016) refer to as "opening-up discussions of unshared goals." Collaborations should have as an early priority to reach a mutual understanding between participants involved (for instance, in a laboratory or multi-institution collaboration) of the goals and scope of the research project, as well as its limitations, outcomes, and relevance. Such alignment should aim for the recognition of the natural scientists of the relevance of the work of the social scientist, and for the latter, recognize what natural scientists may gain or benefit from by engaging in a collaboration. This is important because the result of the collaboration should be useful for the natural scientists involved and reflect the worldviews of the researchers who participate in the engagement.

Misinterpretation of scientists and engineers: methodologically speaking, the social scientist could misinterpret the data collected during fieldwork, the result of observations, interviews, and spontaneous conversations with researchers. For the social scientist, not being self-aware of their own biases and ideas brought into the analysis can lead to exaggerating or misunderstanding perspectives and ideas, leading to faulty analyses. In other words, the researcher risks looking for dynamics that have been described already or looking for what the researcher is expecting to find, without these reflecting the world of the laboratory studied. A way to overcome this limitation is to discuss recurrent topics with researchers, so that consistent points of view can emerge. A second recommendation to ensure that the analysis better reflects the social environment under study is to share texts (drafts) of preliminary analysis with the researchers that were studied, incorporating in the analysis their points of view about the analysis. Scientists are usually too busy to take part in such activity, but some will do so because it is also in their best interest that the text reflects their world properly. This makes the analysis of data longer and more difficult but increases the quality of the picture reflected. For example in my doctoral research, I made the argument that xenobiologist's metaphor of "navigation," away from the biological world (Marliere 2009), was implemented by testing the limits of what is biologically possible, insofar as the entities they worked towards in the laboratory were conceived as safe (Aparicio 2024). Sharing this analysis with the PI was revealing since the PI provided a different understanding of the metaphor, as they wrote in an email:

A metaphor of people walking in the fog (so back to navigation) could be a suitable metaphor for how the team operates. We can start with a vision, which would be equivalent to a map sketched out in a post-it note. The group knows the desired destination but any one member walking too far gets lost and makes the navigation that much harder. The strategy (and I think you can confirm that in survival guides) is for members of the group to take just enough steps to remain visible to the group and a decision is then made on the knowledge that they acquire at the 'forefront'. Maps are improved (and with that the vision and the deep thinking) but the decisions have to be made locally (the how to, the results).

Hence, in what I considered a project of re-understanding the relation of the natural and the unnatural and the norms for experimentation (ibid.), the PI was more concerned about how to ensure responsible decisions were made over a long time, with a rotating group (doctoral students and postdoctoral fellows) that did not necessarily create the vision for the laboratory or had access to the bigger picture.

In a conversation with a member of the laboratory I studied, after I had finished fieldwork, I asked whether my involvement with the laboratory had been useful. The researcher told me that I had brought new ways of thinking about the research they were conducting, questions that had not occurred before I introduced them. A difficult challenge is to move past the 'craft' aspect of collaborating, to have engagements that are relevant, with enduring results, and influence the research trajectory of emerging disciplines, to be more aligned with societal expectations and needs.

In the next section of this article, I provide an overview of two considerations about governance that I brought into the laboratory I studied, important for the responsible emergence of xenobiology. I kept these considerations as points of reference to hold discussions with members of the laboratory. These were not the only considerations I discussed with the laboratory, nor the only ones that deserve reflection in xenobiology or synthetic biology. The first concerns the extent to which xenobiology is a field where diverse actors can contribute, and whether the benefits of the field are constrained by a motivation to privatize knowledge. Secondly, the assessment of risk in xenobiology in its early stage, particularly the 131 environmental toxicity of xenobiological reagents. In the account that follows, I emphasize points of view that researchers shared (which are not representative of the xenobiology community) and barriers to reflection about such considerations that I encountered in my engagement with a xenobiology laboratory.

#### 7.4 Access and distribution of benefits

Xenobiology offers the possibility of 'containing' xenobiological systems (or synthetic organisms), making them dependent on artificial nutrients for functioning or surviving, whose production is controlled by owners of technologies or know-how, or providing 'semantic containment,' the impossibility of microorganisms 'reading' different genetic codes (Herdewijn and Marlière 2009; Schmidt 2010). Biocontained systems can concentrate control in the hands of few researchers or owners, raising concerns about the interests and goals of those who benefit or produce them. This can lead to lock-in scenarios (Arthur 1989), in which the trajectory of xenobiology restricts alternative pathways to those that have been initially set.<sup>39</sup>

Some of the research carried out in the laboratory I studied was intended to be patented, so one of my aims was to question the extent to which patenting developments in xenobiology was a responsible choice (Aparicio 2021). Xenobiology is inherently a technology with reduced access, for example, XNA reagents, enzymes, and assays need to be procured from existing owners of the technology or XNA resources. This raises questions about the role of patenting in xenobiology, since it may limit the distribution of benefits, and embeds questions about the public good. The assemblages that xenobiology enables can potentially concentrate 'control' in the hands of few researchers or owners, which raises concerns about the interests and goals of those in power. The scientists involved in biocontainment and xenobiology control the production and distribution of a synthetic amino-acid or XNA nucleotides. For instance, in an interview, an established synthetic biologist in Europe commented that "everyone can synthesize DNA, and everyone can produce these compounds, not everyone, but is relatively

<sup>&</sup>lt;sup>39</sup> Scientists involved in biocontainment and xenobiology control the production and distribution of synthetic amino-acids, or XNA nucleotides, hence controlling what direction the field will take, and what type of applications are developed, as well as who can develop them.

easy to make this synthetic biology at home or with very basic equipment, as compared to other fields of science." He further comments that for xenobiology approaches, matters of control are different: "perhaps this interest in making bacteria or making some organisms to depend on synthetic chemicals is connected to the fact that if you now are the only source of that chemical, then you have complete control on your production, right?" It has been claimed that an application of "biosafety mechanisms," like those enabled in Xenobiology, can be a physical form of protection of intellectual property. In their article about 'kill switches' for bacterial containment in synthetic biology, (Chan et al. 2015, p. 85) write that "in addition to its use as a biocontainment system, the Passcode circuit may find particular utility as a tool for intellectual property protection, where unauthorized growth of strains without the appropriate passcode molecules would induce cell death."

Hence, it remains to be seen whether the enforcement and policing of proprietary 'rights' of xenobiological systems remain a motivation for developing biocontainment features, designed to circumvent existing intellectual property frameworks. Hurlbut (2017) has previously described biocontainment as a regime of governance that he calls "governance by containment," in which features of law and regulation are embedded in biological systems themselves. These are the kind of dilemmas I confronted the laboratory with, to question technological trajectories that were more reflexive about the role of patenting in the life sciences.

During my participation with the laboratory, my goal was prompting reflection on the dynamics and tensions behind patenting, rather than challenge plans of patenting xenobiological systems. A theme that emerged from my discussions with the laboratory was that controlling access to xenobiology–either by patenting xenobiological materials, or not developing mechanisms for metabolizing XNA reagents–was vital for ensuring that xenobiological systems would be contained; biocontainment was seen as a responsible practice and ethical commitment, dependent on commitments to funding bodies and collaborators. In conversations with members of the laboratory, and other xenobiologists and synthetic biologists, patenting and access to xenobiology were seen as standard practice in the life sciences, necessary for career progression and delivering research outputs to society (i.e., in the form a biotechnology startup). Noteworthy, some of the concerns that participants raised about my engagement with their laboratory was that I could share the results of their research with other laboratories or give away plans for patent applications. It became clear to me that decisions about patenting or not were in the hands of the PI, and members of the laboratory were enthusiastic about patenting, since it would provide equivalent weight to publishing their research. As I have described before (Aparicio 2021), the PI explained to me that decisions on patenting or not were subject to the collaborators he was working with, and the initial agreements that were in place. In principle, the technologies that are developed could be licensed, but licensees would "not develop a way of metabolizing those [XNA] nucleotides. [Licensees would] accept that you will not develop a way of manufacturing those nucleotides in vivo, because that would break the containment." Thus, the PI was conscious about unknown outcomes that were beyond his control, according to his concern that the containment that xenobiologists worked hard to build could be dismantled if an XNA metabolism were developed. This reasoning made sense and went in the opposite direction to the spirit of making xenobiology more open and accessible-the more accessible, the less reliable its safety features would be. Putting xenobiology's aspirations of safety aside, it struck me how normalized the goal of patenting was in the laboratory I studied. I did not notice occasions in which the benefits or purpose of patenting was put into question, at the expense of more open models of science. Patenting has become a feature of the life sciences, encouraged by universities that reward entrepreneurial scientists who found companies and bring to the market what once was considered basic research, an ethos that has dominated biotechnology since its inception in the 1970s (Rasmussen 2014).

#### 7.5 Testing environmental risks

Synthetic biologists and xenobiologists work towards a vision of biocontainment as a strategy to enable the release of microorganisms in open environments. Environmental impacts and sustainability have been a long-standing concern in democratically oriented technologies (Sclove 1995), including toxicity, an important concern about safety in disciplines related to xenobiology like nanotechnology (Kelty 2009). One of the topics I discussed with the laboratory group was the environmental impact of XNA-related materials and xenobiological systems; such concern has already been expressed by synthetic biologists, who have pointed out that environmental release presents uncertainties and can give rise to unintended consequences for the environment (Dana et al 2012; Moe-Behrens et al. 2013). In a similar vein, xenobiologists have voiced concern about the unknown potential harmful effects of

xenobiology–related chemicals on the environment. (Schmidt and de Lorenzo 2016). Following xenobiology's unknown effects on the environment, particularly if a goal for the field is the release of synthetic organisms or biological systems (Schmidt 2010), I brought these concerns to the laboratory, asking whether testing toxicity should be a priority in the laboratory's research agenda. The conversations that ensued offered insights into how researchers think about risk and existing barriers to addressing these issues. As expected, a challenge for testing the impact of xenobiological reagents (e.g., like XNA or synthetic amino acids) in the environment was their short supply–at the time of the study they were not commercially available, only produced by collaborating chemists. Their synthesis is costly and only yields small amounts, which limits the type and scale of experiments that can be conducted.

In the discussions I held, I expected to spark the laboratory's interest in testing the environmental of compounds they were working with. However, such questions were tackled by focusing on evaluating the health hazards of XNA reagents. I was reassured that the laboratory worked with xeno-nucleic acids that have been derived from molecules that have been tested as pharmaceuticals in humans (e.g., anti-cancer agents), for which their toxicity to bacteria and eukaryotic cells has already been tested and shown as safe. Nevertheless, the principal investigator recognized the need to address safety, as he expressed in a meeting, "there is a track record in the field [the biotech industry] of things that are not safe." However, a different question is who is responsible for determining safety. In this sense, laboratory members discussed that the market would take care of safety, identifying products that do not meet safety requirements.

I aimed to push further the possibility that the laboratory would conduct toxicity tests of XNA reagents in the wild or conduct tests that would establish their safety. Agreement in different epistemic communities is required to define what types of experiments and standards should be used to assess impact, or the extent to which models of cell biology and ecology provide an acceptable estimate of hazards. The laboratory I studied focused on constructing xenobiological systems (or tools), which requires a different approximation to knowledge production, making novel biomolecular tools and systems. Hence, evaluating the environmental impact of the molecules the laboratory worked with involved a different set of expertise and understanding of what types of research to undertake. A researcher of the laboratory commented, reflecting epistemological limitations with the testing of XNA-related materials, that "you can test some things, but then, how safe is that? Where is the point where

you say, OK, this is safe enough? I'm happy enough with the results? Where do you get the 95%?" During discussions with the laboratory, a researcher made the point that because xenobiology was in an early stage, assessments of risk would be of little value at that moment. Rather, a researcher proposed, 'trigger points' could be established, similar to *stage-gate* models, in which decisions are made once milestones are reached through a linear process. A researcher also added in a group discussion, that "the only way to prove there is no risk, is by testing every organism on every environment, on every combination, which is unworkable." These are questions about governance that cannot be directly addressed in the laboratory. It requires coordination on guidelines, standards, protocols, and other forms of synchronization between different actors, (Calvert 2014; Gorman 2012).

In a discussion with the laboratory group (as explained above), I presented the suggestion of Moe-Behrens and colleagues (2013, p. 7) of requiring that scientific articles in synthetic biology include a section to report "risk and biosafety information." I explained that the aim of this reporting card was to build the capacity to draw conclusions on risk and safety from a large pool of studies. A theme that emerged was the need for additional funding to conduct testing on toxicity, as grants oriented toward developing xenobiological systems usually do not include this aspect. Most funding agencies nowadays require the consideration of impacts of research in the proposals they admit, but do not consistently support a component of testing or evaluating the new materials or organisms that are constructed. During the conversation with the laboratory about the usefulness of requiring the reporting of risk analysis data, a member of the laboratory commented, referring to safety data,

It will only ever be taken seriously if somebody gives scientists money to actually carry on the experiments, otherwise... if there is a big consensus on the researchers, the funding agencies, the journals, everybody has to be enthusiastic about it.

During the discussion, another researcher commented: "Unless the [funding agency] gives me enough money to carry out those experiments, I'm not going to carry them out." The researcher added that conducting experiments needed for risk assessment is complicated and expensive. Such structural constraints for thinking about risk need to be included in a wider conversation about responsibility in science and xenobiology. Researchers do support measures like examining and reporting risk data, but it is not clear how institutions or cultural norms support such activities. In other words, assessing risk is not among the priorities placed on scientists working in synthetic biology.

#### 7.6 Conclusion

In this chapter, I sought to reflect on my participation as a social scientist in the xenobiology community, particularly on lessons and challenges for engagements between social scientists and natural scientists. Such effort seeks to promote further collaboration between social scientists and xenobiologists, provoking reflection about the role and responsibilities of scientists toward society, seeding terrain for a responsible discipline that delivers social impact. Successful collaborations require the establishment of trust and familiarity with the researchers, understanding the collaboration as a crossing of ideas about science and technology in society; when prompting reflection in the laboratory, particular attention should be paid to the ideas and meanings that scientists ascribe to responsibility and ethics of their own research as the starting point. Researchers may not be aware of frameworks of governance like RRI but enact their own conceptions of what responsibility in science means (Glerup et al. 2017).

In my collaboration with xenobiologists from the start I was aware that I would not be able to balance the power asymmetries that other engaged social scientists have reported (Rabinow and Bennett 2012; Viseu 2015), beginning with the lack of a formal affiliation to the laboratory I studied. As such, my project took the form of an ethnography and an "integration," in which I focused on identifying barriers to interdisciplinary collaboration and understanding the imaginaries that sit behind the unfolding of xenobiology. Having the support of the PI of the laboratory made it easy to have wide-ranging conversations about the politics of synthetic biology, and gave me the confidence to interact with the laboratory was too committed to the ongoing research projects to make substantial modifications, due to their obligations to other collaborators as a member of larger consortia, and to research funders. However, beyond these obligations, members of the laboratory were keen to discuss a variety of topics related to the biotechnology industry that I brought to the table, but were less willing to take ethical, social, and political considerations–like the environmental impact of artificial chemicals used in xenobiology–seriously enough to alter their daily practices and experimental designs.

Xenobiology reinforces a widely held narrative according to which research may continue as long as it is proven safe. The question of biosafety by containment is defined in terms of the tools available to solve it. It is far from optimal to solve problems with the tools that created them. The problems that xenobiology may create (i.e., toxicity and environmental impact) are evaluated with the same tools that scientists use to make XNA-organisms a reality. Proponents of the field bear the responsibility of reflecting upon the framing of the problems and solutions that xenobiology can address, the resulting promises and hype, as well as how research in the field reifies standard practices that can go against transparency, or avoid scrutiny, like patenting and commercializing biotechnological research. Nevertheless, the outcomes of engagements can only be evaluated in the long term. It remains to be seen whether laboratory members will delve further into some of the issues we discussed and were interested in, such as bringing the public closer to the laboratory and opening up the laboratory walls. Xenobiology can provide an opportunity for revisiting ethical and social concerns of biotechnology (Parthasarathy 2016), as well as writing new and fresh narratives about what kind of research society wants and what type of problems require solving with technical means.

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# Part III: Domination and Access to the Field
## White Coats and Carceral Bodies: Ethnographies of Multiplicities Behind Bars

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#### 8.1 Introduction

While Wacquant (2002, 2009) has called for more prison ethnographies, there are numerous challenges to conducting this type of ethnography, both external (e.g., permissions to do research, gaining daily access to the facilities, developing trust) and internal (e.g., emotional toll, re-traumatization). This chapter arises from ethnographic research undertaken in clinics in two New York City jails (Rikers Island), one for males and the other for females. Having worked in public health in the jails nearly a decade prior, I returned to complete my ethnographic dissertation research as someone between an insider and outsider. In working to understand carceral embodiment (both of staff and incarcerated people), the project drew out ontological multiplicities, while engaging phenomenological experientialities elicited through in-depth interviews. Here, experientialities refer to the sensory and affective perceptions of intake, with the importance of this drawing from the phenomenological tradition, and critical phenomenology in particular (Guenther 2013, 2018). This chapter also addresses the importance of the researchers' situatedness and sensorial and emotional experiences in and beyond carceral sites. Some of the primary methodological reflections gleaned here include:

It is important to differentiate between prisons and jails to understand the constant flux of my research site. While prisons hold people who have been sentenced for a crime, jails primarily hold

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people remanded to custody with or without bail to await their trial. This means that people are constantly coming in and out, as new people are remanded to custody and others are released, extradited to other jurisdictions, or sentenced to prison. This flux is present across the jail intake process, which is comprised of two interconnected processes – medical and *corrections* (i.e., tasks carried out by the Department of Corrections; DOC personnel). Understanding this process required engagement with incarcerated people, DOC corrections officers (COs), DOC captains, nurses, patient care assistants (PCAs), mental health counselors, psychiatrists, physician assistants, physicians, health care leadership, and specialty care physicians (e.g., cardiologists). This required a delicate dance in which I sought to understand not just the practices and processes, but also the experientialities. This dance attended to the formal power dynamics of both health care and corrections hierarchies, and the other forms of power that arose from experience, specialization, and/or interpersonal skills. I utilize the metaphor of dance across this chapter to convey the constant movement in relation to others. Here, the dance is high stakes and has rules and connotations that are everchanging and require impossible contortions.

To date, carceral ethnographies have primarily focused on incarcerated people. This is problematic when considering that the median length of stay for someone awaiting trial in jail is thirteen days, while staff may work there for decades (Scrivener 2021). The systems of datafication of newly incarcerated people across the intake process reflects the assumption that they are the ones who will be the subject of study and analysis. They have the least amount of power and are often characterized by the field of criminology as being aberrant in ways that the field perpetually seeks to characterize (Rafter 2009). This is not to say that the experiences of incarcerated people are not important to understand, they are, but it is also important to understand those of people who work in the jails.

Further, prison and jail studies of personnel focus far more on corrections personnel, again vitally, but this means that carceral medical staff are rarely studied (Castle 2008; Comartin et al. 2020). And yet, mass incarceration supports their livelihoods and the type of medicine they practice is profoundly impacted by the context in which they work. The field of correctional health care is typically framed by the problem of loyalties. The framework of dual loyalties is the most frequently used term and refers to the commitments health care workers in prisons and jails have to both their incarcerated patients and departments of corrections (Glowa-Kollisch et al. 2015). This is

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particularly true when health care workers are employees of departments of corrections. The newer triple loyalties, or triple aims, refers to the commitment that carceral health care workers have not only to their incarcerated patients and corrections departments, but also to public health (e.g., the spread of infectious diseases in the community – MacDonald et al. 2013). This addition of public health marked an innovation in the field and yet both frameworks erase the complexities and nuances of the power dynamics, relationalities, and context. My fieldwork grappled with these dynamics and complexities of the jail clinics.

This chapter begins with a summary of the methodologies I used and places them within the context of the broader history of extractive knowledge production that has taken place in American prisons and jails. Given the decades of routinized drug and chemical testing on incarcerated people, the power dynamics of knowledge production come to haunt any endeavor to study prisons and jails (Mitford 1974). For this project, this required careful attention to fluid positionalities and relationalities, and points to the ethical considerations and stakes of carceral research.

I then point to the delicate dance of gaining access and cultivating trust. Building upon these methods and approaches, I address positionalities and the implications of the history of extractive knowledge production in carceral settings. the monitoring of physicians, which reflects the high level of surveillance in the jails that goes well beyond just incarcerated people. This is followed by the gulley between corrections and medical professionals and approaches in the jails. It is also important to contextualize this in the "culture of violence" that ranges from the harms of the filthy environment to sexual harassment. These are vital to future conceptualizations of carceral abolition.

### 8.2 Research in Practice

In working to understand carceral embodiment (of both staff and incarcerated people), the project drew out ontological multiplicities, while engaging phenomenological experientialities elicited through conversations and interviews. I spent the most time in the Anna M. Kross Center (AMKC), which offered the opportunity to shadow the training of newly hired health care staff. This provided insight into the politics and hierarchies, some which were explicit, while others came to play out

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across their training. This training and supervised clinical care revealed how the bodies and minds of incarcerated people were parsed and made digital in the electronic health record systems. The ways to perceive, interact with, and document incarcerated people came to be conveyed and internalized across this training process. Beyond the medical power dynamics, the interactions and interconnectivities with corrections became of particular interest.

As I am not a medical doctor, nor do I have any medical training, observing physicians and physicians' assistants (PA) required a great deal of care as they were at the top of a hierarchy that I was not even on the first wrung of. This made the development of trust and understanding of my project vital. I find that Jefferson and Schmidt's (2019) accounts of prison ethnography comport best with my experience. They offer the term *craft* to refer to the "particular hyper-reflexive methodological approach" that is needed to negotiate boundaries and commitments to secrecy. These are spaces in which secrecy and self-preservation come to be conflated. They suggest that it is by "'doing trust" that relationships can be forged, and boundaries negotiated in carceral bureaucracies (Jefferson & Schmidt 2019).

Further, it is important to acknowledge that jails are inherently violent and harmful institutions and working in or researching them gives rise to impossible situations in which there is no way to know when it is best to intervene or how (Morin 2016). For instance, if I ask an officer about the person in the punitive cell who is bashing his head into cinderblocks, I risk them perceiving my question as overstepping or questioning their authority and *management* of the incarcerated person. This resentment could then lead to them keeping the person in the cell for even longer, to demonstrate their power. The implication is that the notion of ethnography as a passive process of watching, even if imagined to be possible, would be morally and ethically untenable (Boeri and Shukla 2019). There were countless times across my fieldwork that I had to intervene in large or small ways. To be in these sites requires not only a constant vigilance, but a nuanced calculation of how to handle situations and react. This becomes particularly challenging when trying to resist those with high levels of authority in their extremely hierarchical occupational structures. In truth, it is preposterous to think that one could research jails and not find themselves at least complicit, if not an active participant, even if unintentionally, in harms. Jails and prisons are racialized sites of oppression and violence, making any time in them punishing (Semenza et al. 2023; Sung 2010).

Lastly, it is important to make explicit that all details of the vignettes were changed to ensure confidentiality. The letters assigned to individuals were not the letters of their first or last names.

## 8.2.1 Ethnography in the Context of the History of Carceral Knowledge Production

When conducting research in prisons and jails it is vital to grapple with the history of carceral knowledge production. Incarcerated people have long been used to advance Western knowledge. To start, European understandings of human anatomy between the 16<sup>th</sup> and early 19<sup>th</sup> centuries was made possible through the sentencing of people to a fate worse than death – dissection (Mitchell et al. 2011). The bodies of those killed by the state were opened to understand the workings of human bodies, even while they were believed to be divergent or deviant *types of man* (Rafter et al. 2016). The search for criminality in the body came to form what would eventually become medical anthropology that established the construct of *homo criminalis*, or criminal man (Beirne and Bernard 1996).

This became reinscribed in the United States when medical scientists designing experiments were faced with the challenge of eliminating the influence of the environment upon their subjects. In the context of studying humans, this was a particularly difficult challenge. As American scientists sought a way to control for environmental influences and enroll an adequate sample size, prisons offered what was viewed as an ideal way to ensure that only the influence of the tested element was the cause of any differences (Mitford 1974). It undoubtedly also flourished due to the social status and perceived discardability of incarcerated people. This also furthered the notion that part of their *debt* to society could be *repaid* through their contributions to science (Mitford 1974). The concept of social debt arises out of capitalism and reflects the calculus that underlies racialized mass incarceration in the United States. Widespread testing on prisoners continued until 1974 when it was limited by strict parameters codified in the Federal Register (45 CFR 46).

This history of carceral knowledge production felt ever-present as I designed my research and entered the jails. Knowing this history meant an ongoing reflection and monitoring of power dynamics across this research. For me, this vigilance provided additional insight into the positionalities and relationalities of corrections personnel and health care workers. Ethnography is particularly well-suited to attending to power dynamics and has the potential to convey the perspectives and experiences of those who have historically been flattened into metrics and isolated data fragments.

## 8.2.2 Becoming a Shadow: Fitting into the flow

While gaining access to Rikers Island and then to each jail was a tremendous and protracted undertaking, the ability to understand the work of physicians and PAs required entirely different approaches to access. In the beginning, I assumed that once I had access to the jails that the problem of access would be solely one of trust building and deference. I, however; soon came to see that access was a complex dance that changed with each person, role, time, and setting.

Continuing with this analogy, I was taught the idealized version of the dance steps by health care leadership. I spoke with many of those who oversaw nursing and medicine through their administrator roles with the New York City Correctional Health Services department. In these conversations focusing on the intake process I was granted permission to "shadow" clinicians, nurses, and patient care assistants; and told the ideal version of the intake processes I should expect. Observing the training of clinicians provided different insights than if I were to have just observed clinical practices alone.

As I began to shadow the training of two physicians, I became part of the training group and was sometimes used as a sort of stand-in for *the layperson*.

Dr. R says, "we are doing a lot of diabetics, but not strategically." He emphasizes the difference between micro-vascular (eye, foot) versus macro-vascular (heart health) effects of diabetes. He notes that the best way to control macro-vascular effects is to control blood pressure with statins ... There is then discussion about whether Lantus should be given on a sliding scale or not, meaning that nurses are allowed to determine how much to give based on blood glucose levels. Dr. M says ... that the nurses have been coming to them and asking them to sign off on high doses of insulin as a form of backup, which he has not agreed to do. He then suggests that the nurses may be trying to avoid later questions, presumably during an M&M [morbidity and mortality review], when clinicians are reviewed and someone who is not an expert/ specialist says, "Oh his blood sugar was 400, and what did you do, nothing?" He then says that "the people reviewing these cases are like Ariel (me) and how would they know?" (Fieldnotes, 2017)

This was stated by a physician's assistant in one of the New York City jails. It is a statement that I simply accepted in the moment, but later came to see as providing vital insight into the health care hierarchies and the power of their expertise and credentials. It also points to the offsetting of personal liability, as well as the role of the layperson. This role was awkward when I was quizzed by a training provider. For instance, one day, we were quizzed on the HIV window period and how often a person should be tested. When I answered correctly and the training physicians did not, they were chastised for being bested by a layperson. This made responding to questions a challenge as I would try to predict how my responses could be used.

My layperson status for medical and pharmacy questions stood in contrast to the electronic record system component of the training. The two physicians were older, and I would sometimes be paired with one of them to assist with the proper steps needed to digitally document a medical encounter and its associated prescription ordering, laboratory testing, referrals, and follow-up appointments. This reflects the ways in which these digital practices remained outside of what was considered to be the expertise of clinicians. Instead, this was a place where age came to signify expertise.

#### **8.3 Monitoring Doctors**

As was pointed to in the prior vignette, the power of oversight and productivity monitoring was a perennial source of discontent. Physicians and PAs spoke frequently about the metrics used to track their productivity and appropriate documentation. They were monitored onsite by the Site Medical Director (SMD), a doctor, and the Health Services Administrators (HSA), a non-clinical role.

The HSA says that intake is tricky and dynamic and has been for a very long time ... He explains that he can monitor the intake process using the eCW [eClinical Works; the electronic medical record system] "intake registration console in real-time" ... He explains that medical intakes may not be completed on time for several reasons including the fact that DOC has a change of shift at 3:00, which means that health care staff can't see incarcerated people between 3:00 and 4:00 ... He says

that DOC may have twenty hours on the clock and saying that "medical is taking their time on the 12:00am to 8:00am tour. So, when the clock is running out, DOC presents a lot of patients all at once and jam them down their throats and I must investigate if on our clock a patient has eight to ten hours. Maybe it is because they have a STAT mental health, or maybe because of refusals to see medical. The clock starts for us when nursing checks the patient in at intake, but they still may not bring the bodies over from the pens for another two hours." This seems good in comparison to what I see every day, but I don't say that to him (Fieldnotes, 2017).

While the HSA is trying to return blame to DOC for the chronic intake delays, he not infrequently comes into the medical area and furiously hands out intake folders and demands that the health care staff see patients. In what is described by those in leadership as the "culture of punitivity," the levels of oversight manifest themselves at times in public shaming and in others in whatever forms of coercion were available. Despite this, part of the role of the HSA is to liaise with DOC in which they must defend the medical staff, while being responsive to HHC metrics. This is a delicate dance that takes place at the seams, a dance that I recognize.

While jails are known to be sites of intense surveillance and control, this is typically conceptualized as relating only to the people incarcerated within the facilities. The reality of spending time in these jails, as a researcher and as an employee reflects the far more diffuse nature of this surveillance. The constant monitoring and shifting of blame can be punishing and oppressive when it gives rise to shaming and "write-ups" by supervisors.

I found that this surveillance and punitive compliance monitoring increased mistrust of me as an ethnographic researcher. There was often suspicion that I might be there as another form of monitoring and would report my findings to leadership. This mistrust often persisted even after I would assure people that I would not collect or use any identifiable information, nor did I report to health care or corrections leadership. I am sure that my prior work experience in the jails compounded this perception, but it is important for researchers to be aware of the implications of the high levels of surveillance and monitoring in how they will be perceived, initial levels of mistrust, and the existing feelings about being observed.

#### 8.4 The Line between Corrections and Medicine

"It's DOC's sandbox, we just get to play in it." - A medical director (Fieldnotes, 2017)

The tension between corrections officers and medical staff loomed large over my fieldwork and it frequently required me to leave my role as an ethnographer and step in as a mediator and translator between corrections officers and health care workers. In part, I took on the work of mediation and translation due to my prior work experience and understanding of both corrections and health care roles, but this understanding was deepened across my research as were my relationships with health care and corrections. The resentment between health care and corrections staff begins with the training that health care workers receive from corrections officers.

The corrections trainer asks us why we think that we are not permitted to bring electronics in. Some suggest that it is because they could be used for photographing or recording, but she says that it is because they could be used to make "baby bombs." She says that "inmates are smart" and warns us that they know how to turn basic electronics into explosive devices. This seems like a highly specific knowledge and also goes against her opening statement that they just happen to be incarcerated and haven't been convicted of anything. She states that the most important thing is for us to act with INTEGRITY and repeats this several times.

She then goes on to inform us that neither staff nor volunteers can be on methadone maintenance because then we would be "stumbling around and the inmates would be able to tell" that we are "high." She walks around in front of us tilting and pretending like she is holding onto walls and stumbling. This makes me nervous given that my vestibular migraines would make me appear the way that she is acting. "Can you imagine being a nurse on methadone?" She does the stumbling and wobbling in front of us and laughs loudly. She goes on to say that if we do something wrong, she is going to have Officer J come and put the cuffs on us and escort us out because it is important for examples to be made of those who break the rules. She says again that if we get in trouble on Rikers we'll "be arrested right then and there (Fieldnotes, 2017)."

This statement is suffused with violences and identifies multiple threats – from incarcerated people and officers. The implication is that objects that are safe outside of the jails (electronics) become weapons beyond the gates. We are being trained to expect violence. Additionally, it is made clear that we are subject to the power of corrections officers and will be monitored closely. This monitoring is suffused by an intolerance of disabilities, not only are substance use disorders being discriminated against, but also other conditions that influence balance. It reinforces the precarity of access and, for clinicians, job security.

Violences are also reflected in the professional disjunctures apparent in the notable differences between the professional lenses of corrections and biomedicine. For instance, in the clinic a Captain who frequently curses and makes sexist comments about female captains who, he perceives, lack the physical strength to "restrain the inmates" speaks with me one day about his perception of mental health conditions (Fieldnotes, 2017).

The captain tells me that he believes that some incarcerated people "know what they are doing," clearly referring to the man in the "Why Me" [punitive] pen [that often holds people experiencing extreme mental health states], who has taken off his clothes and made a mess of bodily fluids in the cell. The captain has been tapping on the Plexiglas windows of the "Why Me" pen telling the man to put his clothing back on and to stop. The captain tells me that "sometimes they pretend they don't understand authority, but they do. They just act badly anyway." He says that he completed a course on psychology and is aware of mental health conditions but says that "some can control themselves." He then begins to talk about transgender inmates and says that "these days people can just choose what they want when they are here," and he's sorry but he's "just not buying it." He is called away but is clearly frustrated by what has become medicalized and how that removes it from his purview (Fieldnotes, 2017).

While this seems to indicate a tremendous gap between mental health frameworks and those of corrections, not to mention that he clearly sees being transgender to be a medical condition, the opinions of clinicians and officers are far more similar than different across my fieldwork. Despite this, it does reflect the gully between psychiatric and corrections frameworks and the additional harms that are done in the carceral context – by both fields.

Additional tensions were made visible when health care workers spoke about the benefits corrections officers get for working in the same environment that they do.

Dr. P gives an example in which he is the Warden that becomes a conversation about wardens and all DOC employees being eligible for earning half their salary from the three years in which they earned the most money if they work there for at least twenty years. They noted that this leads officers to work doubles [two consecutive shifts], triples [three consecutive shifts], and other overtime any chance they got to build up their pay for retirement. They note that this is not the case for HHC employees ... Dr. R talks about the lack of progress made by the American Federation of Government Employees, their union. Dr. P explains that before they were not earning retirement benefits or time towards retirement at all since they were working for a for-profit company (i.e., Corizon; Fieldnotes, 2017).

These benefits and lifetime pay incentives are often mentioned by health care staff as being unfair given that they are perceived as being "one paycheck away from being an inmate," which is meant pejoratively (Fieldnotes, 2017). The retirement benefits and the amount of overtime they can do are also spoken about by officers, but for them the pay is in exchange for the hardships that come with the job (e.g., being spit upon, verbal or physical assault) dealing with "human trash" (Fieldnotes, 2017).

Across my research, I had to be able to fit on both sides of the *thin grey line*. This meant that at times I had to intervene to assist officers or health care workers with tasks such as putting labels on cups of urine or escorting people from the jail intake to the clinical intake areas. This help was particularly needed when there was a rift between corrections and medical staff. Additionally, the resentment towards corrections officers varied based on the role of the clinician and their reliance on officers. For instance, for health care workers to go to the corrections intake area, they needed a corrections officer to escort them there and unlock the door. The power of keys is felt whenever they go missing or whenever a person with the key is not at work at the start of their shift. This inter-reliance across fields is a constant challenge that requires negotiation but is also informative.

#### 8.5 Studying a "Culture" of Violence

"Rikers is a highly effective plea [deal] machine." – Physician in a leadership position

This section addresses the ethnographic study of carceral violences and the way that it shapes knowledge production. Violence has come to be expected in carceral spaces, as an inherent component of incarceration in the United States. While violence is accepted as inevitable for incarcerated people, even part of their punishment, far less attention has been paid to the violences experienced by those who work, volunteer, and research in prisons and jails. Across my research, I found myself attending to conceptualizations of the culture of violence in the jails that were shaped by gendered, sexual, and racial violence as well as hierarchical power dynamics.

When police reform is demanded, "culture change" is frequently offered up as one of the first sites of intervention (O'Neill 2016; Paoline et al. 2000; White and Robinson 2014). The implication is that through training and support, the culture of the police departments will change, and injustices will vanish. This notion of culture serves to erase the structures, history, and incentivization of racialized violence. It also leaves police departments and their purview intact while offering a veneer of reform.

Culture is also presented as a site of reform for the New York City jails (Jacobson et al. 2018). For instance, carceral systems often tout becoming more therapeutic or biomedical. This can be seen in the adoption of, often minor, trauma-informed and gender-responsive reforms (Duley 2018; Jewkes et al. 2019; Wright et al. 2007). In this context, the conceptualization of culture is monolithic and ostensibly mutable through particular modes of intervention. While this was not an anticipated focus of this research, during my ethnographic work, it kept arising across people's accounts.

The question became what it meant to do ethnography that was both responsive to this assumed context and able to elicit perceptions and understandings of the culture of violence. While this was not a question I entered the research site with, its recurrence across my fieldwork made addressing it necessary. For instance, when shadowing the training clinicians, I observed the following.

Dr. O says that he wants to share with them some of the new health care changes as they are hoping to change the culture in which there has been tension between leadership and line staff, as now that the City took over healthcare provision they are all on the same team. "We are trying to change it from a punitive culture to one in which people can reach out when they're not sure what to do." (Fieldnotes, 2017)

While the author does not accept the conceptualization of *culture* assumed here, a lot can be learned about how *culture* is spoken about and understood in the jails. Here, the training physician is pointing to the accepted understanding of a "punitive" health care culture that has flourished in this carceral setting. It is also important to acknowledge the assumptions insinuated in accounts of culture, such as the implication that punishment is reserved for incarcerated people.

This assumption was undermined when considering that the *culture* of the jails and correctional health care differs based, in part, on a healthcare workers' position in the hierarchy, gender, race, ethnicity, primary language, and country of origin. For instance, the following occurred when a physician in a leadership position was speaking to a group of doctors and PAs.

"I never trust those [preliminary medical screenings completed by nurses]!" He says loudly. "Want to know why?"

"Because she's a nurse?" A doctor guesses.

"No, because she's a woman!" There is a smattering of chuckles. "Just can't trust 'em. Just like driving. Don't trust 'em driving either, not even my wife."

"You need a class man; you need a class or something." One of the physician assistants says laughing and shaking his head. I assume he is doing this because of my presence, but I have no way of knowing.

"Shouldn't be able to drive." His riff continues as if he is doing stand up for the physicians and PAs around him (Fieldnotes, 2017).

Gendered violence across my time working in and researching the New York City jails was not surprising. It did, nevertheless, reflect the power dynamics of my research site and what information was considered credible. Here the nurses' gender and their lower position in the clinical hierarchy open them to such comments. Moreover, their information and knowledge production are always open to being erased and overwritten.

The sexism was something that I had no recourse for as a carceral researcher. I was in his clinical space, and this physician had the power to make me leave. He knows that there is nothing that I can do. Even if I were to report this comment, there is such a shortage of physicians that it is unimaginable anything would happen. So, I sat there, and listened to him talk about women drivers and nurses. There was a female PA in earshot, and I felt a deep empathy for her. She did not look up, but it is impossible that she did not hear what was being said, and likely not for the first time. My emotional response was rooted in my helplessness, and it continued long after the physician in a leadership position returned to his office. It reminded me of the sexual harassment and unwanted touching that I endured from a PA while I was working in the jails years ago as everything was brought to the present. The New York City jails are a hard place to work or research for anyone, but they are even harder for women, non-binary, Queer, and trans people. These gendered violences are important for ethnographers to consider when planning their research. This includes accounting for the cumulative devaluing of knowledge produced by women and people of underrepresented genders over time.

While 90 percent of both incarcerated people and corrections officers are people of color, race and sexuality are both wielded like a weapon in the New York City jails. This is reflected in the rant of a female CO in the clinic that is in no way uncommon, but rather representative of the outbursts that typically occur several times a day in both intake areas.

In the background I hear a CO saying "fuckin' faggot ass dudes. I'm old-school, this place needs a purge! We need to get back in old-school ways. That's all they respect anyway. I knew it was bad when crackheads started crackin' it up (mocking the incarcerated man's movements and demeanor) 'I'm not steppin' in that pen.' One man come in actin' crazy and callin' me a Black bitch. I show him what crazy is. I cracked that nigga' so hard I dislocated my shoulder. Mad disrespectful though. Never got called anything racist in my life, called me a monkey (Fieldnotes, 2017)!"

Here, the sexuality and racial violences are loudly exchanged in the jail medical area. When speaking about the environment of the jail clinics, one of the new doctors says, "there is always

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someone banging, and the COs are always yelling (Fieldnotes, 2017)." This reflects an additional layer of violence that gives rise to a constant feeling of anxiety and distress. It is vital to acknowledge the sounds of violence (e.g., language, banging of heads on concrete walls or metal doors, banging on doors, fighting) that ostensibly become part of the background noise that people adjust to in the carceral setting. While I am told that someday I will stop noticing these sounds, that I will acclimate and my brain will tune them out, this does not happen as it becomes central in my ethnographic research.

Moreover, the physical spaces of the jails are also sites of dehumanization, even the clinics, which are less filthy, dark, and dilapidated than other areas. It is hard to convey precisely how and the degree to which physical space influences you. The sensory experience of the jails is not only harmful for incarcerated people, but for everyone. When you leave the jails, the smell of them clings to your skin and clothing. It is only after long showers and laundering clothing that you are at least mostly liberated from them.

The gruesomeness of the jails combined with the lack of ability to control one's work-life or surroundings cannot help but influence the experiences of health care workers in the jails. While the conditions of the clinical spaces are considerably more hygienic than the rest of the jail, their cinderblocks and thick coatings of paint are still degrading, as are the terrible odors. It is also worth noting that during intake, physicians are spared having to go into the corrections intake pen area, which is unbelievably awful, making its horrors evident only in the accounts of intake patients. Ethnography and its sensorial engagement with a particular place over time reveals violences and illustrates their temporalities. Who is subjected to violence, which types of violence, and for what duration of time are all vital to understanding punitive institutions.

Each of these violences reflects power dynamics and shapes what researchers can access and glean. Moreover, violences take an affective toll on researchers, making sites like jails difficult to research, particularly for extended periods. This toll is also likely to vary based on the characteristics of the researcher (e.g., race, gender, sexuality). The result is that the violences of jails have shaped the prior production of knowledge, and therefore what is currently known about carceral settings.

## 8.6 Conclusion

Ethnographies of prisons and jails remain vital to building an understanding of incarceration outside of White, Western regimes of carceral knowledge extraction. This is particularly important due to the history of extractive knowledge production that has characterized research on incarcerated people (e.g., the testing of experimental medications and chemicals). Despite the potential to resist this history, there has been limited ethnographic research in jails. Moreover, the ethnographies that have been done, have primarily focused on incarcerated people, which is important, but means that there has been scant attention to people who work in prisons or jails. This is of vital importance as people who work in the facilities are the ones who produce carceral information and knowledge (e.g., electronic record system data entry).

Doing carceral research requires continual hyper-reflexivity that spans from research design to analysis. This reflexivity takes on greater import in this setting given the power differentials and potential for harms. Relatedly, given the violences of this research setting, it is also important to attend to when and how you intervene. Such moments of intervention are reflective of specific violences and dynamics. The history of knowledge production in carceral settings has largely eschewed an engagement with reflexivities and disclosures of positionalities.

While gaining initial access to prisons and jails in the United States to do critical research is no small feat, access is another ongoing process. Across this chapter I have used the metaphor of dance to reflect the continual processes of *doing* trust. It is a dance that requires different steps and conventions based on roles and positions in hierarchies, amongst numerous other factors. It is an exhausting part of carceral research, but also an illustrative one. It also reflects how trust and positionalities influence what can be understood by researchers.

Further, given the high levels of surveillance across roles in the New York City jails, the role of the ethnographic researcher is more difficult. For instance, the productivity monitoring of physicians increased suspicions that I might be there to evaluate them and report back to leadership. This type of continual professional surveillance also shapes the texture of observation and interactions in the jails. Similar concerns about allegiances arose when negotiating the tensions between corrections and health care professionals. Building trust and spending time with both types of professionals meant negotiating the tension and blame that existed between them. It also meant stepping into the role of mediator when it seemed necessary to do so to mitigate harms.

My jail research also required perpetual negotiation of the punitive and degrading environment that made intake spaces feel like a tinderbox on the cusp of igniting. While physicians held the most power in the medical hierarchy, they remained engrained in this place designed to punish and fuel plea deals. It is important for carceral health care researchers to acknowledge the affective toll of the punitive environment on themselves as well as everyone in these settings. We imagine carceral borders and boundaries to be firm and implacable, and yet the bent towards punishment and public shaming characterize both the corrections and health care workplace. Punishments and violences are also more acute for some than others, often based on race, ethnicity, gender, sexuality, perceived mental health status, and seniority.

Ultimately, for the abolition of carceral facilities to be accomplished, the nuances, leakinesses, and violences must be delineated. The realities of working in prisons and jails is profoundly difficult and deserves being included in calls for abolition. However, such calls require research that provides insight into this experience from which change can be demanded. The history of carceral knowledge production has been largely extractive and taken mass incarceration as a given and necessary structure. This chapter calls for ethnographic carceral research that makes the researcher's positionality explicit and opens these sites to a future that is *otherwise*.

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# Tentacles of ethnographic conditions: studying biomedical research in the making at a high-security site

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We all know that we are interesting only relatively speaking; but we don't really know it; and secretly we believe otherwise. To be faced daily with the suspicion that actually you may not be interesting at all is a frightening circumstance to negotiate. First you think, it must be them, it can't be me. Then you think, No, it's not them, it is me. Getting to the third thought, it's not them, it's not me, it's the two of us together, that takes some diving. (Gornick 1996, p.122)

### 9.1 Introduction

The material and methodological conditions of any research matter if we aim to unpack the production of certain forms of knowledge and the spurring of particular writings or multimodal pieces rather than others. However, as evident as the above affirmation might sound, current academic writing leaves little room to think about such conditions. Regarding ethnography, Strathern (2018) has reflected on materials from Oceania on what she calls "the infrastructures in and of ethnography," the practical and ideational conditions that make a particular ethnography possible to be carried out in specific ways. In this vein, I continue the conversation on ethnographic conditions in this chapter, drawing on an ethnography conducted at the advanced therapies unit of a regional tissue bank in Spain involved in developing cell immunotherapy. For twenty months between 2018 and 2020, I conducted fieldwork with the unit workers. I followed the development

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of virus-specific cell production (an advanced medicinal product) as a targeted therapy for immunocompromised patients. The study was part of my doctoral dissertation, exploring the daily work, concerns, and practices around human-based biobanks (biological repositories) from the workers' perspective and everyday experience.<sup>42</sup>

The catalyst that led me to study biobanking practices in biomedical research echoes the observations of the historian and philosopher of science and medicine, Karin Tybjerg, who notes that collections of human material "constitute material and epistemic traces of the development of medical knowledge" (Tyberg 2022, p. 221). The ethnographic study of biobanking practices allowed me to approach biomedical research and knowledge production in the making while attending to its material logics and logistics. Driven by the ideal frameworks of ethnography and a previous year devoted to scientific policy document analysis, I wanted to be *there* and get to observe biomedical research in the making from such biorepositories and with their workers. Therefore, the research was born from my wish to "study up" - in Nader's (1974) terms - the biomedical supply chain. Given the flush of funding in different parts of the world for their establishment and the promises attached to biobanks since the beginning of the millennium, they became the selected site for such inquiry. In this case, studying up mainly refers to the site, the blood and tissue bank, and, more particularly, the unit of advanced therapies as a powerful institution due to its economic, scientific, and therapeutic promissory role and significance. A setting in which my positionality and capital put me in a weak position. Throughout this chapter, I provide a reflective account that unpacks access conditions as constant companions. Hence, I account for how such fieldwork was enabled and confined by several actors and two legally binding documents: a collaboration agreement and a non-disclosure agreement, to reflect on the tentacles of such access conditions in configuring the ethnographic work.<sup>43</sup> Following Strathern (2018), I differentiate in this chapter between the *preconditions* and conditions of ethnography in line with what she

<sup>&</sup>lt;sup>42</sup> In this chapter, I use the term *biobank* to refer to any repository that collects, stores, and distributes human biological samples and data with biomedical purposes.

<sup>&</sup>lt;sup>43</sup> I use the verb *configure* following Suchman's (2012) work: "An orientation to configuration reminds us to reanimate the figures that populate our socio-material imaginaries and practices, to examine the relations that they hold in place and the labours that sustain them, and to articulate the material semiotic reconfigurations required for their transformation" (p.58). Also note that I terminologically recognize the nuances between fieldwork, participant observation and ethnography in line with Jociles Rubio (2018) observations.

notes regarding the preconditions as "some of the 'outsides' of ethnographic research before they are, so to speak, positioned as explicit context to it" (p. 51). *Conditions* refer to "supports to the ethnographic enterprise" and (generally) having an infrastructural role (Strathern 2018, p. 51).

In what follows, I unfold the conditions that enabled and shaped my ethnography and explore some of their tentacles, and finally make a plea for a conversation regarding how ethnographers relate to such conditions that are particularly salient when studying-up in medical anthropology, anthropology of science and technology, or science and technology studies, but that almost no-one seems to recognize or wish to discuss. To do so, I first introduce two key preconditions of the ethnography, then flesh out the tentacles of two conditions configuring the ethnography in the form of two formal agreements of confidentiality and collaboration.

### 9.2 Ethnographic preconditions

Before delving into the material and relational conditions of the ethnographic work in the tissue bank, let's first attend to two critical preconditions: the research approach and the ethnographer's locale. One precondition concerns the project design, which focused on developing an ethnography *with* biobank workers *in* a biobank rather than focusing on donors or patients, as my research aimed to account for their daily work and perspectives. Medical anthropologists have been pioneers in developing critiques of the disposal of bodies and their parts in biomedicine (Scheper-Hughes 2000; Sharp 2000). The legacy of this approach around human body parts and samples has grown with the proliferation of an extensive body of literature in the social sciences that pivots around the figure of the "donor," their attitudes, practices, and labor in biomedicine and biotechnology (Cooper and Waldby 2014) and the bioeconomies (Pavone and Gover 2017). In the specific case of human-based biobanking, social sciences literature reviews have shown that these studies rely mainly on surveys and donor interviews (Argudo-Portal and Domènech 2020; Lipworth et al. 2011). A smaller number of qualitative studies include ethnographic work done *in* biobanks (Milanovic et al. 2007; Riso 2022).

There might be multiple reasons behind the unbalanced distribution of scholarly attention around donors' experiences compared to the ethnographic work done in and with biobankers. One reason is linked to the existing legacy of social sciences research on the commodification of the body. This has led scholars to develop an interest in donors' perspectives and relationships with their body parts. Until the last decade, the focus was mainly on the donors rather than exploring the biorepositories that collected, stored, and distributed such biospecimens. This approach cannot be disentangled from the tendency in anthropology of not "studying up" (Nader 1974). Another reason behind the scarcity of ethnographies *in* biobanks might be the obstacles to accessing biomedical settings, at least in Europe and North America. This restrictiveness increases when biomedical or technoscientific settings, such as a tissue bank, are considered high-security sites. Difficult access also affects junior scholars and women in particular ways. These obstacles cannot be cordoned off from the general conditions under which ethnography is done today by many researchers (underfunded research, ableist approach, lack of work permits for fieldwork, the reconciliation myth between work and personal life, etc.), as Günel, Varma, and Watanabe (2020) summarized in A Manifesto for Patchwork Ethnography. As I will show, the type of access and documents I signed to be able to do fieldwork in a tissue bank gave little room for flexibility and patchwork. Thus, the only fixed part of my research design, getting to be in a biobank and with its workers, became a precondition that, in turn, engendered specific conditions – some of which I unfold in this chapter.

The second main precondition refers to the professional and academic locale where I trained as an ethnographer and did fieldwork. Strathern (2018) noted that "the extent to which ethnographic research anywhere requires practical supports and is consequently embedded in diverse locales (whatever the locale is, and it need not be localized) should not be underestimated" (p. 55). I extend it here to the academic and training *locale*. Going into a biomedical or technoscientific setting to do fieldwork remains an exceptional practice in Spain.<sup>44</sup> As a sociocultural anthropology undergraduate at a public university in Spain between 2010 and 2014, I was immersed in the reflexive turn, worries about fieldwork extractivist practices, and considerations on how to "give back" to the

<sup>&</sup>lt;sup>44</sup> Martínez-Hernáez et al. (2015) wrote a genealogy of medical anthropology in Spain, going through the main trends and areas of study. Their work shows the scarcity of ethnographic work being done *in* biomedical settings. There has been no such exercise on the anthropology of science and technology or science and technology studies in Spain, as it is a quasi-non-existent area. For an international take on the genealogies of anthropology and science and technology studies, see Fischer's (2007) piece on recombinant anthropology.

communities we were expected to get involved with. Despite the academic writing undertow from the 1980s regarding ethnography, it was somehow assumed that as an anthropologist, I would do ethnography with people in vulnerable situations, be it in a region of my home country or abroad, as was the general trend. Therefore, little attention and tools were given to "studying up" or considering other ethnographic settings and fieldwork relationships, and it was a kind of training that did not consider the perks involved in being a working-class young woman and ethnographer in settings where the ethnographer has less capital (of the many kinds one might think of).

It is not a matter of good or insufficient training (indeed, I had fantastic professors!). It is more about what constitutes an anthropological object of study that is embedded in multiple contradictions and tensions (Gupta and Ferguson 1997). Therefore, with this second precondition, I want to point out that it is crucial to consider the where and with whom in terms of the ethnographic site and collaborators, but also the *where* and *with whom* in terms of the academic training and professional companions as ethnographers. Lack of ethnographic work in technoscientific settings in a region (or even country, as in the case of Spain) can be translated to a lack of awareness on the part of those in white coats about the possibility of some of "us" (social scientists) conducting ethnographic research with them. Similarly, fieldwork at a site or location at which they are familiar with ethnographers would entail another set of issues. What can be thought of as an object of study or not, and the referents we have at hand to build our research topics and experiences are also part of the ethnographic preconditions.

When talking about the preconditions of ethnography, I also consider it relevant to note the tools and legacies the ethnographer brings in when doing fieldwork or lack thereof in the settings and with the people they are going to be studying and working with. Such preconditions cannot be ignored if we want to expand our understanding of positionality in research, along with the more explicit conditions of the ethnography I unfold in the following sections.

### 9.3 Accessing a high-security site: the tissue bank

#### 9.3.1 Entrance as an eternal external visitor

It was pouring outside, and Barcelona is not well prepared for rainy days. Puddles of different sizes flood the streets. There is always a big one at the bus stop waiting for you to get off the bus. I arrive at the tissue bank hall at five to nine in the morning. The hall is packed with high school students, and a professor is presenting the students' IDs to the security desk, one by one. Cell phone audio, short clips of music, laughs, and morning chit-chat have filled a hall that is usually aseptic, with at most three people waiting for external visitors' checks. Their backpacks wait crowded on the floor next to the security turnstiles, waiting to be scanned. I turn to the hall's windows and see that it is still pouring outside. I am starting to get nervous as I must begin my participant observation at nine o'clock, and to arrive two minutes late here is to arrive late. Despite a year and a half of fieldwork *here*, I remain an external visitor. It says so on my access card and in the steps required to access the building whenever I come here.

I need to go through the security procedure on each occasion. Luckily, in between the high school students' crowd, one of the security guards, Marisa<sup>45</sup>, recognizes me and waves me over to jump the queue and go through the security check. She tells the professor, "She is a regular." I give her my ID (which I will pick up on my exit) so she can give me my tissue bank ID card in exchange. I put my backpack on the security scanner belt and go through the turnstiles.<sup>46</sup> As I do every day I come here. There has not been a day that I have been allowed to skip any of the steps of this access choreography. After eighteen months, I have embraced my eternal external visitor status.

I hear Xisca, head of the tissue bank communication team and who is doing the guided visit that day, tell the students waiting in queue for their backpacks to be scanned: "You know, we need to go through this. You are entering a *high-security* site. Under our feet, we have the blood, tissues, cells, and milk of many people," she said, raising her voice and moving her hands. "So precious! We need to be careful." Already on the other side of the turnstiles, I can see, from another perspective, the students, the professor, Marisa,<sup>47</sup> and the two receptionists, "on the other side" of the turnstiles. Meanwhile, I wait for José, the director of the advanced therapies unit, to pick me up. If you are not a tissue bank

<sup>&</sup>lt;sup>45</sup> All proper names are pseudonyms.

<sup>&</sup>lt;sup>46</sup> Security scanners for entrance to buildings are not common in Spain. In general, beyond train stations or airports, you only find them in governmental buildings where entrance is controlled by the national police or the military.

worker, you cannot access the facilities unaccompanied, no matter if you have already passed the ID check, the scan, and turnstiles and have an ID badge hanging around your neck. The door of one of the elevators opens, and I can see José wearing his white coat without leaving the elevator, waving a hand at me, and blocking the door with a folder to keep it open. I give my tense smile, feeling that once again I am making him waste some of his time to pick me up from the hall, and I get into the elevator. We go to the third floor.

The previous ethnographic vignette captures my entrance to the tissue bank on one day of fieldwork, and the procedure required every time I went in over the course of 20 months. Despite my friendly relationship with the tissue workers, it was clear that I was and remained an "external visitor." One key argument I faced in this ethnography, but more broadly in my multi-sited fieldwork with biobank workers in Spain, pivoted around the comment made by Xisca: tissue banks and biobanks store precious human samples. Therefore, it requires to control and limit who hangs around. That is why I consider the tissue bank where I was based as a high-security ethnographic *site*. It requires identity checks, X-ray scans of your backpack, doors that only open with an ID, white rooms, cryogen tanks, multiple surveillance cameras that I could not take photos of that would identify their location, and the signing of confidentiality agreements. The double or triple check of my visits also resembles how the ethnography was enabled and configured. It even mirrors how my collaborators double-checked ethnography as a methodology during my access process and by the agreements signed to get in.

#### 9.3.2 Armwrestling with ethnographic work undesigned relationality

To gain access to the site for five months, I was involved in the efforts of the tissue bank workers and legal team to reverse what Lederman (2013) and Bell (2019) referred to as the "undesigned relationality" of ethnographic fieldwork. Lederman (2013) described numerous disciplines' endeavors to control research conditions; in contrast, "anthropologists make knowledge by tuning in what those others work so hard to tune-out" (p. 600). In this regard, ethnographic work clashes with the epistemologies of institutional ethics reviews (based on the biomedical framework) due to the undesigned relationality that characterizes it (Bell 2019). Such clashes have been embedded in this ethnographic experience since the very beginning.

It all started in October 2017 when I decided to do ethnographic work in a public regional tissue bank. The first thing I did was check who was working there, and, in the process, I identified Rodrigo, who oversaw the coordination between the tissue bank and all the regional public hospitals. After reading about his work with different hospitals, I wrote to Dr. Fernando, whom I had met a few years ago during a hospital ethnography I did as an undergrad, to see if he knew him. Luckily, they had met a few times. Fernando wrote an email to him with me in copy explaining that I had been in his hospital "doing that thing she calls ethnography" and that he recommended hearing my project proposal. I sent Rodrigo an explanation of my doctoral project and the proposal of doing participant observation at the tissue bank to study the workers' practices around biobanking. Two weeks later, we met at Rodrigo's office at the tissue bank. We chatted about the reasons behind the research proposal, and he told me that he would forward my proposal to the directors of different units of the tissue bank and write back to me. A week later, I got a reply from the Research and Innovation director requesting a more detailed proposal. I sent him a one-page summary of the proposal and an extended version. Two months later, we met. I went to his office to explain that I was studying biobanking practices and wanted to develop an immersive methodology called ethnography to observe the daily work at the tissue bank. I wanted to explore the topic from the personnel perspective. He was excited to hear about my interest in the tissue bank work but did not understand why I needed to be around. He noted that he had assumed I would be interested in accessing donors for a survey and that now that I had explained my methodology in detail, he was surprised by my proposal. We wrapped up the meeting, and he told me that the best thing would be to set a meeting in a few weeks in which I would give a presentation explaining what ethnography is; that way, they could think about the feasibility of my proposal. The undesigned relationality of ethnographic work was intriguing for him and was translated as a problem on "where to place me."

In a glassed cubicle office, one of those in the middle of a corridor where everyone who passes by looks at its inhabitants with even more attention if those who are gathered are three directors of the tissue bank (hospital services unit, advanced therapies unit, research and development unit) and the head of marketing, I met three men aged over 55 years and the head of communication and marketing, who is in his late 30s, two of them wearing white coats and the other two suits without a tie. I explained what I meant by ethnography, and to do so, I filled my slides with book covers and a long reference list as a way to be supported by such companions (Hoeyer 2013; Titmuss 2019; Waldby and Mitchell 2006).

The meeting lasted one and a half hours. In this endeavor, I relied upon the work of various social scientists to show that even though ethnographic work is not standard in biomedical or technoscientific settings in Spain, it was being done elsewhere (Arteaga Pérez 2021; Dam and Svendsen 2018; Pinel 2020). During the meeting, José, director of the advanced therapies unit, noted that it was "true" what I was saying, as he had been on a dissertation committee of a sociologist in the UK that revolved around "the social life of blood, whatever that meant" and that used a similar approach.

At the end of the meeting, I tried to explain in detail what the ethnography would entail for them, which was one of their questions in their efforts to contain the undesigned relationality.<sup>48</sup> I highlighted that my main objective was to learn from the tissue bank workers, observe their work in progress, and talk to all sorts of worker profiles (lab technicians, electricians, science directors, doctors, etc.). They told me that many of the projects were close to the end, except for a project that had just started around T-cell banking for immunotherapy, the T-cell Project. However, they warned me, "this project is so uncertain we do not know how it will turn out, so it might not be the cleverest decision to focus on it if you want to finish your doctoral research" José told me. For me, it was perfect to follow a project in the making (Latour and Woolgar 1986). After two months of meetings, we decided I would be placed in the advanced therapies unit of the tissue bank, and my observations would be limited to the T-cell Project. The unit at the tissue bank was in charge of creating a registry of T-cell donors and the first Spanish bank of lymphocytes for immunotherapy. In this way, my presence and involvement were limited to the work around that project and the sites where that project took place within the tissue bank.

After agreeing on where I was going to be placed in the advanced therapies unit by the end of the meeting, the R&D director told me that I would receive an email from the tissue bank legal committee to proceed to formalize a collaboration agreement between my doctoral dissertation and the tissue bank. It was a requirement to formalize our collaboration and "start" fieldwork. Then, after two months of meetings and emails, what followed were three months of bureaucracy trying to crack the undesigned relationality

<sup>&</sup>lt;sup>48</sup> At first, I proposed six months of participant observation. Fieldwork ended up lasting twenty months, as the collaboration agreement kept being extended without an end date in sight. However, fieldwork ended abruptly two days before the lockdown of 2020, showing once more that ethnographic experiences cannot be anticipated or confined.

with the tissue bank's legal unit, involving emails with their lawyers and exchanging draft agreements.<sup>49</sup> Finally, in February 2018, a legally binding collaboration and non-disclosure agreements were signed.

The final version of the collaboration agreement had six pages. In that document, I agreed to numerous points: data anonymization, signing the confidentiality agreement, no monetary or stipendiary commitment, the unit would review all data from the research before it could be published or presented, a liability and indemnity clause, the acknowledgment of my responsibility to not describe in my work any patentable procedures or models, and that anyone interviewed in the tissue bank must sign a written informed consent. In this chapter, I aim to point out how this type of framing of my fieldwork had several implications for my ethnographic experience, which I have called the tentacles of the ethnographic conditions. In the following section, I reflect upon some of the tentacles of the confidentiality and collaboration agreement.

## 9.4 The tentacles of the ethnographic conditions

We can find some access stories in written qualitative research, yet they are mainly confined to footnotes and provide little understanding of why a researcher might be helped to gain access (Feldman et al. 2003). Overall, the relational aspects of access tend to be neglected, and any reflection on *interests* is avoided. I refer to interest in Stenger's (2000) terms as relating to being situated between (*interesse*), which should not be automatically disqualified as "this not only means to stand in the way but first of all to make a link between" (p. 95). In this context, the portrayal of access reduced to the door metaphor is inaccurate. Indeed, I agree with Feldman et al.'s (2003) observations that if we had to resort to the figure of the door, we would have to imagine numerous doors. And I would add that some are open for us, others allow us to see only part of the room, and yet others seem open but are not. What matters is recognising whether the door's leaf is moving (or not) because someone is opening, closing, or leaving it ajar. Access is processual, relational, involves different interests, and has its tentacles too.

<sup>&</sup>lt;sup>49</sup> During this process, I also obtained approval from my university ethics committee for my doctoral project, an exceptional step in my context, as social sciences researchers do not usually send their projects for approval, even less so doctoral researchers.

After several meetings and months of entrance procedures of different kinds, along with the signing of a collaboration and confidentiality agreement, I gained access to the advanced therapies unit of a tissue bank to follow the making of a white blood cell bank for immunotherapy. However, how I gained entry into the tissue bank was a big part of my ongoing access during fieldwork and how I related to the experience. The conditions that framed the fieldwork had several tentacles. *Tentacles* are the soft, movable appendages of many invertebrate animals that can perform various functions, primarily as tactile or grasping organs. Tentacles also refer to an influence that is hard to avoid. I will briefly note two examples of the tentacles of my ethnographic conditions stemming from the two agreements that framed and configured my ethnographic work.

#### 9.4.1 The tentacles of the non-disclosure agreement, a heavy companion

The acknowledgment section of Alice Street's book Biomedicine in an Unstable Place: Infrastructure and Personhood in a Papua New Guinea Hospital opens with a simple yet crucial sentence: "It is always difficult as an anthropologist to write critically about persons and practices in the places we work" (Street 2014, p. ix). Ethnography entails tensions regarding the politics of representation and decisions around formal or informal agreements and compromises with those we work with. As Simpson (2011) notes, talking about ethnography is relational, not only spatial, and requires recognizing that fieldwork dilemmas are human dilemmas (Bell 2019). The act of writing adds another layer. What is revealed or not in writing entails different effects and affects. Part of our work as ethnographers requires being aware that what and how we disclose our observations can have multiple lives. It is well known that ethnography might harm a particular cause or community studied, sometimes in ways that could not even be expected. Indeed, ethnographers have discussed concerns about confidentiality, using pseudonyms, and omissions to avoid harm to those we do fieldwork with (Howell 2004; Van Der Geest 2003). It is an ongoing task for ethnographers to keep learning how to build, sustain, nurture, or stop fieldwork relations.

However, less attention and reflection have been given to when the ethnographer is the one put in the weak spot. What are the tentacles of signing a non-disclosure agreement with a biomedical institution? In the fieldwork that has been presented, the biomedical assemblage runs over the ethnographer with its tools to protect its science, commercial interests, institutional status, or personnel. In medical anthropology all are well aware of

it. Nevertheless, it becomes even more salient when studying-up the making of knowledge and drugs at a high-security technoscientific site such as the tissue bank. As an ethnographic condition, the agreement crafted a particular unilateral form of confidentiality and incarnated a disciplinary device due to its legal enforcement. It extended up to five years after its signing and established an economic penalty if broken. The confidentiality agreement impacted how I related to my fieldwork and observations. It would be artificial to separate access to the site from the fieldwork done. Ethnography begins while arranging access. The two months of exchanging drafts with the lawyer of the tissue bank ended up having more impact than I thought on the way I related to the agreement. Two years after finishing my fieldwork and with hindsight, I can see that my research was accompanied by a constant concern (even a certain anxiety) about not breaching the confidentiality agreement. As noted earlier, the unit's director had to review anything I wrote based on the fieldwork at the tissue bank. On several occasions, this procedure made me avoid presenting my work at research group meetings or academic conferences during my doctoral journey but also put me in an artificial position as an ethnographer by having to demarcate where/when a particular piece of fieldwork ended. Also, regarding ethnographic writing, as I knew some of the work could be patentable, particularly some of the processes involved in developing the T-cell bank, the agreement has articulated some forms of writing, but not others.

Furthermore, I could only write about technical information that was already public. The only way to confirm if that information was public was by checking the project report, academic publications, and the tissue bank website. However, publications in the making were covered with secrecy, and the institutional website only tends to be updated every year or every two years. Therefore, if nothing is made public, is everything confidential? Under the parameters of the agreement, almost everything I observed was confidential or at least would fall under that category following the signed agreement. A spiral of concerns about confidentiality was an active part of the ethnography, and the figure of the non-disclosure agreement would explicitly show up on numerous occasions during my fieldwork and after it. The agreement has become a silent companion, a tentacle of the particular conditions of such ethnography.

By making explicit the tentacles of the confidentiality agreement in my case, I do not aim for this to be interpreted as a request to tell the story of everything we observe as ethnographers. Instead, it calls for more transparent accounts of how other ethnographers relate to these agreements, including in sites and fields where confidentiality is forged differently. I think that the haunting concern of breaching the confidentiality agreement when "studying up" could be a concern that extends beyond biomedical and STEM ethnographies, and would entail a sort of processual ethics in other areas. Staying with the confidentiality concerns regarding fieldwork activates this point where we break in dry as academics before we say or write about our observations. At the same time, relating to confidentiality in such a rough way made clear the complexity of calibrating precaution and paralyzation, an adjustment exercise that I am still figuring out, and that has configured a particular way of approaching and writing about such ethnography (Argudo-Portal 2023). The objective of recognizing this tentacle is twofold: to provide an embodied engagement with the discussion on disciplining ethnography (Gupta and Ferguson 1997), and to call for a reflection on how contemporary ethnographies engage with institutionalized confidentiality (or protocols), particularly those in technoscientific settings. And also to highlight the need for a broader reactivation of conversations on confidentiality, intimacy, confidence, and secrecy in contemporary ethnographic work, which are currently lacking.

## 9.4.2 The tentacles of the collaboration agreement, I am not a journalist!

Moving from the tentacles of the confidentiality agreement, I turn to the tentacle(s) of the collaboration agreement. To address such tentacles, I need first to emphasize that José, the director of the advanced cell therapies unit, was welcoming from our very first meeting. He quickly included me in the mailing list. He would warmly present me to the other tissue bank personnel at every chance as a "sociologist" collaborating on the T-cell Project. On some days my fieldwork was highly choreographed in time slots (to attend meetings), and at other times I would spend 8 hours a day at the tissue bank in the lab or an entire morning at the donors' call center. However, my timetable was permanently established in advance in one way or another. Given that I had little flexibility and my presence was strictly limited to a unit and project, I decided to wait to start the interviews until I had been around for six months. The first person I interviewed was Ferran, a senior immunologist, after waiting a month for him to give me an appointment.

Prepared with my recorder, copies of the informed consent (which I had sent him in advance), and my notebook, I entered his office. I had not even been in his office for 2 minutes and was taking the materials out of my backpack when he told me: "Violeta, I accepted the interview because it is you, but I am so pissed with journalists. It is always

the same shitshow." I was surprised by that sentence. I did not know how to react. I did not know whether to smile or not. So, I chose to ask him what he meant while I took over the folder with my papers. He went on, "You know, you explain in detail the work you are doing, and they end up writing that you are developing the definite cure to something or, even worse, that you have already developed it." His answer gave me some clues about what was going on. After months of repeating that I am an anthropologist, it had not sunk in, or it had, but did not differentiate a social scientist from a journalist. I explained to him that as a social sciences researcher, the treatment of his testimony would be different. I emphasized that he could refrain from doing the interview and that I would be okay with that. Then, I showed him the informed consent I had sent him a week before. With the document in my hand, I showed that he did not need to tick all the boxes. He could reject the reproduction of verbatims from the interview, recording the interview, or we could go to the tissue bank canteen, have a coffee without a recorder, and chat about the project for 15 minutes because I knew he had a lot to do.

Despite starting the encounter this way, he changed his attitude and said there was no problem. He consented to record the interview and use verbatim quotes from it. However, I was very uneasy standing in front of him, waiting for him to reread the informed consent with my tape recorder on the table. That uneasiness stayed with me while he enthusiastically and pedagogically explained cellular processing on paper with numerous drawings. At the end of the interview, we said goodbye, and as I left, I told him: Remember, I am not a journalist! And he laughed. The interview with Ferran was the only one I recorded during twenty months of fieldwork in the tissue bank. A few days later, I asked a lab technician for an interview after the one I did with Ferran, and she replied to me: "An interview? What for? Are you a journalist now? If you are around all time, what else can I tell you?". I told her I just wanted to chat with her to clarify some of the tasks she was doing, but then I decided not to insist. Instead, I spent a whole day with her at the lab.

The signed agreement required interviews to be scheduled in advance and highly structured, but, in practice, such an approach to interviews in the context of a long-term ethnography, no matter how high-security the site was, was not working. I decided not to propose more interviews to any of the workers. The uneasiness around (semi-structured) interviews made me reflect on the tentacles of the collaboration agreement, not only for me but also the workers at the tissue bank. To what extent would they have agreed to

accept my interviews "voluntarily" if my fieldwork was part of a collaboration agreement with their employer?

After all, most tissue bank employees are under temporary contracts and also signed a confidentiality agreement when hired. Therefore, I preferred not to request interviews but to continue with participant observation and ethnographic interviews (not recorded) during the observations. However, I reflected that observing the development of this project, financed by public funds, was part of an act of transparency and knowledge transfer; as such, my presence was legitimized. That was how I dealt with the uneasiness that formal interviews generated in an ethnography that was highly regulated and with little scope for mingling outside the tissue bank meetings, lab, or, if lucky, in the canteen, and recognizing that I was not the only one with little margin for action.

Regarding the collaboration agreement, I could have written many things, for instance, how I navigated their requests for designing surveys that would record a team of five and a year of work. However, as ethnographers, in our methodological reflective writings, we tend to focus too much on how fieldwork affects us, particularly when exploring the disciplining of research. In considering this tentacle, I aimed to clarify the effects of the multidirectionality of the signed collaboration agreement.

#### 9.5 Conclusion

The description of these tentacles has focused on how I related to particular conditions engendered by how the fieldwork of this ethnography was framed and enabled by legally binding agreements. Putting at the center the agreements signed and their tentacles, I have tried to avoid a simple approach to them as disciplinary devices (which they are). Instead, I have conducted a modest and honest exercise to reflect on the tentacles of such agreements that could spur a broader conversation regarding contemporary ethnographic work in technoscientific settings and beyond. Gusterson (1995) and Hølleland and Niklasson (2020) noted how many ethnographic works to "study up" end up resorting to strategies that could be highly problematic due to the lack of transparency of the fieldworker as the only way to get access. That is not the focus of this chapter nor the case. Instead, the chapter shows how I accessed a technoscientific high-security site by providing detailed presentations on ethnography and accepting their disciplinary devices in the form of legal agreements, generating a particular relationality. The chapter unpacks

the tentacles of the conditions established by gaining access with complete honesty and transparency.

Much has been written about how ethnography is adjusted to our contemporaneity (Fortun 2009; Marcus 2012; Sánchez Criado and Estalella 2018). The tensions between ethnography and institutional research ethics committees have also been analyzed (Bell, 2019; Simpson 2011), but what about the internal legal committees of the technoscientific institutions we do fieldwork in and the agreements we have to sign? I consider that a collective and honest reflection is needed in this regard. What kind of documents are we signing? How do we relate to these documents and agreements as ethnographers, and what can we learn about them? In this chapter, I have illustrated how technoscientific settings use tools to modulate the "undesigned relationality" of ethnographic work. Even though such devices fail in some respects and spur us on in others, they configure ethnography in particular ways requiring more reflection on the tentacles of such ethnographic conditions, particularly for those of us trying to study up.

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# Who's the expert here? Negotiating expertise in palliative care and transplant medicine

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#### **10.1 Introduction**

This year, I experienced a 'first' in my academic career. After publishing an article on the German transplant scandal (Rehsmann 2023a), a renowned German transplant surgeon wrote a 'letter to the editor' (Nashan 2023), which resulted in a back-and-forth between the transplant surgeon and myself in the form of replies, rebuttals and even more replies. These back-andforth exchanges took place during the writing process of this chapter and provided some food for thought and inspiration to expand the focus of this chapter from its discussion on fieldwork practices to what happens after fieldwork when anthropologists write about their findings and present their analysis and interpretations to a scientific community. This chapter delves into differences and commonalities between practices of knowledge production, including ethnographic fieldwork and publishing traditions, when conducting anthropological research among white coats. I use the concept of 'expertise' as a red thread throughout the chapter, giving insights into the fields of transplant medicine and specialized palliative care, and discussing how expertise is claimed, attributed, and negotiated in different sites and contexts and how this affects anthropological research.

I follow the premise that expertise is 'enactment' and inherently interactional (Carr 2010). It is 'something people do rather than something people have or hold' (ibid, p. 18), and a 'process of becoming rather than a crystallized state of being or knowing' (ibid, p. 19). Expertise is performed, or enacted, building upon training and apprenticeship to acquire sufficient special-ised knowledge and vocabulary that one's expertise is unmistakably recognised as such by

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others. In the context of biomedicine, expertise is bound up with authority and credibility (Hogle 2002) and recognised interpretations (in the sense of established, known, and in line with already known patterns of language and thoughts) of images, documents, symptoms or other materialities and objects play a crucial role in the enactment of expertise.

With that in mind, I discuss in the first part of the chapter how expertise is enacted in two different biomedical contexts, transplant medicine and palliative care, and how this shaped my fieldwork in these sites, including reflections on the choice of wardrobe and the role and effect of white coats in these settings. In the second part of the chapter, I focus on the time *after* fieldwork, when anthropologists aim to publish their research findings. Reflecting on publishing anthropological findings in different disciplinary contexts, I discuss how publishing 'among white coats' and across disciplines carries the potential of mis/understandings that are grounded in different publishing traditions and research paradigms. In my concluding remarks, I want to highlight how expertise changes, shifts, and evolves with time, throughout an academic career as well as with personal experiences and highlight the importance of, and increasing call for, experience-based knowledge and participatory approaches in biomedicine, STEM, and anthropology.

#### 10.2 Expertise in transplant medicine and palliative care

Transplantation medicine and palliative care represent two very distinct areas of medical care regarding their underlying paradigms, work culture, technologies and economics. Transplant medicine is centred around organ replacement procedures with a curative intent, whereas palliative care emphasizes holistic, patient-centred care to improve the quality of life for individuals facing serious illnesses. The work culture, technologies used, and economic considerations reflect the distinct goals and approaches of each medical specialty.

#### 10.2.1 Hierarchical transplant medicine: surgical skills at the centre

Transplantation medicine is a prime example of a more curative biomedical approach that focuses on postponing death and prolonging life. It primarily follows a paradigm of surgical intervention and medical procedures aimed at replacing damaged organs to restore function. Utilizing advanced surgical techniques, organ preservation technologies, and immunosuppressive drugs to ensure the success of organ transplantation, it relies on the limited resources of human donor organs. As it is characterised by a high-skilled surgical intervention at the intersection of life and death, transplant surgeons are sometimes placed in a realm of 'miracle' work. In addition, transplantation medicine generates high revenues for clinics with costly surgeries and long-term post-transplant care for transplant recipients. Through a complex interplay of factors, from expanding therapeutic options to increasing patient demand and corresponding changes in health insurance coverage (Kaufman and Fjord 2011), transplant medicine has gradually and successfully transformed 'extraordinary treatments' into ordinary ones (Kaufman 2015). Discourses around organ transplantation often revolve around the moralising trope of the 'gift of life', on the one hand to promote organ donation and increase donor numbers, and on the other to discipline patients into grateful recipients of such a rare gift (Kierans 2011).

Involving multidisciplinary teams, physicians and especially surgeons play a crucial role in facilitating organ transplantation as a necessary treatment for organ failure. Because of their pivotal role in potentially prolonging patients' lives and their expertise in transplanting human organs from one body to another, transplant surgeons tend to be portrayed either as miracle workers or as charlatans and criminals (Crowley-Matoka 2016; Kierans 2020; Sharp 2006), particularly in Germany following the German transplant scandal (Pohlmann et al. 2022; Rehsmann 2023a). Transplantation medicine has been described as one of the most prestigious medical specialties because of the surgical skills required, the mythical idea of shifting the perceived boundaries between life and death, and its economic importance to clinics. With its focus on the surgical intervention at its centre, the understanding of expertise in transplantation medicine tends to be more hierarchical and attributed mostly to surgeons, side-lining the importance of pre- and post-transplant care provided by multidisciplinary teams of other physicians, nurses and other specialists.

# 10.2.2 Horizontal palliative care: interdisciplinarity and the role of nurses

Despite some overlap, palliative care is in some ways the antithesis of transplant medicine. It emerged as a response and alternative to a health care system that was primarily focused on curative practices, while more and more patients were living with chronic conditions for which cure was not an option (Clarke 2016; Lemos Dekker 2023). It is inextricably linked to the work of the pioneering nurse and later doctor Cicely Saunders, who laid the foundations for hospice care in the UK in the 1960s. At its core, hospice and palliative care aims to alleviate suffering, which includes emotional, spiritual and psychological as well as physical pain, and to improve or maintain the quality of life of patients in a highly individualised and personalised way

(Krakauer 2007). Since then, palliative care has evolved into a specialisation that is integrated into various disciplines and specialities and is usually provided by interdisciplinary teams, including nurses, physicians, spiritual care, social workers, psychologists and other therapists, and encourages a collaborative and interdisciplinary approach.

Starting from outside the curative realm of biomedical practice, palliative care has gradually been integrated into national health systems and structures. In Switzerland, this means that specialised palliative care services are provided by hospitals or mobile care services alongside other specialities, with only a few dedicated hospices in the country. Because it emerged as a response to curative approaches, palliative care is characterised by a very reflective and critical attitude towards interventions, therapies and diagnostic procedures that other disciplines and medical specialities consider necessary and unavoidable. This form of care requires conversations, time and work that other specialties cannot provide. By challenging the curative and biomedical impulse for ever more diagnostics and treatments, and by placing the individual patient with their individual needs, wishes, ideas and possibilities at the centre, palliative care specialists challenge the prevailing biomedical paradigm of curing and prolonging life at almost any cost. Moreover, palliative care's interdisciplinary approach, with nurses, doctors and other specialists working side-by-side, challenges traditional notions of siloed medical expertise and clinical hierarchies. Unlike transplant medicine, expertise in palliative care is understood to be more equally distributed, ideally also transgressing interdisciplinary teams and to include patients themselves as well as people in their care network.

### 10.3 Fieldwork in transplant medicine and palliative care

How did the particularities of these two medical fields and their understandings of expertise shape my fieldwork practice? Given these differences in how expertise is understood, and enacted, in these two medical settings, one more hierarchical, surgical and curative and the other more egalitarian, caring and reflective, conducting ethnographic fieldwork in these settings differed significantly from each other.

# 10.3.1 A particular role in the transplant clinic

The fieldwork I conducted on organ transplants, specifically liver transplantation, was part of the ethnographic research for my Ph.D. dissertation that was part of the anthropological

research project *Intimate Uncertaintes*<sup>51</sup> that was situated at the Institute of Social Anthropology at the University of Bern. It followed a more traditional understanding of ethnographic fieldwork, with long-term immersion in an unfamiliar setting, namely thirteen months of fieldwork in Germany in 2014-2015. During this time, I attended patient support group meetings, patient organisation seminars, medical conferences and congresses and, most importantly, was given access to two transplant clinics in university hospitals, one of which served as the main field site with several months of hospital ethnography. *Access* to my main field site was facilitated by a member of the patient support group who introduced me to the local transplant team. This personal introduction laid the important groundwork for gaining access with almost no requirements, and I was able to start fieldwork shortly afterwards. At a later stage, I obtained ethical approval from the local ethics committee, mainly to gain access to a second clinic in another city. Getting access to this second clinic took longer than expected and I was only able to start fieldwork there after several months, resulting in a short stay of one month.<sup>52</sup>

At the main clinic, I conducted problem-centred interviews (Witzel and Reiter 2012) with nineteen pre- and post-liver transplant patients, as well as with the chief surgeon and director of the transplant clinic and one of the clinic's on-call hepatologists (liver specialist), who became one of my key informants. In addition to these interviews, I carried out participant observation in the waiting room and nurses' office of the clinic and conducted ad hoc ethnographic interviews with the nursing staff. A conference room was at my disposal, where I conducted the interviews and wrote fieldnotes in private. Ethnographic methods like participant observation and 'negotiated interactive observation' (Wind 2008) in waiting rooms, nurses' offices and hospital wards allowed me to gain insight into the interactions, informal practices and discourses between patients, doctors and nurses in a transplant clinic. I transcribed most of my collected ethnographic data, interviews and observations, into written text and analysed and inductively coded them to gain an interpretive understanding of patients' and health professionals' experiences of waiting in everyday health care encounters, as well as their perspectives on liver transplantation as a treatment practised in the hierarchical setting of university hospitals. Although highly controversial in anthropological research (Bell 2014; Hoeyer and Hogle 2014), I followed the recommendation of one of my key informants, the hepatologist working in a transplant clinic, as well

<sup>&</sup>lt;sup>51</sup> Funded by the Swiss National Science Foundation; grant number 149368.

<sup>&</sup>lt;sup>52</sup> Anthropologists often struggle to gain access to biomedical institutions because ethics committees fail to understand the specificities of ethnographic research and tend to evaluate anthropological projects according to a logic that follows medical research. Anthropologists have discussed this issue at length in the context of ethics committees (Bell and Wynn 2023) or informed consent in medical research (Hoeyer and Hogle 2014).

as ethics committee conditions, and obtained written informed consent for all recorded interviews and verbal consent for all patient support group meetings I attended.

Most of my interviewees did not mind signing these papers. However, when I asked my key informant, the liver specialist, to sign the papers before our interview, he laughed and asked me if I was serious. Although he had no objection to being interviewed, he did not sign, and I did not repeat my request. This was partly because I was unprepared for this response and did not want to 'bother' him more than necessary – he was already supporting my research by introducing me to patients and offering a considerable amount of his time to answer my many follow-up questions about patients and their liver conditions. This also highlights the challenging role that anthropologists often have in ethnographic research in hospitals, relying on others to gain access and collect data. While anthropologists are always dependent on others to gain insight and collect data, this dependency varies considerably depending on the social position of one's interlocutor. Power relations and hierarchies between anthropologist and patient or anthropologist and doctor affect interview encounters in very different ways, particularly in settings of high expertise such as university hospitals and transplant clinics.

In her book on transplantation in Israel and the United States, Marie-Andreé Jacob (2012) reflects on 'consenting patients' and briefly mentions a situation in which she asked a transplant surgeon to sign a consent form for her research. The surgeon sighed and signed without even looking at it, adding sarcastically 'Oh, I feel much more protected now that I signed this' (ibid., p. 47). Jacob perceived the surgeon's sarcasm as a reiteration of authority above her as a researcher, within the hospital bureaucracy, to 'defuse the submission inherent in signing' (ibid., p. 48). Reflecting on the differences and similarities of these interview encounters, the carefree and light-hearted refusal to sign that I encountered before my interview with the hepatologist struck me as less sarcastic than the situation described by Jacob. But unlike 'her' doctor, 'mine' did not sign. Was his refusal a sarcastic or honest way of addressing the 'emptiness' of these forms? Was it a sign of trust? Or was it, as Jacob discussed, a reassertion of authority and hierarchy within the hospital bureaucracy? Or was it all of the above?

The notion of *informed consent* accommodates many different interests, as Klaus Hoeyer and Linda F. Hogle (2014) discuss in their analysis of informed consent as a political and moral phenomenon. They argue that processes of informed consent are a 'way of demonstrating to the public that "ethics procedures" are in place and there is no reason to worry' (ibid., p. 355) and state that its prominence derives from the fact that the notion of informed consent builds on the idea of the autonomous individual, which is central to Western philosophy and political thought. 'In this tradition, individuals are seen as freestanding, information-processing, cognitively

controlled executioners of rights and personal judgments' (ibid., p. 356). But in a context as fragile as medical care, especially facing a life-threatening disease, this ideal of autonomous, independent and rationalising individuals making well informed choices, crumbles. As some people with liver disease suffer from cognitive impairment due to hepatic encephalopathy, a side effect of liver failure, the issue of successfully communicating necessary information and ensuring that patients know what they need to know is crucial. I consider the possible risks and consequences of consenting to my ethnographic research to be negligible. But what about consenting to medical treatment, especially highly invasive, life-changing treatments such as a liver transplant? Over the course of my research, I became increasingly critical of the importance of 'consent' procedures in health care contexts, particularly the assumption that 'consent' can ever be guaranteed by a signature or considered a completed process.

In discussing her fieldwork in hospitals in Denmark and the Netherlands, and comparing it with more traditional conceptualisations of what this central ethnographic method should entail, Gitte Wind (2008) argues for a more precise way of talking about ethnographic fieldwork, as it 'has become a cliché we often use without much reflection' (2008, p. 87). She criticises the superficial way in which fieldwork is described in many ethnographies – referring to participant observation but without a more detailed discussion of what this means in the particular research. She argues that participation in everyday routines and experiences, in the classic understanding of participant observation, is rarely feasible in clinical settings. She points out that researchers cannot participate in the practices and experiences of doctors, nurses and patients in the same way as anthropologists. Usually, the role of anthropologists in a hospital is clearly delineated – they are present as researchers, not as doctors, nurses, patients or relatives.

Unlike anthropologists in non-medical settings, and like many other anthropologists in medical settings, I did not become fully 'part of the team' by wearing a white coat or other professional attire available to the clinic staff, nor did I participate in any medical procedures. During my hospital ethnography (Long et al. 2008) I continued to wear my private clothes and was always introduced as a researcher studying waiting for liver transplantation from a social science perspective. In the case of my research, 'blending in' was almost impossible in any setting – except at medical conferences, where my blazer prevented me from visually standing out from the mix of medical professionals and pharmaceutical representatives. In clinics, I stood out because the patients were usually in their fifties or sixties, or because the nurses wore scrubs and the doctors wore white coats or scrubs. I, on the other hand, was a twentysomething in everyday clothes. Nevertheless, my *role* at the clinic went beyond that of a mere researcher. Like many other clinics, the hospital had a shortage of psychologists. A high-tech, high-end procedure like liver

transplants would not be possible without surgeons or doctors – but there is more to the 'success' of treatment than prolonging life. Due to the time and the interest that I brought with me, my presence in the clinic was usually welcomed by the hospital's healthcare staff. With little time constraints at hand, the ethnographic interview sessions provided an opportunity for patients, as well as members of the transplant team, to raise issues for which there seemed to be no time or place elsewhere. In the case of patients, these issues went beyond the expertise of surgeons and doctors as biomedical training is usually not set up to deal with the uncertainties involved in medical practice (Fox 2000) and the existential questions patients who wait for a liver transplant deal with (Bjørk and Nåden 2008; Brown et al. 2006). Also, tightly scheduled and streamlined consultations with patients do not leave much time for consultants to address these issues, even if they are willing to do so; clinical workflows are highly regulated. It turned out that in economically oriented health care institutions, psychological support seems to be at the top of the list of expertise that is considered expendable; as an anthropologist, I filled the lack of psychological support that was no longer available due to budget cuts and restructuring of resources.

Before starting an interview with patients, during informed consent procedures, I always emphasised that I was neither a therapist nor a psychologist but a social anthropologist conducting research for my dissertation – an explanation to which most people reacted indifferently. It seemed that the qualities I brought to this clinical space – time, empathy and interest – were welcomed regardless of my training or lack of it. So, when the on-call hepatologist during his consultation hours told me that he had a patient for me who 'seemed like they needed to talk', he was not just addressing me as an anthropologist studying liver transplantation; he was addressing me in the role particular that I had in the transplant clinic. After all, unlike most of the other people working in the clinic, I had the time to talk to patients without any time constraints about whatever issues came to mind in relation to their experience of waiting for, or later receiving, a liver transplant.

#### 10.3.2 Everyday routines in the palliative care nursing team

My fieldwork on palliative care in Switzerland was less multi-sited than my fieldwork on transplant medicine in Germany, and was carried out almost exclusively in a palliative care centre in a Swiss city hospital in 2020-2021. As part of the interdisciplinary research project *Sterbesettings (Settings of Dying)*<sup>53</sup> situated at institute of Nursing Research the Bern University of Applied Sciences, I investigated the role of nurses and nursing expertise in contemporary dying in Switzerland, focusing on the field of specialised palliative care. Access to this site was pre-arranged as part of the proposal stage (unlike the organ transplant project) and facilitated by a fellow researcher and designer on the project team who had conducted some design ethnographic research in this clinic. As a research team, we benefited from the fact that the city hospital was just that: a city acute hospital, rather than a university clinic where health professionals, particularly doctors, often work in the role of doctor-researcher, juggling their own academic research and research interests while working in the clinic. Because it was not a university hospital, the researchers in the *Sterbesettings (Settings of Dying)* project, which included designers, artists, literary scholars, sociologists and myself, were given more freedom and time for fieldwork and design interventions in the palliative care centre than I suspect they would have had in a university clinic, as these institutions tend to be over-researched, with multiple research projects and researchers at any one time, limiting the capacity to engage health professionals and patients and their families in the same way as in less researched settings.

The Sterbesettings (Settings of Dying) research project and its fieldwork coincided with the COVID-19 pandemic. Due to a number of factors, the empirical research for the project was able to proceed as planned, unlike many other researchers and anthropologists whose research efforts were compromised by travel restrictions or lockdowns. The main reasons for the continuation of the ethnographic research were the 'at home' character of the fieldwork, which did not depend on international travel; the method itself, with its contextual sensitivity and flexibility; the 'Swiss' way of dealing with the pandemic, i.e. comparatively few, light and short lockdowns and social distancing measures; and the specificity of research on dying and palliative care, areas that were little affected by the closure of clinics and wards or the postponement of treatment and care, as patients continued to die and need palliative care, and health professionals continued to work locally in clinics to provide it. Because my research was in nursing, the ethics and feasibility of conducting fieldwork during a pandemic were almost exclusively questioned by former social anthropology colleagues. When I confronted the nursing team at the palliative care clinic with the question of whether they perceived my fieldwork to be problematic due to the national and international circumstances, their reactions ranged from raised eyebrows, to counter-questions of 'Why should we think that?', to an exasperated response of 'We have to come in and work every day too, why should your being here be less ethical than

<sup>&</sup>lt;sup>53</sup> Funded by the Swiss National Science Foundation; grant number 188869.

our being here?'. While the flexible and contextual nature of ethnography proved to be an appropriate methodological approach for conducting research in uncertain pandemic times, the ethics of very strict lockdown measures aimed at protecting lives was, conversely, criticised as a 'moral failure' (Monteverde 2023).

From late August 2020 to July 2021, I conducted hospital ethnography twice a week at the palliative care centre, and this more focused period of fieldwork was followed by irregular field days until the end of January 2022. The focus on observing and participating in nurses' practices in the context of specialised palliative care, asked for a different methodological approach than exploring experiences of waiting for a liver transplant. While the fieldwork on liver transplants relied heavily on recorded interviews, at least in the clinical setting, the ethnographic research on nursing practice in palliative care almost exclusively used participant observation and ethnographic ad-hoc interviews, which were documented in fieldnotes. To collect data on nurses' practices, I joined the nursing team in the role of an untrained nursing assistant, working during the morning shift from approximately 8.30am until 3.30pm twice a week. Unlike the fieldwork for my PhD, which involved moving to another country, allowing and requiring greater immersion in the field, the palliative care fieldwork was conducted in another city with a 90-minute commute. With the field so close, the fieldwork was much more embedded in my everyday life and the level of 'full immersion' was less than during my doctoral research. In addition, I was no longer in my twenties and single, having had my first child in the same year as the pandemic hit Europe and I started my fieldwork, resulting in very different frameworks for these two fieldwork experiences.

During my time in the palliative care centre, I accompanied the nurses in their daily work. I helped with patient care, from transfers to personal hygiene or repositioning people in bed. I collected medication from the hospital pharmacy, collected new beds from the bed centre and returned the used ones. I took part in doctors' rounds, patient and family round tables, case reviews and peer consultations. I accompanied patients for walks or smoking, a small pleasure that patients at the end of their lives can continue to enjoy in order to maintain their quality of life. I counted the breaths of sedated patients to ensure that their breathing rhythm remained within a certain range. I sat with patients who died later that day. I helped the nurses wash the bodies of deceased patients, prepare them for their families to say goodbye to, and then take them to the pathologist in the basement. I spent coffee and lunch breaks with the nursing team, asking and answering questions about their practice and expertise, discussing politics and the daily challenges of caring for a baby and soon-to-be toddler, love, life and relationships.

The palliative care team welcomed my presence in the clinic because, due to the participatory nature of my fieldwork, I was adding two more (untrained) hands to an at times understaffed team. With nurses also facing the over-bureaucratisation of health care and spending much of their time not at the bedside but in front of computers documenting every minute of care provided, my pair of low-skilled hands eased their workload as I was able to take on tasks that required less skill, such as patient transfers, bed collection or pharmacy pickups. Unlike at the transplant clinic, I did not work in my everyday clothes, or only partially, but wore regular scrubs with a pair of jeans. This made sense as I participated in nursing practices at patients' bedside, which at times involves close contact with bodily fluids or excrements. As I was not a 'real' nurse, I felt uncomfortable dressing fully in scrubs and thus tried to stand out visually from the other health care professionals roaming around the hospital<sup>54</sup>. Nonetheless, this slight distinction from other team members went largely unnoticed by other staff, patients and their relatives, as did the 'researcher' status on my name tag.

My rather seamless integration into the palliative care team, while beneficial to my being-inthe field and the gained insights, also posed challenges in regard to traditional *informed consent* practices. The research project underwent a Swiss particularity of ethics clearance, a so-called clarification of responsibility, a pre-proposal for ethics commissions 'whether the research project falls within the scope of the human research act (HRA) and / or to request a written statement from the ethics committee in case the research project does not need an EC approval' (swissethics 2023). With its emphasis on ethnographic fieldwork and design research, the project was considered to not fall under the scope of the human research act, and allowed for a context-sensitive adaptation of informed consent procedures that were more in line with anthropological principles and ethics.

The palliative care clinic acted as the project's practice partner, granting official permission to carry out fieldwork on their premises. With information leaflets circulating around the clinic, most of the staff were aware of the *Sterbesettings (Settings of Dying)* research project, although not all were aware that I was part of the project. As I refrained from recording interviews and mostly conducted participant observation and ad hoc informal ethnographic interviews, the informed consent practices that I had used in my doctoral research were neither feasible nor

<sup>&</sup>lt;sup>54</sup> A welcome, unexpected side effect of participant observation in nursing is that this fieldwork allowed me to gain a better understanding of my institutional working environment. As an anthropologist working in a nursing institute, where most of my colleagues were trained as nurses before entering the field of nursing research, my fieldwork supported me in this interdisciplinary environment and helped me to gain confidence with other nursing researchers. I felt that I now knew, at least a little and at a very basic level, what it was like to work as a nurse.

required in this context. With members of the palliative care team, nurses, doctors and other staff such as social workers, therapists, psychologists and spiritual care workers, I continued to rely on repeated verbal consent, reminding them from time to time that my presence in the clinic was for research purposes. In day-to-day encounters with patients and relatives, I adapted my informed consent practice according to the situation. I informed relatives verbally in cases where I had a longer conversation with them and they were not too distraught or emotionally burdened by their relative's illness, decline or death. With patients, I was even more reserved, primarily because most patients were admitted to the palliative care clinic at a very late stage, often in the last days of life, with severe cognitive impairment due to their conditions. As I was primarily interested in nurses' practices rather than patients' perspectives, patients' participation in my fieldwork was a side effect rather than the intended focus.

# 10.4 Publishing 'among white coats'

While anthropologists have written about the 'messy' qualities of qualitative research (Marcus and Fischer 1999), and the emotional labour of gaining access to field sites (Bergman Blix and Wettergren 2015) little has been written on what follows anthropological research, particularly in biomedical contexts. What happens after fieldwork, when anthropologists publish their interpretation of biomedical practices, their local situatedness and global entanglements? Where we publish our work influences the visibility of our research, and I have published several peerreviewed articles and book chapters, most of which have been single-author publications in anthropological journals or edited volumes (Rehsmann 2022, 2021, 2019, 2018). With other anthropologists as the main intended readership of these publications, I have never received immediate responses, was never asked to formulate a reply to another scholars' response to one of my articles or chapters, and certainly not repeatedly. Until, after being invited to contribute an anthropological paper to a special issue on social science perspectives in liver transplantation, I published an article in a medical journal that was less about the patient's perspective (which, I think, was what I was expected to submit) than about the German transplant scandal and how it revealed structural flaws in the national transplant system. (Rehsmann 2023a). I did this from an anthropological perspective - a perspective unfamiliar to most medical professionals. However, despite the unfamiliarity of the disciplinary perspective, I wrote about events and their ripple effects that were well known to most people in the German transplant system, in a language that could be understood outside disciplinary boundaries. To my surprise, not long after the publication of my article, the former head of the national transplant society, a renowned surgeon and public figure in the field of transplant medicine in Germany published an immediate response.

In this response, which was later on followed by a second one, the surgeon states that 'though the article reads quite nice, reflecting an individual view from the outside' (Nashan 2023), I had missed certain references. In accordance with the conventions of scholarly publishing, I replied to his reply, thanking him for the references and pointing out one of my main criticisms, which he had not mentioned in his letter (Rehsmann 2023b). My published reply to his response provoked the surgeon to write another letter to the editor, stating that my article was a mere opinion piece and repeatedly referring to me as an *outsider* who did not follow scientific principles (Nashan 2024). After receiving this letter, I contacted a wide range of people, asking for feedback and input from fellow medical anthropologists and other transplant physicians in Germany on how to proceed. In my subsequent response, I outlined the value of anthropological analysis and how it differs from most biomedical research paradigms (Rehsmann 2024).

Anthropologists have a long tradition of conducting research 'far from home', in communities and contexts with a certain distance to their professional institutions and private homes. Anthropology closer to home or even 'at home' continuous to raise the question whether it is 'anthropological enough' (Logan et al. 2023). While more and more anthropologists embark on fieldwork endeavours close to home – even before lockdown measures during Covid-19 turned this in a necessity for many anthropologists, particularly PhD students who could not follow their research plans as planned (Góralska 2020) - the potential consequences, challenges, and benefits of researching and publishing 'closer to home' requires more thorough consideration that goes beyond the call to merely 'create distance' (Van Dogen and Fainzang 1998). Proximity to the field, a common language, and digitisation with increasingly open access publications entail that anthropologists' representations of the world and their often critical interpretations of social phenomena, experiences and systems are increasingly accessible to fellow anthropologists, to other academics, and increasingly to research participants and people from 'our field sites'. When that site is biomedicine itself, university hospitals and clinics with clinician scientists or nurse researchers, the chances of potential interlocutors and research participants becoming potential readers of our work increase considerably. Where anthropologists publish their research and with whom matters differently depending on research contexts, and if anthropologists are to engage in the interdisciplinary work, this needs to be kept in mind.

I see the surgeon's response as illustrating a common mis/understanding of anthropological analysis among health professional, particularly doctors, as the mere view or opinion of an

individual, even an *outsider*<sup>55</sup>. While this particular example also highlights the hierarchical and exclusionary thinking in transplant medicine that locates expertise in the hands of a highly skilled few, this mis/understanding is also rooted in the different publishing traditions. While anthropologists tend to publish single-authored articles and books, and are expected and encouraged to do so as this is in line with the publishing traditions of the discipline, this mode of publication tends to attract some scrutiny from disciplines closer to biomedicine and STEM, which primarily publish multi-authored articles. This is just one of several issues that arise for anthropologists conducting research 'among white coats', a tribe with whom we share some similarities, such as an affinity and familiarity with research, but also some differences, such as scientific paradigms.

# 10.5 Concluding remarks: The temporality and politics of expertise

When anthropologists discuss the particularities of their anthropological expertise and how it contrasts and compares with other fields or disciplines in biomedicine and STEM, they tend to overemphasise the differences rather than the commonalities. The differences are manifold and concern research methods (oftentimes quantitative vs. qualitative), the importance and im/possibility of objectivity and subjectivity, or the role of theories and concepts in the respective traditions of knowledge production. However, what I consider is being side-lined by these discussions is how anthropologists' expertise, or rather expertises, refrain from being a clearly defined set of skills of conducting research, thinking, and writing. Rather, anthropological expertise itself is temporally situated and changes over time alongside professional and personal trajectories. This is the case for anthropologists following an academic career, whose expertise during their BA/MA studies differs significantly from their expertise during their PhD field-work, to their postdoctoral research endeavours.

This is also the case for researchers whose expertise – understanding expertise as synthesised from specialised knowledge to experience-based knowledge – shifts and changes with personal experiences. In relation to my respective field sites and research projects, my lack of experience

<sup>&</sup>lt;sup>55</sup> I do not wish to present an oversimplified interpretation of health professionals' views on anthropological research. It was in particular communication with another transplant surgeon, who also knew the surgeon who was writing these letters, which helped me to put these letters into perspective and gain some emotional distance from them. If other transplant surgeons considered my anthropological take on the scandal valuable and insightful, I couldn't take these full-blown shots at me too close to heart.

in biomedical settings shaped my doctoral research in terms of the questions I asked, the people I considered relevant to my study, the spaces I dared to visit (bearing in mind the highly regulated nature of clinical spaces and university hospitals). My sense of expertise grew not so much for academic reasons, but rather because of experiences in my personal life. My understanding of my research interlocutors' experiences of their life-threatening liver diseases became more nuanced and personal following the cancer diagnosis and subsequent death of a close friend from home (Rehsmann 2019).

One famous example of deepened understanding through personal experience comes remains Renato Rosaldo's 'Grief and a Headhunter's Rage' (1993 [1989]), in which he mentions how his understanding and interpretation of the Ilongot practice of headhunting, which is rooted in raging grief or grieving rage, was limited until he himself lost his wife Michelle. It was only after experiencing such a significant loss that he was able to better understand the consuming rage associated with grief and its relentless quest for release. Applying these examples to health care contexts, they are closely related to discussions about the importance of including experiential or first-person knowledge in research, teaching and practice. It highlights the limits of know-how and expertise as mostly based on formalised textbook knowledge and shifts the emphasis to an understanding of expertise that underlines the central role of informal and implicit knowledge, deeply rooted in individual experiences, life histories and routines.

Drawing on hospital ethnography carried out in a German transplant clinic and a Swiss palliative care centre, in this chapter, I discussed how the particular understandings of 'expertise' in these two biomedical settings shaped the access to these sites, the methods applied, questions asked, and the potential role of anthropologists in these settings. I argued that while these differences in ethnographic involvement, methods applied, and insights gained can be explained by the respective research foci (patients' or nurses' experiences) and medical fields explored (transplant medicine or palliative care), these methodological and epistemological aspects also shed light on different understandings of who is considered an expert and who has 'expertise' in these settings. It was through my fieldwork in palliative care that I realised my bias towards the perspective and expertise of nurses in my doctoral research. Despite participant observation in the nurses' offices and many informal conversations with nurses in the transplant clinic, my writing represented the perspective of surgeons and hepatologists far more than that of nurses, reproducing the fields' hierarchies of expertise in my writing. While I attribute this bias partly to my lack of knowledge and expertise at the time, I think it also represents a broader issue in anthropological research efforts in biomedicine, which relates to the choice of topic and its epistemological side-effects. Transplant medicine, despite being delivered by a multidisciplinary team, continues to emphasise the importance, skill and expertise of doctors, particularly surgeons, and remains a rather hierarchical field. Conversely, the roles of anthropologists in research in this setting are limited and specific, often placing them in psychosocial or psychological support roles. Palliative care, on the other hand, although practised in the same institutions as organ transplantation, questions the curative paradigm promoted by transplant medicine. With interdisciplinary teams working collaboratively and a more holistic approach to care, anthropologists with their reflective and critical perspective cause less to no friction in this setting.

While I hope I have not overwhelmed potential readers with too much detail, and it might indeed have been easier to choose one field site as an example of anthropological research 'among white coats', it is the confluence of these two sites that provides insights into the significant differences in carrying out research in biomedical and clinical contexts. What I hope to show in this chapter is that conducting fieldwork in biomedicine can look very different in terms of access, ethics and informed consent, methods used and the role of the researcher, depending on the field and setting one chooses to explore, the academic expertise one has accumulated, and the personal experiences that shape anthropologists' research topics and their presence in the field.

Anthropological research in biomedicine or STEM requires an engagement with interdisciplinary communication and negotiation that is often lacking in anthropological training. My personal academic trajectory has taken me from a more traditional disciplinary setting of an anthropological university department to a department of nursing and health research at an applied university. Applied universities in German-speaking contexts, especially in Switzerland, serve a different purpose than 'regular' universities. They are involved in training nurses and other health professionals primarily for practice, for which they receive most of their funding from the state (and canton), while also conducting (applied) research projects and furthering the development of the nursing profession. Working as an anthropologist in this setting requires an engagement with certain taken-for-granted vocabularies, concepts, ways of communicating and discussing, which has led me to continually reflect on disciplinary traditions in both anthropology and nursing, and their differences and overlaps.

Scientific expertise and academic knowledge have been under scrutiny in the rise of post-truth populism. Turning healthy scepticism on its head, the recent surge of 'alternative facts', COVID-19 denial and anti-vax movements highlight the contestedness of scientific knowledge, and the slippery slope between scholarly critique, academic discussions, politics, and public health. Knowledge production is inherently political. Similarly, who is considered an expert

and how expertise is framed, to whom it is ascribed and whose expertise has been excluded from the traditional realms of knowledge production, calls for ongoing anthropological inquiry, 'among the white coats' in biomedicine and STEM and beyond.

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# Ethnography of a socialist innovation: sociological collaboration and power relations in Cuban biomedicine

Nils Graber<sup>56</sup>

In a Cuban province, I established a contact with Geraldina\*, a local representative of the Centre of Molecular Immunology (CIM), a biotechnology institute based in Havana. She helped me to access polyclinics - primary healthcare centres (PHC) - where a clinical trial of a CIM's cancer immunotherapy was taking place. Geraldina even managed to obtain a car from the Provincial Direction of the Public Health Ministry. I had to pay the driver, who was the husband of a local health professional. We drove to a polyclinic in the periphery of the provincial capital. First, we met the polyclinic's director, who knew about our visit and had prepared a synthesis of the actions of the cancer control program performed at her institution. We met the team involved in the PHC clinical trial: a general practitioner, a nurse, a pharmacist, and a psychologist. We also met a patient, a retired accountant who suffered from an advanced lung cancer. I could ask questions to the professionals and the patient, took notes and then left my contact details to possibly meet again the professionals for an individual interview. Geraldina remained present and very attentive to the exchanges. We took a photo all together before driving to another polyclinic. With Geraldina, I would maintain a regular exchange, and we would share reflexions about the dynamic of the PHC clinical trial, even participating together to an interdisciplinary colloquium on cancer research in France. (Fieldnotes, 2016)

#### **11.1 Introduction**

I realized my PhD research on Cuban biomedicine with a focus on a program aiming at integrating locally developed cancer immunotherapies within primary healthcare centers (PHC). For this project, I have received a strong support from the Centre of Molecular

<sup>&</sup>lt;sup>56</sup> Laboratoire d'études sociales des sciences, Université de Lausanne.

Immunology (CIM), a leading biotechnology institute dedicated to cancer immunotherapy and autoimmune diseases. Considered locally as a 'socialist enterprise of high technology industry' (Lage 2013), the CIM aims both to export products and to improve the national health system, including by integrating its innovative products within PHCs in the whole island. How did my ethnography engage with this form of socialist biomedical innovation?

My research in Cuba has entailed specific challenges. In this chapter, I would like to analyze its epistemological and methodological aspects by focusing on the moment of 'access' to the field. In existing anthropological literature, the ethnography of technoscientific institutions can be considered as 'studying up' as it entails examining how scientific practices in high-profile organizations shape the lives of people of different socioeconomic positions (Gusterson 1997). We also know about the possibility of joint epistemic work in interdisciplinary collaboration with health professionals (Bieler et al. 2021), including its limitations (Stavrianakis 2015). Furthermore, we know about the positionality of anthropologists, usually from the Global North, in transnational partnerships and the stakes this raises about the politics of ignorance and invisibility of local people's experiences (Geissler 2013; Biehl and Petryna 2013). We know less about the ethnographic implications of studying technoscientific practices when they are organized in the Global South, including in postcolonial settings with different visions of modernity (Anderson 2002; Adams 2002). Undertaking one of the first fieldworks on Cuban socialist biomedicine, the geographer Simon Reid-Henry has argued that ethnographic research in this context entails 'sticky politics' to refer to 'the way the research process carries within it the politics of other times and places' (Reid-Henry 2003, p. 10). He described how the networks established with different individual researchers within the Cuban biotechnology industry enabled him to analyze both a local technoscientific 'milieu' and how it is shaped by broader geopolitical processes (e.g. the US embargo or the global markets of biopharmaceuticals) (Reid-Henry 2010; Reid-Henry 2003). In a nutshell, Reid-Henry considered that the focus of his project was on the 'intertextuality' between different scales, the biomedical milieu, the global market, and the (post)Cold War geopolitics (Reid-Henry 2003).

While acknowledging the importance of sticky politics, my fieldwork differs from Reid-Henry's one for two main reasons (in addition to the disciplinary lens - human geography for Reid-Henry and medical anthropology in my case). First, I questioned the organization of the 'biomedical milieu' itself, by investigating the perspectives of the different actors implicated in the clinical trials of local cancer immunotherapy within PHC. Thus, I looked for contrasting perspectives between the industry, oncology, and PHC professionals. Following Reid-Henry, I also considered socialism as an ideology deeply embedded in the (post)Cold War context and the global political economy, but I questioned ethnographically how this ideology informs the problematic relations between different health institutions, people, and actants (including how patients understand the local cancer immunotherapy as a form of 'vaccine' - vacuna; see Graber 2022). While Reid-Henry mostly questioned the heterogeneity of socialist biomedicine by interviewing researchers who emigrated, I focused on contrasting perspectives in the course of biomedical practices. In my case, I investigated how socialism became problematized also locally in the very clinical encounters and in the production of knowledge. I drew on a scholarship on socialism as a practical experience, avoiding any idealization or demonization of socialism and/or capitalism (Burawoy 1979). I also considered socialism as a project of modernity enacting a specific form of biopolitics (Collier 2011). In Cuba, state socialism has been investigated through different relations between discourses, practices, and ideology (Holbraad 2014; Gold 2016). With regard to health, at a general level, it has been shown how socialist medicine did lead to massive access to healthcare services, and the existence of specific situations where the ideology would meet people's expectations, thus shaping a 'socialism microcosm' in spite of persisting hierarchies, defective industries, or the declining investment in health (Vargha 2018; Keshavjee 2014). However, the history of science has shown how socialism is deeply rooted in the Cold War context, which fueled transnational collaboration but also institutional rivalries and political repression (Krementsov 2004). In Cuba, socialism is deeply tied to the health system, but in a post-soviet context marked by political and economic crises as well as 'pragmatic' state reforms, the state is increasingly unable to provide health care for all (Brotherton 2012). Nevertheless, 'medical subjectivities' have been shaped by socialist biopolitics, which make people engage in informal practices to maintain both individual and collective health as part of the national development (*Ibid.*).

Second, my work entailed a form of collaboration with socialist biomedicine. As a medical anthropologist, I was producing a form of knowledge that would align with some of the questions of the Cuban biomedical researchers. We already know about the epistemic and political possibilities of joint epistemic work in interdisciplinary collaboration with health professionals (Bieler et al. 2021). Some scholars have also shown how medicine is shaped by direct political engagement, in particular in the case of Leftist health professionals engaged in transnational partnerships (Birn and Brown 2013). This relates to a wider debate on the diversity of the forms of engagement in anthropology (Low and Merry 2010). In the case of Cuba, we know very little about the implications of collaborative work in the field of health. With regard to general social anthropology, Martin Holbraad has written about his collaboration with Cuban anthropologists, thus addressing challenges to provide 'symmetry' between the 'global'

(Western democracies) and Cuban fields (Holbraad 2019). This requires to question both the sharing of resources and the Western and liberal vision of a world available to the Northern anthropologist who has the 'right' to undertake research wherever they desire. In my case, undertaking research in collaboration with biomedical actors has shaped the type of fieldwork I could undertake, which has led to different strategies of research and engagement.

Overall, I argue that my ethnography on Cuban biomedicine is not only related to the relations with actants and sticky politics over the fieldwork, but also to the ethnographer's engagement with both a joint epistemic work and political ideology, in a way that allows to study up and down. In this chapter, I would like to present three moments of this process of accessing the field characterized by both different positionality and forms of engagement: 1) Biomedical diplomacy, or the need to commit to the revolutionary project of making health and medicine sources of political legitimacy in Cuba and abroad. 2) Sociological collaboration, which corresponds to a joint epistemic work with local biomedical researchers. 3) Studying socialism up and down, which means the need to understand the power relations between institutions, professions, and people including grasping the contrasting experiences of less visible and recognized people involved in cancer biomedicine. These three forms of engagement with Cuban socialist biomedicine do not correspond to specific moments, but are actually three intertwined dimensions that still continue to inform my fieldwork in Cuba. Overall, my evolving positionality reflects the dominant power of the domestic biotechnology industry in Cuban socialist biomedicine, but also pervasive professional jurisdictions, the centrality of informal practices, and spaces of reflexivity about political ideology underpinning biomedical practices.

### 11.1.1 Note on my fieldwork

My PhD research on Cuban biomedicine took place between 2014 and 2017. It was a period of hope for national development for many Cubans and relative openness toward the project of a young researcher from Western Europe like myself, as the Obama administration had begun a process of normalizing relations with Cuba, before the Trump administration withdrew it. I first focused my research on the historical development of cancer immunotherapy, before concentrating on the implementation of clinical trials at the PHC level (see below for a more detailed and narrative account of my access to the field). My research was based on semi-structured interviews and observations and, to a lesser extent, on archives to document transnational scientific collaborations. My project was approved by the ethical committee at the

National Institute of Oncology and Radiobiology (INOR, Cuba) and the National Institute of Health and Medical Research (INSERM, France).

#### **11.2 Biomedical diplomacy**

I started to be interested in Cuba while conducting a first research on Medicuba, an NGO based in Switzerland and led by leftist physicians (Graber 2013). Since the collapse of the Soviet Union, the NGO is attempting to provide support to preserve the Cuban public health system, considered as a 'model' for both the Global South and the Global North. Along with support to different public health programs, Medicuba provides funding to the local pharmaceutical industry, including in the field of biotechnology. Medicuba did play a key role in helping me access the field. Concretely, it was essential to obtain an academic visa, which is required when a foreigner wishes to conduct research in Cuba. Medicuba's president wrote a letter directly to the Cuban Ministry of Public Health to support my project. Still, I had to wait about one year to obtain the visa. In the meantime, I could start my research informally, that is with a tourist visa, by relying on the networks of cancer researchers with whom Medicuba had established relationships of trust. Medicuba shows how the medical field is politicized, which partly informs transnational collaboration in health and medicine (Birn and Brown 2013). In my case, I established a form of dialogue with Medicuba, informing them about my projects and research questions, while learning about their activities. I explored Medicuba's practices, which revealed an original political vision not only tied to activism but also to governmental diplomacy. Medicuba eventually begun to receive funding from the Swiss government to form part of ordinary development aid (Graber, 2013).

Health and medical diplomacy are often analyzed by political scientists as an attempt to coordinate actions at a world level – through international organizations or another scale of government – despite political differences and conflicts (Kickbusch and Ivanova 2013). In contexts of high political tension such as the Cold War, biomedical diplomacy enabled to produce significant public health benefits, as illustrated for instance the development of polio vaccines in the 1950s (Vargha 2018), or the bilateral US-Soviet collaboration in cancer research (Geltzer 2012b; Krementsov 2004). The political scientist Julie Feinsilver has argued that Cuban medical diplomacy relies on the constant investments in health to produce a 'symbolic capital' recognized at both national and international levels that the Cuban government expects to convert in both political legitimacy and different kinds of economic transactions (Feinsilver

1993). I would like to add that medical diplomacy takes form in specific places and at different scales, including at the micro-level of a PhD student wanting to undertake an ethnographic research project. I became myself a medical diplomat at a rather modest level, involved in pre-existing networks of biomedical collaborations, facilitating scholarships for individual researchers to develop new collaborative projects.

In parallel to Medicuba's network, I did also rely on French networks of medical and scientific diplomacy. At that time, during the mandate of François Hollande, who visited Cuba in 2015 to enhance bilateral relations, the French embassy was multiplying funding for collaborations, especially for research stays in France or organizing scientific events. I could then facilitate research grants for a few colleagues. In Cuba, this is a key aspect for most researchers, motivating them to stay in the country despite very low salaries and relative isolation. Following Fensilver, we can return to Bourdieu and ask how symbolic capital is produced and distributed. In my case, I was a PhD student based in France, coming from the 'First World' (el primer mundo), with higher economic capital than most of the actors, but also a quite significant symbolic capital stemming from both Medicuba and the French embassy. This was key to obtaining the academic visa, which, I want to emphasize, was obtained at the level of the National Institute of Oncology and Radiobiology (INOR). A tutor, Ana Cristina\*, a cancer immunologist was appointed to my project. In principle, this official status allowed me to carry out research on the healthcare system, which in practice has meant regular access to the INOR, including its library and Internet connection - so rare in those days in Cuba - as well as to the staff canteen. Furthermore, with the support of Ana Cristina, I could conduct certain interviews with experimented researchers and heads of institutions, including at CIM, and also to observe consultations at INOR involving the use of local cancer immunotherapies thanks to my connections with oncologists. However, it did not help me to access what started to become my main topic of interest: clinical trials of the CIM's immunotherapy at the PHC level. As I would gradually understand, INOR was not really tied to this program. Furthermore, I felt that at INOR I was missing connections with the social sciences. Therefore, I made a specific use of my symbolic capital – to keep a bourdieusian language. While I organized a scientific colloquium at INOR, I also helped specific persons to obtain French grants at other institutions, mostly researchers from the CIM and social scientists. Beyond personal sympathy, it was also a choice related to my research questions and the type of knowledge I was aiming to produce. While the concept of medical diplomacy certainly informs about the kind of work I did undertake to establish first key contacts in the field, it does not tell that much about the epistemic nature of the scientific collaboration, in this case, between social sciences and cancer biomedicine.

#### 11.2.1 Sociological collaboration

Thanks to support from Medicuba, I could establish quite early contacts at the CIM. As most biotech centres, CIM is organized in a 'closed cycle', which means it is in charge of the whole process of development of new pharmaceuticals from basic research to clinical trials, industrial production, and sales (Lage 2008). CIM has been led by scientists who are also highly ranked in the political system, which illustrates how the national biotechnology industry holds a central position in the Cuban political economy, both to improve the national health system and generate revenue through exportations (Reid-Henry 2010).

At CIM, when I met one of the heads of the institution, she put me in contact with a social epidemiologist. Elisa\* was responsible for post-marketing clinical trials and was working on a project evaluating CIM's immunotherapies used in PHC. I found this topic fascinating and capable of highlighting how cutting-edge biotechnology can be introduced within the community-oriented PHC where family physicians and nurses work. Elisa also told me that she needed to collaborate with a 'sociologist':

I am interested in a support, at best from a sociologist, that would be very good (...) if you do this approach in terms of process and how the process of diffusion of innovation was realized, that is, of biotechnology, of our products, how they were introduced into the system. And all these issues of barriers, facilitators (*facilitadores*), recommendations... (social epidemiologist, CIM, 2015)

I had an excellent initial contact with Elisa. I had the impression we spoke a common language. She was open to qualitative and 'community' approaches and was also critical of the dominant epistemology at the CIM, which she qualified as 'quantitativist' and 'positivist' (*un enfoque muy cuantitativista y positivista*). She wanted to understand how CIM's products were made accessible, including in terms of socioeconomic and ethnic inequalities. However, her conception of the 'social' was quite different from mine. While I appreciated her social epidemiological approach, I wanted to question not only diverse experiences of health but also the power relations, including the place of CIM within the PHC infrastructures. In any case, I appreciated her approach and thought it showed how socialist biomedicine can be reflexive and connected to social sciences. I moved from a position of biomedical diplomacy to an interdisciplinary collaboration. 'Co-laboration' can be understood as a process of 'joint-epistemic work', which requires a situated process of generating shared analysis and setting a common political agenda between both social and health sciences (Bieler et al. 2021; 208

Niewöhner 2015). What would this mean in the case of a collaboration with CIM? Regarding joint epistemic work (a concept I did not know about at that time), I envisioned a potential collective reflection on both socioeconomic inequalities of access to cancer immunotherapy and the local dynamic within PHC. To this end, I planned to conduct an ethnography of different polyclinics both in urban and rural areas, which I would then adapt to trigger discussion with the different involved stakeholders. However, I was faced with different problems, one of a practical nature: I was alone as a social scientist. Therefore, I tried to establish more links with Cuban social scientists. By attempting to approach local sociologists and anthropologists - two disciplines I feel part of – I realized that cancer medicine was not studied in Cuba from these two disciplinary lenses. There was, however, some interesting research underway on infectious diseases or maternal health. This shows the importance of considering how social sciences of health are locally configured with regard to the health institutions, political history, and foreign disciplinary networks (Gamlin et al. 2020). Eventually, I established connections with health economists using qualitative methods with cancer patients to understand the indirect spending, which has led to a common questioning on ethno-accounting (Galvez González et al. 2020). Also, building on my role as a (modest) biomedical diplomat, I facilitated access to a grant for the health economist colleague with whom I was in touch to foster an interdisciplinary collaboration with the CIM.

Regarding the idea of setting a political agenda, scholarship on social-biomedical collaboration mentions examples such as shaping policies through reports written together by social scientists and health researchers (Bieler et al. 2021); we could also mention the social scientists' engagement with non-professional participants, such as patient organizations, to acknowledge new social identities able to co-construct research content and agenda (Callon and Rabeharisoa 2008). In my case, this could have meant writing a report with the different stakeholders to raise attention not only about unmet needs, but also about new entanglements between patients, PHC, and the biotechnology industry. Of course, this raises the question of how public health policies are shaped in Cuba. I already had the intuition that the CIM did play a key role to that extent, a point that would prove true and would also complicate my fieldwork.

My research did not become less complicated after this first meeting with Elisa. She did not want to provide me with the list of primary care centers to start my fieldwork. Yet she told me: 'But if you manage to do your research, we will be happy to collaborate'. It seemed strange and I felt that my research was reaching an impasse. I thought that my project was perhaps posing a political problem and started to feel anxious about the potential impossibility of conducting my project, associating this to images I had about 'socialist regimes', namely censorship and

surveillance of researchers. I began to call my different contacts and started to realize that my academic visa at the INOR was the main problem. It prevented me from having formal supervision by Elisa, who would have liked so; I had then to seek the help of the INOR to access polyclinics. Yet my supervisor at the INOR, Ana Cristina, told me that she did not know much about the PHC program, but that she would facilitate contacts with oncologists in province. I realized that the INOR had little involvement in this program, which was handled by other oncologists. I also started to realize that several INOR researchers were skeptical about the PHC program for the use of CIM's immunotherapies, because they were far from the global standards. The PHC clinical trials seemed far from their jurisdiction and their institutional priorities as a national cancer institute. This suggests how professional jurisdiction, a sociological concept used mostly in the Global North (Abbott 2014), takes different forms in specific places because they are enshrined in the national history of public health and the political vision of modernity. Then, my difficulty accessing PHC clinical sites was mostly a question of professional jurisdictions, institutional priorities, and perception of standards shaped at a global level. My project of collaboration with CIM seemed problematic, and I had to find another way to develop my fieldwork.

#### 11.3 Studying socialism up and down

Despite this frustrating contact at the CIM, I could meet different PHC professionals. Thanks to my academic visa, I could participate in different meetings of the national cancer control program. There, I met PHC professionals in Havana who were presenting their work. I became quickly aware of Rosa\*, an oncologist at a small municipal hospital in the Cuban capital. She was very appreciated by PHC professionals. She explained to me she had organized the first activities of (general) oncology including palliative care within polyclinics before the CIM. She initially had almost no state support, and organized meetings with PHC professionals at her home using her own resources. I asked her who got the idea of starting clinical trials within PHC. She answered: 'I cannot tell you, it is called socialism' (*no te puedo decir, eso se llama socialismo*). I tried to understand that through other interviews, including with the head of the national control program. I understood that the CIM actually built on Rosa's initiative to elaborate and undertake the project of inserting cancer immunotherapy within PHC. Yet Rosa was not fully recognized as the initiator. I still do not know what kind of recognition she would

have liked; perhaps a better position that would have enabled her to have more research responsibility and limited her exhausting clinical work at a crowded and under-resourced hospital. Indeed, Rosa's institutional position was quite far from that of the oncological leaders from the INOR or Hospital Hermanos Almeijeiras (another tertiary institution). She also told me that she wanted to travel abroad, perhaps to leave the country. There were public secrets, which are knowledge that everyone knows about without talking about them (Geissler 2013), that were clearly going beyond my capacity to understand as a foreign researcher. Yet, these very public secrets were important to understand the position of the CIM within Cuban socialist biomedicine. Indeed, I started to understand how the CIM built on local initiatives to develop its research programs as part of its mandate to improve the national health system. Yet these initiatives were facing tensions. They could be contested because they were far from the global trends (as I indicated before) or because they were not fully integrating the dimension of cancer control. It was actually a critique that I started to elaborate in my discussions with Rosa. She was very aware of the importance of connecting the clinical trial to different cancer care programs activities in PHC (including prevention and palliative care), while there was a debate to limit the role of PHC to the use and evaluation of the cancer immunotherapy. There was no simple solution to this debate, as it was also a matter of avoiding burdening further already overwhelmed PHC professionals with other activities and responsibilities. Furthermore, the CIM had to manage complex questions of personal recognition. Indeed, Rosa had attempted to initiate change and make oncology more holistic by integrating it within PHC. She had followed the value of self-sacrifice central to the revolutionary moral (Holbraad 2014), but in a specific way. She had organized a workshop at her home without institutional support, with the hope of attracting state attention and generating change, which shows how a form of attachment to the revolutionary project is created when the boundary between individual initiatives and state policies, home and institution, informal and formal, is fading to make life more livable (Cumbrera et al. 2020).

Thanks to Rosa's network, I could interview a few PHC professionals. I could conduct repeated observations at some clinical sites. Furthermore, I could also establish key contacts in the provinces through Ana Cristina. Elisa from the CIM maintained contacts with me and eventually also helped me to connect with other polyclinics, where I conducted 'official visits' with biotech researchers – as the one illustrated in the opening vignette. I could also establish contacts with patients to understand their experience of chronicity in relation to both the temporality of the clinical trial and their understanding of the therapeutic vaccine (Graber

2022). Sometimes, when I started to have real trust in my insertion in Cuban biomedical communities, I even went spontaneously to different polyclinics and asked: 'are you using the *vacuna*?'. Hence, I could establish relations with PHC professionals without direct connections to the CIM and multiply the perspectives on the clinical trials.

My exchanges with Rosa and the subsequent unfolding of my fieldwork illustrate the importance of studying up and down socialism. On one hand, I studied up the elite of oncology and biotechnology. This was key to understanding the dominant role of the CIM in shaping cancer control policies. This latter aspect generates tension with oncologists, who maintain a strong control of their jurisdiction, especially at the tertiary level. On the other hand, I was able to access the field by studying down. In my attempt to multiply points of access to the field, through medical diplomacy, collaboration, participation to scientific events, and more informal relations, I identified actors who, despite being less visible, were facilitating the integration of the *vacuna* within PHC at their own level.

Eventually, my collaboration with the CIM took a different form than what I had expected. I multiplied the point of entrances disconnected from their close network. I undertook a process of joint reflection, which entailed presenting my research during different scientific meetings in Cuba, or conceiving a presentation with a CIM PhD student for an interdisciplinary cancer research colloquium in France. Also, during the pandemic of COVID-19, I have maintained a link with Cuban colleagues. I am still involved in interdisciplinary scientific projects on the role of PHC – including cancer programs – during the COVID-19 pandemic with the support of grants mostly from French institutions. These collaborations rely on close personal relations and medical diplomacy, but also on shared scientific questions, where studying up and down remains a methodological, conceptual, and organizational challenge.

# **11.4 Discussion and conclusion**

My research was enabled through both Medicuba – a Swiss NGO made up of politically engaged medical professionals from the Global North supporting the Cuban health system – and the CIM, a prominent actor in Cuban biomedicine. At one point, I thought naively that getting their support would open the doors I needed for my project. This was not the case. There are logics of competition and individual rivalries, where actors mobilize the state's network and infrastructures for their own interests. In this situation, professional jurisdictions remain strong, between hospitals, primary care centers, and the industry. Therefore, I had to establish different

kinds of connections at these three levels. However, the CIM remains a dominant player in socialist cancer biomedicine, shaping the cancer control program. It is a reflexive space of Cuban socialism, where articulating the production of economic value with public health is a key endeavor. My complicated itinerary of access to field shows how Cuban biomedicine is a form of biopolitics, where the power is not only top-down but also tied to local initiatives and forms of subjectivities, described for instance as 'medicalized subjectivities' in its attachment to public health (Brotherton 2012). Furthermore, informal practices and direct relations remain a central aspect of Cuban life, which values self-sacrifice for the common good, care and health, but also different forms of transactions blurring the boundary between the personal and the institutional (Holbraad 2014; Holbraad 2021; Brotherton 2012; Burke 2021). Still, conducting ethnography in Cuba involves different types of public secrets, where institutional actors talk about the socialist government, their use of money, or their desire to leave the country, with often very controlled or sometimes cryptic and ironic discourses.

In any case, this reminds us how state socialism and capitalism are two forms of modern projects entailing biopolitics (Collier 2011), which enables us to shed light on common experiences in the field of biomedicine, related to conflicting professional divisions, problematic relations between health and industry, ideologies of hope, or forms of subjectivities. Differences matter: in contrast to capitalist contexts, in Cuban biomedicine, the biotechnology industry strives to meet national health needs, there is still a state ownership of the means of production, and private capital accumulation is very limited. Furthermore, the Cuban cancer biomedical organization differs significantly from that of the Soviet Union as described in different periods (Geltzer 2012a; Krementsov 2004): the national industry holds a central position, while in the USSR there was little articulation between clinical, laboratory, and industrial spaces. Furthermore, I did not witness dramatic situations as those described by Nikolai Krementsov about Stalinist biomedicine, when cancer researchers were prosecuted for collaborating with Western scientists (Krementsov 2004). In Cuba, collaborating with Western researchers and companies is highly valued as a key aspect of maintaining a socialist project of health and medicine through the possibility of generating economic value through exportation, which that would be then redistributed within the national health system (Lage 2008; Reid-Henry 2010). However, while I did not observe directly situations of state violence in Cuban biomedicine, I do not deny the existence of excessive political control and coercion in specific health-related contexts, as it was documented for instance in the initial response to the HIV epidemic through the isolation of infected people in sanatoriums (Scheper-Hughes 1993), before a communitybased approach was gradually implemented (Castro et al. 2008).

In Cuban socialist biomedicine, social sciences have a significant role through collaboration, thus enabling a modern value of biopolitics, namely that social knowledge can contribute to unveil social injustice and improve the regulation of society (Rabinow 1989). My shifting positionality on the field also sheds light on the condition according to which a form of collaboration is possible in this form of state socialism. According to Anthony Stavrianakis, who did an ethnography on the collaboration between social sciences and life scientists in the US, his project faced an 'impasse [that] indexes power relations at play and showed limits to how a pluralism of forms of expertise can be given an organizational arrangement, one in which social scientists could form part of the transformation of the scientific field' (p. 185). Furthermore, collaborative projects index both social positions and political agendas, which limit the ability to conduct an anthropological inquiry.

In my case, I was grappling with implementing a polymorphous engagement (Gusterson 1997), entailing different forms, from diplomacy to interdisciplinary collaboration and informal transactions. I argue that, thanks to these changing and interrelated forms of engagement, I could move in the social world to studying up and down. This shows how a certain form of shared reflexivity could take place, although sustained by different kinds of capitals and networks that, as a foreign ethnographer, I had to mobilize. These different forms of engagement are still taking place in my research activities, and none of them – diplomatic, collaborative, and studying up and down – are completed once and for all, as they require constant articulation to pursue and maintain research activities in Cuba. Throughout my fieldwork, I could then grasp a certain conception of the 'social' guiding institutional changes in socialist biomedicine, which differed to some extent from mine, leading to forms of alignment but also persisting but tolerated misunderstandings.

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