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### A Research Center at the End of the World A study of local writing practices in a global context

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**Abstract:**

How do transnational flows and collaborations shape scientific research writing? What role do local language practices play in a global science context? Or how do phenomena of globalization and internationalization impact the work of scientists writing for local audiences and “with a local eye”? Through a case study drawing on memory, archival material, and interviews, this dissertation explores the language practices of a team of vaccine researchers working from a country in the global semi-periphery (Chile). Drawing on elements of mobility, activity and genre theories, this study traces the work of these scientists across space and time and shows how they contend with and resist the progressive standardization and *scalification* (Tsing, 2005; 2012) of knowledge making and language practices. This work’s findings show how from the early 90’s to the present time, researchers as writers faced the imposition of increasingly rigid standards in the writing of documents involved in the research activity and a progressive loss of agency in the decisions associated with research design and protocols. In other words, how “global” standards were imposed and preferred over local ones, even in matters concerning the most adequate ways to address local populations. At the same time, I show how these researchers found ways to resist standardization, using language in locally attuned ways and asserting their own standards for ethical research. I argue that an attunement to locality is critical for good and ethical scientific work, especially that dealing with human participants.

This study offers interesting insights for technical writing, especially in the realm of scientific and health science communication. It also advances the understanding of transnational writing practices and writing in a global context, suggesting that more needs to be done in the ways of attending to locality in ethical and productive engagements with research across borders and contexts.

A Research Center at the End of the World  
A study of local writing practices in a global context

by

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Dissertation Submitted in partial fulfillment of the requirements for the degree of  
Doctor of Philosophy in Composition and Cultural Rhetoric

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## Acknowledgements

When I was in middle school my mom once said to me “All you really need to learn in school is good writing and basic mathematics”. So, here I am, *mamá*, working on it. I’m sure there will be time for the basic mathematics later.

This work exists thanks to the support of many dear friends and mentors who have cheered me on, contributed invaluable feedback and perspectives, and trusted me to take this project where I wanted it to go. Special thanks to my advisor Brice Nordquist, and readers Lois Agnew and Krista Kennedy, who have read this manuscript closely and thoroughly all throughout its process of becoming. Thank you, Natalia Ávila and Federico Navarro, for introducing me to this field, for showing me academia can be a place of friendship, collaboration, and respect, and for offering me multiple opportunities to learn and look up to you.

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## Chapter 1

### Introduction

#### Writing vaccine research from the semi-periphery

I have early childhood memories of walking through the pink and yellow hallways of the pediatric hospital, its walls covered in children's artwork, the strong smell of hospital food, and the stinging sound of crying babies. I remember walking briskly, trying not to look through the windows into the care units because the sight of all those sick children was painful. Hospital San Pablo<sup>1</sup> is a public pediatric hospital—the oldest and one of the most complex in Chile. The actual hospital building is a low, five-story structure with heavy concrete walls. On the first floor, one would find most administrative offices, the hospital's laboratory, pharmacy, and some medical specialties. The second floor was dedicated to intensive care and some pediatric units, and the third to surgery. The fourth floor accommodated general pediatric care units and the medical residence. And the fifth floor was mainly designated for oncology.

There was a separate section on the fourth floor, located across double swinging doors with wooden frames and glass panels, where there were offices, freezers, a fax machine, and the first computer I ever saw; an IBM with a black screen and green letters.

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<sup>1</sup> Even though all people and institutions mentioned throughout this work are real, all names, including institutional names, have been replaced by pseudonyms to protect the privacy of participants.



There, the sounds and smells of the hospital were somewhat muted and became background to the stirring of paper, the clacking of high-heel shoes and fingers on keyboards, the buzz of the fax machine and phones ringing. This section of the hospital wing was painted in more neutral colors, there were no children's pictures on the walls, and it looked somewhat neater (perhaps even cleaner) than the rest of the hospital. When in the hospital, I spent most of my time on this side of the wood and glass doors. This small section on the fourth floor was assigned to the offices of Vaccine Research Chile (or VRC): a research center for vaccine development that operated at this location from the early 90's roughly until 2020. Almost exactly my lifespan, and almost exactly the same time my mother was appointed local coordinator for the center—although, as I will explain later, VRC's research trajectory in Chile is slightly longer than this.

In many ways, I imagine Vaccine Research Chile was very much like any other research center. It had computers, researchers doing researcher work, fridges to store samples, assistants filling spreadsheets. In some other ways, however, I believe this center was rather exceptional—or at least out of the norm. Rather than being located on the grounds of a wealthy university, VRC was based on the grounds of a public children's hospital located in a working-class neighborhood and in a developing country. Another peculiarity of this research center is that it was connected to a larger network of research units associated with a center for vaccine development in the US. Hence, though out of the norm, VRC is not unique. There is at least one center that parallels VRC in Mali, and several smaller units of this network located across Asia and Africa, including Malawi, Burkina Faso, Uganda, Kenya, Cambodia, Nepal, and others. As part of this North American research center's global reach program, VRC existence reflects and active effort to build a

transnational scientific endeavor involving a country in the Global North and countries in the Global South.

Growing up, the busy scientific life of VRC was a constant presence in my life. I often found myself doing homework in the center's offices or coming along to the hospital to pick up documents. A couple of times, I rode along with my mom to a research participant's home for one of many follow-up interviews. So, I long wondered about the people who participated in these studies. I knew many of them involved children and babies, which of course, made a big impression on me as a child. Were they safe? Could they get sick? What does it mean for them to be part of an experiment? The VRC also made its way into our home in different forms, like that of coolers for samples or vaccines, scientific and medical publications that came in the mail, or the bi-annual visit of the director of the collaborating research university in the US, who would dine with us, take a nap on the couch, and patiently attend to my nine-year-old self eager to display her English language skills. I would sit through those dinners and eavesdrop on conversations about research projects, public health, pentavalent this, and pneumococcal that. I even recall having been asked to read an informed consent form at age 10 or 11, which furthered my questions and concerns about scientific research with human participants—though I was particularly worried about research with children.

While the influence of VRC has failed to make a medical scientist of me, its constant presence has made me curious about scientific research and the people who do science. (I also suspect that seeing my mother constantly writing, talking about papers, and hearing her complain about colleague's writing that she was peer-reviewing, had an impact on my becoming a writing specialist). In 2020, the rise of a global pandemic and the hectic

race to develop vaccines against the novel coronavirus (SARS Cov2) re-ignited my curiosity for the images, practices, and language about science and vaccines that populate my childhood memories. At the same time, and as I begin working on becoming a researcher myself—one that works across borders and languages, and on building collaborations and exchanges between a country of the Global North and a country in the Global South—I cannot help but notice the parallels between my mother’s trajectory and my own. Though my field is nothing like vaccine research, I too am a Latin American scholar moving back and forth between Chile and the US, trying to collect data while responding to local and international exigencies, and constantly working across languages.

What I am beginning to learn from this backward or *retrospective ethnography* (Ferreira & De Almeida, 2017) is how much locality and transnational movement have impacted our research lives: what we write, how we write, and what encounters foster or hinder our writing practices. Vaccine Research Chile’s research trajectory and institutional history, shaped by its relationship to a US university, the pharmaceutical industry, and regulatory bodies, illustrates that global academia is not a smooth space where knowledge travels freely and evenly, but rather, a bumpy network that eases certain flows and directionalities while hindering others. As John Krige points out:

Global inequalities in the production and appropriation of science and technology demand that we imagine networks as lumpy, three-dimensional structures made up of hierarchical interpersonal encounters. Transnational actors do not simply travel from one place to another; their knowledge is an asset that they deploy to reconfigure existing spaces and themselves and what they know. (Krige, 2019, p.9)

From a writing research perspective, I argue that once we start moving across borders, we start writing transnationally, which means our writing doesn’t just happen at

different locations and in different languages. Rather, writing often happens because we move, thanks to movement, shaped by the constraints of being across borders (Blommaert, 2010; Pennycook, 2010; Nordquist, 2017). My positionality as a transnational and translingual scholar—and the daughter of one— offers me a privileged vantage point on the workings of cross-border writing practices and their complexities. This has led me to raise questions like: *how do transnational flows and collaborations shape scientific knowledge production?* And more specifically, *how do transnational flows and collaborations shape scientific research writing?* As I will explain later, these perspectives are especially valuable for the study of inherently transnational objects such as the scientific study of vaccines and infectious diseases, and the networks of researchers that collaborate to produce such knowledge.

In the following sections of this introduction, I will explain the need for a transnational perspective on scientific research writing and specially on biomedical research. Then, I will explain the role ecological perspectives play in the theoretical grounding of this project. Finally, I will provide an overview of the chapters in this dissertation.

### **Transnational perspectives on science and writing**

As I point out earlier, VRC's research trajectory traces its history to a collaboration with a research institution from the US—I will call it Blank City University (BCU)—starting in 1978. The center for vaccine development at Blank City University's School of Medicine was funded in 1974 and it is dedicated to the whole range of biomedical research

activities on infectious diseases, including laboratory work and vaccine development through clinical trials and pre- and post-licensure field studies. A fundamental principle in the center's mission is a focus on global health, materialized in a global reach program that coordinates collaborations and conducts studies in multiple countries located in South America, Africa and Asia. These collaborations fostered the establishment of regional centers or units in Chile, Mali, and Malawi, each with different research foci, institutional features, and modes of articulation with local governments and academic networks; all of which have also shifted through time.

In Chile, when these collaborations began, the country was under the power of Augusto Pinochet's right-wing dictatorship and going through a major typhoid fever epidemic (Levine, Black & Lanata, 1982; Morris, Ferreccio, Garcia, et al., 1984; Ferreccio, Levine, Rodriguez, et al., 1989). Dr. Friend, the founder of BCU's vaccine research center, was called as a consultant by the Pan-American Health Organization (PAHO) to address the local typhoid hyper-epidemic and collaborated directly with the government, the Chilean Ministry of Health's Typhoid Committee, health services, and local universities to investigate the crisis and develop public policies to face it. With the return to democracy in the early 1990's, however, the incoming authorities grew wary of these researchers from the US and their close ties with the government apparatus of the dictatorship. Thus, in 1993, VRC was constituted as an autonomous non-profit research foundation in Chilean territory and appointed a local director: a Chilean Pediatrician trained in vaccinology and infectious diseases at Blank City University, my mother, whom I will identify as Dr. Susana Arce. By then, typhus was no longer a concern, and research interests had mostly

shifted towards respiratory infections like *Haemophilus influenzae*, viral influenza, or pneumonia (Lagos, Avendaño, Levine, et al., 1991; Lagos, Levine, Avendaño, et al., 1998).

As it is evident from the above, Dr. Friend greatly outstayed the initial purpose of his visit, and these collaborations between Chilean and US researchers outlived the typhoid epidemic. So, what brought a group of researchers from the US to Chile, and—perhaps more important—what made them stay? Was there anything particularly interesting about this specific location? For sure, the Chilean case could have been gripping for an epidemiologist interested in enteric diseases. The country at the time seemed to be an unlikely place for a typhoid epidemic to break out. Overall sanitary conditions had been improving steadily over the last four decades, yet cases were surging both among low and high socioeconomic groups, “even those who live under apparently nearly optimum sanitary conditions” (Black, Cisneros, Levine, et al., 1985, p. 899). Indeed, even though mortality due to typhoid had decreased significantly and consistently since the 1940’s, the number of cases continued to rise. “Paradoxically, this increase in morbidity occurred during a period in which access to potable water and sewage disposal in the home increased and became almost universal in urban areas” (Black et al., 1985, p. 899). Indeed, both urban development and public health infrastructure in Chile, at the time, were quite advanced for regional standards. So, the typhoid epidemic posed the rare scenario of an underdeveloped-world problem unfolding in a country with advanced developing-world life-standards and infrastructure. Perhaps the peculiarity of this case and the unique conditions of the country, which supported scientific research, explain why, by 1978 the PAHO appointed Dr. Friend to cooperate with local authorities and health services in addressing the epidemic.

I believe VRC's case also attests to the expanding efforts to internationalize science and healthcare, as scholars of the history and sociology of science have described as taking place post World War II (Krige, 2008; Turchetti, Herran & Boudia, 2012). For certain, science has always been a global enterprise (Briggs, McCormick & Way, 2008; Turchetti, Herran & Boudia, 2012), but in the second half of the twentieth century, the internationalization of science acquired a new character. It materialized in regulatory bodies and associations such as the World Health Organization and International health regulations (Yach & Bettcher, 1998) and was actively used by the US government as an instrument of foreign policy (Doel & Harper, 2006). John Krige and Kai-Henrik Barth claim that "World War II did not simply consolidate the links between science and the state to achieve specific practical objectives; it irreversibly embedded science at the heart of political processes" (Krige & Barth, 2006, p.2). And Clark Miller makes the point that taking science and development across borders to less powerful European countries and the developing world was a means to keep communism at bay and maintain international peace (Miller, 2006).

I don't mean to argue that VRC researchers in Chile or BCU as an organization were on a mission to advance the US's global hegemony and crush communism in the Global South—though collaborations did begin during a US-sponsored dictatorship. But internationalism and the internationalization of science as historical processes are undeniable background facts of the development of these collaborations between the US and countries like Chile. Indeed, internationalization understood as "the idea that international cooperation in science contributes (...) to the furtherance of broader goals of international peace and prosperity" (Miller, 2006, p.135) is discernibly echoed in BCU's

mission to “harness the power of vaccines to prevent disease and save lives in the most vulnerable populations” (web)—most often identified with people in developing countries where BCU extends its global reach. More than a simple asymmetry, this kind of description seems to describe the unidirectional flow of knowledge and technological capacity from powerful countries to weaker, less powerful countries or regions.

But VRC’s history is also shaped by other kinds of global mobilities. As described above, when this center began operating it worked in connection with its US-based parent institution. Later, however, it worked directly with pharmaceutical companies in conducting clinical trials and relied on other private and public sources of funding for etiological and epidemiological studies. Over the course of its research life, VRC saw a moment of transition in power balance, from a relative equilibrium between academic, government-sponsored and industry research, to one where the pharmaceutical industry became the dominant actor in vaccine research (Fulghieri & Sevilir, 2001). This change in power balance brought about profound transformations, from the way researchers could claim or be assigned research funds, to the amount of agency and intellectual input scientists had on the actual research design, including data collection strategies and the writing of consent protocols. Indeed, as industrialization advanced, researchers’ writerly agency (Lu & Horner, 2013; Zavala, 2011) dwindled and became almost nonexistent. What is known as *contract research* or *physician research* entailed an atomization of the research process, where the “researcher” became a mere data collector, ticking boxes and filling-in forms handed down to them by the sponsoring pharmaceutical company, data that they would later pass on to be processed by a data management agency.



This transformation favored the standardization of research procedures and protocols across the globe, and, in turn, the *scalification* (Tsing, 2005; 2012) of clinical trials for vaccine products. As described above, for researchers, this entailed the imposition of increasingly rigid standards in the writing of documents associated with the research and a progressive loss of researcher and writerly *agency* in the decisions associated with research design, protocols, and language. The concept of *agency* that I use throughout this work follows Virginia Zavala's (2011) definition of it as the "socially mediated capacity that individuals have to act and choose within the frame of the effects of the ideological forces that have constituted their subjectivity"<sup>2</sup> (p.52). As critical and translingual perspectives on literacy and writing propose, *agency* highlights individuals' possibilities to participate in meaning-making practices (Ávila Reyes, Navarro & Tapia-Ladino, 2020; Lu & Horner, 2013). In VRC's case, attention to agency or its loss, allows me to point to the effects of the growing dominance of global North actors and practices in transnational vaccine research on local language practices, specifically in a peripheral middle-income country like Chile.

As I will show throughout the work, the case of VRC shows how "global" standards were imposed and preferred over local ones, even in matters concerning the most adequate ways to address local populations. This phenomenon can be compared to what Jan Blommaert (2010) calls the *glocalization* or McDonaldization of language. Namely, the exportation of American English and symbols as the single means towards (upwards) mobility. While Blommaert's use of the metaphor of language economies describes how

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<sup>2</sup> Personal translation of the original in Spanish: "capacidad socioculturalmente mediada que tienen los individuos para actuar y elegir en el marco de los efectos de las fuerzas ideológicas que han construido sus subjetividades."

dominant—more prestigious—languages can displace the use of local languages, the *scalification* or industrialization of scientific knowledge production describes a very material decision to do away with local perspectives on scientific research in the name of efficiency and profit.

The internationalization and further industrialization of scientific research can be understood as a processes within globalization, defined by Blommaert as the deepening and expansion of capitalism characterized by the “intensified flows of capital, goods, people, images and discourses around the globe, driven by technological innovations mainly in the field of media and information and communication technology, and resulting in new patterns of global activity, community organization and culture” (2010, p. 13). In *The Sociolinguistics of Globalization*, Blommaert offers a nuanced analysis of this concept, where he distinguishes *geopolitical* from *geocultural* globalization. In this work, however, I am not as concerned with providing further definitions of such concepts as globalization, transnationalism and internationalization, but rather with having a conceptual apparatus to describe the kinds of challenges VRC faced over the course of its research life and creating some operational distinctions.

Hence, and mainly for the sake of clarity, I distinguish internationalization from transnationalism and globalization. Following Diana Brydon, I take transnationalism to describe an active engagement with world movements. She argues that this concept is needed

to signify the reclamation of agency, a reclamation that [in a globalized world] can no longer be claimed at the national level alone. We cannot ignore globalization but we can ask how to restore the agency once exercised through the state under changing global conditions. (Brydon, 2004, p.60)

For Brydon, this concept also describes a project to participate in meaningful cross-border exchanges. Similarly, transnational perspectives on literacy and writing “accentuate the need for cross-border practice, space, identity, and disposition” (You, 2018, p.2). Thus, while internationalization describes the unidirectional expansion of knowledges from Global North to Global South—or from center to periphery—I take transnationalism to focus on the spaces *in between* (Pandey, 2015), where cross-border encounters produce transformations in knowledge and knowledge-making methods.

Ishwari Pandey (2015) writes about the in-between spaces that migrant (transnational) subjects inhabit. In his view, the position of immigrants is one of being “caught between the centripetal (read: assimilationist) pulls of the host nation and the centrifugal forces from the nations and communities imagined transnationally” (p.30). This reflection can be extended to knowledges produced transnationally, from the place of tension between the pulls towards internationalization (universalism), and the efforts to preserve and reclaim local knowledge-making practices. As a product of the internationalization of science, VRC’s history exemplifies the (centripetal) project to take “Western” science, together with its values and ways of doing, across the globe. As I discuss throughout this work, VRC experienced the growing complexity of international norms and regulations for biomedical research and faced the transformations of the pharmaceutical industry that moved towards the standardization and scaling of knowledge making practices in vaccine science. All the while, researchers at this center were committed to producing knowledge *with a local eye*, with respect for local needs and attuned to local publics. As Jan Blommaert points out, “We have an act of communication which at the same time orients towards transnational indexicalities and to strictly local

ones, and the effect is that the [*language*] used in these signs has to make sense here” (2010, p.189). What it meant to produce knowledge *with a local eye* and how these researchers managed to do it is, in part, the subject of the present work.

The case of this Chilean vaccine research center is interesting because it represents a kind of North-South collaboration very seldom examined by the literature. This was not, as Suresh Canagarajah discusses in *A Geopolitics of Academic Writing* (2002), an extractive relationship, between Global North researchers who produced scientific knowledge and a country of the Global South understood merely as a source of data. Because this is a retrospective ethnography, this work does not deal with the challenges of English as the default language of academic communication. The issue of language hegemony and access that Mary Jane Curry and Theresa Lillis (2010) examine does not appear to be a very straining source of asymmetry for researchers at VRC. Though some asymmetry certainly existed, the issue of language difference, and English specifically, was never raised during our conversations. But, of course, if this ever was a difficulty during these researchers’ lives, this kind of study could not observe it. In any case, VRC’s researchers were all fluent users of English. Not only this, but stable collaborators from the US—like Dr. Friend—were also competent Spanish users. Back and forth communications and work around publications would happen in both languages, with commentary and revision going both ways.

To this point, Argentinian sociologist Leandro Rodriguez-Medina and his collaborators (2019; 2021) offer a valuable caution around the idea that North-South exchanges are merely extractive or colonizing. In agreement with Lillis and Curry (2010), the authors describe how peripheral scholars adjust to the standards and conventions of

mainstream actors. He understands this as *leveling up* by adopting English as lingua franca—and I believe this is how VRC researchers would have experienced it. Further, according to Rodriguez-Medina, periphery scholars also find ways to “criticize metropolitan scholars’ arguments in innovative ways and, above all, in their own terms. [They also] adapt their research and writing strategies to meet the expectations and, perhaps more importantly, to make their research appropriable by metropolitan colleagues” (Rodriguez-Medina & Vessuri, 2021, p.410). This perspective emphasizes the role of scholars in peripheral countries as co-producers of scientific knowledge (Rodriguez-Medina, Ferpozzi, Layna, et al., 2019), as opposed to mere victims of hegemonic powers’ epistemic colonization. At the same time, it shows how engaging in exchange entails some degree of compromise and complicit participation in the project of science as a universal (perhaps “Western”) project.

As I will show throughout this work’s chapters, at least during a window of time in the center’s history, this group of vaccine researchers experienced transnational work and exchange as genuinely collaborative. In a way, they actively “bought in” to the idea of English as the language for international academic exchange and played by the logics of the North’s dominance in the advancement of science at the global scale. They benefited from the prestige conferred by these collaborations and from the access to international networks and sources of funding. In other words, they *leveled-up*, by adopting the more prestigious code of international communication, as well as through the symbolic power tied to the networks these collaborations gave them access to. Additionally, for the timeframe that I study, VRC was also able to resist the logics of epistemic extractivism described by Canagarajah (2002). As I discuss in Chapter 3, by constituting an independent research

center and developing local standards and conditions for engaging in collaboration, VRC researchers made sure to be active—even if not always equal—participants in the production of scientific knowledge.

The former is the reason why I hesitate to describe international standards and networks of knowledge as “Western”. Doing so would entail understanding Chile and Chilean researchers and their modes of knowledge production as “non-Western”—a category which I doubt they would choose to describe themselves. Instead, I would rather describe these encounters as moments where locality meets the global, or the universalist project that is advanced by internationalization. Universalism, however, is a paradoxical idea. As Anna Tsing (2005) explains,

Universalism is implicated in both imperial schemes to control the world and liberatory mobilizations for justice and empowerment. Universalism inspires expansion—for both the powerful and the powerless. Indeed, when those excluded from universal rights protest their exclusion, this protest itself has a twofold effect: It extends the reach of the forms of power they protest even as it gives voice to their anger and hope. (2005, p.9)

Thus, while VRC contributed to the generation of locally valuable knowledge, they did so by extending the power of English-language communication in academic spaces, as well as collaborating and contributing to the expansion of a US-based internationalist project. *Leveling-up* is a double-edge sword. Encounters between the local and the global happen not without tension or power asymmetries, but this doesn’t mean they can’t be productive, even fruitful. In this work, I am interested in how vaccine researchers based in a research center located in Chile worked across borders and power asymmetries—differences in material, symbolic, and linguistic resources—and how they contributed to universal scientific knowledge. Using Anna Tsing’s concept, I am interested in the

transnational collaborations as sites of *friction*, that is, “the importance of interaction in defining movement, cultural form, and agency.” Friction, she adds “is not just about slowing things down. Friction is required to keep global power in motion” (2005, p. 6). Thus, attention to friction at research sites like VRC bares the tensions that *enable* collaborative work. Friction is also, as I explore throughout this work, one way we can describe what stands in the way of the smooth advancement of the industrial scaling of knowledge production processes and the standardization of language practices in the context of global exchange.

As a local research center involved in the transnational production of public health science, VRC’s activities weave together the advantages of an independent center with the public health concerns of the local health authorities. As pointed out by Rodriguez-Medina and collaborators about the nature of transnational research exchanges, VRC’s research and writing practices had to attend and adapt to the characteristics of the local context, while also complying with international standards regarding ethics and publication. Aside from the use of English for publication and Spanish for local communications—with teams, staff, participants, and local authorities—these exchanges engage multiple instances where VRC researchers face conflicting decisions about local and transnational *indexicalities* (Blommaert, 2010), where their knowledge and understanding of clear and appropriate communication is at odds with international expectations. This complex web of collaborations and activities calls for a perspective on writing that takes into account the networked, spatially (and temporally) distributed nature of writing practices, while also revealing the points of friction, where power asymmetries call for negotiation and both shape and constrain agency.

## **Ecological perspectives for a transnational context**

This vaccine research center in Chile was once a vibrant organization housed in a major public hospital with connections to one of the country's main universities; fully enmeshed in the global vaccine research network and navigating its complexities as a small research center from the semi-periphery. Today, in 2022, what remains of VRC is in a small private office where the center's director and a secretary meet some days a week, and a storage room filled with archival material from the center's more active years. VRC's archive contains documents for different kinds of studies, with different objectives, methodologies, and sizes, and of course, different sponsors. I will describe this archive in detail in the next chapter. For now, it should be enough to say that the documents stored there include study protocols, patient's clinical records, informed consents, correspondence, among others. These documents, VRC researchers' and collaborators' recollections, and my own memories are the materials available to me as I try to tell the story of this research center and its writing practices.

I argue that accounting for the kind of transnational scientific work conducted by VRC calls for an ecological perspective on writing. This metaphor (ecology), however, has been understood to have several meanings (Barton, 2007; Weisser & Dobrin, 2012), and this is also true here. The main hurdle this project deals with is accounting for the situatedness—that is, the ecological nature—of texts and writing practices while being unable to conduct the kind of on-the-ground observation and ethnographic work that would allow for the documentation of such practices. I will understand ecology in three main and interconnected ways: as the global network of actors and activities involved in vaccine



research; as the set of texts (and practices) that make up the research activity; and genres themselves as frameworks or ways of inhabiting textual activity.

The actors involved in transnational vaccine research are multiple and the power dynamics among these actors—who has the power to make decisions about how a clinical study is designed and conducted—has changed through time and across world regions depending on their level of development, economic capacity, and local infrastructure. Depending on who sponsors, and therefore leads and has predominant agency in the design and development of the research, we could distinguish studies as “industry research,” purely “academic research” (or “researcher research”), or as “government-sponsored research.” As mentioned above, power dynamics among these actors—researchers, international agencies, and the pharmaceutical industry—have changed over time bringing about changes in research models and writing practices.

When I say my approach to texts and writing is ecological in this sense, what I mean is that we need to pay attention to this broader context in which writing takes place, as changes in textual features reflect decisions and adaptations to a changing (global) ecology of the research process. Jan Blommaert argues that “globalization forces sociolinguistics to unthink its classic distinctions and biases and to rethink itself as a sociolinguistics of mobile resources, framed in terms of trans-contextual networks, flows and movements.” (2010, p.1). Attention to global landscapes re-defines what it means to attend to the context of writing practices, and de-stabilizes the idea that we learn to write within stable discourse communities. For the study of scientific writing practices this means that not only the context of the laboratory is relevant to understanding how scientific knowledge is produced—as Latour and Woolgar suggest (Latour & Woolgar, 1986)—but also the global

context. To understand how scientific knowledge is produced and how writing is shaped, it is important to turn our gaze towards this larger landscape, to the place where researchers stand in relation to it and the trajectories texts follow as they move across space and time.

Expanding the work of Activity Theory and New Literacy Studies (NLS) (Barton, Hamilton & Ivanič, 2000; Street, 2003) Catherine Kell (2009; 2013) proposes to study activity systems from the perspective of how people try to “‘make things happen’ [...] through projecting meaning making across space and time” (Kell, 2013, p.8). To do this, she proposes to attend not to *literacy events* (as NLS had traditionally done), but to *trajectories*, or the paths texts follow as people move them from context to context. Her text tracings show how writing can gain or lose function as it is moved across different contexts or spaces and how these *recontextualizations* impact the way writing makes meaning. In the author’s words, as “discourse forms move across spaces, they are subject to changed sets of evaluative criteria, which are part of stratified economies of literacy” (2013, p.3). Kell’s is an attempt to account for human agency while capturing what goes on with texts.

Crucial to both these authors’ accounts of texts in action is how people make sense of the texts they produce, though Catherine Kell’s approach offers an additional tool to describe how a text’s meaning and value changes and is perceived differently in different contexts or points in the network. The notions of *recontextualization* and *mobility* are relevant because they explain not only that writing emerges and interacts with people, objects, and spaces, but also that the way contexts are configured—the peaks and falls in the landscape—can determine the success or failure of the action a person is trying to mobilize through words. This tells us that communicative spaces and interactions are

anything but flat. They are layered in ways that create or restrict access to modes of social participation and agency.

In line with the work of Jan Blommaert (2008; 2010) and Catherine Kell (2013) this work aims at tracing texts across contexts, analyzing how these are *recontextualised* and *resemiotised* as they move. Now, Blommaert and Kell's work aims to describe and understand migrant literacies, and the resourcefulness of language users often working with limited resources, truncated linguistic repertoires, or less prestigious codes or language varieties. Their approach relies on a thorough ethnographic account of language practices, which entails following texts and writers as they move. The current project, on the contrary, deals with highly “mobile” language users, drawing on advanced and prestigious language varieties, though still working in an uneven world and crossing different scales of language use and language value—the local and the global, the center and the periphery. At the same time, physically following these researchers and texts across the global landscape is not feasible here, not only because it would be immensely costly, but because these travels took place in the past. For this reason, what I can offer here is an incomplete, retrospective ethnography, a study of texts and their contexts achieved through textual analysis enriched through interviews and narrative accounts, memory, and an experience of some of the places where these texts have lived, and the people that produced them. It is an ethnographic perspective, yet not an ethnography.

In a way, this work echoes John Swales' (1998) *Other Floors Other Voices*. In this book he studies the writing practices of seven individuals in a small university building, paying attention to the construction of their texts as well as the rhythms, social and work dynamics that surround their production. Because his observations are centered around the

circulation of texts, and he judges his account of people's activity to be less thorough than that of an anthropologist, he calls his approach a *textography*, rather than an ethnography: "by which I mean something more than a disembodied textual or discursal analysis, but something less than a full ethnographic account" (1998, p.1). Swales situates this work in a middle ground between linguistic analysis and ethnographic or contextual account (he also integrates photography as part of the documentation method). Like Swales, I offer an ethnographic perspective that pays special attention to texts, and that requires working with people and places that are changing and have changed in time, as is the case with VRC in Chile. Unlike Swales', the study of writing practices I propose here is not bound to one place (a university building or campus) but distributed across the globe.

In the absence of present literate activity to observe, follow, and account for writing practices and habits at VRC, I turn to texts as the remaining evidence of such practices. Further, I argue that texts and genres carry traces of their movement and, like socio-rhetorical studies of writing have suggested, of the social world they shape and are shaped by (Bazerman & Prior, 2004). As Anis Bawarshi (2001) puts it, "Our interactions with others and with our environments [...] are always already mediated not only by physical contexts but also by rhetorical contexts which [...] are ideologically and discursively embodied and reproduced by genres" (p.72). Bawarshi expands on this idea through the metaphor of genre ecologies, which suggests that "genre sets" or "genre systems" allow us to understand literate activities, the macroenvironment or "biosphere of discourse" (p.74). This understanding of the metaphor of ecologies is in line with Clay Spinuzzi and Mark Zachry's definition of a genre ecology as "an interrelated group of genres (artifact types and the interpretive habits that have developed around them) used to jointly mediate the

activities that allow people to accomplish complex objectives.” (Spinuzzi & Zachry, 2000, p.172). Thus, genres and genre ecologies provide a look into the way literate practices or interactions unfold. I propose to trace the intertextual relationships that configure genre sets and understand them not as a list of the things people do with texts within a community of discourse, but as the pieces of a story that needs assembling.

I also draw on the New Literacy Studies’ metaphor of ecology because it reconciles the tension between different theories of complexity (or network theories), where human agency and the distributed nature of knowledge and action seem to be at odds, sometimes at the cost of erasing the power relations that govern these relationships (Spinuzzi, 2008; Prior & Schaffner, 2011; Smith & Prior, 2020). NLS’s concept of ecology and “*literacy practices* offer[s] a powerful way of conceptualizing the link between the activities of reading and writing and the social structures in which they are embedded and which they help shape” (Barton & Hamilton, 2000, p.7). Indeed, the concept of *literacy practices*, captures the study of human activity as mediated by texts. In the case of this work: texts like scientific articles, informed consents, or project protocols mediate scientific activity; the production of scientific knowledge. Further, the concept of *literacy practices* entails the habits, values, and beliefs that surround the life of texts (Barton & Hamilton, 2000). This relationship between written artifacts and social structures is particularly important for a project like this one, which relies so heavily on texts, or what James Paul Gee (2000) calls the *literacy bits*. To use this author’s words, “‘Literacy bits’ are used almost like a radioactive isotope that allows bits and pieces of the whole configuration to be lit up.” (Gee, p.190). Throughout this research I use *literacy bits* or written artifacts as ways to trace literate activity in the past. I interpret these written artifacts, trace their connection to other *literacy bits*, and get

their authors to talk around them, in the hopes of *lighting up the configuration* of the scientific activity of vaccine researchers.

Hence, this work expands the notions of text trajectories, genre systems and genre ecologies by advancing what I call *mobility systems*. Through a mobility system I aim to trace the intertextual threads that weave knowledge making practices, while also re-writing into the knowledge system elements of space, time, and power. Ecologies are, after all, never flat. There are peaks and depressions in the landscape, smooth paths, and points of friction. I argue that our understanding of the layered and distributed nature of writing practices should account for this textured nature of writing ecologies, precisely because it is texture—friction (Tsing, 2005), negotiation—that shapes knowledge making, and enables movement in the form of cross-border exchange and collaboration.

### **Scientific writing across scales**

The scientific object most often studied in writing and rhetoric scholarship is the research article (Bazerman, 2008; Gross, Harmon & Reidy, 2002; Harmon & Gross, 2007; Hyland, 1995; Peat, Elliot, Baur & Keena, 2013), and perhaps to no surprise. The research article is, after all, together with the treatise (which is very much out of fashion) and the textbook, the main vehicle through which science researchers make their findings known to the world and other scientists. This genre can be used as a site to study the conventional features of scientific language (Halliday, 1989; Swales, 1990), or used to trace the evolution of such language conventions through history (Atkinson, 1992; Bazerman, 2008). It can be analyzed to describe the kinds of decisions made by science researchers about

how to inscribe themselves as authors in the text, their degree of certainty or hesitation about their own claims (Hyland, 1995). And because scientific writing is so dominantly lead by a few anglophone countries (Lillis & Curry, 2010), learning to write a research article in English means you can publish almost universally. That is, if that you conform to the standards of these dominant publications, and that you write in an acceptable English variety.

For this very reason, however, traces or indexicalities of the *local* tend to disappear from research articles, especially in contexts of transnational collaborative work. A research paper authored at VRC Chile, for example, would usually include authors both from the US and from Chile. It would be exchanged back and forth between authors multiple times, undergoing revisions from both sides, and while it would hypothetically be possible to identify differences in dominance or leadership in those collaborations while they are unfolding —and therefore, competing varieties or approaches to scientific writing— the final text would carry no traces of them. Yes, the research article travels. It is a highly mobile text. Yet, having been checked and revised to fit the “universal” standards of international academic publication, it tells no story about its travels, except, perhaps through mentions to data collection sites, or the authors’ institutional affiliations.

Hence, because I am interested in mobilities, transnational exchanges and collaborations, I’ve turned the focus of my study to other kinds of genres involved in the scientific research process. Indeed, the current work deals (in different degrees of depth and detail) with a variety of textual objects, none of which are the scientific article. The ones I pay most detailed attention to are informed consents and correspondence. Correspondence, of course, is meant to move and communicate across scales: the local or national and the

global or international/transnational (Blommaert, 2010). In this project, correspondence also documents principles and beliefs around the scientific knowledge production process, and how these are negotiated by VRC researchers in the context of cross-border collaborations. The informed consent as a genre is interesting because it not only crosses spatial scales (the national and the international) but also social scales. This genre's main purpose is to communicate delicate information adequately to unspecialized audiences, while also conforming to the exigencies of ethics committees, international partners, and sponsors. My efforts to account for local language practices in the context of global vaccine research through attention to these genres and mobility systems is organized in chapters as follows.

In Chapter 2, I tease out the methodological aspects of this work. I first contend with issues of positionality and the ethical questions and implications of doing research on close family members and working from personal memories. Then, I describe the kind of archive and archival work I engage with in conducting this project. Finally, I discuss how I weave text and genre analysis with narrative and interview material to produce the kind of backward or retrospective ethnography (Ferreira & De Almeida, 2017) that I argue this work constitutes.

In Chapter 3, titled "Mrs. Mom: We invite you and your child to participate" Historical Transformation of Informed Consents throughout VRC's History, I analyze all IRB approved informed consents for clinical trials performed throughout VRC's history and documented in its archive (from 1996 to 2009). The chapter offers a diachronic view of what has changed in the writing of these documents through time. I interpret these changes in light of the broader socio-historical phenomena developing during this timeframe, such



as the increase of norms and regulations for human subject research, and the advancement of internationalization and industrial models of scientific research.

In Chapter 4, “A sponsor you can still work with”: Negotiating Vaccine Research Writing on the Verge of the Industrial Model, I analyze data from one of VRC’s latest clinical trials (2007-2008), before the industrial model displaced the kind of scientific research conducted by this center in Chile. Drawing on archival material, I offer a view into the array of genres involved in the scientific research process at VRC, pieced together by following the intertextual threads, or the ways texts call upon other texts (Bazerman, 2004). In other words, I reconstruct the study’s genre ecology in order to describe the center’s networked activity. I also analyze correspondence and changes across versions of the informed consent document for this study to get at the kinds of negotiations VRC researchers engaged in during these moments of productive encounter or *friction*.

In Chapter 5, “With local eyes” Defining the Local in Transnational Scientific Research, I use interview data to delve into a situated theoretical exploration of the concept of locality. What do we mean when we talk about locality in relation to biomedical research? With the advancement of the industrial system, what has been lost and who feels the loss of sites of productive friction like VRC? Indeed, if the value of scientific knowledge is universal, and indeed, if researchers aspire to produce knowledge that is universal, what value do local perspectives add to scientific collaborations? I argue that the local has a value beyond exoticism. Local knowledge is not simply an alternative to “Western” ways of knowing, but a necessary element to productive and ethical transnational work.

In this concluding chapter I synthesize the findings and contributions of this work, and discuss the relationship between friction, locality and propriety in transnational scientific communication and knowledge making. I also assess the contribution of this work to transnational writing, rhetoric of health and medicine, and technical communication. I also describe some of the lines of future work that stem directly from this dissertation, or what I imagine could become additional chapters in this work as a book project. These conclusions also raise some general questions regarding the conditions for conducting scientific work from the peripheries in a globalized world. Can peripheries and semi-peripheries ever escape erasure and displacement from industry-dominated transnational narratives? Is there a sensible middle-ground between assimilation and isolation? How do local language practices look like in scientific environments lead by big transnational industries? (Can these be found at all?)

## Chapter 2

### Notes on Methodology

#### **Family history and personal entanglements: writing about my mother**

In March 2021, I was working on the research proposal of this project for the ethics committee at Santiago Chile and trying to get it past the filter of the first reviewer: the legal representative and director of VRC, my mother, whom I identify throughout this manuscript as Dr. Susana Arce. As the director and legal representative of VRC, Dr. Arce had to sign a cooperation letter, stating that she would allow and support my work at the research center she directs, facilitating access to archival material and contact with former research participants.<sup>3</sup> In fact, because she is the legal custodian of the participants' data and all other information stored in the VRC archives, she is the appointed responsible investigator facing the local ethics committee in Santiago Chile. For these reasons, even though she is not a supervisor in this research, the research proposal document has her name on it. Further, although the project is beyond her expertise and is framed under a research methodology and a body of literature that she is altogether unfamiliar with, because it pertains the research center she directs, she would not approve it without having a fair understanding of the project and its objectives. This involved her thorough reading

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<sup>3</sup> At the time, my research design included interviews with former vaccine research participants aimed at describing their understanding of biomedical research ethics and the implications of their own participation (or their child's participation) in a clinical trial. Once I embarked on the research and dug into archival material, I realized this part of the plan exceeded the possibilities of this dissertation project, and I decided to mark it "future work."

and commentary of the proposal—plus some engagement of her own with literature on the topic—and several rounds of revisions on my end.

The predominant feeling that accompanied me as I faced multiple rejections and suggestions for revision from Dr. Arce was one of frustration and defeat. The experience took me back to my early middle school years, doing homework under my mother’s critical eye, but also—and more importantly—faced me with the complexities of writing for an audience with a radically different understanding of research, writing, and knowledge-making. From my epistemological standpoint—disciplinarily somewhere in between the humanities and the social sciences and methodologically ethnographic in orientation—I understand research questions and objects of study will likely change as the project moves forward and data starts informing these defining elements. I imagined I would start with an exploration of the archive material, do some more reading and refining based on my preliminary findings, and then further define other elements of the research. I was prepared to put together a research proposal that described the general purpose of the study, explaining the kinds of data I intended to collect, and outlining the methods I was planning to implement, including guiding topics and sample questions for potential interviews. Dr. Arce, however, is a biomedical researcher and works from a positivistic epistemological standpoint. Her understanding of research calls for clearly defined and definitive research questions, ideally a working hypothesis, a clearly delimited object of study, a sample design, and justification for it.

I did my best to adhere to these guidelines, knowing these expectations were ill-fitting with a qualitative study and an ethnographic orientation to research, and while parallelly preparing the documents with a completely different framework for IRB approval

at my institution of affiliation in the US. The table below describes the sample design included in the project protocol submitted to the local ethics committee in Santiago. This proposed to contact research participants from three of VRC's past clinical trials (*estudios clínicos* or *EC* in the table), with four different research profiles, plus present and past VRC researchers and staff.

**Table 1: Example of a sample desing**

<b>Perfiles de Elegibilidad</b>	<b>Estudio Clínico 1</b> N	<b>EC 2</b> N	<b>Ensayo 3</b> N
<b>A:</b> Padres o madres que otorgaron consentimiento informado para la participación de sus hijos menores de edad al momento de la inclusión	0	2 a 3	2 a 3
<b>B1:</b> Exparticipantes que ingresaron al estudio clínico con consentimiento de su madre/padre y aún no han alcanzado edad legal para consentir (adolescentes)	0	5(*)	
<b>B2:</b> Exparticipantes que otorgaron asentimiento para el ensayo clínico y actualmente son mayores de edad	0	0	5
<b>C:</b> Exparticipantes que eran mayores de edad al momento de ingresar al estudio	5		
<b>D:</b> Directora, miembros y exmiembros del staff que llevaron a cabo las tareas de implementación y ejecución de los ensayos	5		

One day, at the peak of my frustration, and after having completed several rounds of revisions, I uttered (in Spanish): “I just need this to go through the ethics committee so I can do the research, have data, and finally refine my questions and objectives. *Esto es un*

*trámite*.<sup>4</sup>” To which my mother replied with irritation: “No, it is not. The ethical design of the work is not, as you say, *un trámite*, it *is* the work itself. A study that is not well-designed is not ethical. If it is not ethical it is not well-designed. The mere investment of time and resources in a study that is not well-designed and cannot justify its contribution is unethical and should not be approved to move forward.”<sup>5</sup> A couple of weeks after this conversation I submitted the project proposal to the local ethics committee in Santiago and it was approved after a round of simple revisions.

The project’s questions and scope have since changed, and the design presented to the local ethics committee was of little consequence for the work as it is written here. The writing process of this protocol and the exchanges around it I sustained with my mother, however, were immensely meaningful for my own understanding of this project and its methodological framework. Indeed, I take this much space to relate this event because I find it very telling of Dr. Arce’s understanding of writing as a part of her scientific activity, and because the experience itself allowed me a small peek into writing processes, practices, and ideologies of which I have little actual records. Of course, writing ideologies and practices do not always match neatly. Indeed, in the context of an interview, Dr. Arce described her own process of learning to write scientific articles as an iterative process of trial and error guided by some of her professors.

I: You say trial and error. Explain a bit more what that trial and error looked like.

Dr. Arce: Well, writing something. A paper. And to go to the closest professor—in my case, I remember, G.D.—and have him guide you. Paragraph by paragraph,

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<sup>4</sup> A formality.

<sup>5</sup> This is, of course, not a transcription of a recorded conversation, as the exchange was not a planned interview. But the words made such a strong impression on me that I made a note of them shortly after, transcribing the words as they were ingrained in my memory.

really... There are also guidelines. When you are studying, you have to read, and if you are going to publish something, in the *Revista Chilena de Pediatría* there is a guideline. In short. A lot of trial and error. Saying: "No, this is wrong". Just like that.

[...]

I: And what was the most formative thing?

Dr. Arce: Patience. He [Dr. G.D.] used to arrive, I remember, very early at the hospital. And, well, he was busy all day long, he was teaching classes, he was visiting patients. So, to catch him for half an hour I had to get there... I would arrive at half past seven. And, well, I would sit there for half an hour with him to review the thing. And, to begin with, well... First, I went to him with a bunch of observations that I had made during my shifts looking at baby poop under the microscope. And... "Look," I said, "this... it's interesting because this anticipates or allows you to pre-discriminate which children with diarrhea need antibiotics and which don't." At that time, we were giving antibiotics to everybody. "So, I want to publish it." —"Well, but what's the protocol? What's the statistical method? How do you handle the..." I had no protocol, I had nothing. So, to start by—after I already had plenty of observations—to start by writing down what I should have done first. The protocol of the systematization of the data collection. Anyway, starting there.

(Interview #3 with Dr. Arce. July 14, 2022.)

In line with authors like Bazerman (Bazerman & Prior, 2004) and Prior (1998/2013), the narrative of my experience co-writing a research proposal with my mother and the interview fragment above suggest that writing is not a mere medium for communicating scientific knowledge. Rather, science is a literate activity. The production of new knowledge is mediated and enacted through the manipulation, exchange, circulation, and production of written artifacts. Observations are written down, methods are designed and formalized in writing, article drafts are composed, examined, negotiated, and through that process, what we know as scientific knowledge is made. Writing is constitutive of science and scientific knowledge-making, and, despite my mother's

obfuscation about my own (apparently) messy approach to writing and research, her first experiences of these science-making processes were far from linear and well-planned.

Perhaps most importantly, these examples also illustrate the kinds of entanglements that underlie my orientation to this research as ecologic and ethnographic. This research is not ethnographic because I have spent several months (*à la* Latour) sitting in the offices of the VRC watching scientists do scientific work, taking notes, and asking questions. It is ethnographic because it stems from a sustained involvement with these scientists' lives over many years—more than thirty years—over the course of which I have had formal and informal conversations with them, watched them work, sat through work dinners, and accompanied them to conferences. As the anecdote that opens the chapter illustrates, this project has also invited close interactions and the co-production of knowledge with members of VRC (Blommaert, 2009). We have collaborated in the writing of documents, planned visits to the archive, meddled in the writing they have done in the past and talked through its implications. Thus, the anecdotes I share above also serve as a good reminder—for myself and the reader—of the kind of relationship I have with this project and the participants involved in it. This is, after all, my mother's work, and in the process of doing research about it I often turn to my own recollection of events, my knowledge of shared spaces, my second-hand experience of research activities.

Like Paul Prior (2018), who has written about his daughter's path of semiotic becoming, my understanding of writing practices in this project stems from the close involvement and witnessing of the *moments that add up to* VRC's research life. Like Prior, I have contended with the question about the implications of doing research about a close family member, haunted by the idea that I might be “too interested, too close, too biased in



effect” (web), and by the concern that one of the sources my methods rely on is one as elusive as memory. Following Prior, I argue that closeness and caring are not necessarily obstacles to a good understanding of literate lives. Quite the opposite—as Chapter 3 of this work suggests—I believe that closeness and caring for participants can constitute good ethical orientations: they invite caution in the amount of exposure to harm or visibility that we subject our participants to, and they help us keep in mind that our representations of them should be fair and not only provocative or intellectually engaging. But these orientations are not enough, as caring and closeness can also lead us to construct romanticized narratives about the lives we research and write about.

Memory, on the other hand, lives in a domain close to that which makes us tell stories and is therefore permeable to fantasy and elaboration. About this, Prior claims that the kind of case studies we conduct is not more problematic in this sense than any other qualitative method which relies on memory and interpretation—such as participant observation or ethnography. I would further argue that fantasy and elaboration can be problematic or not depending on what we do with them. Theory is, after all, a creative elaboration of sorts, and one necessary if we want to produce explanations and understanding of phenomena around us. In this sense, the problem is not whether anecdotes and narratives about writer’s lives are *per se* relevant or generalizable, but whether they allow us to further our understanding, and whether we are able to judge if our case study constitutes an *exemplar* or an exception to the kind of reality we are trying to understand.

To make this distinction, however, it is necessary to map our narratives or case studies onto larger social theories that provide a framework for interpretation. In the case of this project, theories of mobility and critical approaches to literacy (NLS) discussed in the

previous chapter provide an understanding of global contexts and language difference in an uneven world. This is what critical discourse analysis (CDA) proposes we do with the interpretation of language variations in the social world (Fairclough, 2013). This is also what authors such as Ruth Wodak (2015) take to be the meaning of *historic* in her definition of historical discourse analysis: to turn to the historical context of discursive phenomena such as racism or populism to make sense of what goes on with language features at the level of text, syntax and lexicosemantics. This relationship between individual case study and social theory—a particular instance and the broader social world to which it belongs—is also what makes acknowledging and underlining positionality in this and other qualitative research necessary.

But this work draws on more than personal memories and narrative as a source of data. One of the ways I go about reconstructing VRC’s research life is by working closely with archival material. In the next section, I describe the kind of archive and archival documents I work with throughout this project, as well as the importance of this work for their preservation.

### **A walk through the archive**

Vaccine Research Chile’s archive was housed in Hospital San Pablo’s grounds from the early 1990’s until 2020. Part of it was in an underground storage space and part of it was in an outdoor warehouse—a roughly cubic, windowless shed with a locked door. It contained all the documents from all the studies conducted by the center since its foundation, in 1993, and some from its earlier years, when the center was still

administratively connected to a University in the United States. In 2020, however, VRC vacated its offices at the hospital, and moved to a smaller location, which meant that the archive had to be moved as well. Before moving, VRC researchers and staff cleaned, organized, and curated the stored material. Some of it had been rendered useless and impossible to classify by the passing of time, eaten by mice and insects, and some was considered superfluous.

Most of it, though, was safe. Of course, all participants' contact information and clinical records, informed consent forms (ICFs), approved research protocols, and key correspondence records were preserved and transferred to a new location: my mother's underground storage room at her residence. Materials in the archive include all sorts of documentation: study protocols and their development drafts, IRB approvals, correspondence between researchers, as well as between researchers and pharmaceutical company representatives, data charts and participant journals, among others. I even found a copy of my mother's first conference paper, with handwritten marginal notes in pencil. Now these documents live—or lie—there, in cardboard boxes organized in several rows of steel archive shelving, sharing space with old winter coats, out-of-use furniture, Christmas decorations, questionable house décor, and an outdated optic microscope that made the journey from the hospital together with the archive documents. They will remain there until the center officially closes business, and the center's director obtains permits to finally dispose of most (if not all) of these records. Hence, I write with a sense of urgency because, as this research progresses, so does the work to make all this documentation disappear.

A walk through the archive shelves shows that, aside from clinical vaccine trials, the center performed a range of valuable research activities for local and global health. For

example, conducting vigilance studies regarding infectious diseases of global interest; epidemiological studies on local endemic diseases, to measure their incidence in the local population; etiological studies, determining the most frequent causes of hospitalization and death in young children; and longitudinal studies on the most common respiratory diseases frequently affecting young infants and children in the Metropolitan Region. When I pull any one of these boxes and flip through the documents, I recognize the familiar hospital smell impregnated in the pages, and I find it both unsettling and amusing that this should be, for me, such a distinct smell of childhood.

I stop to describe this archive and its becoming with a fair amount of detail because, aside from personal stories, it is the richest account of the center's activity that we currently have access to. If I could choose to do so, I would sit in VRC's offices in the hospital, watch as research staff bring back data from fieldwork, hear the fax buzzing, eavesdrop on conversations between nurses and mothers coming into the vaccination clinic with their babies, take note of the scraps of papers researchers and secretaries have lying around as they type on their computer or fill in physical data charts. Instead, what I have are just these traces and memories of the center's busy life. This archive and the written artifacts in it are—as I have mentioned before—some of the most important resources I possess to distinguish local social history from my own memory and its elaborations. Highlighting the parallels or juxtaposition between archival and ethnographic methodologies, authors like Karen Gracy argue that the archive provides evidence of people's archiving practices, “communities of practice build and maintain webs of meaning through record creation and record-keeping activities.” (Gracy, 2004, p. 338). In this sense, working with archival

documents is also a way of studying what people do: how they archive, what they archive, and perhaps even why they archive.

Borrowing from authors like Karen Gracy (2004), Stephanie Decker and Alan McKinley (2020) and others (Geiger & Ribes, 2011), the archival methods I employ in this ethnographic project can be described as “archival ethnography.” But while these authors define this term as an approach to the archive as a field-site where one goes to observe, take notes, and understand the activity of those who do/did the archiving, I adopt this term to describe the methods involved in doing ethnography while turning to archival material for corroboration, richer documentation of my participant’s narratives, and to find pieces of documentation that may bring about stories. In this sense, if ethnography studies communities and practices, archival material provides traces of it. Decker and McKinley also draw parallels between ethnographic and archival work:

The ethnographer watches and listens, shares—somewhat vicariously—in the lifeworld of others. In this sense, archival ethnography is, by definition, nonparticipant observation. No doubt, the reliance on text, perhaps leavened by some images, means a loss of being able to observe gesture or the tone of conversations. (Decker & McKinlay, 2020, p.19).

In the case of the present work, the loss of instances of direct observation are somewhat compensated by personal memory and interviews with VRC researchers and staff. I have witnessed the physical relocation of the archive, observed moments of its coming to be. I’ve also had the chance to delve into VRC’s archive with researchers by my side, pointing out boxes, picking out documents, talking through them.

As Decker and McKinlay—and Arlette Farge (2013) before them—have pointed out, both archival and ethnographic methodologies are messy. There is no single method or

set of steps to go about this kind of work. We can't predict or plan when we might come across an important finding, a revealing string of conversation, or a key piece of documentation, or what will be the best way to articulate an argument around/about those materials. Aware of these challenges, in this work I have made decisions that have helped me put some method into this messy methodological work. The first, is to produce a panoramic view of the archive through the narrative account I have shared here and through a diachronic approach to documents in the archive that allows me to tell a story about what happened at VRC during the timespan I study. I describe this diachronic approach in more detail in Chapter 3, where I trace the changes in one specific genre throughout VRC's years of clinical research.

While the panoramic view of the archive can offer some broad strokes about the transformations VRC saw throughout its research life, to understand what research at VRC looked like, what kinds of collaborations and power articulations moved the work forward, I zoom in at a particular moment in time. This is what I refer to as a synchronic approach to the archive. For this synchronic analysis, I focus on a study (conducted in 2007-2008) happening relatively late in VRC's trajectory. This allows me to study a moment of transition in power balance between researchers and other actors in the research network which I began noting both through the diachronic approach and interviews. I delve into this analysis in Chapter 4.

Both these approaches to analysis—the diachronic and the synchronic—rely on texts, so both of them have the limitations of working with non-living materials: the traces of people rather than people. As I mention before, I work through this difficulty by supplementing the analysis of documents with interviews and through observing the

interaction of VRC researchers with these documents. Indeed, in addition to other considerations, one of the reasons I chose this particular study for the diachronic analysis had to do with a participant's reaction to this set of documents. One evening, early in the research process, my mother and I were sitting on the floor of my apartment, picking documents from boxes scattered around us. While looking through one set of documents and noting what study they pertained to, she uttered: "Ah! This was a sponsor you could still work with..." This remark triggered a series of questions and later, conversations: "What do you mean, you could *still* work with this sponsor?" "What does working with a sponsor look like now?" "What about before?" In this sense, by archival ethnography I don't only mean that I find parallels between archival and ethnographic approaches, or that I establish a close relationship with these materials, their history, and how they feel to me. Archival documents are also a way in which I generate interactions with participants, and therefore, qualitative data that calls for an ethnographic lens.

Finally, working with texts also has advantages. Texts remain still. They offer evidence of language decisions and practices at specific moments in time. They crystalize language ideologies. I speak to this in the next section of this methodology.

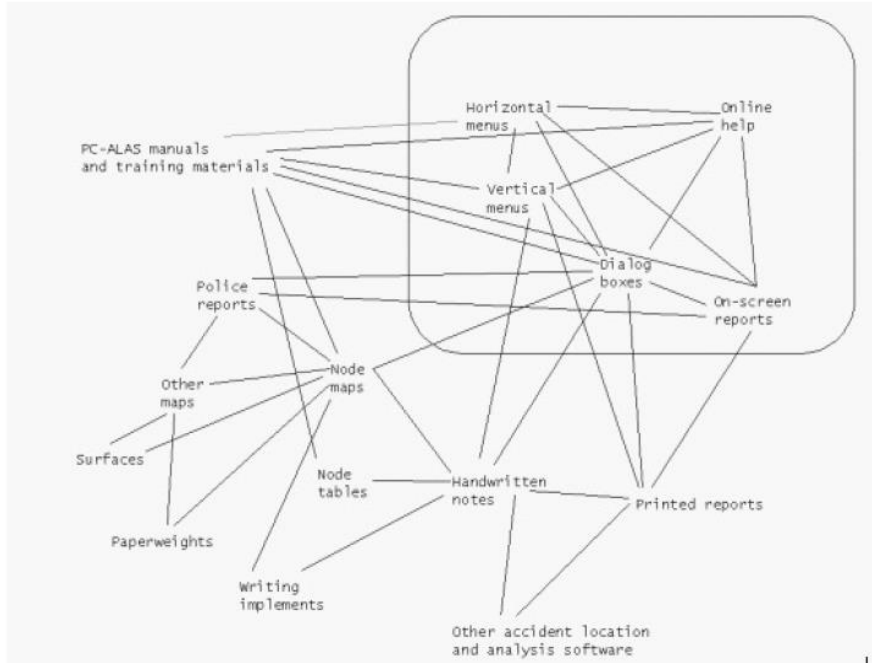
### **Working with texts**

This study deals with texts. Texts constitute the main driving element and the main object of analysis of this work. How they change, how they relate to other texts, what they reveal about peoples' practices, and what writers can say about what they try to do when writing them. Throughout this work I deal with texts in a couple different ways and at least

through two major theoretical lenses. I will start with the more concrete aspects of the methods I use for analyzing textual material.

Because I am interested in the way texts account for a complex human activity such as scientific knowledge production, I draw on frameworks that are oriented to account for and illustrate such complexity. I have found that network theories broadly understood (Spinuzzi, 2004) provide useful conceptual and methodological tools in this sense. The metaphor of the network, which together with Clay Spinuzzi and Mark Zachry (2000), I see as overlapping with that of ecology, describes the kind of complex interweaving—of actors, activities, texts—that is involved in knowledge production systems. Network methodologies also generally produce graphic representations of networks to show the interweaving of elements that constitute an activity, tracing the presence of texts across and throughout human activity. For this particular project, this metaphor and its visual representations are important because they also reflect what the work of piecing together the activity of a clinical research study from archival documents looked like: sitting on my apartment floor with documents scattered around, placing texts that call on other texts (Bazerman, 2004) close to each other, trying to understand which documents came first and which later, and figuring out how this order and interaction between documents tells a story about the research process unfolding.





*Fig 1. A diagram that illustrates the genre ecology used for locating and analyzing traffic accidents. Lines indicate coordination between genres (i.e., mediatory relationships).*

**Image 1: Genre ecology from Spinuzzi and Zachry (2000)**

However, as I went through the process of constructing a genre ecology—one very much like the one in the illustration above, and which I understand very much as a visually spread-out genre set (Devitt, 2004)—I found myself needing to write actors and activity (back) into the representation. As a network of texts alone, it seemed to me, the representation remained flat; it said too little about the kinds of tensions and power imbalances that can arise between different actors. When writing actors back in, these relationships could at least be deduced or described. When writing activities back into the representation, the network gained an added dimension, that of temporality, marked not by dates but, rather, by the progression of research moments or stages and the movement of texts from one context to another. To describe this dimension of my uptake of network methodologies I turn to Catherine Kell’s concept of text trajectories, which she describes as

“mapping each event as a recontextualisation of meaning making across contexts along a horizontal axis” (2011, p.610). This means following a text as it moves across space and time, different contexts, and different activities. Trajectories are meaningful here because they speak of movement: of how texts often function not within fixed text/genre sets but, rather, because they need to make sense in different situations, for different publics, and within different intertextual frames.

This particular assemblage of methodological approaches—network and activity theory and new literacy studies’ text trajectory tracing—is what I call, in this work, a *mobility system* (Sheller & Urry, 2006). The term serves this work well, as it captures the transnational nature of this work—how these texts function across national borders and on different scales (the local and the global)—as well as the movement and immobility across different social(-economic) groups and contexts—how texts engage different publics. Because dynamic work is slippery, my approach to knowledge systems does not aim to be exhaustive or to fully describe the complex activity of scientific research. Not all texts/genres, actors, and activities are mapped into the visual representation of the network. Mine is, like Spinuzzi and Zachry’s (2000), an open-systems approach to networks or *mobility systems*. I chose to take a perspective, an entry-point so to speak, to the system and start mapping the most important connections around it by following the intertextual threads I find between them: a piece of correspondence would reference a protocol approval by an ethics committee, the research protocol would reference the documents related to the informed consent protocol, versions of consent forms would reference adverse event reports, and so on. I expand on the details of this methodology in Chapter 4.

As I anticipate earlier, in this work I deal not only with the ways in which knowledge is produced through networked systems, but also with how meaning-making happens (and changes) within and across texts and text genres. To work with texts, in this sense, I consider their formal, generic, linguistic, and rhetorical features. I approach the qualitative analysis of rhetorical features following Johny Saldaña's (2009) guides for descriptive, question-driven qualitative analysis. This means that I was not innocent to what I wanted to find in the data: I went into the coding process with the purpose of finding answers to my questions about the writers' rhetorical choices and created coding categories that were descriptive of the answers I found in the data. The resulting coding scheme describes what I saw as the most salient rhetorical features of my data set, creating categories that allowed me to tell the story that I saw emerging from this and other elements in the research.

I approached the description of the linguistic features of texts with a Critical Discourse Analysis mind-frame but not through one specific CDA method or methodology. By this, I mean that I have not conducted a systematic, line by line analysis applying a specific grammar or model. Rather, I have described some salient language features that align with and realize the rhetorical strategies that I identify through the qualitative analysis of the data and that exemplify aspects of the general argument that I saw emerging throughout the research, turning to different language categories or tools for linguistic analysis as the description needed them. Though I do not consistently draw on this author nor apply the linguistic or *sociosemantic* categories that he proposes, my approach follows Theo Van Leeuwen's in that it does not start from "linguistic operations, such as nominalization and passive agent deletion, or from linguistic categories, such as the

categories of transitivity, but instead will draw up a *sociosemantic* inventory” (2008, p.23), or in this case, a rhetorical inventory, and then delve into the linguistic operations through which these are realized. The table below shows the different layers of this analysis process, from the broader, classical appeals, to the rhetorical coding categories emerging from the qualitative coding of the data, and then the identification of salient linguistic features.

**Table 2: Categories for rhetorical and linguistic analysis**

<b>Classic rhetorical appeals</b>	Ethos – Pathos – Logos
<b>Emergent rhetorical coding categories</b>	<b>Examples:</b> Showing credentials Wearing the participant’s shoes
<b>Salient linguistic features</b>	<b>Examples:</b> Use of the first person Use of diminutives

In this work, the CDA perspective understood as a “critique of dominant discourses and genres that effect inequalities, injustices and oppression in contemporary society” (Van Leeuwen, 2009, p.278) materializes through the tracing of transformations in language practices that account for the expansion of hegemonic powers in scientific knowledge production. Concretely, the ways in which scientists at VRC faced the standardization of research procedures and genres, progressively effacing local language practices. As such,

this work is also theoretically aligned with Theo Van Leeuwen's understanding of language phenomena in a globalized world:

Global media, for instance, allow content to be diverse and localized, but homogenize formats and genres to an unprecedented degree [...]. Everywhere, there are fewer (and more powerful) procedures and formats and templates, and more (but less powerful) discourses." (Van Leeuwen, 2008, p.4)

What Van Leeuwen describes as the superseding of meaning (discourse) by function—the progressive increase of less powerful discourses and the rise of a few dominant discursive forms—has a parallel in what I observe in vaccine research: the diversification of actors who participate in knowledge production, contributing data from multiple points of the globe and from increasingly diverse populations, but through increasingly standard procedures and genre norms.

Perhaps most importantly, Theo Van Leeuwen's *sociosemantic* approach to critical discourse analysis—one that works first from social meaning and then to linguistic operations—lends itself well to an approach that combines elements of rhetoric and discourse analysis.<sup>6</sup> As I have mentioned, in this work, the analysis of texts relies on elements of critical discourse analysis, such as the understanding of these texts in their social and historical context (re)constructed through theory and literature. But for the construction of context and an emic perspective on texts, I also turn to different kinds of interviews. In the next section I briefly explain how I use interviews throughout this work.

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<sup>6</sup> Work in this direction has been advanced by scholars like Ruth Wodak (see Wodak, 2001; 2015)

## **Some words about interviews**

The exigency for this work emerged from a conversation I had with my mother at the beginning of 2019. It was not an interview, but a casual phone call. The Covid-19 pandemic was beginning to unfold. What this virus was, how much harm it could do, and how long it would be around were all questions with no answers yet. The one thing we did know was that we would only begin to see an end to the pandemic when a vaccine was developed and distributed widely. Though the outlook was grim, a part of me was ignited by this perspective. A new vaccine was about to be developed and tested. I envisioned a project. Perhaps VRC would play its part in this global event, and perhaps this time I would be old and wise enough to be an active observer of these developments from the backstage.

So, of course, I brought the question to my mother, full of hope: “Will VRC be participating in research for the Covid-19 vaccine?” And my question was met with a disappointing answer: “Well, no. Not exactly. You see, it’s just not the same anymore.” Once I got over my disappointment, I had new questions: “What is not the same? What has changed in vaccine research over the last 20 to 25 years? Have changes happened for the worse or the better?” This project is my way of easing my puzzlement and producing an answer to these questions. In doing so, the project that I originally imagined as a study of writing and research practices of the present became one that called for studying and piecing together practices of the past. To do so, many other casual and not so casual conversations have taken place between me and my mother, as well as with other staff

members and collaborators of VRC. I have, therefore, worked with different kinds of interviews.

The personal histories and narrative accounts I have gathered in order to understand VRC's work and its socio-historical context have emerged in the context of semi-structured interviews with VRC researchers and collaborators. Key collaborators include a doctor and researcher from the United States, Dr. Friend; my mother, Dr. Arce; a member of the VRC staff, Mónica; and a former member of the ethics committee designated to review most of VRC's research protocols locally. Some of the topics covered in these interviews include:

- The participant's history and relationship with VRC
- The role international relationships or collaborations have had in their work
- The kinds of research collaborations and the collaboration dynamics participants have had with VRC researchers and/or researchers across borders
- The process of writing documents when working with colleagues across borders

These interviews were recorded and partially transcribed as needed. However, as I have suggested throughout this methodology chapter, other non-recorded conversations have preceded and followed these interviews and have often been critical to the development of the work. Those conversations provided a background for these semi-structured interviews and helped me identify topics and points of inquiry.

Because this work revolves around texts and language practices, I have also turned to talk-around-text interviews with VRC researchers. This methodology, developed by Roz

Ivanič, is described by Theresa Lillis (2009) as a conversation or series of conversations (talk) that have texts and text features as their main focus:

Such talk may focus on a text type, text, or section/feature of a text: the specific focus at any one moment in time may be something as small as a specific use of a full stop, to patterns of vocabulary or grammar, such as the use of particular pronouns across a text, to a specific convention emblematic of academic discourse, such as the use of citations. (Lillis, 2009, p. 171)

Throughout this work (but especially in Chapter 3) I use this methodology to understand participants' language choices, especially how they chose to contest or push back against standards or procedures advanced by more powerful actors in vaccine research global networks.

Against my predictions and expectations, talk-around-text interviews were most productive with Dr. Arce, my mother. While I hoped conversations with former VRC staff members would reveal interesting aspects of how research staff perceived language negotiations, especially with international actors, on-the-ground staff were, for the most part, sheltered from many of the tensions of working transnationally and negotiating power struggles. Indeed, so much of this work is about my mother not only because her story is one that I am particularly fond of, or because she was the resource most readily available to me, but because she operated as a *literacy broker* for VRC in the context of academic exchanges and negotiations with international stakeholders. She was the main representative going to conferences, the person in charge of negotiations with pharmaceutical companies, and making the decisions about whether or not to take on a new clinical trial or study.



Lillis and Curry present in their book about academic writing in a global context the role of literacy brokers as “relating to network activity for mobilizing resources and people in support of research activity and writing” and they add “in many instances ‘literacy brokers’ occupy a powerful position straddling the ‘boundaries and peripheries’ between communities and groupings” (2010, p.88). At VRC, Dr. Arce often did the work of a translator for translators. Even when official translations were required by sponsors, she drafted texts with the English version in mind, choosing the wording that would most easily translate to English. She managed collaborations with sponsors for the research center and chose to engage only in those that would advance the center’s interest and ensure that there would be space for the production of valuable knowledge at the local level. She was also the representative of the center in conferences locally and abroad. In this sense, the politics of academic spaces were mostly navigated by her.

The narratives produced in the context of interviews have also helped me understand the complexity of what is negotiated in these international exchanges. The work of brokering or mediating scientific work entails finding ways to navigate difference and power asymmetries, it enables movement and has the potential to stall it. Thus, I use interviews as the starting point for a theoretical consideration of locality, friction, and their importance for language practice in a global context, which I develop in Chapter 5.

I end this methodology chapter with (perhaps) some notes to self: to the person I was when I embarked on this project and to the person I will be when I have the chance to walk other researchers through the early stages of their own work. These notes are rather obvious and common-place and yet, we are bound to forget them (I have, several times). As the narratives on my own process and those I have gathered on my mom’s show, research

and writing trajectories are not linear and straightforward. They are recursive and multilayered, and their rhythm changes. We can devise a method to keep us moving forward, chart a way so we don't get lost or strive too far off from the path we intended to take, or set general goals or expectations for the work. But sometimes, movement requires us to take a pause. The moment before we take a leap forward may look as though we were stagnant. We are not. Feet together and knees bent, we are simply gaining momentum. Methodology chapters or sections that describe a neat and smooth process are not exactly dishonest, but they are inescapably deceitful, as in the process of making a project's becoming communicable, we reduce its complexity.

In writing this methodology, I have gone back to Paul Prior and Jody Shipka's article on chronotopic lamination (2003) many times, thinking over and over on how much the rhythms of writing and life are entangled (and how often these entanglements are left off the page). Throughout these texts, narratives and examples also serve as reminders of how meaning and knowledge making happen interwoven with life. The early stages of this work I wrote pregnant with my first baby, thinking of my mom doing her specialization in microbiology and infectious diseases in the United States while pregnant with me. Other chapters I have written while my new-born slept soundly by my side, typing away to the compass of her breathing (and sometimes soft snoring too), writing cycles scheduled around breastfeeds and naps. The final chapters I wrote as she began to learn how to walk, with babysitting aid during the day, doing my best to keep myself in the chair as I heard her babbling and laughing in the next room. These too are reminders of the way meaning/knowledge is made. As I mention earlier in this chapter, small, every-day

moments of personal history are also enmeshed in and speak of larger historical phenomena. As Prior and Shipka (2003) explain:

Activity, the whole, is concrete historical practice, the total, the union and disunion of all the things going on; it is what is happening. Activity is the analytical plane that pulls out the collective and motivated as opposed to action and operational levels. Activity points to durable human life projects, like getting food, establishing shelter, creating social relations and institutions, providing for security, reproduction (literal and social), play—all immensely transformed and complicated by the sociohistorical development of specific practices. (pp.206-207)

I have aimed to write this work attending to this kind of understanding of how life, writing and research, personal history and broader historical moments fold into each other. Data and story, textual analysis and memory, always go hand in hand throughout this work. This is also a methodological choice.

In the next chapter, I analyze informed consent documents used at VRC throughout its research life. I show how changes in the way these texts are written reflect broader changes going on nationally and globally, which impacted the way vaccine research was conducted, especially at research centers in the semi-peripheries, like VRC.

## Chapter 3

### **“Mrs. Mom: We invite you and your child to participate” Historical Transformation of Informed Consents Throughout VRC’s History**

#### **The informed consent: between scientists and participants, the local and the global**

Being involved in international research, my mother’s work-life entailed traveling often to all kinds of exotic-sounding places: France, Egypt, Switzerland, Indonesia, Panama, to name just a few. Most of these were conferences or work sessions. But some involved field work or getting to know and sharing experiences with similar research initiatives in other countries. That was the case with the trip to Mali in 2003. In Bamako, Mali, there is a center analogous to Vaccine Research Chile—although with different relationships to both the local government and BCU, the “parent” university in the US (we will call it CVM, Center for Vaccines at Mali). This center in Mali was founded in 2001, just two years prior to my mother’s visit, so there was plenty researchers and staff there could learn from and share with their Chilean colleagues. From my mother’s recollections of that trip, I keep the memory of one story that was fundamental to my understanding of what informed consent entails and the importance of finding ways to make local sense of this international standard for ethical research.

During their trip to Mali, VRC researchers visited rural and semi-rural communities near Bamako, where Malian medical researchers and professionals both conducted medical

research and provided public health services. There was, however, a challenge to the implementation of informed consent in these communities, as the local public's understanding of consent and autonomy did not conform to “Western” standards, and schooled literacies and science concepts were mostly foreign to them. In most villages around Bamako, important decisions were made not individually but collectively. A group of men would meet with the *chief du village* and discuss the implications of any important decision or course of action (Gikonyo, Bejon, Marsh, 2008; Molyneux, Peshu & Marsh, 2005). Given this population's limited access to schooled literacies, communication delivered to individuals through a written document would have proven largely ineffective with most people, in addition to being culturally nonsensical. To deal with these challenges, researchers in Mali had to devise new and creative strategies. In one participant recruitment campaign witnessed by VRC researchers, information necessary for consent was conveyed orally, in a communal act involving percussions, music and singing. Then, a middle ground was achieved with a combination of a prior approval of the *chef du village* and council of men and individual participant's agreement to enroll.

I will not elaborate here on whether this strategy was or was not more effective in communicating the research's purpose and implications to this group of participants. Nor will I delve into the ethical implications of this solution—if collective decision-making and male authorities have such power and influence, can we assert that Malian participants freely and autonomously manifested their consent to participate? These questions matter, however, because these are exactly the same questions VRC researchers faced over the course of their research history in Chile. When the center began its activities, communities around Hospital San Pablo, where VRC recruited participants, were mostly low-income and

most participants' tutors (parents or legally responsible caretakers) were women (mothers) with relatively low educational levels. In this context, VRC researchers found themselves constantly considering the challenge of communicating enough technical information as to be honest about the characteristics and risk implications of the study, but in a way that was simple enough for this kind of lay public to understand. What kinds of strategies are necessary and appropriate? Is using technical words to designate the clinical research as such always necessary or does it rather hinder communication? How can risks be described accurately without raising disproportionate fear or mistrust?

The literature on biomedical ethics and social studies in medicine has consistently pointed out that informed consent forms present important readability challenges. They are lengthy, complex, and contain too much information (Paris, Cracowski, Ravanel, et al., 2005). These problems are not easily fixed (Ménoni, Lucas, Leforestier, et al., 2010; Paris, A., Brandt, C., Cornu et al., 2010), and some studies have found that attempts to improve these documents often fail to improve participants' understandings and rather have the consequence of discouraging participation in research (Paris, Deygas, Cornu, et al., 2015). Additionally, as the Mali experience confirms, studies conducted in peripheral regions argue that a consideration of local context and sociocultural aspects of communication are critical for informed consent procedures, especially in places other than traditional Western countries (Gikonyo, Bejon, Marsh, et al., 2008; Mithal, 2014).

This raises questions about the necessary conditions for conducting ethical human-subject research in the peripheries, and points to the importance of having “cultural insiders” be the ones designing and implementing informed consent procedures. In this sense, we might ask: How does an understanding of the local context and culture inform

researchers' writing of informed consents? And how is the ethical standing of research affected when informed consents become more complex and lose readability and cultural attunement? The analysis of informed consents from VRC's archive that I present in this chapter shows how informed consents at this location changed over time in response to changes in international regulations and other forms of the internationalization of science. In time, we see these informed consent documents become progressively longer and "denser" in terms of their use of technical language. Not only this, but also the rhetorical strategies utilized by writers changed, shifting from a language of empathy and proximity to a language of authority. In other words, we see how authoritative, *ethos* appeals in the form of showing credentials and references to the developed world tend to displace *pathos* appeals and proximity from communications between researchers and participants. A change in strategies that could also impact accessibility and readability and that signals a change in the relationship between different actors in the research process.

### **Doing research in a changing world**

A panoramic look at these boxes of archived material from across VRC's history reveals traces of some major historical transformations. Changes in typography and paper quality suggest shifts in technology from handwritten notecards to more stylized even-sized files and from thin fax paper to print emails. The quality of the material and features of the documents' organization suggest an increase in formality and standardization. Newer boxes tend to look neater and seem to follow a set protocol for their filing organization. A closer look will also reveal changes in the actors and power dynamics involved in the research

process. This deeper kind of transformation, however, is harder to account for and understand without a narrative about the broader local and global transformations that were going on in vaccine science and around it during VRC's history: changes in the actors involved in scientific research and the relationships among them, local socio-historical transformations and changes in the pharmaceutical industry and its relationship to vaccine science researchers.

The actors—people and organizations—involved in transnational vaccine research are multiple. They include researchers and research institutions, pharmaceutical companies, philanthropic foundations or NGO's, governments, international regulatory bodies, data quality monitoring companies. Like technologies, their power and agency change through time and vary across world regions depending on their level of development, economic capacity, and local infrastructure. Depending on who sponsors, and therefore leads and has predominant agency in the design and development of a research project, we could classify studies as “industry research,” “researcher research” (or academic research), or “government-sponsored research.”<sup>7</sup> In VRC's archive, it is possible to find different kinds of studies, with different objectives, methodologies, sizes, and of course, different sponsors. Researchers' work and writerly agencies are shaped and constrained by their relationships to all of these actors, and most importantly by changes and growing exigencies of national and international research ethics regulations.

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<sup>7</sup> I deduced this categorization from a semi-structured interview (January 18, 2022, 1st interview) and a series of non-recorded conversations with VRC's director, Dr. Arce. The distinction is also supported by literature on the subject (see Fisher & Kalbaugh, 2012; Klein & Fleischman, 2002; Miller & Shorr, 2002).



Indeed, in Chile the 1990's and early 2000's decades were a moment of important advancements in terms of regulation and increasing awareness of the importance of ethical standards for biomedical research. Though the National Commission for Scientific and Technological Research (CONICYT<sup>8</sup>) was created during the 1970's, the organism did not contemplate the ethical review of research protocols until 1991 and did not require the implementation of informed consent protocols until 1999 (Sotomayor Saavedra, 2008). Further, local regulations did not require the approval of research protocols by the study's sponsoring institution until 2001, the year in which the first local ethics committees were created and certified (Acevedo Pérez, 2002; Sotomayor Saavedra, 2008). It is, then, perhaps no surprise that informed consent documents at VRC's archive seem to experience a sudden increase in complexity and sophistication from 2001 onwards, as I will discuss through this chapter.

But there were also other important transformations that could impact, though perhaps indirectly, the writing of ICFs during this period. Chile of the early 1990's was in the process of re-building its reputation internationally as a democratic country after the fall of Pinochet's dictatorship. Of course, this meant opening to international trade and developing an international policy, especially with Europe and neighboring countries (van Klaveren, 2011; Wilhelmy & Durán, 2003). This also involved a rise in the circulation of public discourse about internationalism and globalization. Additionally, during the 1980's there was an expansion in the access to education in Chile (Bellei, 2007; Puga, 2011), the effects of which would have been felt during the 90's and early 2000's. This would have

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<sup>8</sup> Comisión Nacional de Investigación Científica y Tecnológica CONICYT.

changed the general public's literacy levels and, in turn, researchers' understanding of and relationship with the audiences they addressed through documents like informed consents.

Finally, as I explore in the next chapter, transformations in big pharmaceutical companies' development models made research progressively networked and atomized: scalable. This model of industry-sponsored research has brought about changes in the relationships between sponsors and vaccine researchers, as well as new questions about ethics, especially related to the role of researchers and their ethical and intellectual engagement with the work of producing scientific knowledge (Fisher, 2008; Fisher & Kalbaugh, 2012; Miller & Shorr, 2002).

Analyzing informed consents can tell us something about what changed in researchers' writing practices and contexts over these years, and how these translated to changes in communications with prospective participants or their tutors. What changes did researchers perceive in their audiences as participants became more educated and aware of the international landscape? What differences in demands or exigencies did they experience from regulatory bodies? How did relationships with an increasingly atomized and networked pharmaceutical industry change research writing dynamics? Given the complexity of the transformations going on during this period, it is not possible to pin down causal relationships between changes in writing and any one specific phenomenon, so the questions that guide this chapter are broader and aim to describe and understand changes as they materialized in textual change.

- What shifts can be traced in textual features and rhetorical strategies of informed consent documents across VRC's history? and,

- What do these changes suggest about the sociocultural and historical transformations going on around these texts' lives?

In the following section, I explain the methods I applied to the analysis of informed consents forms from VRC's archive to answer these questions.

### **Methods: Reading activity and practice in(to) textual change**

To make sure I was comparing informed consent forms (ICFs) of a similar nature, I worked only with documents from clinical trials. Since these weren't too numerous, I was able to work with the informed consents for all clinical trials in VRC's archive. The table below shows the complete sample with each document categorized by year, the age of the participants, the type of antigen the vaccine or pharmaceutical product was designed to prevent, and the type of sponsorship the study received.

**Table 3: Identifying information for each ICF in VRC's archive**

<b>Year</b>	<b>Age of participants</b>	<b>Antigen/Product</b>	<b>Sponsor</b>
1996	2, 4, 6 months of age	DTP-ac & Hib-B	Industry
2001	6-36 months of age	Influenza trivalent A & B	Industry
2002	2-10 years old	Meningococcus (groups A, C, Y & W-135)	Industry
2004	Adults	Measles nasal	Academic
2005-2006	2, 4, 6 months of age	Pneumococcus	Industry
2007	< 12 months of age	RSV*/Motavizumab	Industry

2007-2008	9-12 months of age	Meningococcus (groups A, C, Y & W-135)	Industry
2008-2009	11-17 years old	Meningococcus B	Industry

\*Respiratory Syncytial Virus

I used NVivo (a qualitative data analysis software) to perform a word frequency count for each informed consent document, correcting the automated counts manually when necessary. Using this software’s word query features, I constructed a list and calculated the number of lexical words for each ICF, and then manually identified and counted the number of technical words in each list.<sup>9</sup> I used these two numbers to calculate the density of the technical language in each ICF sample (the percentage of technical words per total number of words).

I then tagged all sub-sections in each document, following the author’s sub-headings or other graphic or formal features, and later consolidated descriptive categories to describe analogous sections across different consent documents (Ex.: “Introduction” and “General information” were both tagged as “Introduction”; and “Participant rights” and “Participant rights and obligations” were both tagged as “Participant rights and obligations”). I did this instead of coding for moves (Swales, 2004), functional parts or themes because I was interested in accounting for formal variation decisions between these texts. Then I constructed a table with the parts or subsections in each ICF, which allowed me to identify commonalities across samples.

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<sup>9</sup> I considered technical lexical items all those describing diseases or symptoms in medical terms (Ex.: influenza would be considered technical but not flu); specialized language describing scientific processes or procedures; terms stemming from scientific subdisciplines like anatomy or microbiology; and specialized terminology related to scientific research, or the actors involved in it (Ex: ethics or sponsor).

Finally, I coded common sections across all ICFs in terms of their rhetorical strategies. The list of rhetorical strategies emerged from a question-driven descriptive qualitative coding (Saldaña, 2009) oriented by the questions:

- What strategy does the researcher use to persuade the reader? And,
- What kind of activity is being enacted in this text fragment?

The unit of analysis was semantic rather than grammatical since the question of where an activity or strategy starts and ends cannot be neatly tied to a grammatical unit like the sentence or the clause. The coded strategies were, then, grouped into three large categories corresponding to the classical rhetorical appeals: *ethos*, *pathos*, and *logos*. I will define these categories based on Aristotle's (1926) rhetoric as follows:

*Ethos*: The writer attempts to establish their own credibility or reliability, typically by showing their titles, affiliations, or credentials.

*Pathos*: The writer appeals to the reader's emotions, using language or examples that aim to move the reader to feel sympathy, feelings of fear, anger, or sense of moral good.

*Logos*: The writer shows their reasoning and trusts the reader will be persuaded by understanding.

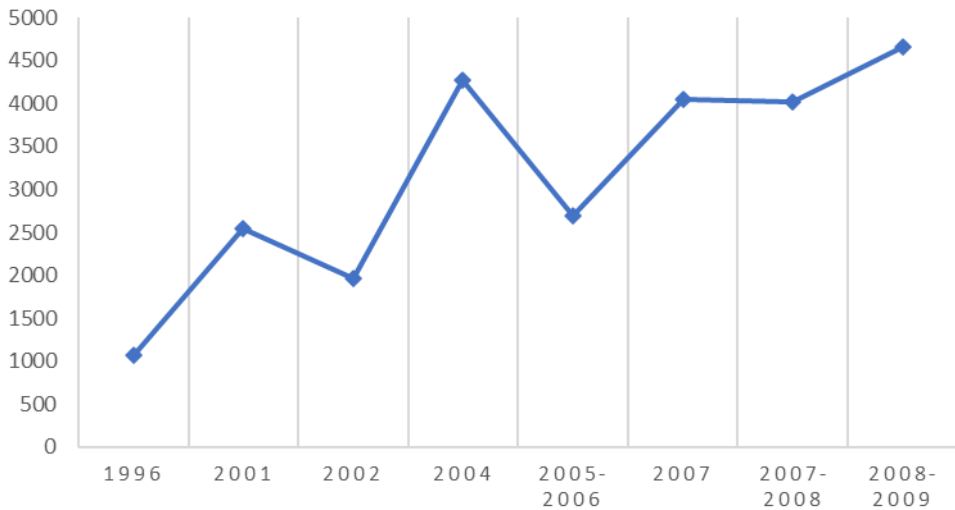
I use the classical appeals as categories because they provide a widely shared framework to describe the kind of persuasion work that I see these strategies doing. Thus, while strategies that emerge from description account for specific activities or ways of

enacting persuasion in the informed consents' text, rhetorical appeals allow us to trace broader patterns across these texts and account for their general effect on the reader.

### **The growing complexity of Informed Consent Forms at VRC Chile**

As the literature has described (Ménoni et al. 2010) and as the histories unravelling throughout VRC's research life suggest, there is a tendency for informed consent documents to grow in extension and complexity over time. Though it is unclear whether there is a direct association between extension and legibility (Menoni et al., 2010), common sense and experience does indicate that people are more likely to read shorter documents than longer ones, and that simpler text structures—with three or four parts—are easier to follow than complicated ones. As Graph 1 below shows, the number of words in each consent form increases quite consistently between 1996 and 2009. The one anomalous peak in this line is produced by the ICF from the year 2004. This corresponds to an academic study conducted with an intranasal Measles vaccine. It is the only study of the sample conducted with adults instead of children or adolescents, and the only one that involved a complex selection process before enrollment which required a consent procedure by itself. It is, then, understandable for this study's ICF to be atypically long.

*Graph 1: Word Count in ICFs from 1996 to 2009*



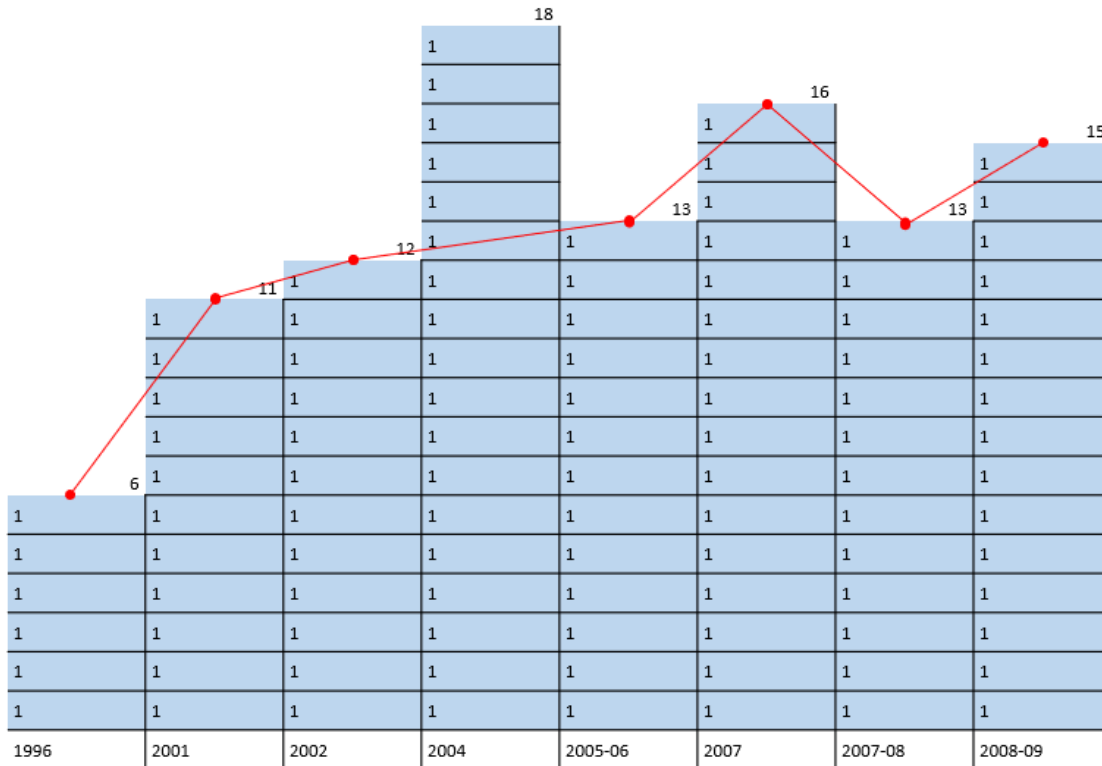
Additionally, a simple count shows that, like the number of words, the number of sections or elements in ICFs tends to grow over time, making the genre more complex and analytic.<sup>10</sup> The first sample from 1996, for example, was a relatively simple four-page document with five or six subsections, including: a description of the project and its purpose; potential risks; potential benefits; general conditions of participation; plus an initial salutation and final declaration of consent. In contrast, the last sample, from year 2008-2009, is a complex twelve-page document with fifteen elements and sections providing details that were absent from VRC's earliest consent protocols. It contains, for example, a section on alternative vaccines to the experimental vaccine used in the study, alternatives to participation, and a section describing what will be done with the remaining

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<sup>10</sup> See Table I in Appendix 2 of this document for a detailed view of the sections in each ICF.

samples obtained during the study. Graph 2 shows the number of sections counted in each text sample, identified by year.<sup>11</sup>

Graph 2: N° of Sections of ICFs per year/sample



Another indicator of this change in complexity is the variation in the density of technical language. Graph 3 shows how technical language density tends to increase between 1996 and 2009. Of course, as individual data points show, there are density drops and peaks throughout the years, but the general tendency is for technical language density to increase within this interval of time. This increase in the density of technical language, added to the increasing length of the documents and the emergence of sections dedicated to Nand inclusion criteria, research methodology, or procedures—would most likely make

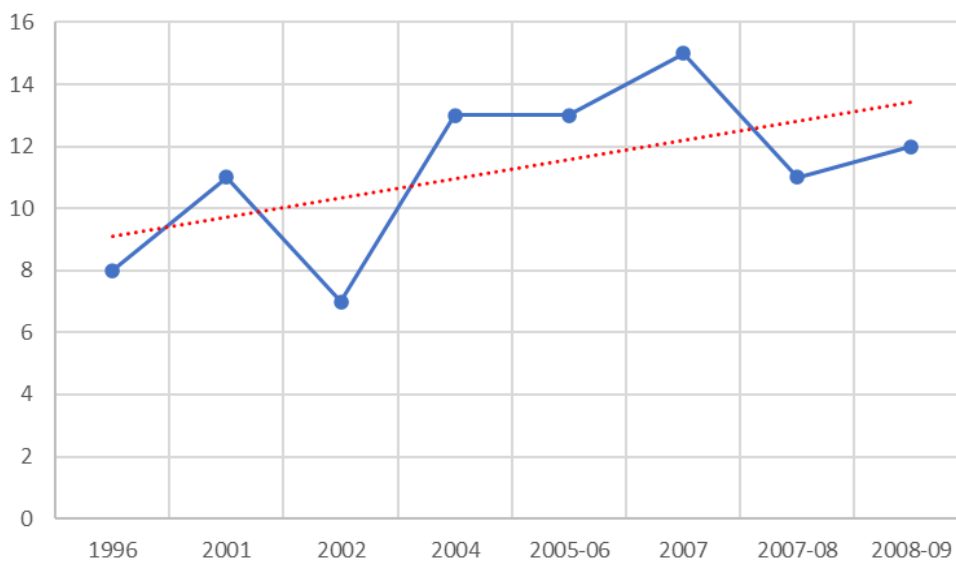
<sup>11</sup> The line skips year 2004 for the reasons I describe earlier in this chapter that make the 2004 Measles studies atypical.



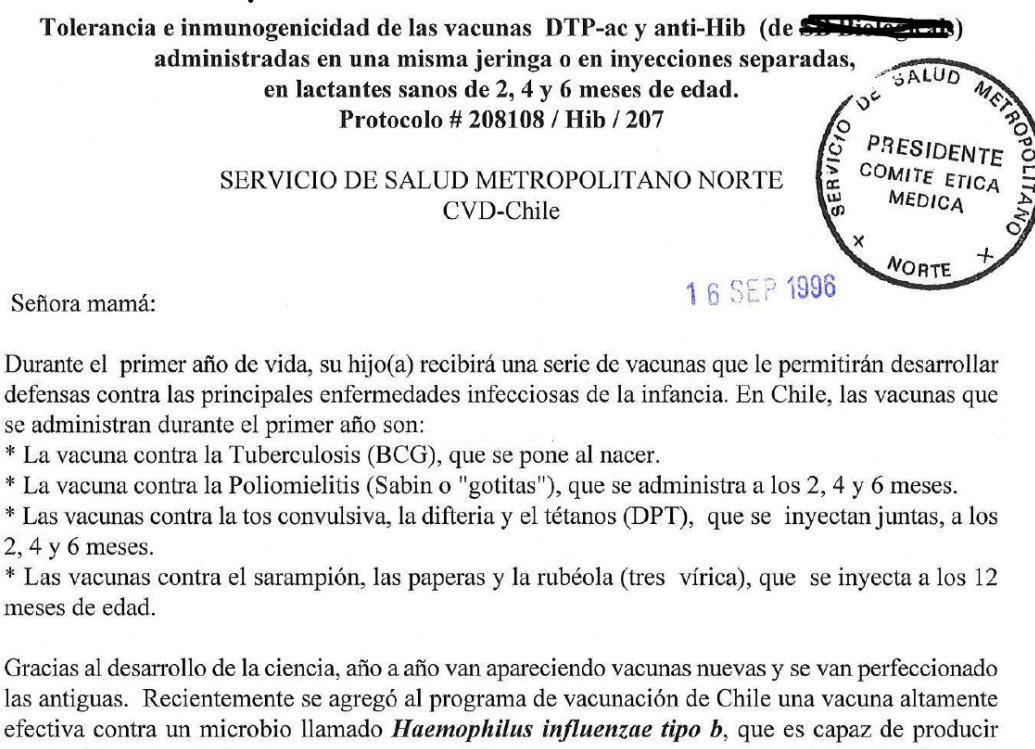
these texts more difficult for the lay reader to understand, and therefore, more distanced and removed from the general public.

I believe, based on my conversations with VRC researchers, that these issues of legibility (and proximity) would have been a constant and pressing concern for researchers at this research center (I delve more into this in Chapter 5, when I discuss nurse Mónica’s experience of writing practices and consent protocol). I also believe that the instability in the formal features and structure of the ICF genre at VRC over time reveals these writers and researchers’ hesitations as they grappled with how best to achieve their aims to address potential participants in a language that was, all at the same time, clear, persuasive, precise, and respectful of the contemporary standards and regulations on informed consent communications. I continue to examine this question of variability and instability throughout this section.

*Graph 3: Density of Technical Language in ICFs per Year*



My findings suggest that the great degree of formal variability between these documents reveals not a simple accumulation of new parts or sections, but also a degree of instability and experimentation with the genre over time. Some elements go in and out of the text from the beginning to the very end of VRC's history. This is the case, for example, with the initial salutation. An initial salutation suggests understanding the informed consent form as a type of letter addressed to prospective participants. The image below shows what the first page of the informed consent from the 1996 study (the first on in this sample) looked like.



**Image 2: Informed consent form from DTB/HiB 1996 Study**

Though there are no other formal features typical of letters, there are other elements that index conversational interactions as ways to establish proximity, as I discuss later. The

absence of a salutation, on the other hand, shifts the nature of the genre closer to an informational sheet or contract. Indeed, while some informed consents without a salutation preserve an opening sentence where the author addresses the reader directly, others completely shift their tone at the beginning to an informational one and only address the reader directly in brief passages further into the text. See, for example, the two fragments below corresponding to the first sentences of the ICFs from two different studies, conducted in 2002 and in 2005-2006:

<b>Example 1:</b> <b>Meningococcus vaccine (2002)</b>	<b>Example 2:</b> <b>Pneumococcus vaccine (2005-2006)</b>
<p>Los Meningococos son bacterias (microbios) que pueden producir infecciones graves de la sangre (septicemia), de las membranas que envuelven el cerebro (meningitis) y de otros órganos como los pulmones, huesos y articulaciones. Existen varios tipos de Meningococos...</p>	<p>Queremos invitar a su hijo/a a participar en un estudio con una nueva vacuna contra los microbios conocidos como Neumococos. El propósito de este documento es entregarle información que le ayude a decidir si le interesa o no que su hijo(a) participe en este estudio.</p>
<p><i>Meningococci are bacteria (microbes) that can cause serious infections of the blood (septicemia), the membranes surrounding the brain (meningitis) and other organs such as the lungs, bones, and joints. There are several types of meningococci...</i></p>	<p><i>We would like to invite your son/daughter to participate in a study with a new vaccine against the microbes known as Pneumococcus. The purpose of this document is to provide you with information to help you decide whether you are interested in having your son/daughter participate in this study.</i></p>

As these examples suggest, there is no clear transition from the informed consent understood as a letter-like genre to a straightforward informative sheet, presenting facts to

the participant in a detached manner. Indeed, the instability of letter-like features such as salutations and direct addresses to the reader can be found until the very last of the analyzed samples. This is, after all, a corpus from a very short time span, where, as I mention earlier, instabilities in genre changes or shifts can be expected. I also read this experimentation as the researchers' different attempts to sort out the difficulties presented by the genre: the need to convey information accurately; to engage and establish an identification with the reader; to persuade but not pressure potential participants to take part in the study. The instability of this kind of feature suggests this kind of pondering about the best way to establish closeness, to engage the participants in the research process.

Another feature through which ICFs maintain an interaction or dialogue with the reader is by organizing the different sections of the texts as a series of questions and answers. This kind of organization can be found quite consistently throughout ICFs until 2004. From that year on, certain section headers start to lose the question form and are replaced by a descriptive noun group. Example 3, shows the headers for the section on contact information for three ICFs, from years 2004, 2005-2006, and 2007-2008:

**Example 3:**

2004	2005-2006	2007-2008
A quién debo llamar si tengo preguntas o algún problema?	PERSONAS QUE LE PUEDEN DAR INFORMACIÓN ADICIONAL.	Información de contactos
<i>Who must I call if I have questions or a problem?</i>	<i>PEOPLE WHO CAN GIVE YOU ADDITIONAL INFORMATION</i>	<i>Contact information</i>

Note how the use of the first person in the fragment from the year 2004 introduces the reader's voice in the text. In the fragment from the following sample (2005-2006), by contrast, both the first person and the question form are dropped. Finally, the sample from 2007-2008 uses a short nominal group header, much more synthetic and less dialogic. A similar progression can be observed in Example 4 below, which shows the headers for the consent forms' section describing what will be done with any remaining samples after the study. Like the 2004 fragment referenced in Example 3, this fragment introduces the reader's voice in the text by using the first person in a header formulated as a question. Then the fragment from 2005-2006 abandons the first person but maintains the question form. Finally, the header from 2008-2009 is a long noun group, which retains little of the dialogic quality found in earlier headers.

**Example 4:**

2004	2005-2006	2008-2009
Qué pasará si sobra algo de mis muestras de sangre, saliva, etc.?	¿QUÉ PASARÁ CON LO QUE SOBRE DE LAS MUESTRAS DE SANGRE?	Autorización para el uso futuro de las muestras sobrantes
<i>What will happen if there are any remaining samples of my blood, saliva, etc.?</i>	<i>WHAT WILL HAPPEN WITH THE REMAINING BLOOD SAMPLES?</i>	<i>Authorization for the future use of remaining samples</i>

These changes could be described as shifts from more dialogic, or *heteroglossic*, to more monologic, or *monoglossic*, in the Bakhtinian/Voloshinovian sense of these terms (Hood & Martin, 2005; White, 2017). In other words, by these linguistic mechanisms, especially in earlier versions of the ICF at VRC, authors allow the text to be filled with the

voices of other actors—in this case, those of the readers themselves. The graduality in the use of *heterogloss* goes from a complete switch in the speaker—the intrusion of the reader’s voice in the text—to an acknowledgement of their presence and of the rhetorical situation represented in and enacted by the text, and then to a complete removal of any traces of this interaction. This entails, of course, banishing the reader’s voice (or its simulation) from the text, but also a gradual retreat of the researcher’s subjectivity from the text. The *monoglossic* statement, “the bare declarative” (White, 2017, p.74), is a nude nominal phrase, with no signs of commitment or engagement with the rhetorical activity mobilized in the informed consent.

Other features, such as the kinds of rhetorical strategies utilized and other more subtle elements of tone, such as the ones the reader might have picked up on in the examples discussed above, also suggest this tendency for researchers to gradually distance themselves from participants. In the next section, I describe changes in researcher’s use of rhetorical strategies and linguistic devices and argue that these speak of more complex phenomena surrounding these interactions, including of course, changes in international standards regulating the implementation of informed consent protocols, but also a transformation in the way researchers conceive their relationships to participants, and possibly the process of the informed consent itself.

### **Researchers and participants: from proximity to authority**

During our conversations, my mother often recalls how during VRC’s early years, it was not uncommon for participants’ parents to ask researchers for their opinion on whether

enrolling their child in the study was a good idea. Researchers would take the time to explain the study's purpose in detail, go over the consent form with parents, explain the risks and benefits, and go over kinds of actions parents would have to comply with were they to enroll their child in the study. But at the end, more often than not, parents (mothers) replied with puzzlement and a question akin to: “*¿Pero qué haría usted, doctorcita? Dígame qué hacer.*”<sup>12</sup> As I have mentioned before, in the early 1990's, VRC researchers were well aware that the audience they addressed in documents such as the informed consent were predominantly working-class women with low levels of formal education and schooled literacies. In this context, grappling with the best, most effective, accurate, and persuasive ways to convey information to ensure valid consent was one of VRC researchers constant and pressing undertakings. I believe the instability in the genre's formal features examined in the previous section attests to this grappling. This instability is a trace of researchers' activity, trying out different ways of rhetorically doing the work of the informing potential participants and obtaining valid, autonomous consent.

As I mention in the previous section, one evidence of this instability are changes in the genre's parts and structures. One feature of this instability is the (inconstant) use of salutation formulas. When looking at these more closely, they also speak of the gradual distancing between researchers and participants (or, in this case, participants' parents) and of a transformation in this relationship: from one of empathy and proximity, to one of authority. Example 5 shows how salutation formulas in ICFs changed over VRC's history.

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<sup>12</sup> “But what would you do, *doctorcita*\*? Tell me what to do.” (\*Literally, *little doctor*, affectionate).

**Example 5:**

1996	2004	2007	2008-2009
Señora mamá:	Estimado (a) Voluntario (a):	Estimado Señor o Señora,	Estimados padres,
<i>Mrs. Mom</i>	<i>Dear Volunteer:</i>	<i>Dear Sir or Madam,</i>	<i>Dear parents,</i>

The first salutation, from 1996, reveals an understanding of context and an eagerness to establish a proximity with the reader. The lexical choice, “mom” (*mamá*), hints at the fact that the population visiting the children’s hospital and caring for VRC’s potential participants was predominantly female. The choice also addresses the reader in their role in relation to their child; a role and position linked to this reader’s private life. Note, also, that the choice is not the more formal “mother” (*madre*), but the subtly more affectionate term *mamá*. Later versions, from 2004 and 2007 will indeed turn to more formal vocatives: Sir, Madam, Volunteer. By the last sample, however, the communication has ceased to be a one-to-one interaction between the researcher and the reader. Since the audience of the text here is collectivized (Van Leeuwen, 2008)—this is no longer “Mrs. Mom” but “Dear parents”—the communication acquires less the tone of a letter, addressed personally at one specific reader, and more that of a call, addressed to a broader potential audience. I understand this as a move away from rhetorical and language strategies that aim to establish a close, personal relationship between the participant and researchers, and more clearly reflecting the roles of these actors in a research context.

In this same sense, the qualitative coding shows that the variation and changes in emphasis of the persuasive strategies in use across these texts speak of a gradual



“distancing” between researchers and potential participants: a shift from the affective to the authoritative. Table 4 below shows the coding scheme for rhetorical strategies found across all common sections of the analyzed ICFs (introductions, risks, and benefits sections) and the number of instances in which each was found. These strategies are also grouped in terms of rhetorical appeals. For example, “Underlining participant rights” is a strategy oriented to establish the researchers’ reliability and trustworthiness, so it can be understood as a type of Ethos appeal. “Appealing to the reader’s sense of altruism” aims to persuade the reader by trusting that they care for other people’s well-being, it can be understood as an appeal to emotions or Pathos. And, by showing the reasoning behind the study through strategies described here as “Argumentation,” or “Explaining rationales or procedures,” the writer of these documents is appealing to the prospective participants’ reason, trusting they will be persuaded by understanding.<sup>13</sup>

As the table shows, “Basic information” appears distributed across all ICFs without a clear tendency or pattern for obvious reasons, as all informed consent forms must provide basic information about the study. For this reason, I will not go into a detailed analysis of this code. I apply a similar criterion to the discussion of other codes in this section: I pay closer attention to those in which there is a clearer pattern or tendency through time, and to those which are most interesting or significant for the central argument of this chapter.

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<sup>13</sup> A detailed description of all coding categories can be found in Table II, in Appendix 2 of this document.

**Table 4: Strategies coded in introductions, risks and benefits sections in all ICFs**

<b>Appeal/Strategy</b>	1996	2001	2002	2004	2005-2006	2007	2007-2008	2008-2009
<b>Ethos</b>								
Referencing the developed world	0	0	1	0	1	0	3	0
Showing credentials	0	0	0	1	0	2	1	2
Underlining participant rights	0	0	0	0	0	5	4	4
<b>Pathos</b>								
Anticipating concerns	2	0	0	2	0	2	2	0
Appealing to the reader's altruism	0	0	0	1	0	1	0	1
Inviting positive attitudes towards science	3	0	0	0	0	0	0	0
Offering access to social goods	1	1	0	0	3	0	1	0
Wearing the participant's shoes	1	0	0	0	0	0	0	0
<b>Logos</b>								
Argumentation	3	2	3	0	1	0	1	1
Avoiding misinterpretation	0	0	1	2	1	2	2	0
Explaining rationales and procedures	2	3	2	7	0	1	1	4

Signposting	0	0	0	1	0	1	2	2
Referencing existing knowledge	0	3	3	2	2	3	1	1
** Basic information	5	10	4	4	4	8	14	4

Now, based on the number of instances a code appears or disappears, we could interpret changes as being small or not very telling of significant change. See, for example, what happens with codes like “Wearing the participant’s shoes”, which appears only once, or “Inviting positive attitudes towards science”, which appears coded only in one ICF exemplar. Indeed, a strategy that is coded only once could be a contingent, accidental occurrence in the sample. In part, this is due to the fact that the data set that I’m working with is small and the timeframe fairly narrow. But the thinness of the data represented in the table is deceiving. As I point out earlier in this chapter, the data corresponds only to a partial analysis of the ICFs (only introductions, risks, and benefits sections were coded) which means that instances of these codes may appear more than once in the same or different consent form samples but in a section that was not coded, making change seem more subtle than they really are when whole texts are analyzed. The detailed discussion of findings in this section will help balance out the limitations presented by these initial methodological choices both by extending the discussion beyond the coded sections, and by looking at the rhetorical strategies listed in conjunction with other textual, linguistic, or rhetorical features that contribute to the production of a similar rhetorical effect.

There are, indeed, a couple of strategies where we can observe notable transformation over time. Taken as a whole, these strategies suggest a transition from communication that relies on *pathos* appeals to others that lean on *ethos*. As I begin to describe at the beginning of this section, it seems that, in VRC's early years, researchers were most inclined to attempt to reach their audiences by creating proximity, demonstrating empathy, or being relatable. Later, they started relying more and more on authority as a mode of persuasion. For example, in the very first ICF sample from a 1996 Influenza Hib study, the writer uses a strategy that I've called "Wearing the participant's shoes," which entails using the first person to represent the reader's voice in the text. Instances of this code appear also in other noncoded passages from the 1996 as well as the 2004 nasal measles vaccine sample, which suggests that the use of this strategy was more than simply accidental (see Examples 6 and 7).<sup>14</sup>

**Example 6: Influenza Hib (1996), Ref.1**

Que riesgos tendría para mi niño participar en esta evaluación?

*What would be the risks for my child to participate of this evaluation?*

**Example 7: Nasal measles vaccine (2004), \*Uncoded fragment**

Qué pasará si sobra algo de mis muestras de sangre, saliva, etc.?

*What will happen if there are any left-over samples of my blood, saliva, etc.?*

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<sup>14</sup> Of course, the first person is also used often in the consent declaration sections of all analyzed ICFs. However, this is a more predictable decision, as the consent declaration is, precisely, the participant's statement that they voluntarily agree to participate in the study.

Note how “Wearing the participant’s shoes” serves the purpose of anticipating and reflecting the reader’s concerns regarding the study. The use of first person in these fragments is usually followed by a response written in second person (“you”, “you and your child”). Again, through these questions, the reader’s voice is included in the ICF, and the question-response structure mimics a face-to-face interaction, contributing to the construction of proximity and familiarity.

Proximity and empathy are also achieved through other resources such as the use of familiar or colloquial language, diminutives—very typical of Chilean Spanish—and expressions of endearment, the subtleties of which may easily be lost in translation. Take, for instance, the same fragment from Example 6 above. Here, the participant is alluded to in the parent or guardian’s voice as “*mi niño*” (“my boy” or “my child”). In this context, the possessive and the lexical choice *niño* (boy), instead of *hijo/hija* (son, daughter or child), produces the effect of endearment or affectionate tone. This is partially maintained in later ICFs where the participant is often described to the parent or guardian as “*su niño/niña*” (your boy/girl). This would likely be translated to English in the more neutral form “your child”. This usage alternates with the more affectively neutral “*su hijo/hija*” (“your son/daughter”) or “*el niño*” (“the child”). Example 8 below shows instances of this phenomenon across different ICF samples:

<b>Example 8:</b>	
2001	Queremos invitar a <b>su niño</b> <i>We want to invite your boy (child)</i>
2002	Usted podrá optar libremente por que <b>su niño</b> no participe

	<i>You are free to opt your boy (child) out of participation</i>
2005-2006	Le pediremos traer a <b>su niño(a)</b> al Consultorio <i>We will ask you to bring your child to the clinic</i>
2008-2009	Entiendo que puedo retirar a <b>mi niño(a)</b> del estudio en cualquier momento <i>I understand that I may withdraw my child from the study at any time</i>

As these fragments suggest, through these more subtle linguistic choices, VRC researchers are able to maintain elements of empathy and proximity in their communication, despite writing within the boundaries of a highly (and increasingly) standardized and regulated genre. These choices at the lexical-semantic level also show how the local seeps into these textual objects. This is evident in the use of diminutives—typical of the way Chilean Spanish indexes endearment or proximity—and local idioms. Examples 9 and 10 below show the use of diminutives in the description of pharmaceutical products (vaccines) and in the “translation” of standard metric units to every-day measurements.

<b>Example 9</b>	
1996, Influenza Hib	La vacuna contra la Poliomiéлитis ( <b>Sabin o "gotitas"</b> ), que se administra a los 2, 4 y 6 meses <i>The vaccine against Poliomyelitis (Sabin or “droplets”), that is administered at 2, 4, and 6 months</i>
2001, Influenza A&B	que se transmiten de una persona a otra a través de las <b>gotitas de saliva</b> que se expulsan con la tos y los estornudos <i>transmitted from one person to another through saliva droplets expelled when coughing or sneezing</i>

<b>Example 10</b>	
2007, Motavizumab	También tomaremos una muestra de sangre (alrededor de <b>una cucharita de té</b> ) de una vena del brazo del niño (a)  <i>We will also take a blood sample (around a teaspoon<sup>15</sup>) from a vein in the child's arm</i>
2008-2009	Cada muestra será de 15 ml, es decir <b>como 3 cucharitas de té</b>  <i>Each sample will be of 15 ml, that is, like 3 teaspoons</i>

In the fragment from 1996 in Example 9, the researcher uses the every-day name for the polio vaccine, the “gotitas” (droplets) vaccine—probably due to the fact that it is an oral vaccine. Example 10 shows how the use of non-standard measuring units is used to make blood sample amounts more understandable as well as less intimidating (one or three teaspoons is, admittedly, a small amount). All these examples show attempts to present as much information as possible in terms that are known and relatable to participants or their tutors. But this is not simply plain language; it is warm language that extends the rhetorical work done through strategies like “Wearing the participants shoes,” which tend to disappear in later years of VRC’s history.

Another strategy that reveals an important shift from proximity to authority is in the switch away from strategies like “Inviting positive attitudes towards science” towards “Showing credentials.” Both these strategies aim to engage the reader with science as a concept to persuade them that enrolling their children in the study is a valuable and sensible thing to do. But while the first does this by framing science in a positive light, in a way that

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<sup>15</sup> In the original text in Spanish, the word “*cucharita*” entails the use of a diminutive “-ita,” typical of Chilean language of endearment.

implies that scientific progress is something to be enthusiastic about, the second relies on the respectability of institutions and titles to convey authority. Example 11 shows this tone of optimism about the advancement of science that I code as “Inviting positive attitudes towards science”. Relying on an implicit premise in the inherent good of scientific advancement and progress, the development of new vaccines is framed as something desirable, and novelty is emphasized as something positive.

Example 11: 1996 (Influenza Hib)

**Gracias al desarrollo de la ciencia**, año a año van apareciendo vacunas **nuevas** y se van **perfeccionado** las antiguas. Recientemente se agregó al programa de vacunación de Chile una vacuna **altamente efectiva** contra un microbio llamado Haemophilus influenzae tipo b, que es capaz de producir meningitis y otras infecciones graves en el niño. Esta **nueva** vacuna se administra a los 2, 4 y 6 meses, al igual que el DPT. [...] Esta vacuna (llamada vacuna pertusis acelular, DTP-ac) **es igual o más protectora** que la vacuna tradicional, pero produce menos molestias.

*Thanks to the development of science, new vaccines are appearing year after year and the old ones are being perfected. Recently, a **highly effective** vaccine against a microbe called Haemophilus influenzae type b, which can cause meningitis and other serious infections in children, was added to Chile's vaccination program. This **new** vaccine is administered at 2, 4 and 6 months, as is DPT. [...] This vaccine (called pertussis acellular vaccine, DTP-ac) is **equally or more protective** than the traditional vaccine, but causes less discomfort.*

In later ICF samples, by contrast, persuasion about the safety and reliability of the study relies on ethos appeals, materialized in the explicit mention of titles, overlooking institutions (such as ethics committees or IRBs), and prestigious collaborators. As shown in Example 12, there even seems to be an evolution in this strategy of “Showing credentials”, as the institutions and titles mentioned become more sophisticated through time. Thus, in the earliest sample, from 2004, it seemed enough to mention that the study was being



conducted by a group of medical doctors from different research institutions; then, in the sample from 2007, researchers are described as “professionals specialized in vaccine research”; and by 2008-2009, the reviewing ethics committees that authorized the study are mentioned.

<b>Example 12:</b>		
2004 (Measles)	2007 (Motavizumab)	2008-2009 (Meningococcus B)
Este estudio será conducido <b>bajo la dirección de las Dras. R. L. y A. M.</b> , del Centro para Vacunas en Desarrollo-Chile, y del Dr. J. C., del Center for Vaccine Development de la BCU.	Este estudio es <b>patrocinado por una compañía Norteamericana llamado MedImmune, Inc.</b> , y será realizado en Estados Unidos, Chile, Panamá, Nueva Zelanda y Australia. En Chile, el estudio estará a cargo de un equipo de <b>profesionales especialistas en investigación médica</b> (en Centro para Vacunas en Desarrollo-Chile) dirigido por la Dra. R. L..	Este estudio es <b>financiado por Novartis Vaccines and Diagnostics ("Novartis Vaccines")</b> , la <b>compañía fabricante de la vacuna</b> , y fue <b>autorizado por el Programa Nacional de Inmunizaciones del Ministerio de Salud de Chile</b> , por el Comité Ético-Científico del Servicio de Salud Metropolitano Oriente y por el Comité Ético-Científico del Servicio de Salud Metropolitano Norte.
<i>This study will be conducted under the direction of Drs. R. L. and A. M., Center for Vaccines in Development-Chile, and Dr. J. C., Center for Vaccine Development, BCU.</i>	<i>This study is sponsored by an American company called MedImmune, Inc. and will be conducted in the United States, Chile, Panama, New Zealand and Australia. In Chile, the study will be conducted by a team of professionals specialized in medical research (at the Center for Vaccines in Development-Chile) led by Dr. R. L..</i>	<i>This study is funded by Novartis Vaccines and Diagnostics ("Novartis Vaccines"), the manufacturer of the vaccine, and was authorized by the National Immunization Program of the Chilean Ministry of Health, by the Ethical-Scientific Committee of the Servicio de Salud Metropolitano Oriente and by the Ethical-Scientific</i>

		<i>Committee of the Servicio de Salud Metropolitano Norte.</i>
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Together with titles and research institutions, the sponsoring pharmaceutical company is also mentioned in ICFs from VRC’s later years. This likely conforms to a change in exigencies and regulations requiring that ICFs explicitly mention their sources of funding. This kind of information, however, would almost certainly make the consent forms more obscure to participants. Indeed, while the notion that science and scientific progress are good is likely an idea that the reader can agree with, even without a full understanding of their meaning and implications, understanding what it means for a study to be sponsored by a pharmaceutical company and approved by an ethics committee requires knowledge of more technical and specialized aspects of scientific research which are hardly accessible to most lay readers.<sup>16</sup>

Another interesting element that begins to come through in the examples above, and that also speaks of authoritative appeals, is the allusion to the developed world, mostly Northern hemisphere countries. This is a strategy used in ICFs from 2002 onwards and through which the writers try to convey to participants’ tutors that the study and the vaccine products being studied are safe because they have been tried or used in more developed countries. See, for example, the fragment below (Example 13) from a study with a Meningococcus vaccine conducted in 2007-2008:

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<sup>16</sup> However, I make this interpretation based on common sense and my own understanding of what kind of information seems to be more familiar or accessible to the general public. I would need to conduct further research to understand how VRC participants perceived and experienced communications with VRC researchers.

### **Example 13: Meningococcus (2007-2008), Ref. 2**

**Pneumoc\*** es utilizada por rutina en los Estados Unidos, Australia y muchos países europeos, y ha demostrado ser bien tolerada y muy efectiva para prevenir infecciones graves, neumonías e infecciones de oído causadas por neumococos.

*Pneumoc\* is routinely used in the United States, Australia and many European countries, and has proven to be well tolerated and very effective in preventing serious infections, pneumonia and ear infections caused by pneumococci.*

Here, the Global North and the knowledge that flows from developed regions are used as references for what is trustworthy and prestigious. The underlying premise here is that, if more developed countries use this vaccine (Pneumoc), then it must be more than safe enough for less developed countries, like Chile. Now, if the Global North represents respectability and high standards, the Global South is presented as in need of aid. Though there are few of these, passages where developing countries or regions are mentioned, are used to justify why research is needed by providing an example for the types of populations that would benefit from it. In the fragment in Example 14, for instance, the author is explaining why vaccine innovations that develop new forms of administration—in this case, the nasal administration of the measles vaccine—are necessary and urgent global health initiatives.

### **Example 14: Measles (2004)**

...como el virus del sarampión es altamente contagioso, para erradicar la enfermedad a nivel de todo el mundo es necesario que todas las personas, de todos los países, estén vacunadas. Eso no es fácil de conseguir en las regiones más pobres (como en el África), donde existen múltiples dificultades para poder vacunar a toda la población.

*...as the measles virus is highly contagious, in order to eradicate the disease worldwide, it is necessary that all people in all countries be vaccinated. This is not easy to achieve in the poorest regions (such as Africa), where there are many difficulties in vaccinating the entire population.*

The increasing use of strategies like “Referencing the developed world” also speak of the growing internationalization of science and the permeation of a discourse about the global to communications with local audiences. As mentioned earlier in this chapter, this does not have a simple explanation (especially in the Chilean context) but likely obeys to a series of complex transformations going on nationally and internationally at the time. As Chile’s newly established democratic governments were intently working on re-building the country’s political and commercial relationships with the world (Wilhelmy & Durán, 2003), the international landscape itself was becoming more global, and the vaccine industry was progressing towards increasingly scalable research and development models that relied on wide-reaching international multicentric studies. What we see in VRC’s consent forms, then, might be the traces of this historical context and this awareness of the, not simply universal, but global character of science, seeping even into very context-dependent genres like the informed consent.

### **Final thoughts**

Con su participación en este estudio, usted y su hijo(a) estarán ayudando a reunir información científica acerca de esta nueva vacuna, y a que en el futuro lleguemos a tener un método efectivo para prevenir las enfermedades y muertes causadas por Meningococos grupo B. (**Meningococcus B study, 2008-2009**)

*With your participation in this study, you and your child will be helping to gather scientific information about this new vaccine so, in the future, we have an effective method to prevent the illnesses and deaths caused by Meningococcus B.*  
(**Meningococcus B study, 2008-2009**)

Looking back over 13 years of informed consents, we see traces of VRC researcher's constant grappling with the challenges of communicating with lay audiences: trying out different genre structures and formal features, adapting to changes in exigencies and regulations, shifting their rhetorical strategies. Through the diachronic analysis of the center's informed consent documents, we see researcher's rhetorical strategies switching from ones oriented toward constructing proximity and empathy with readers to others that communicate authority and create a certain degree of distance between researchers and participants. As I discuss through this chapter, this transformation could reflect researchers' necessary response and adaptation to international standards for scientific communication in informed consent documents. This adaptation could be understood as a setback from more locally attuned forms of communication. However, this change could also speak of a growing awareness about the nature of the informed consent, and the need to ensure that patients and participants are indeed making informed and autonomous decisions. Indeed, through VRC's history we see researchers' growing discomfort in engaging their subjectivity and personal opinions in guiding and aiding participants through the informed consent protocol. In this sense, distance may not be a problem but simply evidence of this new coming to terms with the implications of the informed consent as an activity.

However, if distancing is paired with increasing complexity and challenges to readability, we must wonder about the consequences of these transformations in the publics' understanding of science and research, and about who is left out—displaced from participation—when both these new *ethos*-oriented strategies and legibility challenges become the norm. This raises questions about science's imagined publics and actors. Who is expected to interact with scientific information? Who are the actors that part-take in

scientific knowledge production? What kinds of reason and reasoning are legitimate when making decisions about whether to engage in biomedical research as a participant? When VRC's research work began, in the working-class north zone of Santiago, researchers had a clear answer regarding who they intended their audience and prospective participants to be. They were interested in working with working-class populations; with people too often marginalized from participation in science production and the benefits of the most recent scientific advancements. As the Mali anecdote and VRC's case suggest, working with vulnerable populations is, certainly, ethically fraught, but so is marginalizing these groups from the potential benefits—and the possibility of making decisions—related to participating in clinical research.

In VRC's archived consent form documents, we see how authoritative, *ethos* appeals in the form of showing credentials and references to the developed world tend to displace *pathos* appeals and proximity from communications between researchers and participants. Yet, there still remains subtle forms of *warm language* in VRC's consent forms until the very last items in the sample. These traces of affectionate language that resist being erased from the text—"mi niño/su niño", "pequeño moretón", "cucharita de té"—perhaps continue to reflect VRC's original orientation to communication with local audiences, and a refusal to completely abandon all forms of local appropriation of the genre. In the next chapter, I trace the ecology of one clinical trial conducted at VRC and show how Chilean researchers exercised this kind of resistance to the advancement of standardization and *scalification* of scientific writing and knowledge production.

## Chapter 4

### **“A sponsor you can still work with” Negotiating Vaccine Research Writing on the Verge of the Industrial Model**

#### **Introduction: working the not-yet industry model**

My mother tells stories of the time when VRC conducted large research projects, training and deploying teams of staff and researchers across multiple health centers in the north area of Santiago, engaging all their skills to get research funded, protocols approved, going out to working-class homes for follow-ups with participants, finding ways to influence public policy through science. I remember this time. I too went along in some of this house-to-house visits, witnessed the buzzing activity in VRC’s offices, and was made tangentially participant of it. It was around this time that I remember having conversations with my mother about informed consent forms, and the participation of children in research. It is also around this time—I must have been nine or ten years-old—that I would locate my memory of being sat down in front of an informed consent form and asked whether I understood what it meant, if I found it confusing, clear, or perhaps scary. I was, unknowingly, being asked to proof-read the document for clarity. VRC researchers were, indeed, intensely invested in producing writing that would, clearly and accurately, communicate the complex scientific work of studying vaccines to families that often did not have a very broad repertoire of schooled literacy resources. Being able to speak to these

audiences required an understanding of this place and time. This entailed, among other things, giving local researchers enough writerly flexibility and agency (Ávila Reyes, Navarro, Tapia-Ladino, 2020; Lu & Horner, 2013; Zavala, 2011) to decide what was an adequate, clear and accessible use of language. With the advancement of big-industry studies and the rising demands of international research standards, however, these careful decisions regarding language and procedure became more and more difficult.

To be clear, most clinical vaccine trials—studies with experimental vaccines—are, indeed, industry-research, since it is mainly pharmaceutical companies who are interested in testing and introducing new vaccine products into the market. And so, it is the case that many if not most clinical vaccine trials in VRC’s archive are sponsored by the industry. But the change from researcher-lead studies to fully standardized industry research did not happen overnight. It was a gradual process that spread unevenly across the globe. Richer countries can still today count on powerful research institutions that get government funding for basic research and other development projects; and low-income countries can sometimes—though not reliably—count on funding for vaccines and vaccine research from philanthropic organizations and international agencies such as the World Health Organization (WHO) (Kaddar, Schmitt, Makinen & Milstien, 2013; Nossal, 2004). As Chile gained a reputation internationally as a stable and successful middle-income country, it became less appealing to those interested in aiding the world’s most vulnerable. When this happened, VRC was faced with the harsh challenge to find ways of doing vaccine research in world dominated by big transnational pharmaceutical industry. As I explain in detail later in this chapter and in the next, this is a struggle that VRC finally desisted, as the new conditions for international vaccine research proved incompatible with this research



center's principles and research model. But before vaccine research became fully industrialized, there was a period of transition, where centers like VRC had room for pushback and negotiation against the standards and impositions of transnational vaccine research.

This chapter focuses on a study conducted by VRC between 2007 and 2008 to examine the kinds of pushbacks and negotiations that VRC engaged in with other actors in the research process, especially (but not exclusively) pharmaceutical companies. The study was titled "Safety Study of MeninO<sup>17</sup> (Meningococcal [Groups A, C, Y and W-135] Polysaccharide Diphtheria Toxoid Conjugate Vaccine) when Administered with Other Pediatric Vaccines to Healthy Toddlers." I will call it "Meningococcus study," for short. This was a phase-three clinical trial sponsored by a French multinational pharmaceutical company and it involved multiple research centers in Chile and the US. As Dr. Arce explains, this was a transition study, of sorts. It falls somewhere in between studies completely led by pharmaceutical companies, where researchers have no say in the design and conditions of the study, and earlier models of vaccine research, where researchers (through research institutions like VRC or universities, and often sponsored by local governments) were the main actors driving the research, designing the project based on local needs, and making a case to pharmaceutical companies to sponsor the research.

In the Meningococcus study, VRC was still given enough time to collect a good sample-size and, as the data in this chapter suggests, there was still space for pushback and negotiation regarding research protocols, procedures and their language during the project's

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<sup>17</sup> The commercial name of this and other vaccine products have been replaced by a pseudonym and the name of the laboratory was deleted, at request of VRC's director.

development. Thus, the Meningococcus study speaks about a moment in vaccine research history where internationalization and scaling (Tsing, 2005; 2012) of scientific knowledge-making systems was becoming the dominant model and *local* science—i.e., academic or researcher-lead and generally more locally attuned studies—was gradually losing ground. Still, this case offers a peek into what resistance to those standardization processes looked like, and what was lost as industrialization finally imposed itself.

The purpose of this chapter, then, is to describe how knowledge-making systems at this point in VRC's history were becoming increasingly distributed and networked, re-defining (and narrowing) the limits of researcher's writerly agency, as well as researcher's moves to counter the advancement of globalization in the form of standardization and make space for their own values in the research process. The questions I attempt to explore here, then, are how does researcher agency look like in a global context? and, what objectives or values does the exercise of agency pursue?

To explore these questions, as I have done before, I use the informed consent as an entry-point. I situate this genre within the larger ecology of genres and activities in the research process, capturing some of the information flows between North and South, as well as the distributed nature of knowledge produced transnationally in an industry study. To do this, I identify the texts/genres that define the work of this research center and map out their relationships through a mobility system visualization to show the network that produces knowledge in industry studies such as this one. Then, I trace changes in the informed consent both through text analysis and talk around text interviews, to find what motives and values drive local researchers' writerly agency. Finally, I zoom into two specific moments documented in correspondence records that provide salient evidence of

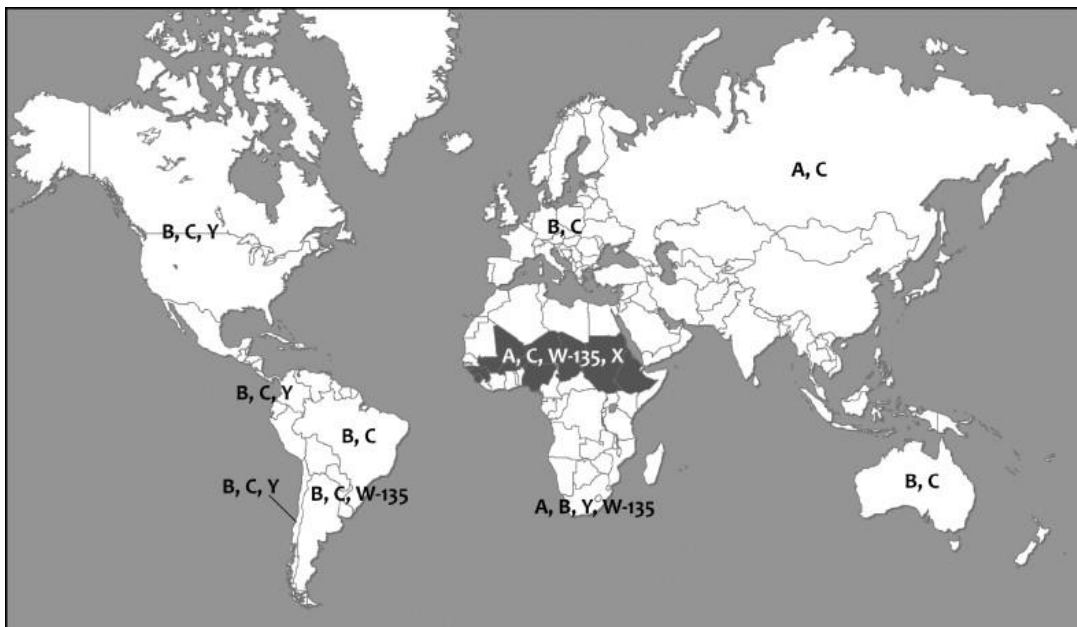
instances of friction and agentive resistance to scaling and standardization in scientific research. I argue that the ways in which local researchers work to assert their values and rewrite documents for the local context and public is critical to their understanding of good and ethical scientific practices.

But first, I offer some background information on meningococcus and the meningococcus vaccine in clinical trial for the study I analyze in this chapter. This section also provides an opportunity to show some of the complex intertwining that collaborative international research entails.

### **The meningococcus vaccine study and meningococcus here and the world**

The purpose of the Meningococcus study was to try a new vaccine to prevent meningococcal disease in young infants under one year of age. Meningococcus (*Neisseria meningitidis*) is a bacterium that causes severe infections such as meningitis and other kinds of life-threatening sepsis, and it is most deadly for young children under two years old. Meningococcal disease outbreaks and epidemics have been described as cyclical, and their distribution across the globe is highly regional (Harrison, Trotter & Ramsay, 2009), which means that different varieties of the bacteria (groups or serogroups) can be found distributed unevenly in different regions of the world. The map below (from Harrison, Trotter & Ramsay, 2009)—constructed with data from the mid 90's to the early 2000's—shows the distribution of meningococcus serogroups across the globe. It is interesting to note that the bacterial sub-groups found in the US and Chile were likely the same by 2007. This, together with the fact that the vaccination schedules for children in both countries are

very similar, makes these two locations good research sites for conducting a study involving populations from both countries.



**Image 3: Distribution of Meningococcus serotypes across the globe (Harrison, Trotter & Ramsay, 2009)**

Conducting the Meningococcus study meant, among other things, that there needed to be coordination between centers in Chile and the US, including agreement on the sampling methods, a work timeline, the application of near to identical informed consent protocols—except, of course, for the difference in languages—and the implementation of identical vaccination schedules for participants. To do this, Chilean children participating in the study had to be administered the same vaccine products received by children in the US. The table (Table 5) below shows current vaccination schedules for Chile and the US (according to CDC Recommendations) with the vaccines that were not part of the immunization program marked in grey (including the Meningococcal conjugate vaccine in trial for this study).

**Table 5: Vaccination schedules for Chile and the US**

Age	Chile	US
New-born	<ul style="list-style-type: none"> <li>- BCG (tuberculosis)</li> <li>- Hepatitis B</li> </ul>	<ul style="list-style-type: none"> <li>- Hepatitis B</li> </ul>
2, 4 y 6* months	<ul style="list-style-type: none"> <li>- Hexavalent: Hepatitis B, Diphtheria, tetanus, acellular pertussis, Haemophilus influenzae type b (Hib), Poliovirus</li> <li>- Pneumococcal conjugate*</li> <li>*Only premature children</li> </ul>	<ul style="list-style-type: none"> <li>- Hepatitis B</li> <li>- DTP: Diphtheria, tetanus, &amp; acellular pertussis</li> <li>- Haemophilus influenzae type b (Hib)</li> <li>- Poliovirus (2 mo.)</li> <li>- Pneumococcal conjugate</li> <li>- Rotavirus</li> <li>- Meningococcal conjugate</li> </ul>
6 months		Influenza (IIV) (Annual)
12 months	<ul style="list-style-type: none"> <li>- MMR: Measles, Mumps, Rubella</li> <li>- Meningococcal conjugate</li> <li>- Pneumococcal conjugate</li> </ul>	<ul style="list-style-type: none"> <li>- MMR: Measles, Mumps, Rubella</li> <li>- Haemophilus influenzae type b</li> <li>- Meningococcal conjugate</li> <li>- Pneumococcal conjugate</li> </ul>
15 -18 months	<ul style="list-style-type: none"> <li>- Hexavalent: Hepatitis B, Diphtheria, tetanus, acellular pertussis, Haemophilus influenzae type b (Hib), Poliovirus</li> <li>- Varicella</li> <li>- Hepatitis A</li> </ul>	<ul style="list-style-type: none"> <li>- Poliovirus</li> <li>- Varicella</li> <li>- Hepatitis A</li> </ul>

The differences that matter to this chapter, though, have to do with the vaccines that would have been administered together with the experimental meningococcal vaccine, meaning vaccines administered to children between 9 and 12 months of age. At the time when the Meningococcus study was conducted (2007-2008), the CDC recommended the MMRV vaccine (for Measles, Mumps, Rubella, Varicella), a pneumococcal conjugate vaccine (PCV), and the Hepatitis A (HepA) vaccine, for U.S. children around 12 months old. In Chile, the Hepatitis A and pneumococcal vaccine (PCV) were not part of the national immunizations plan. Instead of the MMRV, the vaccine in use was the MMR (Measles, Mumps, Rubella). So, for the duration of the study, Chilean participants had access to a series of vaccines that were not included in the national immunizations plan, some of which—like the MMRV—were considered a technological advancement as they reduced the number of shots administered in early childhood. For this reason, these study conditions were presented as a beneficial aspect of participation to parents of participants. A fragment from the study’s informed consent’s section regarding the potential benefits of participating in the research reads:

“Todos los participantes tendrán la posibilidad de recibir en forma gratuita vacunas que están disponibles en el comercio, pero que no forman parte del programa rutinario de vacunación de los niños chilenos.”

*“All participants will have the possibility to receive free vaccines that are available in the market, but are not included in the routine vaccination schedule for Chilean children.”*

The table below shows the experimental design as it was originally approved by the Chilean ethics committee and IRB in the US. As shown in the table, one group would receive the experimental anti-meningococcus vaccine (MeninO) in two doses, and the other

would act as a control group. Later in the research process, this original design had to be modified to respond to changing conditions in the study.

**Table 6: Experimental design of the Meningococcus study**

	Vaccines administered	
Group 1	Vaccination visit 1 (age 9 months) <b>MeninO</b> vaccine	Vaccination visit 2 (age 12 months) <b>MeninO + MMRV + PCV + HepA</b> vaccines
Group 2	Vaccination visit 1 (age 12 months) <b>MMRV + PCV + HepA</b>	

A look at both the current vaccination schedules in Chile and the US and the design decisions adopted for the Meningococcus study suggest that there is a tendency towards standardization. As Table X shows, the Chilean vaccination schedule evolved to look more and more like that of the United States. At the same time, as the diachronic look at informed consents in Chapter 3 suggests, as vaccine research became increasingly dominated by pharmaceutical companies, modes of writing and making knowledge started becoming more and more uniform across borders; a tendency towards scalability that threatened projects like VRC which derived their wealth and value from their understanding of difference and locality. The global health ideal, it seems, aims for universality and standardization, and scalability is coherent with this aim. This, however, might contradict the uneven distribution of pathogen varieties, access to vaccines and other

forms of medicine, and inequalities in terms of material conditions. I've found that attention to the differences that conflict with universality and scalability are what shape sound ethical and scientific decisions at the local level. As I discuss here, and in the next chapter, it is often attention to locality that determines what is good and ethical science and the other way around.

### **A method for tracing textured genre ecologies**

Mapping the scientific activity of the VRC from archival material requires piecing together the scattered fragments of its work's traces, reconstructing the relations among archived documents, and deducing the ways the work of researchers and staff was mediated and enacted by these documents. Many written artifacts that were once vital for the everyday life of the center would have been discarded before they could ever make their way into one of the archive boxes. A post-it where a personal memo was recorded—gone; marginalia scribbled on papers or project protocol drafts—forgotten; bullet-points jotted down during a phone call—wiped off the table at the end of the week; the notes that one nurse took during training—never even accounted for.

The method I attempt here follows previous works in writing studies that aims at offering a (visual) representation of activities as mediated by writing, such as Tim Lockridge & Dereck Van Ittersum's (2020) workflows; Clay Spinuzzi & Marck Zachry's (2000) open-system approach to representing genre ecologies; or traditional activity theory representations of the interaction between people, tools, and relationships among them (Engeström, 1999; Russell, 2002). But since mine is a trace or archival ethnography



(Geiger & Ribes, 2011) the representation I put forward offers less of an insight on the way these pieces of writing do work in the every-day life of the center. I cannot, like Spinuzzi and Zachry, sit in VRC offices and take note of the writing activities that go on in its busy daily life. Nor do I have access to these researchers' composing processes as they unfolded in order to track or document their workflows. Finally, though I draw some inspiration from activity theory, I believe the work of piecing together the center's research activity from archival documents lends itself poorly to neat classical activity theory representations.

The data that I analyze in this chapter is pulled from a type of box in VRC's archive tagged "Regulatory documents." These contain records for the development of the study: different versions of the study protocol and consent form, together with a summary of changes from one version to the next; memos to the file issued by the monitoring agency; the participant log or full list of participants enrolled in the study; a great deal of correspondence; guidelines for researchers and information on the pharmaceutical product from the sponsoring pharmaceutical company; a record of adverse events including correspondence and case-by-case documentation; among others.

Mapping the genre ecology is a critical step in making sense of these records and their function. To do this, I take the informed consent as an entry-point and follow instances where the genre is negotiated and transformed throughout the research. I follow Spinuzzi and Zachry's concept of a genre ecology understood as a framework to "account for how official and unofficial documentation genres are animated by and connected through contingency; how the documentation's functionality is consequently decentralized, distributed across the ecology; and how ecologies of genres achieve relative stability despite their contingent, decentralized nature." (Spinuzzi & Zachry, 2000, p.173). But

while these authors include only genres and their relation to each other in their mapping, I incorporate activities, actors, and moments of *junction* or *tension*. Activity theory describes these as *moments of contradiction*, when actors encounter cross-purposes (Russell, 2002), but I use the term *friction*, developed in mobility theory (Tsing, 2005; 2012; Nordquist, 2017), which more clearly conveys power asymmetries between the actors involved, and the mutual dependency between agency resistance as it traces “the ways that contact across difference can produce new agendas” (Tsing, 2012, p.510). I also include a middle axis that divides the visualization in two. A top part, symbolizing the geographical north, and bottom part, symbolizing the geographical south. Thus, lines across these spaces reflect the exchanges between actors and locations in this system. I understand this representation as a textured genre ecology that aims to capture the different kinds of elements playing a role in the movement and negotiation of texts across space (and time).

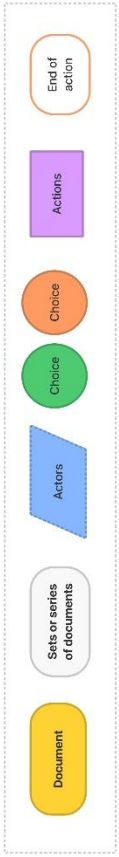
With the previous framework mind, I make my way through the archive documents, locating moments where the informed consent is mentioned, and identify the documents “around it,” either by association or direct mention, in an attempt to understand the activity that these documents mediate. I synthesize my understanding of the relationships between documents, actors, and activities in a Mobilities visualization. The chart is by no means exhaustive. It represents the elements closest to the informed consent and leaves out or simplifies others. It is “open” in the sense that some elements have been deliberately left out for the sake of clarity and simplicity and also in the sense that this system is not self-contained, but permeable to other genres, actors, and activities which are not included in this visual representation. This representation should be understood as a schematic view of

this particular knowledge system based on a very concrete set of materials, and not as a generalizable model of the knowledge system underlying vaccine science.

The construction of the visualization allows me to map-out the system as a whole and point to moments in the research process where the informed consent played a prominent role. In tracing the genre ecology, the objective was to “zoom out” in order to capture a landscape view of the system of activities involved in the research process and around the informed consent. Then, however, I “zoom in” at two different points in the network to highlight aspects of the ecology’s texture. The first, early in the research process, traces writerly agency in changes to the informed consent as it was negotiated by Chilean researchers and the pharmaceutical company. For this I use the informed consent model provided by the sponsoring pharmaceutical company and talk around text interview material from two conversations with Dr. Arce, the main author of these texts. These interviews were each between 30 to 45 minutes and I have partially transcribed passages that were relevant for this chapter. The second, from both early and late in the research process, analyzes how local (Chilean) researchers exercised and constructed agency rhetorically in their correspondence with the local ethics committee and the sponsor. In the following, I explain what came of my explorations and what I learned about VRC and transnational vaccine research in the process.

## **A textured genre ecology: how the North acts upon the South and the other way round**

As the reader may deduce from a first glance at the flow chart below, the work of tracing dynamic and textured genre ecologies is messy. As I have mentioned before, this representation is by no means exhaustive and I don't expect it to work independently from this written explanation, so in this section, I unravel some of that complexity. Due to this recursiveness, it is difficult to identify an end to this system. One could, perhaps, even understand it as having multiple endings depending on what actors you are engaging: for participants who decide to remove themselves from participation, their engagement and contribution to the forward movement of the project ends somewhere around the middle; for researchers and research staff, the process is often open, continuing even after the production of publishable research products.



**Ecology of the informed consent: a mobile system flow-chart**  
 The flow chart traces the informed consent throughout the research process, its interaction with actions, documents, and actors.

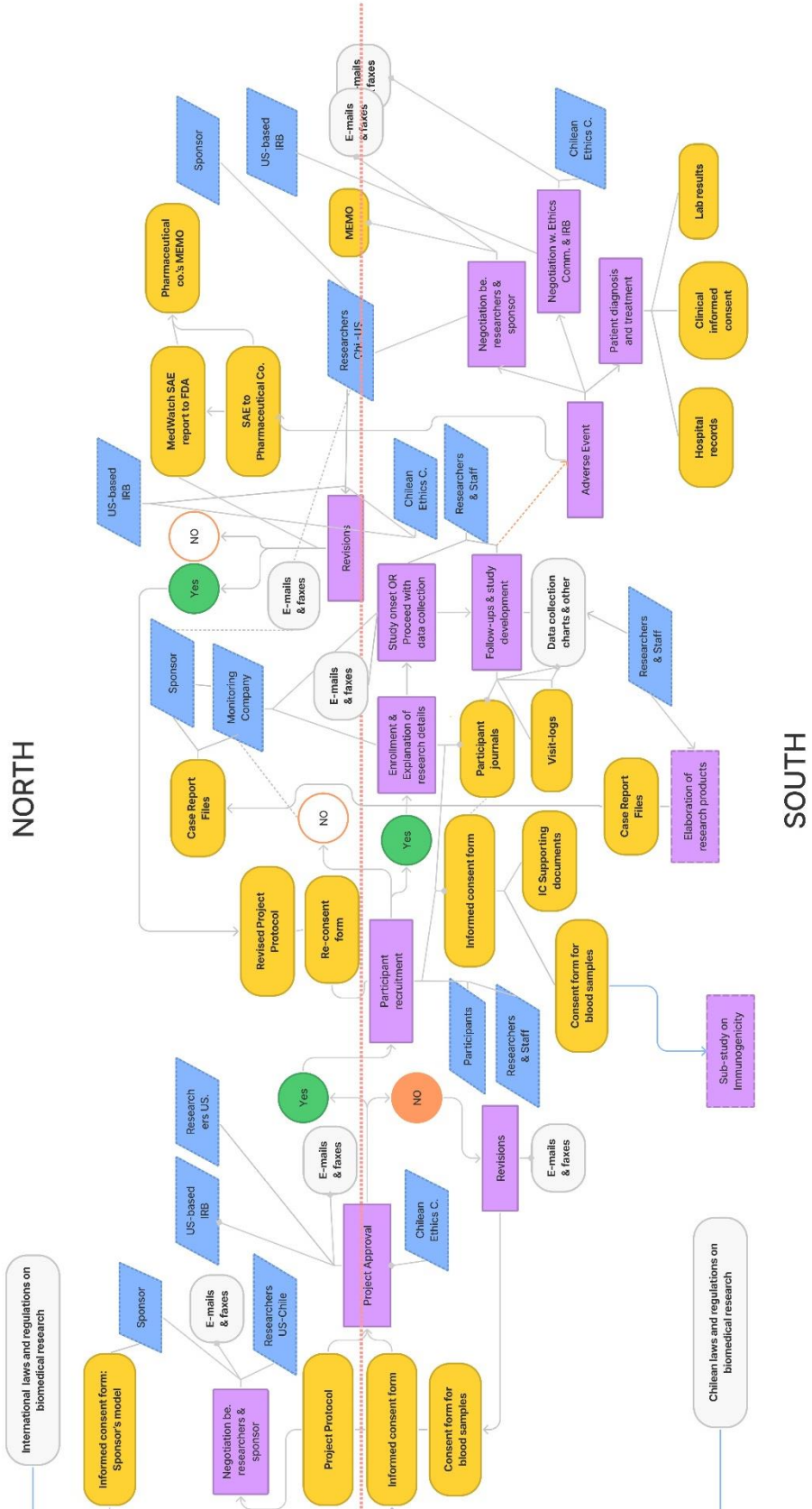


Image 4: A mobility system

A beginning, however, is easier to locate. At the left of the diagram, close to the red dotted line we find the project protocol and the consent form (in yellow boxes), associated to the project's approval by the ethics' committee (and IRB). The consent form is informed by national and international laws and regulations. While these are not part of the contents of this set of archive documents, I have decided to include them as a reminder that this is not a closed system, but one that is permeable to texts, actors, and activities whose traces cannot be found in specific documents in these archive boxes.

At this point in the research process, protocol and consent are also being negotiated and fine-tuned between researchers and the sponsoring pharmaceutical company. Indeed, the pharmaceutical company (referred throughout the diagram as the *sponsor*) provides an initial model for the consent form which is then adapted by the researchers (see first yellow box at the top left). A closer look at these documents reveals how much of the consent form is "pre-written" for researchers in the sponsor's model. And, as noted before, many of the contents are also determined by national and international regulations and guidelines which establish the required contents, type of language expected, and general structure of the informed consent<sup>18</sup>. Researchers, then, are not the only authors of this critical document. Yet, as I will show later in this chapter, they do have a clear stance on what constitutes clearer and more transparent information, and therefore, find ways to be agentive writers even in this highly distributed and constraining genres and genre systems.

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<sup>18</sup> See, for example, the WHO informed consent template for clinical studies: <https://www.who.int/ethics/review-committee/ethics-InformedConsent-clinicalstudies.doc>.

The approval process for the protocol and consent form by the local ethics committee and the US-based IRB are also documented in faxes and other correspondence, as well as in the different iterations of these documents themselves. The project may move forward, or it may be stopped; or as in this case, revisions are made which also require approval. Too much resistance from the ethics committee—too much *friction*—and the project could be brought to an end altogether. This study was, indeed, refused approval by the Chilean ethics committee on a first revision. To reflect this moment of *friction* I have included a bifurcation (Yes/No bubbles) to represent that conflict and potential sudden arrest in the project's motion.

Now, since this particular project eventually got approval, it moved to the stage of participant recruitment. At this point, the consent form and other accompanying documents are key to ensure that information is delivered to participants—or in this case, participants' tutors. Again, a bifurcation is included to show that parents may refuse to enroll their children as participants. Those who agree to participate will encounter an additional set of documents: supporting informational documents; a participant journal where parents must keep track of any symptoms or reactions their children experience after getting the vaccine; and a second journal, to record any doctor's visits. Understanding these supporting materials and how to use them are necessary elements of understanding participation, and therefore, of consenting to participate. Thus, these supporting documents and the oral explanations provided by research staff are crucial to participants' informed consent. From this point of view, the informed consent is not a document, but literate activity, distributed across and mediated by multiple documents and engaging multiple actors.

This part of the process, including recruitment, record of participant's information, and initial data gathering, involves participants and research staff, of course, but also a monitoring agency—in this case, one called MedWatch. This external agency is concerned with the quality (and veracity) of data production. It is an external company hired by the sponsor (the pharmaceutical company) to overview aspects like the recruitment process, making sure that participants on record exist in real life, that consent forms are properly signed, and that data charts are filed correctly, look careful and legitimate (in other words, that there is no made-up data). This is the kind of actor which will become more and more prominent as the industrial scale of vaccine clinical trials continues to grow. For this study, however, the monitoring company played an important but relatively narrow role.

Both participant journals and follow-up notes by research staff are kept and contribute to the production of data for the study. The production of research results for publication and for the sponsor's own information about their product can be seen as an end-point in the research (purple action box at the bottom). But no such products are found in this particular box from the archive, nor are there traces of consolidated data. If we were to locate them, these texts would still have to do a lot of traveling before constituting publishable products. There is, however, another activity associated to vaccine research that these records document in detail, and that is the finding and documentation of serious adverse events (SAE). Serious adverse events are any serious health conditions that appear after the administration of the vaccine and which require hospitalization: very high fever, seizures, or paralysis are some typical examples. The emergence of a SAE sets in motion a complex set of actions oriented to determine whether there is a causal relation between the adverse event and the vaccine, as well as the best way to proceed with the research and in



the future administration of the product. This deliberation is documented in correspondence, and decisions about the best way to handle or communicate about the vaccine product is documented in a memo issued by the pharmaceutical company. For the Meningococcus study, this also entailed the revision of the original project and the production of a form to re-consent all participants who continue in the study.

As has been explained so far, the flowchart represents three recursive processes in the development of the research: the approval of the project, participant recruitment and data collection, and the documentation and rationalization of adverse events in the research process. As seen throughout the flowchart, at every point in the process there is an exchange between processes going on in the South and actors or processes going on in the North. This exchange becomes especially intense after the emergence and reporting of an adverse event. The documentation of a vaccine-related adverse event impacts every actor in the system, from the pharmaceutical company down to local participants, and requires actions at every level: the generation of new guidelines for the use and recommendation of the vaccine product; the revision of the study's design by researchers in collaboration with the sponsor; the revision of the project protocol and the re-consent of all research participants, whose participation conditions have changed as a consequence of this new knowledge about a vaccine involved in the study.

This map of the genre ecology shows that the informed consent can be found throughout the research process, at different critical moments of the knowledge-making process, and enters in relationships with every actor in the network: researchers, research staff, and participants, ethics committees, sponsors, and monitoring companies. As an activity having to do with enacting an ethical aspect of the research, the informed consent

does work and is negotiated at different moments in the research process, from the project's approval to the engagement with participants, and late-stage revisions of the research project. As an activity that has to do with the information and enrollment of participants, it is distributed across multiple texts, reaching beyond the consent form itself to oral texts and interactions, and visual aid materials. The variety of modes and material texts involved in the consent procedure suggests that the informed consent is more than a text or document. It is an ongoing process that extends throughout the whole of the research process. This is consistent with genre theories that understand genres as forms of social action (Miller, 1984) but has even more implications to the understanding of genres as ecologies, not only typified social action, but also frames for social interaction where texts are one element mediating human relationships (Bawarshi, 2016; Devitt, Bawarshi & Reiff, 2003).

However, and despite the fact that points of potential conflict are marked by yes/no intersections, this kind of representation—as any other static representation of dynamic systems—falls short of accounting for moments of *friction*, the real dimension of texture that is bound to be found in any (genre) ecology. It is, for example, difficult to weigh actors and their level of agency in the forward or ongoing movement of the research. In a representation like this one, research participants and IRB's or ethics committees seem to have the same “weight” in determining movement. But in reality, they don't: participants may decline or refuse to participate, but they cannot stop the forward movement of the project individually, as the ethics committee could. In terms of documenting agency and power, some relationships are traced quite transparently. For example, the influence of a model document provided by the sponsor on VRC's version of the informed consent form reads quite clearly. Other relationships, however are documented in occluded genres

(Swales, 1996), such as correspondence, and their impact in the overall functioning of the system, is hidden or opaque. As I will argue later in this chapter, these power relationships and exchanges are paramount to understanding how local researchers define agency for themselves and find ways to exercise it.

At this point, it may also be worth noting that the very fact that these relationships between researchers and sponsor can be traced in a more or less uncomplicated manner — showing that agreements could be reached between these actors—is itself a sign that a full shift towards an industry-led model had not yet reached this research center in Chile (and never would). As Dr. Arce explains in our conversations, later on, it would become impossible for researchers to negotiate changes in a protocol directly with the sponsor. Instead, all exchanges would have to be discussed with a multiplicity of other actors, such as the monitoring agency and other organs involved in the collection and processing of the data, and the company’s lawyers, in addition to the pharmaceutical company’s representatives and national and international review boards. All of this requires investing a great deal of time and energy, often unfruitfully. As industry-lead research becomes scalable (Tsing, 2012) at a global level, it becomes increasingly removed both from researchers and pharmaceutical developers. As Anna Tsing (2012) explains, “modern science demands scalability, the ability to make one’s research framework apply to greater scales without budging the frame. This kind of expansion is only possible when the research framework parses stable data elements —the *nonsoels* of science” (p.522). In other words, *nonsoels* are data bits, like pixels, that can be added infinitely, without attention to context or location: without friction. For vaccine science, working with *nonsoels* means distributing standard consent forms that researchers merely apply and generating standard

data charts which researchers merely fill-in. In sum, fragmenting the research process into small data fragments (or *nonsoels*) that can be easily and quickly aggregated.

Now, in order to account for the ecology's texture, one needs to dive back into the actual documents, and search for those moments of *friction* and exercise of agency. In the Meningococcus study, I have found notable instances of such moves both through tracing changes in the informed consent itself, and in two instances of negotiation documented in correspondence. One at the very beginning of the project, the revision and approval by the local ethics committee, and one later, in the stage of revisions that were required following the emergence of serious adverse events related to one of the vaccines involved in the study (the MMRV). In the following two sections I will analyze examples of such moments of friction and exercise of agency.

### **“A sponsor you can still work with.” Re-writing as agency**

Genres, as scholars in writing studies have long understood, crystalize long traditions of knowledge making, typifying—and therefore, reproducing—discursive patterns which reflect a form of action (Bakhtin, 2014; Devitt, 2004; Miller, 1984; Russell, 1997). The question this raises for writers and readers is whether there is any space for creative or agentive engagement with disciplinary written genres (Negretti & McGrath, 2020). These questions and constraints are intensified in a research context like the one we have described here for contemporary clinical vaccine research: intensely regulated, tightly networked, distributed, and often atomized. For researchers at VRC like Dr. Arce, these questions go beyond an issue of personal voice and creativity, and they are, of course, not

conceptualized as an issue of genre. The problem of agency in scientific research is directly related to how much intellectual input the researcher has on the research study. Writerly agency, then, cannot be separated from researcher agency.

In this section, I zoom into a moment at the very beginning of the research process—the negotiation of the consent form with the sponsoring pharmaceutical company—in order to show the kinds of decisions Dr. Arce (and team of researchers) made as a writer regarding the description of the project in the informed consent form, when given space to do so. As she suggested in one of our informal conversations “This is a sponsor you could still work with,” meaning there was enough flexibility and room for negotiation. I analyze how the researcher—in this case, the primary investigator (PI), Dr. Arce—re-writes the pharmaceutical company’s model or template to better reflect the researcher team’s values and priorities in the document.

While I have not had access to the sponsor’s or their representatives’ rationale, I assume that what the pharmaceutical company was interested in was, mainly, complying with international standards and regulations. The researcher, on the other hand, is much more aware and knowledgeable of her audience and is concerned with communicating the scientific rationale driving the study to that audience. What I have found most salient about these re-writings is that the researcher’s explanations consistently provide the potential participant with deeper explanations and evidence to ground their decision about whether or not to enroll their child in the study. See, for instance Example 15 below:

Example 15	
<b>The company’s model</b>	<b>VRC’s Version 1</b>

<p>What is the purpose of this study?</p> <p>This study involves medical research. The purpose of this study is to see if giving MeninO is safe and effective (how the vaccine is tolerated by the subjects) in subjects as young as 9 months of age. We also want to see the safety of a second dose of MeninO when given at the same time as routine pediatric vaccines at 12 months of age. (p.3)</p>	<p>¿Por qué estamos haciendo este estudio?</p> <p>Como le señalamos anteriormente, MeninO está registrada para ser usada a partir de los 11 años en los Estados Unidos, y a partir de los 2 años de edad en Canadá. El propósito de este estudio es investigar si el uso de la vacuna puede extenderse a niños más pequeños. Específicamente, el objetivo de estudio es evaluar si MeninO es segura y bien tolerada cuando se administra a los 9 meses de edad. También queremos evaluar la seguridad y tolerancia de una segunda dosis de la vacuna, a los 12 meses de edad cuando se administra en forma simultánea con las vacunas contra Sarampión-Rubeola-Paperas-Varicela (RuPaVi); Hepatitis A (HepA) y contra Neumococos (Pneumoc). (p.2)</p>
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As the example shows, the sponsor’s version very quickly addresses mandatory content that doesn’t seem directly related to the heading question about the purpose of the study. This first sentence points out that this participation involves research; in other words, that it involves participating in an experimental study. Dr. Arce is hesitant about the language used by the sponsor. She expresses a double concern about the level of technicality of the language, as well as the issues that it rises for translation.

Aquí hay términos muy complejos. ¿Cómo se traduce “This study involves medical research study”? [...] Si uno lo quiere traducir literalmente, o como se dice muchas veces, estudios de investigación médica, eso en español suena redundante. Un estudio es como sinónimo de investigación. Cuando tú lo lees en inglés, siempre aparecen los dos términos “research study”, “medical research study” ... No lo sé... [...] como te digo, esas traducciones, no fluyen tan fácilmente.

*How do you translate "This study involves medical research study"? [...] If one wants to translate it literally, or as it is often said, medical research studies, this sounds redundant in Spanish. A study is synonymous with research. When you read it in English, both terms are always used "research study", "medical research study"... I don't know... [...] as I say, those translations, they don't flow so easily.*

This level of hesitation about an expression is interesting because it reveals a (perhaps unexpectedly) high degree of concern for language, and one that has to do specifically with translation. As the work of Laura Gozález, Rachel Bloom-Pojar, Griselda Perez, et al. (2018) suggests, translating an expression is a problem of communicating meaning in a way that is locally (or culturally) relevant and not simply conforming to regulatory mandates regarding the contents of an informed consent document.

The VRC's version does, indeed, communicate the idea that this project involves scientific research, but in a way that provides more context and, rather than using specific scientific terminology, describes what is new about this usage of the vaccine product. It explains that the vaccine is already used in older children and that researchers intend to find out whether this application can be "extended to younger children." For Dr. Arce, this serves a double purpose: to provide more detailed background information that she believes their public is unaware of—this is a logical appeal—and to balance the sense of risk and appease any sense of unnecessary worry—this is a concern for pathos. In her own commentary to this fragment, Dr. Arce argues:

Por ejemplo, decir "in subjects as young as 9 months of age" omite que existe harta experiencia en personas mayores... en niños mayores. Y eso puede ser un desincentivo o una preocupación para las personas que no saben. Entonces en realidad el propósito de este estudio era ampliar el registro sanitario de este producto en forma escalonada, hacia abajo, desde personas mayores, en forma

decreciente. [...] Yo creo que es importante decir que existe información y que se utiliza en niños hasta esa edad, [...] eso es más informativo y también tranquilizador.

*For example, saying "in subjects as young as 9 months of age" omits that there is a lot of experience in older people... in older children. And that may be a disincentive or a concern for people who don't know. So, in fact, the purpose of this study was to extend the sanitary registration of this product in a staggered way, downwards, from older people, in a decreasing way. [...] I think it is important to say that there is information and that it is used in children up to that age, [...] that is more informative and also reassuring.*

For the researcher, re-writing in a way that produces a more informative text also means highlighting the science and the reasoning behind it. As Example 16 shows, the reformulation here is aimed at making the purpose of the required actions clearer to participants.

#### Example 16

##### **The company's model**

##### **VRC's Version 1**

<p>At each study visit you will receive the following:</p> <ul style="list-style-type: none"> <li>• a diary card: you will be asked to measure, on the day of the study vaccination and for the next 7 days (...).</li> <li>• a memory aid: the study staff will give you a memory aid (which is similar to the diary card) and tell you how to use it. You will use the memory aid to record any bad events your child has (...). (p.4)</li> </ul>	<p>¿Cómo se evaluará la tolerancia y seguridad de las vacunas?</p> <p>Todos los participantes deberán permanecer en el vacunatorio durante 30 minutos (...).</p> <p>Le pediremos controlar y mantener un registro diario de la temperatura, las molestias locales (...). Para ello, después de la vacunación la enfermera le proporcionará una tarjeta, un termómetro y una regla (...).</p> <p>Le entregaremos una segunda tarjeta, para que usted anote visitas médicas, problemas de salud (...). (p.3)</p>
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Even the differences in the formatting of these passages is telling. While the sponsor's version lists a number of elements that will be given to participants, VRC's version frames these contents under a question about how the tolerance and safety of the vaccine will be assessed: that is, the larger purpose these actions have in the study and the role participants play in it.

Esto que dice aquí: "at each study visit..." Pero no dice para qué. Lo que me importa es que volvamos al objetivo. Es secundario que le vamos a dar un termómetro, una tarjetita y un lápiz. Lo que importa es que ellos, los voluntarios, sus papás, que se yo, van a ayudar a cumplir el objetivo y para eso tienen que comprometerse. Si no están dispuestos, no tienen tiempo, qué sé yo... no firme.

*What it says here: "at each study visit..." But it doesn't say what for. What matters to me is that we get back to the objective. It is secondary that we are going to give them a thermometer, a little card and a pencil. What matters is that they, the volunteers, their parents, what do I know, are going to help meet the objective and for that they have to be committed. If they are not willing, don't have time, what do I know... don't sign.*

It is also interesting that, while the sponsor's model highlights materials, VRC's version highlights participants and participation. The direct relationship between researchers or research staff and participants also makes actors more transparent and language more concrete and approachable. For example, "We will ask you" (Le pediremos) replaces "you will be asked to", which erases researchers or staff from the action. Dr. Arce's commentary on the passage also reflects a deeper sense of the contribution of participants to the study: "*the volunteers, their parents [...] are going to help meet the objective*" and, therefore, the researchers need them to understand its conditions and make an informed commitment to participate. This shows that the researcher cares for the participant's agency as well.

This last point is in line with other edits made by the researcher with the aim of making scientific reasoning more transparent to participants. Example 17 shows an explanation given within the section discussing risks in the informed consent (also a mandated content), where the specific risk of a serious neurological illness is discussed (Guillain Barré Syndrome or GBS). In addressing this delicate topic, the sponsor falls into apparent contradictions and produces a text that is redundant and lacking in coherence and clarity. Note, for instance, how the fragment reiterates in three different ways that the causal association between MeninO and GBS cannot be established: *(1) this does not mean that the vaccine caused GBS. (2) It is not known if the vaccine caused GBS. (3) The cause of GBS in these vaccine recipients has not been identified.* VRC’s version is slightly longer but avoids such contradictions. By providing additional background information, the reasoning behind the notion of an increased risk or association between the MeninO vaccine and an increased risk of GBS becomes clear.

Example 17	
The company’s model	VRC’s Version 1
Although there is an increased risk of getting GBS following MeninO vaccination, this does not mean that the vaccine caused GBS. It is not known if the vaccine caused GBS. The cause of GBS in these vaccine recipients has not been identified. The evaluation of these reports suggests a potential for an increased risk of GBS following MeninO vaccination. (p.5)	La vacuna MeninO salió al mercado en Marzo de 2005. Entre esa fecha y Septiembre de 2006 se aplicaron más de 6 millones de dosis de esta vacuna. Durante este período, el sistema de vigilancia de vacunas de los Estados Unidos fue notificado de 17 casos de una enfermedad neurológica rara conocida como Síndrome de Guillain-Barré (SGB), que se presentaron entre 2 y 23 días después de la administración de la vacuna. La evaluación de estos datos sugiere la posibilidad de un

	aumento en el riesgo de SGB después de la vacunación con MeninO. (p.4)
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I find it noteworthy that the researcher here decides to disclose information— “hard facts”, as Dr. Arce calls them—and presents to the audience the complete deductive logical chain, which looks something like this:

Premise 1: More than 6 million doses of the vaccine have been administered in 1 ½ years after its release to the market.

Premise 2: 17 cases of GBS were reported shortly after these vaccinations.

Conclusion: There is likely something in the vaccine that increases the risk of GBS

She shares these “hard facts” because she feels they contribute to clarity and informativity.

In her own words:

Encuentro que eso [points to the sponsor’s model] es mucho más enredoso. Es absolutamente teórico. O sea, no hay ningún dato duro. Dice, bueno, afirma que existe un aumento de riesgo de Gillain Barré después de la administración de MeninO. No habla de cuánto es ese riesgo, para empezar. Y luego dice, algo que es bien confuso: “Esto no significa que la vacuna *cause*...”

*I find that [points to the sponsor's model] much more convoluted. It is absolutely theoretical. I mean, there is no hard data. It says, well, it claims that there is an increased risk of Gillain Barré after MeninO administration. It doesn't talk about how much that risk is, for one thing. And then he says, something that is quite confusing: "This does not mean that the vaccine causes..."*

The decision to share this complex information suggests, to me, that she judges potential participants to be just as capable of this logical reasoning as herself and the VRC team. To my question about why the sponsor’s model looks so different from the one they produced, she answered “I think those who produce the model are far more distant from the target audience than we are.” This is, of course, a commentary on the team’s understanding of

local audiences and conditions. But it is also a commentary that speaks of identification. VRC researchers write for an audience that they understand and care for because they are like themselves in so many ways. They share the same hospital and neighborhood; like VRC's researchers and staff, most participants' primary caretakers are women—mothers and their children often visit the same doctors. This kind of care that stems from locality and identification emerged when local researchers were given enough flexibility to be agentive writers of critical texts in the research process such as the informed consent. This understanding of locality goes beyond the rigorous compliance to regulations and mandates. It answers the question, “Would I understand and agree with the contents of this consent form?” and “Would I enroll my own child in this study?” While I wouldn't go so far as to make a comment on the quality of the science this kind of work produces, I find it difficult to believe this is not necessarily more ethical work (and isn't more ethical science also better science?).

### **Friction and agency: making a case for local knowledge-making logics**

Representations of the scientific research cycle often depict it as a logical set of steps or stages, smoothly transitioning into each other. This is coherent with the notion—which is also science's notion of itself—that science is universal, unchallenged by power or politics, true regardless of its location. As Alan Gross discusses in his work, science imagines a *universal* audience, “it is the audience that scientists must see themselves as addressing when they write or speak. It is by means of this universal audience that the natural sciences come within the sphere of rhetoric” (2006, p.56). An ecological description

of North-South collaborations such as this one suggests otherwise. In the process of making knowledge, actors' interests prove to be in conflict with each other. They must negotiate power, rhetorically assert their agency and authority, and create space for themselves. Analyzing the way these negotiations unfold in the Meningococcus study's archive reveals something about the power dynamics in North-South collaborations for the VRC center at this moment in history, about the models of knowledge-making that were becoming dominant at the time, and about the pushback against these models from local scientists. This case suggests that ethical considerations are locally situated; they cannot be scaled or reproduced unchanged across borders but require an understanding and orientation to locality.

The passage in Example 18 is extracted from a response letter from VRC director to the Chilean ethics committee (Comité Ético Científico SSMO). The general purpose of the letter was to counter the ethics committee's rejection of the study on the basis of a flaw in methodology and concerns about how these methodological decisions proportionally overburdened Chilean participants in comparison with US participants. The number of participants per location, suggested the reviewer, should be proportional to the total population of each location; therefore, there should be many more American than Chilean participants. To this, the primary investigator (PI) replies:

**“This investigator is not aware of any multi-center clinical study in which a prorated sample system has been used as suggested by the reviewer. Typically, these types of studies apply a competitive enrollment strategy where each center contributes a number of participants according to its capacity to enroll within a set period of time. This strategy favors the interests of the sponsor (...), but is detrimental to the possibility that centers with lower recruitment capacity can generate representative information on the behavior of the product in their own population.**

**It is [*this center's*] policy to participate only in clinical studies that can provide potentially useful knowledge [*at the local level*].”**

**Example 18:** Response letter from VRC’s director to the Comité Ético Científico SSMO in Chile (August 17, 2007)

What stands out first in this fragment is how the PI relies on her own authority and knowledge to ground her argument. In 2007, when Dr. Arce wrote this response letter, VRC had been doing research in Chile for 29 years, and she had been in this position for 14 years. Compared to the center, the Chilean ethics committee—officially created in 2001 (Sotomayor Saavedra, 2008)—was a relatively young institution with a shorter trajectory and less experience in research than VRC as an institution. Dr. Arce also had a long research relationship with the founding center in the US, which in turn was a vaccine research center with more than 30 years of experience and working by strict international ethical standards. It seems then that relationships with institutions in the North gave VRC researchers authority and leverage through their connection to transnational networks; they have “leveled up” (Rodriguez-Medina & Vessuri, 2021) in terms of knowledge and authority—*academic capital*. Hence, the claim “This investigator is not aware of any multi-center clinical study in which a prorated sample system [*like the one suggested*] by the reviewer [*is used*]” is not an admittance of ignorance, but a sideways attestation to the reviewer’s limited understanding of methodologies in the field.

What follows is an explanation of the recruitment strategy currently used in multi-centric vaccine studies, and then an acknowledgement of the potentially problematic aspects to this recruitment strategy. However, in her response, Dr. Arce reformulates the terms in which this objection is posed. As I show in Example 19 below, the reviewer’s critique questioned the scientific validity of this methodological decision:

The sample is divided into a ratio of individuals of 2.5 (1300 North American children and 520 Chilean children) while the ratio of populations between the two countries is 18.5 (296,000,000 North American inhabitants versus 16,000,000 Chilean inhabitants). An equitable sample and selection of subjects requires that science, not factors unrelated to the research, dictate who and how many to include as potential subjects.<sup>19</sup>

**Example 19:** Rejection letter from the Comité Ético Científico SSMO in Chile to VRC's director (August 8, 2007)

In her response, Dr. Arce not only dismisses the point about scientific validity but offers nuance and complicates the ethics committee's understanding of the recruitment strategies currently utilized in vaccine research. The researcher seems to suggest that the issue is not so much science, as it is power. As she acknowledges, "This strategy favors the interests of the sponsor [...] but is detrimental to the possibility that centers with lower recruitment capacity can generate representative information on the behavior of the product in their own population." Here, she implies that the recruitment strategy in discussion is promoted by pharmaceutical companies, who can benefit from collecting relatively small samples quickly and at many different locations. This method, however, does very little for research centers such as VRC, who are interested in producing knowledge themselves. If a sample size is too small, they are unable to make observations and draw conclusions of their own. Because VRC researchers are aware of this imbalance, they have as an internal policy to only engage in research that is indeed, "relevant to the community of origin of the potential participants" (Response letter, August 17, 2007). The issue is one of power because it relates to who gets to produce and analyze data, report research results, and

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<sup>19</sup> La muestra se divide en una razón de individuos de 2,5 (1300 niños norteamericanos y 520 niños chilenos) en circunstancias que la razón de poblaciones entre ambos países es de 18,5 (296.000.000 habitantes norteamericanos versus 16.000.000 habitantes chilenos). Una muestra y selección equitativa de sujetos requiere que sea la ciencia y no factores no relacionados con la investigación, la que dicte a quién y cuántos incluir como probable sujeto.

claim knowledge. But this is also an ethical concern about the local community. If local researchers are unable to produce data on the behavior of the vaccine in the local population, it becomes more difficult or impossible to design public health policy and interventions based on such data.

Later in the development of this study, there were several serious adverse event reports both in Chile and the US, some of which were found to be likely related to one of the vaccines involved in the study: the MMRV. The SAE in this case were described as an increased risk of suffering high fevers and febrile seizures after the administration of the vaccine. As explained before, the emergence of vaccine related SAE triggered a response in the whole network: the redesign of the study's protocol to remove MMRV vaccine from the vaccination scheme; the need to re consent all participants; and, of course, the negotiation around these conditions for the continuation of the study. Here, the pharmaceutical company's interest to move forward with the study with the higher number of possible participants comes up against the local researcher's interest protecting local participants from unnecessary risks, especially when the possibility to gather significative data at the local level has disappeared. At this point, many of the participants' parents had declined to keep their children enrolled in the study due to the increased risk it seemed to pose. The following excerpt corresponds to a response letter from Dr. Arce to the sponsor's representative, explaining her views on the best way to move forward with the study.

**Although we recently received approval from the ISP<sup>20</sup>, I personally maintain the opinion that I conveyed to you yesterday, in that we have no scientific reason to justify administering the second dose of MeninO to the participants who have not yet been discontinued from the study. Indeed, by rescuing all the children**

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<sup>20</sup> ISP stands for *Instituto de Salud Pública*, which translates as Public Health Institute.



who have not yet reached 13 months of age we could complete the study in a maximum of 30 participants (less than 10% of the original sample) which is obviously insufficient to leave any valid knowledge on the behavior of the vaccine in the local population. **Since the intervention has lost scientific rationality, the ethical underpinning of the intervention is also questionable.**<sup>21</sup>

**Example 20:** Correspondence between the researcher and the sponsor

As opposed to the exchange with the Chilean ethics committee, in this case, the researcher appeals to the scientific rationality of this decision, rather than her own knowledge or authority. She argues that, since the sample size has been reduced so considerably, there is no reason to expose the remaining participants to a second dose of the experimental vaccine (MeninO). The researcher then makes a direct connection between the scientific rationality and the ethics of the study. This is a decision made with the local and not the global context in mind. Indeed, it is likely that the pharmaceutical company could have used this data from Chile, aggregating it with data collected at other centers to obtain significant results. Yet for Chilean scientists, this solution no longer sticks to the fundamental criterion to perform research that is locally relevant. There is, then, something non-scalable (Tsing, 2012) about ethical decision-making for these researchers.

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<sup>21</sup> Pese a que hace poco rato recibimos la aprobación del ISP, personalmente mantengo la opinión que le transmití ayer, en cuanto a no tenemos una razón científica que justifique administrar la segunda dosis de Menactra a los participantes que aún no han sido discontinuados del estudio. En efecto, rescatando todos los niños que aún no han cumplido los 13 meses podríamos completar el estudio en un máximo de 30 participantes (menos del 10% de la muestra original) lo cual es obviamente insuficiente para dejar algún conocimiento válido sobre el comportamiento de la vacuna en la población local. Puesto que la intervención ha perdido racionalidad científica, el sustento ético de la misma también es cuestionable.

## Final thoughts: the industrialization of vaccine research

Dr. Arce: El modelo que se impuso es competitivo, en el fondo, mientras más [investigadores] hay, más rápido se hace el estudio. [...] Y los pagos no son en función de etapas de avance, en función de la meta comprometida, sino que *por sujeto*, y más que por sujeto, *por procedimiento por sujeto*. [...] Para cada una de [las] actividades propias del estudio el espónsor fija una tarifa, y en función de eso, retribuye a los investigadores. Ese sistema, no se adapta al modelo de funcionamiento y de organización de [VRC]. Porque nosotros, la fortaleza que teníamos era un equipo central de gente altamente capacitada, capaz de capacitar a otros si es que había que agrandarse rápidamente, pero ese equipo estable y altamente capacitado tiene que tener sueldo fijo. No le sirve por gotera. [...] yo siempre tuve conflicto con este pago por ... de hecho, nuestro personal en [VRC] recibían el mismo sueldo, un sueldo, digamos de mercado, sin turno, con bastantes garantías de ambiente laboral, flexibilidad, etc. Pero no por reclutar más gente iban a tener más sueldo, o menos sueldo. Asumiendo que todos iban a hacer su pega profesionalmente, éticamente y responsablemente. Hay, está llena la literatura, y en América Latina también, de cómo funciona a la inversa. O sea, un incentivo del rendimiento, y del pago por rendimiento, por reclutamiento puede ser bien perverso. Entonces, el consentimiento, la prolijidad, bajan los estándares de ética...

*Dr. Arce: The model that was imposed is competitive, basically, the more [researchers] there are, the faster the study is done. [...] And the payments are not based on progress stages according to the committed goal, but rather, per subject, and more than per subject, per procedure per subject. [...] For each of [the] activities involved in the study, the sponsor sets a fee and, based on that, pays the researchers. This system is not adapted to the operating and organizational model of [VRC]. Because the strength we had was a core team of highly qualified people, capable of training others if it was necessary to expand quickly, but this stable and highly qualified team must have a fixed salary. It's no good by droplets. [...] I always had a conflict with this payment for ... in fact, our staff at [VRC] received the same salary, a salary, let's say market salary, without shifts, with enough guarantees of work environment, flexibility, etc. But not because they recruited more people, they were going to get more pay, or less pay. Assuming that everyone would do their job professionally, ethically and responsibly. There is, there is plenty of literature, and in Latin America as well, about how it works the other way around. In other words, a performance incentive, and pay for performance, for recruitment, can be very perverse. So, the consent, the care for the ethical standards is lowered...*

From interview# 1 with Dr. Arce (Jan. 18, 2022).

In the interview fragment above, Dr. Arce describes, in part, what a shift towards a fully industrialized model of vaccine research would have looked like for VRC, with increasingly standardized and atomized processes. As she explains at a different moment during this interview, in a fully industrialized model, collaborations would no longer happen directly between the researcher and a sponsor, but rather, with a network of companies and agencies: monitoring agencies, data management companies, data quality overview bodies. Researchers would collect bits of data, as quickly as possible, complete certain procedures, and get paid for each product; i.e., a signed consent form, a vaccine dose administered, a follow-up form filled. The creation of this knowledge *nonsoels*, as Anna Tsing (2012) calls these identical bits of aggregable data, reduces the role of researchers to that of mere managers of standard procedures and protocols.

As Dr. Arce explains, over the course of the last couple of VRC's years working with big pharmaceutical companies, they would often experience the frustration of having to work with a data management company's generic data base format. These were not designed to fit the exact needs of this or any particular study—they were not “tailor-made” or functional for the purposes of the study. The process of using these generic forms entailed making multiple adjustments along the way, which also never fit the study perfectly, and were made with little to no input from researchers themselves. This new research model was designed for the medical practitioner. A physician, in their private practice, would enroll a small number of their own patients in a clinical trial. They would invest very little of their time in research: they would merely get consents signed, fill in a couple data charts with any positive or negative responses to the product, and thus earn a

bit of extra cash on the side per completed procedure. The change, while it benefitted the multicentric model, allowing the fast collection of data from multiple locations and from different kinds of populations and contexts, made the negotiations VRC was used to burdensome and unnecessarily convoluted and, eventually, made their own research model economically unsustainable.

Throughout this chapter, I have shown how knowledge was produced at VRC during a transition period, before this shift towards a scaled, industrial model became the norm everywhere and made VRC's work unsustainable. We see the emergence of monitoring companies, but they still played a relatively minor role in the study. The process of conducting the research was, as the mobility system visualization shows, highly networked and distributed, yet researchers still had an important degree of agency and intellectual input in the study—as shown in the amount of flexibility the researcher had in re-writing the template informed consent form provided by the sponsor. Important negotiations would still take place with the sponsoring pharmaceutical company and these had a significant impact on the direction of the research. More importantly, researchers at VRC were able to set their own standards for good and ethical research, and produce locally relevant knowledge.

Zooming in at this moment in VRC's research history gives us a glimpse into what is lost with the dominance of an industrial model of research. The history of VRC is, in a way, a history of the ruins *progress and scalability have left on its wake* (Tsing, 2012, p.23). As I talked through this with Dr. Arce, she refused to frame these changes in terms of loss or decline. Perhaps loyal to the idea of scientific progress, she understands—at least outwardly—these changes as a means for the fruits of applied science to reach more people

faster, and in a cost-effective manner. I, on the other hand, feel less of a commitment to this idea of progress and feel nostalgia unabashedly for a time when it was possible to do late-stage clinical research with careful attention to locality from a semi-periphery like Chile. In the Meningococcus study, for example, agentively re-writing and contesting sponsor's guidelines and decisions in the research process also produced a sharper attention to participants' agency and safety. In turn, the kind of knowledge produced by VRC was relevant both for global science and the local context, it provided empirical data on which to ground public policy decision-making and fostered local networks of scientific literacy.

Finally, I would like to point to what I understand as the main limitation of mobility system representations like the one I explore in this chapter. Namely, that while these can be productive in terms of revealing the complexity of the networked entanglements, they always fail to capture the “texture” of these relationships. When it comes to accounting for power asymmetries and friction, they remain frustratingly flat. Further, this kind of representation becomes progressively flat as knowledge production systems become increasingly distributed. This is because the larger the number of actors, objects, and activities that need to be accounted for in the system, the harder it is to introduce any kind of order or hierarchy that can visually account for difference. Meanwhile, in the lived experience of these relationships, power relationships become starker, impossible even to contest, as dominant actors (like big pharmaceutical industries) reduce less powerful actors (like semi-periphery researchers) to friction-less *nonsoels* (Tsing, 2012)—replaceable, context-less pieces of data—or simply push them “off the map”. Indeed, VRC's model of science-making eventually gave in to the advancement of large industry-led research. The center has stopped conducting clinical trials for some years now and will soon close its

doors for good. As I have mentioned in previous chapters, the archive documents I work with throughout this project, will likely be disposed of in a few years' time, when VRC's legal obligations to preserve these records expire. So, where does scientific knowledge production happen now in a semi-periphery like Chile? With the advancement of the industrial system, what has been lost and who feels the loss of sites of productive friction like VRC? In the next chapter, I explore some of these questions through interviews with VRC researchers and key international collaborators.

## Chapter 5

### “With local eyes” Defining the Local in Transnational Scientific Research

#### Foreign eyes and local of entanglements

Scientific exchanges between the Global North and South—the geopolitical centers of scientific knowledge production and the peripheries—have been described as asymmetrical, extractive, or colonizing (Canagarajah, 2002; Hwang, 2008; Piller, Zhang, Li, 2022). Within writing studies, and adjacent fields like applied linguistics and academic literacies, scholars have researched and pointed out the challenges academics face when trying to make relevant contributions (and succeed professionally) in a global landscape dominated by English medium communication (Beigel, 2014). I believe VRC’s case tells a slightly different story, where personal ties and serendipitous allyships created the opportunity for genuine collaboration between researchers, albeit in an uneven global landscape, shaped by uneven forces, and heir to imperial traditions of occupation, intervention, and epistemic colonization (Pratt, 2008). In this sense, I understand the case of VRC illustrating the effects and operation of *friction*. A place where North encountered South enabling the movement of people and knowledge, while at the same time, furthering the entanglement of forces that sustain geopolitical power asymmetries. Indeed, these exchanges and mobilities were often facilitated by such asymmetries or fraught socio-

historical conditions, and in some other ways, they reinforced the existing power

(im)balances between North and South. As Ana Tsing explains:

Friction is required to keep global power in motion. It shows us (as one advertising jingle put it) where the rubber meets the road. Roads are a good image for conceptualizing how friction works: roads create pathways that make motion easier and more efficient, but in doing so they limit where we go. The ease of travel they facilitate is also a structure of confinement. Friction inflects historical trajectories, enabling, excluding, and particularizing. (2005, p. 6)

For scientists at VRC, working with researchers from the US, and becoming part of a scientific network sponsored by this country opened pathways by which to participate and contribute to biomedical research at a global scale: it gave them access to resources, economic, technical, and epistemic, and it increased their visibility and prestige internationally. In turn, the work conducted by scientists at VRC made tremendous contributions to the Chilean public health system. It was in great part thanks to the work of VRC researchers that Chile developed one of the most robust immunizations programs of the region, and a most efficient vaccine distribution infrastructure, comparable even to that of high-income countries (Aguilera, Mundt, Araos et al., 2021; Castillo, Dintrans & Maddaleno, 2021). In short, VRC benefited from its collaboration with researchers from a more powerful, richer, and more prestigious partner from the Global North.

At the same time, as I explain later, these collaborations contributed, though tangentially, to strengthening the US's global reach and military power. And, in their beginning, they benefited from the existence of a dictatorship in the country (a US-sponsored dictatorship, nonetheless). The regime facilitated US researchers' work in the country: it gave them privileged access to public infrastructure, allowed them to work with little to no bureaucratic hurdles and was funded mainly by the US military without raising any eyebrows. As Dr. Friend recalls: "Now when this started, remember, there was a



military government in Chile, and so there was no compunction on either side to do this together.” (Interview with Dr. Friend conducted May 5, 2023).

Throughout this work, I have also written about VRC as a *locality*. A place emmeshed in the global landscape, from where local scientists sometimes borrow and participate in, sometimes oppose and resist globalizing forces. Here, I draw from the notion of locality as Alastair Pennycook understands it:

To the extent that I am trying to maintain a sense of the local and locality here, and that at some level this will need to be related to place, I also want to divest the local of notions of fixity and tradition. Following Massey (1994), I see space and place as intertwined rather than juxtaposed” (Pennycook, 2010, p. 80).

Pennycook is interested in the ways local language practices make up world language phenomena, while at the same time, being shaped by their being in the world, subject to global movements pushing on localities. Similarly, I am interested in how locality as a concept emerges in the context of this study to speak of this tension between place, space, localization, and globalization. In other words, I am interested in *localities* as places of friction, where the *local* is constructed both by place or fixity and entanglement with global flows.

In this chapter, I work with interview material from conversations with my mother; a key collaborator from the United States, Dr. Friend; and Mónica, one of VRC’s former nurses to tell a story about VRC’s collaborations, especially its early days and its undoing in the contemporary era of industrial research by contract. Through this story, I delve into questions like, what do we mean by *locality* in the context of biomedical research? If the value of scientific knowledge is universal, and indeed, if researchers aspire to produce knowledge that is universal—valid everywhere and anywhere across the globe—what value

do local perspectives add to scientific collaborations? With the advancement of the industrial system in vaccine research, what has been lost for knowledge production centers in the peripheries and for global scientific knowledge as a product of these *localities*? In other words, who feels the loss of sites of friction like VRC? *Locality* as a concept also offers an interesting way to re-visit the traditional rhetorical notion of *propriety*, which in the context of scientific communication as studied here, has implications beyond political correctness in the meaning-making and rigor of science. I argue that local language practice and local knowledge is not simply an alternative to “Western” ways of knowing, but a necessary element of productive and ethical transnational work.

### **Open roads and foul waters**

As I mentioned in the introduction to this work, when the collaborations between scientists from Chile and the US that originated VRC began, Chilean health authorities were concerned about an ongoing typhoid epidemic in the country and sought international help to find a solution to the crisis:

in 1973 as a PAHO consultant I went to a number of countries in South America looking for a site to set up a unit to study bacterial enteric infections, and to do field trials of vaccines to prevent those infections. I went to many places. I did not go to Chile.

But in 1978, PAHO contacted me and asked me if I would be willing to go to Santiago Chile as a consultant at the behest of the Ministry of Health and of PAHO to look at the problem of persistent endemic typhoid that was perplexing from its epidemiologic reason for being persistent. (Interview with Dr. Friend conducted December 8, 2022)

At his arrival in Santiago, Dr. Friend found the Chilean Health Minister had gone to Geneva, so he was not greeted or officially onboarded (at least not right away). Instead, he

found open roads and doors, resources available, and a city waiting to be explored: “He [the Minister of Health] left a note that said: ‘Everyone in my department and all the resources are at your disposal. Do what you have to do.’” Indeed, he describes his first day in Santiago as one where the city was particularly devoid of human presence and open to exploration. While the narrative takes off with him settling-in at a hotel downtown, he soon takes us to the peripheries, where we can imagine the cityscape giving way to nature.

I arrived November 1<sup>st</sup> and stayed in a hotel downtown, to go to the Ministry. Nobody told me that November 1 is a holiday, a religious holiday, and everything is shut down. I showed up at the Ministry, very formal, wearing a suit... and the place was closed. So, I went back to the hotel, I changed into jeans, and I hopped on a bus, went out to the end of the bus line, and started hiking. It was a beautiful spring day. Gorgeous! Already I fell in love with Santiago de Chile in those days. (Interview with Dr. Friend conducted December 8, 2022)

I make a note of these reflections because they highlight one interesting aspect of these research collaborations in their beginning: they seemed extremely easy, one might say, *frictionless*. This ease, however, was possible due to several conditions that speak of the very precarious balances of an uneven world. Dr. Friend first came to Chile in the context of the country seeking international aid, during a dictatorship, and a moment of both economic boom and the appearance of social tranquility fostered by political repression (Dietz, 2016). Hence, relationships with the local authorities were notably simple, in part, because during the dictatorship, state bureaucracy was reduced to a minimum. Pathways into the country’s public health system, its resources, and buildings, were cleared and smooth for US researchers to travel.

As a matter of fact, at the Chilean Ministry of Health, there was a team dedicated to investigating and designing a solution to the typhoid problem: the Chilean Typhoid Committee. Under Friend’s direction, they created the Typhoid Fever Control Program,

located right inside the Ministry of Health's building, close to the Minister's and Subsecretary of Health's offices. As he points out, this was a privileged and quite strategic location, that made work easier and more productive in many different ways:

“...so convenient for us, so good! Where we passed people on the stairway and on the elevator and at the drop of a hat pretty much, we could get to see the *Subsecretario* of Health (whoever it was) at the end of the day for 5 minutes. You know, you can't find that in any paper. But that made the Typhoid Fever Control Program extremely productive.” (Interview with Dr. Friend conducted December 8, 2022)

But, as I hope I've shown here, research doesn't move forward simply for the sake of knowledge and the love of science. Indeed, while Dr. Friend was in Chile at the Ministry of Health's and PAHO's request, most of the funding for the typhoid research in Chile came from the US Army, which means the US military had—not entirely scientific—interests invested in this research venture. For Dr. Friend, contact with Chile posed an opportunity to solve a fascinating epidemiologic enigma. Here was a field epidemiologist specialized in enteric diseases, who had recently founded a center with the purpose of studying these kinds of infections, faced with the rare case of a country with a relatively modern infrastructure and widely available potable water, that just couldn't get rid of its problematic endemic typhoid. For him, this case was puzzling and fascinating:

...we did environmental studies trying to understand how you could have typhoid when 96% of the population has potable water. [...] It contradicted what had worked in Europe and North America... (Interview with Dr. Friend conducted December 8, 2022)

How do we explain this? It doesn't make sense?! This is like the exception! Everybody's got good water...” We couldn't quite figure it out. (Interview with Dr. Friend conducted May 5, 2023)

For the US military, however, this was an investment in the solution of a longstanding problem: the relationship between typhoid fever and war. As it turns out,

enteric diseases like typhoid were not only a problem in South America, but in many lower-income countries without modern sewage and sewage water treatment, where the US had military interests. It is also a recurring problem in war conditions, where soldiers don't always have access to amenities like a functioning sewage system or potable water. As Dr. Friend explains:

Typhoid historically has been very important to all militaries across the world. In 1898, there was the Spanish-American war, and that took place mainly in Cuba. [...] in camps, as they prepared to send troops to Cuba, more soldiers died of typhoid—way, way, way, more soldiers died of typhoid—than died of anything in the Spanish American war. (Interview with Dr. Friend conducted May 5, 2023)

In the 1940's, effective treatment was discovered and mortality due to typhoid had dropped considerably. But the US military continued to invest in research on enteric diseases like typhoid, specifically, on the discovery of a good typhoid vaccine. Because, of course, for countries at war, treating ill soldiers is not the main goal. Hence, by the late 70's when Dr. Friend was in need for funding, the US military was very willing to support the Chilean Typhoid Control Program, which included clinical trials for a new typhoid vaccine.

According to Dr. Friend, the clinical trials alone (which were big) began to produce a drop in cases among Chilean children (the population most affected by the typhoid epidemic) in different areas of the metropolitan region:

We had vaccinated so many of these school aged kids, that modelling showed that typhoid was really coming down and was quite convincing: the data showed efficacy and it showed long-term efficacy. (Interview with Dr. Friend conducted December 8, 2022)

However, for a city, the ideal priorities on strategies for typhoid control look different from those of the military camp. For the latter, vaccines that prevent disease are a great fix. For the former, a working sewage system, widely available potable water, water treatment, and

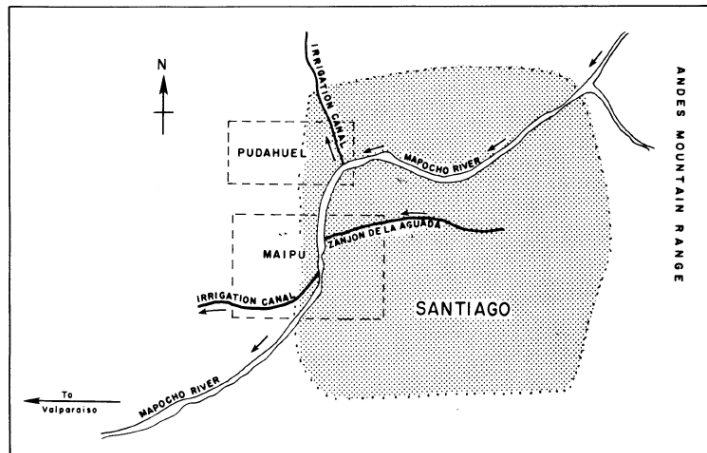
general sanitation are more important to prevent typhoid and other enteric infections. And in Santiago, by the late 1980's the main cause of the typhoid epidemic remained unaddressed. This, despite the fact that the Typhoid Control Program lead by Dr. Friend did indeed succeed in describing the cause, in part thanks to the funding received from the US army, and in part due to chance. Indeed, a critical breakthrough happened one day, as Friend and his research fellow at the time were walking down the street and decided to go into a local market to get some fruit:

It was this big market in Providencia. And in that market, you would go from little stall to stall. There were these beautiful fruits! Magnificent fruits! And we were walking along, we were literally buying fruit to take back to the apartment. We come to this one guy, who was selling strawberries. And his strawberries were several times the price of anybody else, and I asked him: "Why are your strawberries so special?" And he reaches down under the counter where the boxes of fruit are and he takes this big sign [...] and it says: "Regadas con agua potable". His strawberries were irrigated with potable water. Was it true? I don't know. But for some people that went to the market this was important. [...] After hearing that we went back to the Ministry and asked to see the maps that show the collection of sewage water and what happens to it. (Interview with Dr. Friend conducted May 5, 2023)

Following the lead of this information stumbled upon by chance, the Typhoid Fever Control Program did further research. The environmental study that followed was conducted and published five years later under the title "The Use of Moore Swabs for Isolation of Salmonella typhi from Irrigation Water in Santiago". The fragment bellow, together with the illustration, are taken from that article, and describe the main cause of the typhoid epidemic:

The two major waterways in Santiago that carry wastewater are the Mapocho River in the north and Zanjón de la Aguada canal in the south (figure 1). Untreated sewage flows directly into these waters, which are used for irrigation in the agricultural districts of Maipú and Pudahuel (on the perimeter of the city). (Sears, Ferreccio, Levine, et al., 1984, p.640)

**Figure 1.** Irrigation system of Santiago, Chile and surrounding farmlands.



**Image 5: Diagram of Santiago's irrigation system**

Here was the solution to the typhoid enigma. The farms that supplied widely consumed ground-level vegetables to the city—like lettuce, cabbage, and celery—were being irrigated with black waters from the city.

80% of the households had a flush toilet that went somewhere, through a *cloaca*. It went into the *alcantarillado*—you know, the sewage system. But there was no treatment of sewage. So that sewage ended up in the *Zanjón de la Aguada* and it went out to the west of the city without any treatment. [...] If you visited the *Zanjón* at 8 in the morning or 7 in the morning in *Área Sur*, when you were several blocks away, it... well... you could smell! It's like you were in a latrine! And if you followed the smell you would come to the *Zanjón*. This giant open sewer! I followed where that went, and it was used as irrigation in the summer months... (Interview with Dr. Friend conducted December 8, 2022)

Now, how could a giant open sewer have gone unnoticed by local people and authorities? And how was it possible that no-one before thought it was a bad idea to irrigate crops with the foul waters from the *Zanjón*? The answer is, of course, that it didn't, and they had. As the strawberry farmer's anecdote suggests, local people were indeed aware

that eating raw vegetables in Santiago was somewhat dangerous. Local authorities too had looked into the practice of irrigating local crops with water from the *Zanjón*:

As you can imagine, there were people, particularly at the *Instituto de Salud Pública*, who considered this dangerous, and they carried out environmental bacteriological studies to show that the water irrigating the crops contained salmonella typhi. They did multiple studies to approach that, and they published them. The person who was the lead on this was A.C., Dr. C.. And A.C. was surprised by the results, but it was her data, so that's what she published: she couldn't find typhi. (Interview with Dr. Friend conducted May 5, 2023)

The Typhoid Fever Control Program collaborated with Dr. C., but they tried a new approach to sample collection: the Moore swab (Sikorski & Levine, 2020). Using this technique, Dr. Friend and his team managed to isolate salmonella typhi and prove that water from the *Zanjón de la Aguada* was contaminating the vegetables eaten by most of Santiago's citizens, especially during the summer season.

We made reports to the government, the government knew of this and they just would not take the steps—under the same government—would not take the step to make this enormous investment to change that. Typhoid was very treatable in those days, with oral chloramphenicol, inexpensive. It controlled mortality. The hospitals had typhoid wards in the summer [...] it was accepted. (Interview with Dr. Friend conducted May 5, 2023)

Also, by then, the economic and socio-political scenario in Chile had turned: there was a terrible economic crisis and palpable resistance to the dictatorship was once again rising. So, shutting down farms or enforcing a different and more expensive irrigation method was likely unattractive and potentially unfeasible at the time. So, prohibition to irrigate crops with water from the *Zanjón* was not issued until the 1990's, when a cholera outbreak—much deadlier and difficult to control—threatened to follow the route of typhoid and become endemic in the country's central region.



Until then, as I have mentioned in this section, the number of typhoid cases dropped thanks to the ongoing vaccine clinical trials, which were already a huge success for the Typhoid Fever Control Program. However, these trials, which began 1983, were not without hurdles. While 1980 and 1981 were years of economic expansion (Coloma & Rojas, 2000; Drake, 2003) and social quiet (Dietz, 2016), in 1982 the country faced an economic recession that once again shook this superficial calm (Coloma & Rojas, 2000; Drake, 2003). Conducting clinical trials during these times of unrest involved navigating a complex social and political environment both inside the Ministry of Health and in the field and relying on the knowledge and social savviness of key local actors. I delve into what navigating these troubled times entailed for US researchers.

### **Local gatekeepers and mediators: socio-cultural literacy brokers in research**

Scholars in literacy studies use the term literacy broker or cultural broker (Curry & Lillis, 2014; Szasz, 1994) to describe actors who mediate access to materials, language resources, or cultural/disciplinary conventions in academic or educational spaces. Mary Jane Curry and Theresa Lillis define literacy brokers as “collaborators and gatekeepers who support or constrain access to publishing both before and after submitting to a journal” (Curry & Lillis, 2014, p.12). In anthropology—where the term was originally coined—the term is used to describe mediators in cross-cultural communication, such as translators or interpreters (Szasz, 1994). Cultural brokers ease negotiations between cultural others who often sit across power differentials, in addition to varying degrees of cultural competence. Here, I use the term cultural/literacy broker to describe actors who mediate access to local communities, not to bridge language barriers or differences—or not in the main—but to bridge *otherness* itself, that is, to exist as insiders in teams lead by foreign researchers.

Indeed, for US researchers doing research in Chile during the dictatorship years, finding local mediators was key to getting the work done, not because Spanish was particularly challenging for them, but because having access to potential research participants required earning the trust of local gatekeepers: powerful organizers in the political left who “controlled” access to low-income communities. Cultural brokers for these research endeavors did not only have to be competent scientists and users of Spanish and English, they also had to be politically aligned and connected in the right ways for a specific political moment. These actors exchanged cultural capital and “mobility”—the ability to move across and within local communities—for training and expertise. One such actor was the person Dr. Friend hired (quite strategically) as the coordinator for the Typhoid Fever Control Program. We will call her Dr. Carolina Ponteferro.

Very much like my mother, Dr. Ponteferro was an advanced graduate student when Dr. Friend came in to aid the Chilean Ministry of Health during the typhoid crisis. She got acquainted with Dr. Friend’s research teams during her final years in medical school and was offered some years of training in a prestigious University in the United States. In addition to being a brilliant student and a promising researcher, she was also well connected with people on the political left:

She had been a high school student during the *Unidad Popular*<sup>22</sup> era. [...] She had good relations with people in the far left. And in 1980’s, I think it was 83’, when we started our third field trial with typhoid vaccine. It was in *Área Sur*, and it was in *poblaciones*<sup>23</sup> that were controlled... I mean, the government, they had no control over these places. They were controlled by folks from the MIR.<sup>24</sup> You couldn’t get in, you couldn’t do anything there: vaccinate in schools, do things in health centers,

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<sup>22</sup> Left-wing political coalition that backed President Salvador Allende’s government.

<sup>23</sup> In Chile, the term “población” is used for low-income communities, often removed from the city-center and with little to no urban planning.

<sup>24</sup> Acronym for *Movimiento de Izquierda Revolucionaria* (Revolutionary Left Movement).

without their permission. No *carabinero*<sup>25</sup> went into these *poblaciones*. It was dangerous! So, [Carolina] was actually a very helpful entrée because she knew many of those people as a high-school student and then in the middle of the Allende era. It was kind of fascinating. (Interview with Dr. Friend conducted December 8, 2022)

Indeed, typhoid research during the early years of these collaborations greatly benefited from the relatively smooth conditions created by the military dictatorship's public administration. But doing environmental studies, studying public records, and clinical data was one thing, while working with local populations and recruiting participants for clinical trials was a completely different one. While the government could ease access to public buildings and facilitate conversations with authorities and higher-level decision-makers, working with lower-income communities required a kind of trust that the average citizen (and especially poor-citizens) did not award the Pinochet administration.

This was another era. This was during the Pinochet military regime. And particularly when we started working, in the late 70's early 80's, it was a period of transition [...] Because the economy was good. In exchange for giving up social liberties, the economy was absolutely booming and there was a lot of stability. [...] But then in 82-83, there was a terrible recession. And things changed. Then, when you have no freedom of expression and the economy is really bad, then things started up, and for the rest of the years, there was always, always problems, and resistance, etc. (Interview with Dr. Friend conducted December 8, 2022)

Working locally, in this sense, entailed encountering the rough texture of this territory. Dr. Friend also discusses the complexities of working within the Ministry of Health during these times, and how he learned to understand and navigate social interactions withing a ministry torn across the political spectrum. According to his

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<sup>25</sup> Police.

narrative, during the most politically tense times, the ministry was not a simple hierarchical organization, but an intricate network of power balances:

“Throughout all these years, these twelve years, [...] within the Ministry, it was like there was three ministries. In terms of hierarchy, people reported informally to other people who were left middle or right, in addition to the formal reporting. So, we learned, we were physically inside the Ministry, but [*the reality was more complex*<sup>26</sup>]” (Interview with Dr. Friend, December 8, 2022).

These interview fragments show that in academic research and publication, cultural or literacy brokering does not only happen and matter from the top-down—from the center to the peripheries—but also from the bottom-up—from the peripheries to the center. Powerful actors may be highly competent in prestigious academic and technical language repertoires and social practices, yet they often require the aid of local entrées or mediators to access and navigate the complex local contexts where data exists. In this sense, not only did local actors—including cultural brokers—contribute and benefit from these exchanges with US researchers, but they made this work possible. To describe these contacts as merely colonizing or extractive would be, in this sense, unfair. Not only to US researchers whose care and respect for local populations and researchers was genuine, but also towards local scientists, who were also invested in the development of better public health as well as in the contribution to science at a global scale.

But all of what I have related above—the early research on typhoid fever and the collaboration around it—happened before VRC was founded as an independent, locally established foundation. Once the typhoid era was over, the dictatorship too came to an end, and with the arrival of a new democratic government these research relationships and all

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<sup>26</sup> Dr. Friend does not finish the phrase, so I have completed the sentence to favor coherence.

that their operation entailed suddenly fell on the realm of the un-regulated or downright illegal. Further, the presence of these foreign researchers inside the Ministry of Health's building no longer remained uncontested:

When the new government came in, we got this notice that we had to vacate because there was so little room in the Ministry of Health building. And they offered us space anywhere we wanted to go. [...] Anywhere else that was a Ministry of Health facility.

So, we moved. And of the possible places we went to [*Hospital San Pablo*]. Where we had, for many, many years a special relationship with [Drs.] I.O. and A.A.<sup>27</sup>, who were the closest, the best friends we had... it was a most comfortable place. They had no room, of course. Hardly any room at all. But they squeezed us in. (Interview with Dr. Friend conducted December 8, 2022)

Not only did these research collaborations have to change buildings and modes of administration. The local cultural brokers that gave them a local anchorage also changed. For a variety of reasons, the professional relationship with Dr. Ponteferro did not survive this transition. I suspect that, among other factors, the new era of North-South relationships no longer gained so much from a person with strategic ties to the political left. President Aylwin's administration was the time of centrists, the politically neutral, and the technocrats (Silva, 1991). All of these elements likely factored into the appointment of the new person that would carry these collaborations forward:

And we picked your mom. We had known her; she had been a fellow with us. I.O., A.A. thought the world of her. [...] She was a total integrity person. The daughter of a coronel in the *carabineros*. Very—you probably know growing up—there's right and there's wrong, and there's nothing in between. And she suggested we explore with these lawyers to set up a foundation, going to this famous law firm. [...] So that's how the *Fundación VRC* came to exist. (Interview with Dr. Friend conducted December 8, 2022)

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<sup>27</sup> Upper-level hospital administrators at the time.

It was indeed the change in circumstances that called for such a solution, but it was ultimately Dr. Susana Arce who suggested VRC should become an independent research entity, with special ties to, but no longer stemming from a “parent” university in the United States. Contrarily, I suspect that Dr. Friend always regarded VRC as a unit of his research center in the US<sup>28</sup>—an idea that my mother was always uncomfortable with and resisted in her discourse. These contrasting takes on VRC’s standing in relation to its international ties exemplify what Alastair Pennycook (2010) calls “the perspectival heterogeneity of locality” (p.4); the idea that “any understanding of the locality of language must also encompass an appreciation of the locality of perspective, of the different ways in which language, locality and practice are conceived in different contexts”. In other words, localities are not fixed spaces or places; they are experienced and defined differently by different actors depending on their vantage point. Chilean VRC researchers sought self-determination and independence from foreign institutions, for US researchers engaged with VRC—Dr. Friend in particular—this was their life’s work, their personal history, “the good old days” of their own professional life, which traced a very clear line extending from the US to South America.

Within this more dynamic account of space, place can then be seen not so much in terms of the flatly local but rather as the circumstance of our practice. Our words are produced and understood in places that are themselves constructed and interpreted. (Pennycook, 2010, p.7)

As Pennycook (2010) points out, the local is always in relation to—opposition, tension, collaboration, or dependency—the global (or something else). The fact that locality

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<sup>28</sup> I perceive this in the way he talks about these collaborations, and there is some evidence of this in publicly available information that I cannot quote without breaching the confidentiality duties I have towards my participants.

is relational and *heterogenous* strains local VRC scientists' aspirations for independence or autonomy. In this sense, VRC can be understood as a center for *local* scientific production because of its history and anchorage in a larger landscape: a broader research network extending its reach from the US, the international academic community, a Global North to which VRC is a point of reference in the South—a point in the periphery or semi-periphery. From this perspective, VRC's "parent" university in the United States is also a locality: a point in the Global North, in the center of global academic knowledge production. It is this centrality (which is also a feature of its locality), that explains why regarding this and other institutions in the Global North there are seldom (if ever) questions about the *local* features of this knowledge, how *locality* shapes this knowledge, or what this *local* knowledge contributes to science as universal. What does it mean for knowledge to be *local*, anyways?

While this research offers little in the way of answers to the question about what local language is, it does allow me to say something about what a local perspective on knowledge can do for scientific research processes and for the communication of science. When and how does *locality* matter for scientific writing and other knowledge-making practices? What do *local* perspectives on writing contribute to science at a global scale? In the next section I share some of the insights about the importance of locality when judging language choices in the publication of scientific findings, especially how locality can offer an interesting perspective on the notion of rhetorical *propriety*.

### **Local eyes: transnational writing and propriety**

*Lest there be a word or a reading that can be politically incorrect...*  
(Interview with Dr. Arce conducted on July 14, 2022)

In this project, the question about what locality has to do with scientific communication came from an interview with my mother who used the term in a way I did not exactly expect. She mentioned reading “with local eyes” to describe a certain sensitivity for political correctness applied especially to peer review activities, but also to her own writing and oral communications in academic contexts:

These scientific *papers* are in the public health realm, so there are things that, if you make reference to, in a paper, to a local policy or local program in the matter, one has to be careful not to—I don’t want to say offend—but even, touch local sensitivities. There may be an evident weakness in the modus operandi of the local policy, but the way one discusses that has to be careful not to hurt local or institutional sensitivities. It’s not about pointing fingers and saying “you know this was very poorly done, so we did X and Y”. No. And that, even without the intention to present it that way, has to be read by someone local that has the sensitivity to see where it can touch (Interview with Dr. Arce conducted on July 14, 2022)

Indeed, though based on scientific evidence, public health policy is still a matter of complex decision-making, where critical judgement plays an important role. When designing policies there is not a single, perfect solution but an assessment of the best possible approach to a problem with the available resources and information, for a specific context, “science can identify solutions to pressing public health problems, but only politics can turn most of those solutions into reality” (Oliver, 2006, p.195). For this reason, a harsh commentary on a policy, one that reads as over-critical or dismissive, can also be read as a critique on the people who designed and implemented it.

For VRC, an independent research institution with close ties to the public health sector, “touching local sensitivities” could mean losing key allies, or raising animosity among stakeholders whose support could be needed in future projects. During one of our interviews, Dr. Arce recalls an event that took place during her early years as director of VRC. At the time, the Chilean public health institute was implementing a new technique



for the diagnosis of whooping cough (*coqueluche*), which at the time was tricky to diagnose based on laboratory cultures. This was "the first of the techniques that appeared (molecular), which avoids culture or eludes culture [...] it is an immunofluorescence technique, which searches [for pathogens] in respiratory secretion, no longer culture." (Interview with Dr. Arce conducted on July 14, 2022). In other words, the traditional technique to diagnose whooping cough required taking a sample of mucus and observing whether pertussis bacteria grew in a Petri dish in the lab. But, as Dr. Arce explains, *Bordetella Pertussis* is very difficult to reproduce in laboratory settings. This newer technique allowed to search for the bacteria directly in mucus samples, without the need to "culture" or grow bacteria from a sample. It so happened that, once laboratory technicians and health workers were trained in this new technique and a protocol was put in place, the number of reported cases sky-rocketed:

they started to find *coqueluche* under every stone! From children who were suffering from other virus, say RSV<sup>29</sup> virus, and they did both things [lab tests] to them. Then I talked to the locals [public health workers], and they were also going half-crazy with all the *coqueluche* reports that had to be made. (Interview with Dr. Arce conducted on July 14, 2022)

So, Dr. Arce started reading on the subject and found that the latest literature advised against the use of this technique for diagnosis. The technique was, she found out, known to be imprecise and to yield many false positives and false negatives. She also collected some information about whooping cough cases at her own institution,<sup>30</sup> and then presented what she had learned at a local conference:

I presented the casuistry of the hospital, of the cases of *coqueluche* that had been diagnosed with this technique, and what had been the evolution, and where the great

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<sup>29</sup> Common acronym for Respiratory Sinitical Virus.

<sup>30</sup> I have called it Hospital San Pablo here.

majority of the cases had no correlation with the clinic and what happened with the children. And, well, afterwards I probably made a review of the literature, of other experiences... and in the room was the head of the diagnostic department of the ISP who had been the promoter of this technique. She chewed me out when we left the room! And she didn't speak to me for I don't know how many years! ... [She said] That this was outrageous! How could I discredit the orders of the institute in that way? [...] Maybe I could have said it differently. I *should* have said it differently. (Interview with Dr. Arce conducted on July 14, 2022)

Dr. Arce's remarks remind us that science is a social activity where language choices need to be negotiated not only in terms of the currently accepted truths and facts, but also in attention to audience's feelings and expectations. Here, scientific communication meets politics and the rhetorical exigencies of speaking in the public realm. Propriety, then, is perhaps not such an outlandish tool in a science rhetorician's repertoire. Lois Agnew defines this concept as follows:

In classical terms, propriety serves not as a tool for constraining the rhetor's language in keeping with rigid standards of "politeness," but instead provides a framework through which the rhetor and audience together negotiate the complex factors, including issues of style, that construct an effective rhetorical response. (Agnew, 2009, p. 474)

In my mom's anecdote above, her reflection is not on whether the facts and findings she presented were accurate or necessary. The flaws in the new technique were indeed causing trouble for the health system, straining workers and resources due to an over-demand to process whooping cough reports—most of them wrongly identified. But she acknowledges that these same facts could and should have been presented in a different way, and that the one she chose was ineffective. The way she figured her remarks at that presentation failed to deliver the message to her audience—especially the head of the local Public Health Institute's diagnostic department—and therefore, likely lost any chance of mobilizing change to this troublesome policy. In the next passage, she goes into further

detail about some specific strategies now in her rhetorical repertoire, that would have been useful to her back then:

If you tell me now, I could have said the same thing in a different way. Raise it as an issue of controversy. I could have found a way to say, “Let's look at this technique. Yes, it offers something but let's look at it critically because it doesn't seem to be the panacea either.” You know what I mean? But the way I did it meant gratuitous enmity with a person who was critical to VRC collaborations and ties. That was something completely local and stemming from sheer inexperience. (Interview with Dr. Arce conducted on July 14, 2022)

This isn't exactly news in scientific communication. Softening and mitigating claims or *hedging* in scientific writing has been researched amply by applied linguists like Ken Hyland (1995; 1996). As Hyland argues, hedging is not only a rhetorical strategy to lessen one's commitment to certain statements, or express varying degrees of certainty. It is also a way to construct polite claims and show deference for the opinions and findings of colleagues (Hyland, 1996).

But the way Dr. Arce refers to a “local eye” in scientific writing also entails attention to rigor and higher scientific standards in the work of others; in this case, centric researchers writing about the peripheries and with data from peripheral countries. She offers one specific example of a more recent study (late in VRC's trajectory), that returns to the topic of typhoid, this time not tackling an outbreak, but tracing chronic carriers in the Chilean population. The project gave rise to a series of other adjacent publications and collaborations, including doctoral research projects using the data collected by VRC. One very important collaboration involved an institution in the UK dedicated to genomic sequencing:

One of the papers written by two PhD candidates in very specific aspects of genomic sequencing, in their discussion they alluded to something that the sequencing study they carried out detected and that the local surveillance system

could not detect or had not detected due to a failure. The way in which this was written, as a local person, I did not like it. In other words, there were incorrect concepts about the logic and formulation of the surveillance program that was ... the program is correct, it is adequate to the local reality. (Interview with Dr. Arce conducted on July 14, 2022)

This interview fragment suggests that what from the point of view of the author can initially work as a mechanism to ensure politeness or deference, can prevent them from making false or imprecise claims, visible to a *local* reader, but difficult to anticipate by the writer. This can be due to a lack of knowledge about the local context, in this case, the reasoning behind a public health program and how it functioned for the local reality. Or, as the passage below suggests, it can also be due to the impossibility of being aware of all the existent literature on a topic, especially when this knowledge circulates in academic venues outside the mainstream or the academic geopolitical center:

On the other hand, there was an implicit omission because it said that this finding that had allowed this genomic sequencing, in short, was a discovery due to the application of this latest generation technique. Not so much! Because the public health institute—I don't know, 8 years ago—in relation to that same outbreak or something that happened, with the techniques available at that time, had made the same observation, except it was published in gray literature, not indexed, or local, or not within the scope of the review that she made. (Interview with Dr. Arce conducted on July 14, 2022)

Dr. Arce's point highlights the complexity of scientific knowledge circulation. As we know, not all publications are made equal. English-medium publications are more prestigious than those made in other languages; indexed publications are more highly regarded, and confer higher academic credentials to authors; and both the former are generally controlled by geopolitically centric countries, which are more difficult for scholars in the peripheries to access (Curry & Lillis, 2004; Navarro, Lillis, Donahue, et al., 2022). This uneven access to international academic publication venues usually contributes to obscure advances made by researchers in the peripheries and semi-peripheries of the

global landscape. International exchanges and collaborations such as those generated around VRC help bring some of those blind spots back into focus. Dr. Arce argues:

...even if all we locals have done is provide that material, the bacteria, and some information on how they were obtained, and all the intellectual and rhetorical genesis of the issue has come from elsewhere, you have to review it [that work] with local eyes. (Interview with Dr. Arce conducted on July 14, 2022)

“Local eyes,” then, are critical to prevent or un-do such inequities in access and visibility in international academia, especially in the context of collaborations where more powerful researchers rely on data provided by scientists in the peripheries, as extractive academic practices lend themselves to inaccurate attributions of novelty and authorship. In this sense, *local* eyes and *local* knowledge describe not so much a plurality of knowledges and epistemologies, as a heightened attention to knowledge production and circulation spaces: the unevenness of the ground where we stand.

The inclusion of local researchers in research teams about their own contexts is critical for this reason. Cross-border collaboration and exchange allow for local researchers to contribute with their understanding of their own context and see that this is reflected in appropriate (*proper*) language choices. Here, *locality* does not conflict with the universality of scientific knowledge, or the aspiration that all scientific knowledge—produced in any corner on the globe—can contribute to a fuller understanding of natural (or social) phenomena. It does, however, conflict with the idea that knowledge can be made whole—global or universal—when produced unidirectionally, from a single vantagepoint or perspective. But in a progressively globalized world, local language and knowledge practice is threatened by standardization and homogenization. In the next section I visit some of my participant’s views on the evolution of research practices led by the industry, and the coming to an end of international academic collaborations around VRC. Different

actors have different views about what brought these collaborations to an end, yet they point to a common problem: that international research from the peripheries, when it wants to claim some degree of *locality* is often fragile and may succumb to shifts in global flows that take interests and resources elsewhere. I will explore this in the next section.

### **Periphery and the fragility of places of friction**

That is lost. And besides, it wasn't the spirit. Or at least not the way I wanted it. It may work better for all the purposes of accelerated development and whatnot. But how we conceived, imagined and operated VRC is not like that. (Interview with Dr. Arce conducted on July 14, 2022)

As I have tried to show throughout this work, for many years VRC was a successful research center, a critical ally for research partners in the Global North, and a productive contributor to international science on vaccines and infectious diseases. This success was built on a combination of productive collaboration and local expertise. Part of what made VRC special was that it was tied to influential allies in the Global North, which in turn, gave it a reputation and earned it respect as an independent institution. VRC also earned respectability for its productivity, the quality of its scientific work, and the standards that this group of scientists set for themselves. These standards included, among other things, a local attunement of the purposes and procedures of each study VRC engaged in. As nurse Mónica highlights during interviews, this was true both for studies initiated by VRC researchers—what I have called academic research—and for industry-led studies:

There were two types of studies. There were the industry studies and there were studies that were like the VRC studies. In those studies, it was much more

participatory, in the sense that we looked at, we did a review of whether it was understandable for a mom, etc. etc. etc. The ones from the pharmaceutical industry, well, [Dr. Arce] also made sure that she put her stamp on the consent document, in the sense that it was not written in a pharmaceutical industry style, but that it was understandable and in line with the reality of... and she gave us the drafts for us to read, understand, and make suggestions. (Interview with Mónica conducted September 26, 2022)

Mónica's comments in this interview fragment are revealing in several different ways. For one thing, they show (as I have pointed out in Chapter 3) what VRC staff's understanding of the research center's main audience was: mothers of children. Knowing this audience, understanding who these mothers were, what they cared for, and how this population changed over the years was critical to the kind of attunement to local audiences that VRC cared and stood for. As Mónica explains, this is what they had in mind as they revised and proof-read participant-oriented documents.

Her remarks also show that this work was perceived by VRC staff as collaborative; it involved the people who were on the ground, in contact with participants and potential participants on a regular basis. For this reason, the inadequacies of the language in informed consent documents produced by the industry were not only felt at the very top—by VRC's director—but also by nurses working in the field. I read a sense of pride in how Mónica describes Dr. Arce's and VRC's team revision of these documents. In her words, even in studies, where researchers usually have less freedom to intervene in the design of procedures and the writing of documents, Dr. Arce made sure to “put her personal stamp” on them, rewriting and making sure they were legible for VRC's public:

She [Dr. Arce] did not accept the document as it came, but rather tore it apart and left it as [...] for starters, in an understandable, friendlier language [...] they [the industry's IC forms] brought a lot of analysis of the expected results, the antibody meters [...] or they were very basic and poorly designed for a good understanding.

They did not explain well the disease they wanted to prevent. Also, the legal type background sometimes was lacking in terms of stating who was responsible. (Interview with Mónica conducted September 26, 2022)

The way Mónica describes the research staff's relationship with participants and potential participants, their interactions, including the very first recruitment procedures—whether successful or not in enrolling a participant—often served a pedagogical purpose. Working class mothers were unaware of or did not understand what infectious diseases, vaccines, or scientific research were, and VRC's recruitment and consent procedures made sure this complex information was well understood. They took the time to sit with mothers and show them visual aids and answered questions, even before they presented the informed consent document for them to take home and discuss with their families. Indeed, over time, VRC's research team developed different kinds of supporting material to facilitate informed consent procedures, like flipcharts, or slideshows which they would display in a computer screen as they talked to potential participants. According to Mónica, “people appreciated it, because they learned something.”

But this work to develop rhetorical strategies aimed at improving communication with participants, grounded in an understanding of local publics and needs—which VRC researchers understood as central to ethical research—disappears with the emergence and dominance of large industry-led research, especially clinical research run by intermediary organizations known as CRO's: contract research organizations. This too was felt by field researchers like Mónica as a loss, a deterioration of ethical standards and quality of scientific research procedures. She states it quite bluntly: “That figure, the famous CROs, that's when the devil dipped its tail in this and messed it all up.” In her opinion, researchers



recruited by CROs are not real researchers, as they are not involved in knowledge production:

And that's what messed everything up because those researchers, they're mere doers of... they're shoddy researchers. They're just putting their signature on it. They don't participate in the development of anything. They don't write the protocol. Everything is imposed on them. [...] Then the documents to fill out, for the participant, were made by a CRO that may be in an office, I don't know, in Dubai. And they are for 50 countries (I am inventing) 50 different places, so it's a standard document. Hence, there are these blatant errors, where [you can have a document that] says, in case you need, please contact John Doe in Geneva... (Interview with Mónica conducted September 26, 2022)

In her experience as a worker at VRC, but also as a local clinical studies supervisor and a research participant, this kind of researcher and research model are often careless about a participant's understanding of the science and ethical implications of engaging in clinical trials. As a paradigmatic example of the complete lack of local attunement of industry-led research she mentions the case of one informed consent document she reviewed, that provided contact information for Chilean participants indicating an address and phone number in Geneva. She mentions that she couldn't hold back a tongue in cheek comment when she paid the study's principal investigator a visit: "We had to get tickets all the way to Geneva to get to you, Sir." As this remark and the interview fragment above suggest, paradoxically, the more "global" vaccine research becomes through industry-led multicentric clinical trials, the more scientific processes and language practices become fixed, standard, immobile. Rather than growing in complexity and gaining from the richness that *local* applications can contribute to the understanding of vaccines as pharmaceutical products in particular or to research with human participants in general, globalization in the form of industrial research brings about a flatness of sorts; an

undrawing of worldly<sup>31</sup> diversity and its replacement for the indiscriminating replication of a standard that does not really come from anywhere or speak to any place. Globalization, in this sense, does away with localities, and places in the peripheries are especially vulnerable to such erasure.

Indeed, when inquiring with Dr. Friend about this shift—described so clearly by my mother and Mónica—he seemed rather perplexed by the question, as if he didn't quite grasp its meaning. His explanation of VCR's undoing is a completely different one. From his perspective, the fact that VRC's work came to an end is related to the changing of leadership, both of VRC and VRC's original parent institution, which includes his own circling out of the position of director of this research institution in the US. As he explains, when a new director came in, he and my mother were unable to design a plan in collaboration with this new person, to maintain the cross-border research collaborations they had long sustained:

When she came on board, your mom and I asked, well, what is the future of VRC? [...] For my successor, the options were essentially, you know, I'm retiring, your mom is going to retire, do we make this a Latin American continuation, like was done in Africa, or does something else happen to it. But that has to be the decision of the new director, who has the resources. And she, for whatever reasons, was not interested in doing that. And I have my own belief as to why she made that decision, which I think is the wrong decision [...] But... we had our place in history.  
(Interview with Dr. Friend conducted December 8, 2022)

Dr. Friend's words here are ones of grief. As I mention before, VRC was an important part of the best years of his career as a researcher. Still—or perhaps because he feels so personally tied to VRC's fate—he sees the end of this research center as part of the

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<sup>31</sup> For a more in-depth discussion of the concept of worldliness and its contrast with global or globalization see Alastair Pennycook's (2010) *Language as a Local Practice*.

natural life cycle of research endeavors. Very much like his own trajectory, initiatives like this center in Chile are founded, flourish, and then come to an end. Institutions are so tied to the people and the work they do. As Friend explains:

There are people in [this US institution] who have to buy into it. I have this special attachment to Chile, and everyone who has been down there loves it. But not everyone is willing to make a long-term commitment. Every institution has its ups and downs, and sometimes certain individuals make or break institutions. (Interview with Dr. Friend conducted December 8, 2022)

VRC's "parent" center in the US, however, will very much survive. It is housed within a prestigious university in the Global North, it receives public funding and has ongoing relationships with powerful philanthropic foundations. Even in an international research environment where late-stage clinical trials are completely dominated by big pharmaceuticals and run by CRO's, this kind of institutions can continue to do basic science research and early development on vaccines and infectious diseases. Their priorities may change, but the institution will live on, one way or another. Their fate is not made or broken by one individual and their contingent priorities. Within the frames of the community that this institution is anchored—its neighborhood, its city—the way research centers like this operates may continue to have an important degree of local attunement. The Global North does not suffer globalization in the same ways as the South.

### **Final thoughts**

I would like to end this chapter with a caveat, or what could be understood as limitations to the scope of the theoretical reflections developed here. While I believe that VRC's experience speaks of broader global phenomena—and the literature on the

industrialization of clinical trials, the emergence of CRO's and standardization of research processes attest to this (Kamat, 2014; Petryna, 2007)—there may very well be other stories to be told about vaccine development and biomedical research in South America and the peripheries. One such story was mentioned tangentially during interviews with my participants in this very study. It is the case of a research center in Argentina, similar to VRC in that it collaborates with research institutions in the Global North, and in part modeled after VRC's experience. This center did, in fact, participate in clinical trials for Covid-19 vaccines and could be seen as a case of successful survival of a research initiative from the periphery in a global landscape dominated by big pharmaceutical industries. But that research center's story is not the one I tell throughout this work, and understanding how it operates and the measure and quality of its success are questions for another study.

Further, though I often argue that the industrialization of vaccine research is detrimental for local perspectives on scientific development, especially in vaccine research, there may be advantages to this model. Accelerated development responds to a very real need to provide prompt access to pharmaceutical products which the world population may be in dire need for—as was the case with Covid-19 vaccines. A need that is shared by low- and middle-income countries in the periphery. However, one thing that the accelerated development of these vaccines demonstrated is that the development and production of a new pharmaceutical is one thing, but ensuring its equitable distribution across the globe is a completely different matter. Indeed, Covid-19 vaccines seem to have failed in doing research in locally attuned ways, and they have also failed to reach populations in low- and middle-income countries of the peripheries (Kunyenje, Chirwa, Mboma, et al., 2023;

Ramachandran, Ross, & Miller, 2021). A problem that has slowed down the world's ability to control the pandemic.

As I have discussed here through VRC's case, scientific research can be conducted under the pretense of homogeneity, through standard procedures and practices, as if the world was a borderless, frictionless space. But in reality, the world is far from flat and smooth, and the unevenness between localities reveal themselves in many ways. Stories like VRC's show how the advancement of globalization and standardization can efface local projects, and global crisis as the Covid pandemic reveal the striking unevenness in the capacities that countries have to deal with emergency and crisis. Localities are not all made equal, and doing collaborative research across borders entails engaging in the fraught dynamics that shape the geopolitical landscape: re-enforcing, benefiting from, countering, resisting, being complicit with them. But friction, as Tsing (2005) tells us, rather than keeping everything in place, creates opportunities for the uneven corners of the world to rub against each other and produce movement. As VRC's case illustrates, this movement may not undo global inequality, but it may at least offer local actors mechanisms to counter it, to choose paths for action, to be complicit in the making of the power patterns that shape the world.

## Chapter 6

### Conclusions: Precarity, nostalgia, and hope

I don't remember how old I was, but likely old enough to know better because I felt embarrassed very soon after. My mom had taken me along to one of her conferences, where I was able to see her casually mingling with colleagues from all over the world: places like France, India, Mali, Switzerland, the US. I remember hearing these researchers speak in different English accents and varieties. I was aware that everyone sounded differently, yet I was embarrassed at my mother's accent. I remember thinking *I* certainly didn't sound like that. *I* didn't produce sibilant "th" sounds like "*somesing*." In my conception of my own language ability, my English was better: I was *passing* and sounded more like a native. The truth is the extent of my ability—especially back then—could at best be described as a certain skill for mimicking sounds (sometimes to a fault). My mother, on the other hand, was and is a skilled user of English. She had successfully written and published multiple scholarly pieces in her second language, delivered countless conferences and oral communications, and participated successfully in delicate negotiations. She had fostered friendships and caring collaborations with colleagues across borders. She has and still does live a bilingual life and neither her nor the sound of her English have completely given up a sense of locality.

Of course, when I made that judgment on my mom's English, I was not fully aware, or rather, was unable to articulate the raciolinguistic (Flores & Rosa, 2015; Rosa & Flores, 2017) and monolingual (Horner, Lu, Royster, et al., 2011) underpinnings of my thinking—although something about it made me uncomfortable. And though it's been a long time since I understood in how many ways the assessment I made as a teenager was wrong, going about

this research has brought me a new realization of how narrow my understanding of language practice and difference was. I began this work with the expectation of finding many instances of discomfort and miscommunication across languages between VRC researchers and their international partners. To my surprise, throughout this study I have very seldom (if ever) encountered the challenges international researchers face being second language users. I have, however, found multiple examples of their skill and linguistic awareness. Collaboration across languages conceptualized as work to overcome barriers is notably a non-issue in VRC's history. As I mention in the introduction, this has a lot to do with the limitations of this work's methodology. The kinds of retrospective, archival ethnography that I conduct here lends itself poorly to the observation of the day-to-day challenges of writing in a second language, or the discomfort of speaking a foreign language in professional contexts. How prominent these challenges might have been or can be in the context of scientific exchanges or collaborations like the one I study here may be the subject of further study. Still, language practices at this research center reveal friction and agency at work. The questions raised by this case study are not so much about how to tackle the challenges of an English-dominated world, but how to use English—or Spanish, or any other language—in a way that acknowledges local contexts and differences. How do researchers from the peripheries do research and use language in ways that make sense locally, while conforming to the abundant and expanding standards of a progressively globalized academic environment?

Implicit in my assessment of my mother's English, there is a misconception (a monolingual conception) of what proper language usage means, and what it sounds like. I could have been paraphrasing Horner, Lu, Royster et al. (2011) when they explain that "Monolingualism teaches language users to assume and demand that others accept as correct and conform to a single set of practices with language" (p.321). As the examples I analyze

throughout this dissertation show, rhetorical propriety in cross-border exchanges has little to do with reproducing any particular English standard, and plenty to do with how well anyone's language choices adequately bridge local attunement and global acceptability. As the evolution of informed consents and the examples of rhetorical re-writing of these documents at VRC show, researchers at this center adapted to changing exigencies in the international landscape. They had to both comply with international standards and regulations and remain aware of local audiences, their rhetorical and linguistic repertoires, and their own sense of the strategies that seemed more appropriate to communicate with these local publics. Working towards rhetorical propriety, in this sense, entails engaging in places and moments of *friction* (Tsing, 2005), navigating the distance between audiences at different scales—the local and the global—and writing for rhetorical situations happening in different moments.

As Tsing (2005) reminds us, “speaking of friction is a reminder of the importance of interaction in defining movement, cultural form, and agency” (p.6). Indeed, as I have shown through this work's chapters, VRC researchers find opportunities to exercise writerly and scholarly agency in moments of friction; instances where interaction with other actors in a knowledge system raises what is perceived as challenges and could be understood as an encounter across difference—differences in understanding, approaches to language, goals, or objectives. Through VRC's case, we learn how North-South, center-periphery relationships constitute the writing contexts that define locality for these researchers, not through simple contrast or opposition, but through the complex tension and interdependence between these spatial orientations. Or as Pennycook argues:

“To take the notion of locality seriously, rather than merely juxtaposing it with the global, the universal or the abstract is to engage with ideas of place and space that in turn require us to examine time, movement and interaction.” (2010, pp.1-2)



What this work offers, then, is a look into the ways researchers travel between the local and the global, the center and the periphery. To consider how they try to define themselves against imposed global standards, yet often depend and rely on the existence of these standards.

In Chapter 3, for example, I discussed how informed consent documents used at VRC changed throughout the center's history in response to the expansion of international norms and regulations in human subject research, as well as the progressive industrialization of vaccine clinical trials. My findings show that, over the years, these documents became longer, more complex and analytical, and denser in their use of technical language. More importantly, rhetorical strategies displayed in ICFs changed from ones where persuasion was sought through proximity and dialogical rapport with the audience (the potential research participants), to ones where the main persuasion strategies relied on the establishment of authority, which also entailed a distancing between the researcher and the participant. Earlier consent forms contained letter-like and conversational features such as salutations or direct addresses to the reader, reflecting the researchers' attempts to find the best way to establish closeness, even identification, and affectionate communication with the research participant. Later consent forms shift towards a more distant tone, they rely more on authority claims, and direct addresses or nods to the reader were mostly dropped from the text.

The variability in ICF features suggests that there was a great deal of hesitations and experimentation regarding the best ways to achieve clear, effective, and ethical communication with research participants. Transformations in the language of consent protocols could be due to multiple facts, including local historical transformations and changes in international standards and regulations, but my researcher participants suggest that it was the progressive advancement of the industrialization of vaccine trials that was felt as the heaviest constraint for researcher's writerly agency. Still, even in the very last of

informed consents at VRC, there are traces of these researchers' attempts to use language and implement informed consent protocols in locally attuned ways that reflect not only a responsibility for ethical research standards but also care and identification with research participants.

As I argue in throughout the dissertation, changes in informed consent language practices that restrict researchers' agency also threaten to impact the quality and ethics of clinical trials. Less accessible consent forms lend themselves to weaker research ethic practices and can marginalize populations with lower levels of schooled literacy from participation in clinical trials. In this sense, VRC's case suggests that further research on communications between clinical researchers and research participants, especially in peripheral low- and middle-income countries, is urgent to understand how transformations in informed consent protocols impact the quality and ethical standard of scientific knowledge production. Scholars in technical communication, the rhetoric of health and medicine, and applied linguistics have plenty of work to do in the development of guidelines for locally attuned communication directed at research institutions and the pharmaceutical industry. This line of work would expand our understanding of the interdependence of the local and the global, or how friction shapes local language practice in research and medical communication. What I also find urgent is the study of the ways in which local language practices in science resist standardization and erasure.

Indeed, one of the big problems I describe through VRC's story is the slow displacement of centers of local knowledge production in semi-peripheries like this one. This work highlights the value of local ways of meaning and language making and aims to show what science understood as global or universal loses when such local practices disappear. In Chapter 4, through the detailed examination of one study's genre ecology, I discussed how

the advancement of industry-led research begins to restrict researcher's participation in vaccine clinical trials. In this particular study, the external monitoring company plays a very restricted role: supervising the documentation and veracity of recruitment, consent procedures, and data collection. Still, the visualization of the research mobility system as a whole—especially the critical moments of interaction between researchers and sponsors—allows us to imagine how a research process where these relationships were replaced by the mediation of external actors, like a contract research organization (CRO) would look like and how it would impact the process of conducting a clinical trial. Indeed, as vaccine clinical trials become more scalable and industry-led, interactions between researchers and sponsors become more complex, mediated by CROs and their lawyers, and research processes and written documents generally standardized. In turn, researchers must increasingly navigate several layers of bureaucracy or are simply unable to make any relevant contributions to the design of the research and its implementation protocols.

As VRC's experience discussed in this chapter suggests, it is often local researchers, engaged in the production of locally relevant knowledge, that constitute the strongest advocates for research participants. As my findings in this chapter suggest, in caring for the quality and relevance of the work, local researchers also made sure that participants were not exposed to unnecessary risk or involved in a research project without fully understanding what their involvement entails and genuinely consenting to participate. This raises questions like: Through what mechanisms can research participants be properly protected against harm in research conducted by CROs? What are the possibilities of producing locally relevant knowledge in an industry-led international vaccine research context? And, where does local vaccine research happen in the peripheries once vaccine research is completely dominated by big pharmaceutical industries? While these questions remain unanswered in this work,

this chapter does provide some orientation in the understanding of why local research and perspectives on clinical research matter. I argue that ethical considerations are locally situated; they cannot be scaled or reproduced unchanged across borders but require an understanding and orientation to locality. The complex network of interactions between researchers from different locations, sponsors, and international agencies, as well as the exemplary instances where VRC researchers argued for what they saw as the right way forward in a research project like the Meningococcus study suggest just how much influence relatively “minor” peripheral actors could have in pre-industrialized vaccine research collaborations. I suspect, as well, that these collaborations went a long way in putting these researchers—and Chile as a country—on the international map, and that this, in turn, facilitated access to much-needed vaccine products. In an international context where equitable access to vaccines is urgent to control global pandemics, and where the participation of diverse actors is an important move towards social justice in scientific knowledge production, understanding what underlies these dynamics matters.

In this project, I explore center-periphery collaboration dynamics and how these shape localities, the narratives about the local, and locality as language practice. In Chapter 5, I use interviews to tease out what the concept of locality means throughout this project for US researchers collaborating with colleagues in Chile and for VRC researchers engaging in international research in ways that remain locally relevant and locally attuned. Following Pennycook (2010) and Tsing (2005), I argue that locality and friction are related concepts. Friction speaks of how the unevenness of the world is felt by actors when moving across borders. Friction is both necessary for movement, and a product of opposing forces that could eventually stall it. Likewise, locality is a relational concept. It describes the relationship, between “here” and other places (localities); between a specific place, and the world; the

peculiar ways phenomena are experienced in one location, and the way these are tied to global movements. So, I am interested in *localities* as places of friction, where the *local* is constructed both by place or fixity and entanglement with global flows. Through this chapter I examined how throughout its research life VRC attempted to construct and represent itself as an independent research center, responding to local needs, defining and asserting its own principles, and pursuing its own research interests, while being historically tied to a research institution in the US and depending on the global networks that sustain vaccine research. VRC's case exemplifies how local researchers who intend to participate in international academia are inevitably entangled with global phenomena and are often complicit in the dynamics that sustain global asymmetries. But this case also shows how local perspectives on international scholarship can help counter the narrative that knowledge is only produced in the Global North, by powerful high-income countries.

Indeed, the examination of rhetorical propriety (Agnew, 2009) in scientific communication offers an opportunity to visit moments in which researchers from VRC checked centric countries' scholars on the academic rigor of their claims. Propriety in scientific writing and speaking, I argue, is more than a mere nicety or deference towards the audience, it is also the rhetorical enactment of intellectual restraint. That is, proceeding with caution there where we cannot ensure the certainty of our statements, which in turn, protects us—and especially scholars in geopolitically more powerful countries—from committing epistemic injustices against less powerful peers out of ignorance or neglect. These kinds of findings also suggest the need for further work on the concept of propriety and its rhetorical enactment changes in time in scientific communication, especially in the context of North/South collaborations. On this same line, a more extensive look at how scholars from the peripheries review the work of colleagues from more centric regions would offer

interesting insights into the occluded ways in which these scholars contribute to shaping scientific knowledge.

The nostalgia that drives this project hints at VRC's story is also a story about good things coming to an end. As I have phrased it before, it's a story about what the scalification of vaccine research has left in its wake (Tsing, 2005) or what happens when the industrialization of vaccine clinical trials expands making research at centers in the peripheries, like this one, unsustainable. Stories like the one I tell through this work show how the participation of researchers from the peripheries and semi-peripheries in international academia is often precarious, and how their emergence and success is often tied to the whimsical goodwill of more powerful partners in the geopolitical center. As Dr. Friend points out, in these cross-border collaborations across differences, a single person can often make or break important collaborations. This project underlines the importance of expanding our understanding of the context of writing practices beyond disciplines, communities, or situations. As Kell (2009; 2013) argues, the literacy event as a unit is often not enough, text trajectories travel time, space, and cross national borders. In other words, what explains local language practices at VRC is enmeshed in global-scale phenomena.

I expected to reach this point in the writing of this project with a sense of closure, fulfillment, and even a degree of saturation or fatigue with my research topic and questions. But the truth is that I find myself with more questions, hungry for more of these stories, uneasy about the extent of my ignorance. I look back on the guiding questions I formulated for myself at the beginning of this process—which I spell out in the introductory chapter—and I find them perplexingly naïve: *How do transnational flows and collaborations shape scientific knowledge production?* And, *How do transnational flows and collaborations shape scientific research writing?* These seem now like questions for the work of a few

lifetimes. In the understanding of transnational/global movements of knowledge and knowledge production, I have not even scratched the surface. I have, however, gained a better understanding of the stories that shaped the research life of this vaccine research center located at the very end of the world. This tells the story of the challenges that VRC researchers encountered as they faced an increasingly globalized and industrialized international research context; the kinds of research and language practices through which they asserted their principles and values and made space for their intellectual contributions in an uneven world. And I have gained a sense of the stories that would make this understanding more complete, the future projects that stem directly from this one. I will outline three of these possible lines of work below.

This project so far has dealt with written documents from VRC's archive, their linguistic and rhetorical features, and how researchers, and most often VRC's principal investigator (Dr. Arce) describe their language practices, both in written documents and throughout their research lives. However, there remains a big gap in the understanding of these communications, and that is research participants' perspectives on them. As I mentioned in the methodology chapter, it was my initial purpose to reach out to former VRC research participants to gather their narratives on their experiences of being confronted with complex documents like informed consent forms and being involved in clinical research in general. On this same line, it would be interesting to have a fuller account of the way research staff—nurses and health technicians recruiting and implementing the consent protocols on the ground—worked with the documents when communicating with potential participants. What kinds of translations (Gonzales, Bloom-Pojar, Perez, et al., 2018; Halliday, 1992) were necessary when walking participants through consent documents and the implications of participating in a clinical trial? What kinds of questions did they most often get? And what

ethical challenges emerged during these conversations? This is the first of these lines of inquiry that I see as an immediate continuation of this work.

A second line of work also deals with consent protocols and procedures. During my work in the archive and during conversations with my mom and nurse Mónica, I realized that throughout the years, researchers at VRC tried out different strategies to communicate the complex information they needed participants and potential participants to understand. This led them to produce different kinds of visual aids and supporting documents for the informed consent procedure. To understand informed consent as a complex practice and genre, it is critical to consider these supporting documents too, as well as the researcher's discourse around them, regarding both the decisions they made in the construction of this material and the decisions they made in their implementation. This line of work would put this project in conversation with current discussions in Rhetorics of Health and Medicine that discuss graphic medicine or the use of visual aids in medical and biomedical research settings (Brand, Gao, Dreger, et al., 2021; Garcia-Retamero, & Cokely, 2017; Heerman, White & Barkin, 2015).

The third line of work I imagine stemming from this project would study cases that resemble VRC. One of these, which I have mentioned as an example in Chapter 4, is the case of the research center in Mali within the same network as VRC—that is, with the same “parent” university in the United States. The Mali case would offer interesting parallels to the discussions I develop here around the strategies that researchers in the peripheries utilize when trying to find locally attuned ways to communicate complex specialized information to the local public. Additionally, most likely, researchers in Mali have also suffered the transformations in vaccine research models I have described here. Another interesting case would be that of a center in Argentina, founded after VRC, also in collaboration with a



research institution in the US that is still operating today. The fact that this center exists shows that, though the industrialization of vaccine clinical trials can transform the conditions under which researchers work, it does not make them impossible. Looking at cases like this one in Argentina could help answer the question about where vaccine clinical trials happen in peripheral countries when industry-led research is dominant, what it looks like, and what kind of agency local researchers have in this new kind of collaboration. Thinking of these possibilities fills me with curiosity and gives me hope.

Finally, I believe the work I have done throughout this dissertation has implications for transnational writing studies more broadly, especially as we try to imagine a more socially just international academia and try to build collaborations and partnerships across borders. As I have shown, VRC's precarity and inability to outlive transformations in global dynamics was not due to the quality of its scientific work or the value of its contributions, but rather, to its inability (or the impossibility) to create mutual dependency and institutional allyships beyond the capacity of one or two very invested individuals. VRC's exemplary case of friction is also a good reminder that isolation is a poor approach to decolonizing academic spaces. Further, the history of this center's contributions to international knowledge on vaccines and infectious diseases, and the important contributions that local perspectives contribute to the field show that it is not only the peripheries that can lose with such isolation, but also knowledge understood as universal, or *worldly* (Pennycook, 2010).

## Appendix 1

### **A note on interview transcription and translations practices for this work**

Throughout this work I use brackets [- -] to identify elisions in interview transcriptions. Elisions are not meant to distort the meaning of a participant's words, but rather, to favor succinctness, making examples speak to a specific point, and avoid bringing too many tangential themes into the text. In this same sense, I have used brackets to insert language in interview transcriptions and translations in order to complete the sense of a phrase when this was left incomplete or open-ended by the participant. I took the liberty to intervene interview fragments like this only when the general sense of the participant's words was evident from the context of the interview.

All translations are my own and I have done my best to capture language choices, and have translated figurative language, when possible, though I have sometimes opted for more idiomatic translations.

## Appendix 2

This section contains materials supplementary to Chapter 3.

*Table I: Sections of the ICF per year/sample*

	1996	2001	2002	2004	2005-2006	2007	2007-08	2008-2009
Sponsor ID								X
Participant ID				X	X			
Salutation	X			X		X		X
Abstract					X			
Introduction	X	X	X	X		X	X	X
Abt. the antigen					X	X	X	X
Abt. the vaccine				X	X		X	X
Alternative vaccines								X
Study rationale				X	X	X	X	
Vax. administration procedure				X				
Conditions & procedures		X	X		X	X	X	X
Inclusion/Exclusion criteria		X		X		X	X	
Methodology				X		X		
Duration of the study				X				
Risks	X	X	X	X	X	X	X	X
Benefits	X	X	X	X	X	X	X	X
Alternatives to participation		X	X		X	X	X	X
Precautions taken						X		
Participant rights & obligations		X	X	X				

Researcher obligations		X	X					
Confidentiality				X	X			
Use of remaining samples				X	X	X		X
Costs and compensations				X		X		
Ethic & responsibility statement			X		X			
Statement of ethics approval		X	X	X			X	X
Other aspects of participation	X					X	X	X
Contact information		X	X	X		X	X	X
Consent declaration	X	X	X	XX	X	X	X	X
Assent declaration			X					

Quite telling of the growing complexity of the genre is that the number of sections in these documents tends to increase over time. Table I above shows the sections found in each ICF of the sample. Highlighted in green are the longest sections of each document, and in yellow, the second longest section. These parts or sections do not describe contents or themes, but formal structures created by the texts' author. Thus, some ICFs may contain information about a topic but not a specific section dedicated to it. For example, contact information can be found in all consent forms in one way or another, but the sample from 1996 has no section specifically dedicated to this content; instead, the leading researchers' information is included at the very end of the introductory section. Other text sections or parts are unstable over time and don't follow a clear pattern or rationale for when they appear or disappear as parts of the text. The study from 2004, for example, contains a specific section discussing the vaccine administration procedure which is absent from all other ICFs; the study from 2005-2006 is the only one with an initial section akin to an abstract, synthesizing the purpose and contents of the document; and the sample from 2007 is the only one with a "Precautions taken" section, explaining all the measures that will be taken by the research team to safeguard participants' safety.

Table II: Rhetorical Strategies in ICFs

Appeal / Strategy	Description
<b>Ethos</b>	
Referencing the developed world	Mentions the conduction of similar studies or the use of the experimental product in more developed settings.
Showing credentials	Mentions to the author's titles or positions or institutional affiliations.
Underlining participant rights	Highlights participant rights such as privacy, confidentiality, or autonomy.
<b>Pathos</b>	
Anticipating concerns	Presents information to counter possible sources of hesitation for the reader regarding risks, pain, or discomfort associated with participation.
Appealing to the reader's altruism	Points out that participating in the study may help build new knowledge, contribute to public health or help vulnerable populations.
Inviting positive attitudes towards science	Describes scientific knowledge using value-language. Usually implies is the idea of progress or advancement as associated with science as something desirable.
Offering access to social goods	Presents the conditions of the study as an opportunity to access social goods such as health care or medications that might otherwise be unavailable to participants.
Wearing the participant's shoes	The author adopts the reader's stance within the text using first person. Ex.: <i>What are the risks for my child?</i>
<b>Logos</b>	
Argumentation	Presents the development of a logical thought process with premises or evidence and conclusions. Argumentative passages are characterized by an abundance of logical connectives.
Avoiding misinterpretation	The reader is stirred away from drawing conclusions that may result in misunderstandings of the conditions, especially benefits, of participating in the study.

Explaining rationales and procedures	Explains the purpose of the study and the way in which it will be conducted.
Signposting	Language used to guide the reader through the ICF, anticipating parts or contents of the text.
Referencing existing knowledge	Mentions studies or accumulated knowledge to substantiate a claim or position.
**Basic information	Facts regarding antigens, pharmaceutical products, diseases, adverse reactions, or other information that the potential participant should be made aware of.

I hesitate to categorize “Basic information” as a persuasion strategy. Many of the fragments coded in this category provide definitions or describe potential adverse effects or risks associated with the pharmaceutical products or the procedures involved in the study, and these are sometimes mitigated with hedging. When hedging is used, it is difficult to judge whether it is aimed at easing the reader’s fears or hesitation, or simply a mechanism to convey the degree of the risk involved in participation as accurately as possible. See, for example, the two examples below:

**Example A- Hedging: Motavizumab (2007), Ref.6**

Puesto que motavizumab es una proteína extraña, **existe la posibilidad** de que el organismo reaccione desarrollando anticuerpos contra el medicamento. Estos anticuerpos **podrían causar** una baja de las plaquetas...

*Since motavizumab is an extraneous protein, **there is a possibility** that the organism reacts developing antibodies against the medication. These antibodies **may cause** a drop in platelet counts...*

**Example B- No hedging: Meningococcus B (2008-2009), Ref.3**

La toma de una muestra de sangre **produce dolor** momentáneo en el sitio de la punción...

*Taking a blood sample produces momentary pain at the puncture site...*

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## Vita

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Ana Cortés Lagos is a Chilean writing studies scholar, she is a doctoral candidate in Composition and Cultural Rhetoric at Syracuse University and holds a BA in Literature and Linguistics from Pontificia Universidad Católica de Chile. Her research interests include WAC/WID, rhetoric of science, rhetoric of health and medicine, and transnational writing studies. Her current research studies writing and language practices at a vaccine researcher center located in Chile working internationally in a changing global landscape. Her most recent publications include “Mirroring Lautaro's Gesture: Toward a Canon in Latin American Writing Studies” (*College English*) and the co-authored piece “Do we train teachers on writing? Writing opportunities across the curriculum in elementary teacher education programs” (*Calidad en la Educación*). She is currently co-editor of the Latin American Section of the WAC Clearinghouse International Exchange in the Study of Writing book series, and Associate Editor of *RLEE* (*Revista Latinoamericana de Estudios de la Escritura*).