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Transformative Consumer Research Conference 2021 (online)*

**Developing Transformative Consumer Research  
Methods and Engagements for Hard-to-Reach  
Populations**

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# 1. Introduction

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## **Improving Strategies for Engaging Hard-to-Reach populations: A Casebook for Inclusive Research**

In an era where the principles of equality and diversity rightly permeate every aspect of our lives, this casebook originates from a compelling need to align empirical research with these values. Often, research expediency takes precedence over inclusivity, resulting in data drawn from readily accessible and available channels. This practice, however, stands in stark contrast to the core ethos of academia—a mission that calls for pushing the boundaries of knowledge, testing theories in unexplored territories, and venturing into the unknown. Achieving this mission necessitates looking beyond easily accessible data and study groups just because they are more easily available. By deliberately or inadvertently excluding those populations who are hard-to-reach, we risk drawing inferences and conclusions about the world that are, at best, insufficiently nuanced, or at worse, inaccurate or just wrong.

In the dynamic landscape of Transformative Consumer Research (TRC), understanding the complexities of Hard to Reach (H2R) populations has never been more crucial. By their very nature, H2R populations are challenging to access, wide ranging, and often lack a clear definition. They might be physically remote (e.g. in the Amazon), face personal circumstances limiting access (e.g. street children), be hiding their background (e.g. sex workers), be underrepresented in the wider demographics (e.g. neuro-diverse individuals), pose political challenges for the researchers (e.g. organizations in Russia), or have fuzzy boundaries (e.g. youth). While these groups are usually merged into the H2R designation, each presents distinct methodological challenges, and needs unique research strategies. Additionally, many researchers lack the formal training, skills, experience or networks to undertake successful data collection with H2R groups.

This gap persists despite the presence of researchers in social sciences and related fields (e.g., education, health) who have a wealth of experience working with specific H2R populations. In fact, disciplines such as anthropology, medical/health

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studies and education have deeper history of working with H2R populations (e.g., Bonevski et al., 2014; Kakos, Müller-Hofstede and Ross, 2016), and thus can give social scientists insight into how to capture the H2R. Likewise, the varied perspectives of social science scholars have the potential to bring additional clarity to both definitions of hard-to-reach and how to reach them. Yet to date these disciplinary insights often remain siloed. Engaging meaningfully with H2R communities, often marginalized and underserved, offers invaluable perspectives that are instrumental in shaping a comprehensive understanding of consumer behavior. This casebook seeks to fill an unaddressed gap, aiming to frame H2R groups in dignified ways and support researchers in the business, management and organizational studies fields to understand and effectively connect with these populations.

This compendium of case studies is the result of the collective wisdom of international scholars who contributed to Track 1.6, led by Dr Laurel Steinfield and co-chaired by Professor Diane Holt, at the TCR Conference (online, 27-30 June 2021). Together, researchers delved into TCR methods and engagements for H2R populations, working towards a more inclusive landscape in social science research. A framework was co-created with conference participants and used by each participant to prepare a case study that explores the challenges, cautionary measures, and successes on how they researched, engaged, and cultivated solutions/programmes with a certain ‘type’ of H2R population. Details of the takeaways from the conference session are elaborated in [Chapter 2](#).

Building from this session, we present case studies that serves as a testament to the transformative potential that arises from bridging theory and practice in these often-overlooked communities. The key objectives are:

1. to capture how researchers engage with H2R groups in practice by considering best practices for (1) negotiating access, effective engagement, improving recruitment, decreasing attrition, (2) producing high-quality research and (3) navigating the lived messy reality of H2R research;
2. to improve understandings of H2R groups in different contexts, to add clarity to the conceptualization of hard-to-reach, and to develop methodological techniques and cases for those engaged with different H2R groups in a variety of fields;
3. to support the establishment of best-practice techniques field researchers might use to access and obtain high quality data from different types of H2R populations.

Aiming to advance quality social science research in these arenas, this casebook represents a significant resource for current and future researchers, with the

potential to shift the perception and skillset of those investigating H2R communities.

### **H2R Populations in the Social Sciences: State of the Art**

The imperative to reach H2R populations is fundamental across various disciplines within the social sciences. These populations encompass individuals (or organizations):

- facing spatial disadvantages such as those in rural areas (Corus and Ozanne, 2012; Steinfield et al., 2019);
- located in prison settings (Hill et al., 2015);
- residing or operating in (post)conflict zones (Barrios et al., 2016);
- living transient lives (Abrams, 2010; Rogers, 2019);
- being rendered invisible, marginalized, or forgotten by policies, societal norms, and/or market dynamics (Cortis, 2012; Hill, 2002; Kakos et al., 2016; Mahrt et al., 2020; Saatcioglu and Ozanne, 2013);
- concealing their identities due to the risk of social stigma (Machin et al., 2019; Raymond et al., 2019; Yeh et al., 2017);
- engaging in hidden behaviors or facing personal risks (Faugier and Sargeant, 1997; Hill, 1995);
- being elusive because prior engagements with researchers, policy makers or practitioners has resulted in injustices, including unethical and harmful medical experimentations (Harris et al., 1996), cultural genocides, extractive practices and epistemic injustices (Goodman et al., 2018; McGregor, 2018; Tuhiwai Smith, 2021); and/or
- requiring researchers to put themselves in physical or political risk to be accessed (Crotty, 2009).

Establishing meaningful connections with these groups is essential for expanding engagement with research informants. However, researchers continue to struggle to gain access with them. Consequently, government censuses frequently fail to capture H2R populations (Ibarraran and Lubotsky, 2007; Mathy et al., 2002) and businesses often misunderstand how to effectively engage with these groups (Pechmann et al., 2011). Furthermore, definitional and methodological fragmentation, and the potential for pathologizing H2R groups as ‘vulnerable’ or ‘victims’ (Kakos et al., 2016) can further undermine research efforts. Thus, a more robust understandings of suitable practices for identifying and engaging with H2R groups are needed.

Social science research, particularly that in business and management, is being called upon to conduct research with H2R groups to push the boundaries of existing theories. To do so requires addressing the geographical and Western-bias challenges (as evidenced by calls to include research settings such as sub-Saharan Africa (George et al., 2016), and to expand research into more diverse institutional and organizational settings (such as those in low or middle-income countries). While work in management/marketing studies has started to extend into new H2R settings in places such as sub-Saharan Africa (Rivera-Santos et al., 2015; Steinfield et al., 2019), within micro-enterprises set in the informal economy (Holt and Littlewood, 2017) and in non-profit organizations advocating rights protection under autocratic rule (Crotty and Ljubownikow, 2020), many H2R groups remain under-explored. Rural community groups, those who undertake personal risk in participating in research, or who are physically challenging to reach, e.g. in Extraction Reserves in the Amazon or in warzones, are just a few examples.

The pilot study of academic literature conducted by Professor Holt from June 2019 to March 2020 provides a compelling example of the lack of engagement with H2R participant populations in this disciplinary field. This pilot study was carried out to operationalize a framing typology (see [Table 1.1](#) below) developed by Dr Andrea Rossi. Rossi (2020) is the former Director of the Harvard Measurement and Human Rights Programme at Harvard Kennedy School of Government (USA) and Senior Advisor on Social Policy and Economic Analysis for the United Nations in East Asia.<sup>4</sup>

This pilot study reviewed 908 Business and Management articles published during the last three years to identify populations researched. The analysis of these papers found a demonstrable absence of H2R participant populations with only 11.8% of the sample classed as having moderate or high engagement with hard-to-reach as described by [Table 1.1](#). To contextualize this engagement, a scoring system ranging from 0 to 6 was established, with 0 indicating no discernible engagement and 6 signifying a study exclusively focused on individuals classified under the H2R category. Notably, the majority of the articles exhibiting moderate to high engagement scored within the range of 4 to 6. Where there was a focus on those considered as hard to reach these studies demonstrated an absence of recognition as to the diversity of H2R groups, little consideration of specific methodological

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challenges, or a lack of consistency in how H2R was defined across the extant studies. Very few studies also self-identified as researching a H2R population, which may be indicative of the latent stigma attached to such populations. Methodologically there also seems to be little engagement with different collection techniques suggesting a need to expand knowledge on how we can engage effectively with the hard-to-reach.

*Table 1.1: Hard to Reach categories of respondents utilized in pilot (adapted from Rossi 2020)*

<b>Type</b>	<b>Description</b>	<b>Examples</b>
Small/rare	Small number/proportion within overall population. Not hidden but small ratio difficult to sample in larger population.	Rare illness
Hidden	A group in a population that is difficult to physically access or have characteristics hard to identify by the researcher.	Indigenous peoples, trafficked women, people with mental illnesses
Elusive	A group who hides from researchers in a population through non-reporting, non-response or hiding.	Drug-addicts, homeless
Marginal	Not considered of interest/relevance to the broader research/ policy/practice community, with lack of interest by society.	Topic such as gentrifying communities
Excluded	Excluded from the mainstream by a lack of agency or freedoms often administered by a third party.	Prison inmates, Roma, campaigners in non- or semi-democratic regimes
Blurred	A group whose definition is contested or changes over time or depends on situation, making consistent sample difficult.	Street Children, Autism, Youth

In addition, the variety of uses of the H2R term across disciplines creates a methodological challenge. Social science related studies, tend to categorize H2R populations based on types of behaviors or social conditions that push people to the margins of society, making them difficult to find or hidden (Flanagan and Hancock 2010), ‘marginalized’ (Faugier and Sargeant, 1997, p. 790) or displaced (Rogers, 2019). Within social welfare studies, hard-to-reach focuses on inaccessibility,

namely those who do not or choose not to access services available to them (Cortis, 2012). Within health and medical fields, H2R populations are often defined by demographics (e.g., ethnic minority), and/or environmental (e.g., rural) characteristics (Cooper et al., 2014), and so are physically hard to reach. Indeed, the state of the literature may be best summarized by Flanagan and Hancock (2010) who note that:

“the sheer multiplicity of alternatives reflects the divergence in the discourse as well as the difficulty in arriving at a definitive description of its meaning...There was an overarching sense that trying to engage the ‘hard to reach’ is problematic...and this may be due to the inherent ambiguity and lack of clarity of definition. Assignment of the term appears largely dependent upon the context of the organization doing the reaching” (p. 2).

In addition to the definitional dilemma, H2R populations can also be viewed negatively, “pathologiz(ing) groups as abnormal and aberrant: they are seen as deviant, resisting the normalizing agencies of the dominant society.” (Kakos et al. 2016, p. 11).

In this context, the progress of work with H2R groups is also being hampered by definitional vagueness. The boundary definitions of what the term hard-to-reach means, and the nature of those within it, is often framed at a superficial level that sees hard-to-reach as one population, failing to recognize the diversity that exists within. Moreover, not all researchers have the skills, experience or networks to undertake successful data collection in the challenging environments where H2R populations are often located, and so revert to the easy to reach.

### **Significance and Potential Beneficiaries**

The methodological challenge of engaging H2R populations in research transcends international boundaries. This casebook responds to the imperative to deepen our comprehension of this methodological challenge and outlines the innovative approaches needed to tackle it. It contributes to a more nuanced understanding of different types of H2R research participants, offering invaluable insights for researchers targeting these groups and thereby making a significant contribution to the development of more inclusive and effective economic and social science research and researchers. The resulting insights hold the potential for far-reaching policy and practice implications. For instance, they can facilitate the re-evaluation of previous survey data, enabling direct comparisons between different H2R groups. Specifically disaggregating into different types of H2R groups allows researchers to truly compare like with like across prior datasets, or to explain variabilities in what might appear at first glance to be the ‘same’. Additionally, this research can inform the development of more precise targeting strategies for

including H2R populations in census-style studies, social programs, and market-based initiatives. The issues identified in this casebook, based also on researchers' real-life experiences, not only engage with but also resonate with international academics, organizations, and communities on a global scale. This diversity, spanning both geographical and disciplinary realms, enriches the research findings and expands their practical application.

A selection of the work of participants to the TCR conference is profiled in this casebook. A summary of the case studies' contributions, along with detailed biographies of the respective authors is provided in [Chapter 5](#). There were a wider range of examples presented and discussed during the conference. In this book, we provide a selection of this to deepen the H2R conversation that we present. Given that sampling H2R populations and achieving effective access presents a universal challenge for researchers worldwide, the outputs from this casebook carry significant potential impact and benefits for international academics. This casebook serves as a vital resource for researchers at all stages of their academic journey, both in the UK and abroad, who are keen on conducting research that is both effective and inclusive with individuals, organizations, and communities classified as hard-to-reach. Its relevance is particularly pronounced in ongoing dialogues concerning marginalized groups and inclusivity. Moreover, it aligns with the imperative set forth by the UK Research and Innovation (UKRI) to advance our comprehension of and address methodological challenges. Ultimately, it supports methodological advancements for academics who seek to design and deliver research activities within H2R populations to improve access, response rates and data quality from within the hard-to-reach that is currently missing from both practical and theoretical perspectives.

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## 2. Developing TCR Methods and Engagements for H2R Populations: The Takeaways from a Dialogical Engagement

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The Transformative Consumer Research (TCR) Conference offers an opportunity for people to come together and discuss topics that are key to addressing social and environmental problems. TCR, which grew out of the Association of Consumer Research (Mick, 2006), aims to “encourage, support, and publicize research that benefits the quality of life for all beings engaged in or affected by consumption trends and practices across the world” (Mick et al., 2012, p. 6). Over the course of the dialogical conferences (held every two years since 2015), numerous articles and engagements have pushed forward the mandate, resulting in highly-cited and impactful research (Davis et al., 2016; Davis and Ozanne, 2019). A significant part of this work is premised on the format the conference adopts. Rather than presentations or panel sessions, scholars and practitioners come together to collaborate and discuss insights around key topics. There are three different types of tracks to which (co)chairs may apply: Track 1 is based on establishing capacity and a shared theoretical framework through sharing perspectives; Track 2 furthers the work of Track 1 by undertaking theory-guided research work, which may involve the collection and co-analysis of data; Track 3 focuses on implementing

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solutions by bringing together academics and practitioners (Davis and Ozanne, 2019). The session we undertook in June 2021 was aligned with Track 1.

In this session (Track 1.6) we brought together scholars to discuss their experiences of engaging with Hard to Reach (H2R) populations. In this chapter we summarize this experience, starting with the call for scholarly and practitioner engagement to help frame the conversations, followed by a description of the process, the outcome and the key takeaways.

### **The Call**

Researching ‘Hard to Reach’ consumers is a common element of TCR research given its goals of improving the quality of life for consumers. As noted in Chapter 1, these include studies with those who are geographically elusive or marginalized because they live in difficult-to-reach rural areas (Corus and Ozanne, 2012; Steinfield et al., 2019), are in prisons (Hill et al., 2015) or in (post)conflict zones (Barrios et al., 2016)); who may be made invisible or marginalized by policy, society and/or market places (Hein et al., 2016; Hill, 2002; Saatcioglu and Ozanne, 2013); who face risks of social stigma due to mental health (Machin et al., 2019; Yeh et al., 2017); and who may desire invisibility due to illegal behaviors or vulnerable status (Hill, 1995).

A core takeaway from a transformative consumer lens has been for research to be done in such a way that can advantage these populations (Corus and Ozanne, 2012; Hill, 1995; Pechmann et al., 2011). Yet how to do this has yet to be fully articulated.

During the conference session (Track 1.6), practitioners and academics advanced this work by drawing on their insights to create an open-access repository of best practices. These best practices explore how to research, engage, and cultivate solutions to improve the wellbeing of different types of H2R populations. As academics in health and social sciences note (Bonevski et al., 2014; Ellard-Gray et al., 2015), there is heterogeneity in these types of populations that need to be appreciated and recognized by research and practitioners. Indeed, within the TCR scholarship, while some scholars advocate participatory action or community action research for marginalized communities (e.g., Corus and Ozanne, 2012), others have taken a different approach given the high-risk stake of the research contexts (Barrios et al., 2016) or risks to participants [i.e., law offenders (Hill, 1995), unregistered immigrant communities (Crockett et al., 2011)].

In order to facilitate this session, the co-chairs (Laurel Steinfield and Diane Holt) provided a baseline of information on how relevant extant studies have undertaken research with H2R populations. However, while this information may be helpful,

we acknowledge that the very definition of ‘hard to reach populations’ implies less conventional methodologies that are rarely communicated in sanitized versions of academic publications. The time at the TCR conference allowed us to delve deeper into the realities that are often hidden in methodological write-ups.

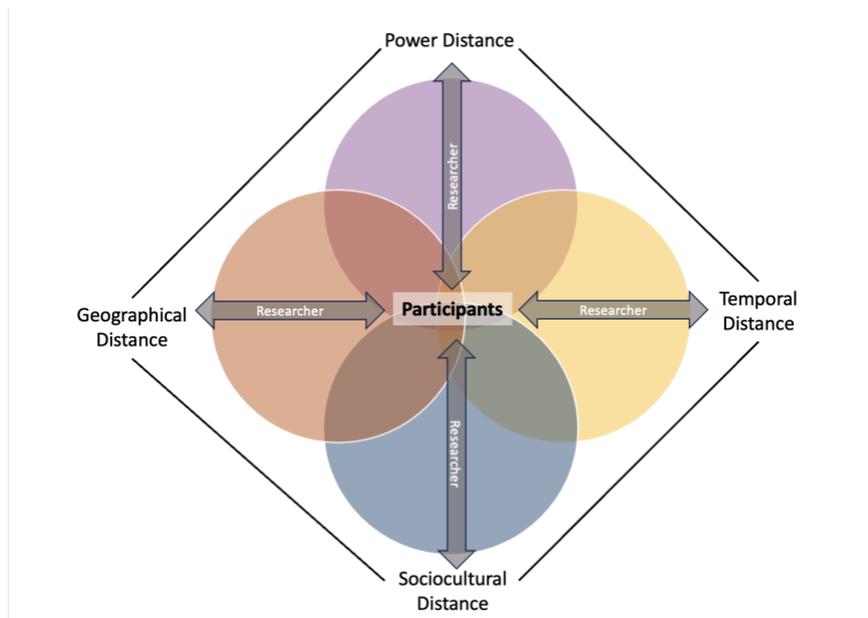
### **The Session**

Over the course of two days, through a virtual dialogical session (due to Covid 19), we shared many ‘behind-the-scenes’ challenges and successes of doing research and developing programs to improve the wellbeing of different types of H2R populations. [Table 2.1](#) presents the conference participants, composed of academics at different career stages with experience in working with various H2R populations.

While the session started out with the table proposed by Rossi (2020) focused on the characteristics of H2R populations (see [Table 1.1](#)), the conversation soon turned to the interaction between researcher and the H2R populations. The following question was posed: *What was it that made it difficult for these populations to be reached?*

Delving further into this question revealed distances between the researcher and consumer to be a fundamental challenge. These distances included:

- **Geographical:** Distances between where we were physically located;
- **Temporal:** Time zone difference but also conceptual differences in regard to time with Western-centric ideals being more rigid, linear, and present-focused than Indigenous and Global-South ideas that can be more highly developed, complex, and longer-term focused (Mughal, 2023);
- **Socio-Cultural:** Distances between cultural understandings and ways of doing things, which could also be framed via institutional theory as representing differences in expectations of regulations, norms/ideals, cultural-cognitive meanings (Scott, 1995).
- **Power:** Distances between the researcher and consumer given symbolic status or privileged positionality of the researcher, with a recognition that these distances needed to be challenged and flattened to establish trust and mutually beneficial relationships.



*Image 2.1: Various distances between researcher and participants that can contribute to H2R phenomena.*

Building from this, the conversations explored how this ‘Hard to Reach’ phenomenon involved other elements as well. It was not just the people involved in the engagement, but also the structural mechanisms and the data. To build out this idea and to test whether it had merit, each participant took their individual case and, on their own individual jamboard, detailed how these elements showed up in their experience. An example of individual jamboard is presented in [Image 2.2](#). The resulting outcome is detailed in the next section. The session concluded on day 2 with the team coming together to discuss the jamboards, to create an outline for case chapters that could capture these insights, and to share brief recaps of the cases they could write.

*Table 2.1: Research participants and affiliations at the time of the conference or currently.*

<b>Participant Name</b>	<b>Affiliation</b>
Laurel Steinfield	Ivey Business School, Western University, Canada
Diane Holt	University of Leeds, UK
Samanthika Gallage	University of Nottingham, UK
Jo Crotty	Edge Hill University, UK
Professor Robert Newbery	Northumbria University

Jessica Weaver	University of Liverpool, UK
Srinivas Venugopal	University of Vermont, UK
Rohan Venkatraman	University of Melbourne, Australia
Jennifer Sedgewick	Schulich School of Business, York University, UK
Roua Al Hanouti	University of Lille, France
Anthony Beudaert	Savoie Mont Blanc University, France
Daniela Alcoforado	Federal University of Pernambuco, Brazil
Katherine Sredl	Loyola University Chicago, USA
Aurelie Broeckerhoff	Coventry University, UK

### **The Outcome**

Based on the insights shared, we created a framework that recognizes that H2R populations exist for numerous reasons, including:

- 1) The characteristics of respondents;
- 2) The researcher's positionality and characteristics;
- 3) The structural challenges; and
- 4) The type of data sought.

These dynamics are not mutually exclusive. Some may be more apparent in certain circumstances than others. They may all occur simultaneously to augment difficulties, and some may cross over between areas. For example, institutional aspects or misalignments (differences in regulatory conditions, normative expectations and cultural-cognitive meanings) can make data hard to collect, can cause difficulties in accessing research participants, and may also be a structural impediment. The important takeaway is that this framework is one way to think about the research experience in its entirety.

Using this framework uncovered some similarities in experiences but also differences. The words that each researcher shared produced the word clouds visualized and explored in the following sections. Words that are larger capture common themes, although we want to emphasize that words that are smaller, while they may be more specific to certain cases, are just as important to consider. In sum, four themes emerged, as detailed below.



Image 2.2: Example of jamboard prepared by one of the participants during the conference session.

### 1) H2R Because of Characteristics of Participants

*Expanding Rossi's H2R Characteristics – Recognizing Fear, Vulnerability, Stigmatization, Shame and Resistance:* While the framework provided by Rossi (2020) was a starting point—as evidence by words such as excluded, hidden, marginalized, rare, elusive, and blurred—other elements that contribute to creating a H2R phenomenon came to the fore. This included the aforementioned distances (geographical, temporal, socio-cultural or institutional dynamics, power), but also fear, vulnerability, stigmatization, shame and resistance. Participants might be hard to reach because they are fearful or feel shame in being found in situations that go against regulatory or socio-cultural norms, they may fear being stigmatized or punished for participation (by governments, organizations, or friends and family), and they may fear the re-traumatization that could occur in retelling their traumatic experiences. These conditions can result in resistance to participation and put participants in more vulnerable positions. Building trust between participants and researchers, adopting an ethics of care (Groot et al., 2019; Tronto, 2013), and challenging hierarchical power dynamics that place the researcher above participants, emerges as some important steps to take when addressing fear, vulnerability, shame, trauma and stigma.



*Image 2.3: H2R Characteristic of Participants Word Cloud.*

*Nuancing H2R Characteristics:* The jamboards also nuanced some of Rossi’s (2020) descriptors. For example, participants might appear hidden or elusive because there is liminality (transitional rites of passage) in their experiences and/or fluidity in their identities that make it difficult to identify them (e.g., transpeople undergoing transitions). They may be elusive because there is too much heterogeneity with a subcommunity and a lack of uncommon shared experiences, resulting in difficulties in ensuring sufficient representation from the community is achieved. H2R participants may be elusive because of prior epistemic injustices (injustices that occur in the collection and retelling of knowledge) (Fricker, 2007), as has occurred with many Indigenous (Tsosie, 2012), exploited, and marginalized communities (Kidd et al., 2017). They may also be hidden because the identifying characteristics on which the research focuses (e.g., invisible (dis)abilities, distresses, or diseases) require participants to self-identify.

Gatekeepers, trust, and seeking epistemic justice are critical to overcoming these H2R dynamics. The shared perspectives, however, also noted that leveraging gatekeepers is not without challenges. Dependency on gatekeepers can undermine

the research process when tensions arise. Moreover, there are power dynamics between gatekeepers and participants that are rarely considered but that demand attention (Emmel et al., 2007).

*Barriers to Access (Beyond Gatekeepers):* We also note that barriers to access, including language barriers and differing access to technology, literacy levels, and neurodiversity, as well as different world views, can create H2R conditions by making communication difficult between researchers and participants. We raise these concerns to the fore to acknowledge that they often exist—to the determinant of participants—because researchers go in with a colonial mentality that presumes the researchers' way of communicating and collecting data (e.g., interview protocols, surveys) should be adopted. Countering these tendencies demands a bottom-up approach that starts with an understanding of participants and how they would prefer to communicate. This may include recognizing the importance of oral traditions, verbal arts and storytelling, and working with communities through respectful engagements to co-design the research approach (Baskin, 2005; Bishop, 1996; Corus and Ozanne, 2012; Datta, 2018; Finnegan, 2003; Iseke, 2013). It also involves challenging colonial presumptions that participants should willingly give their time to research. Recognition and compensation need to be built in to research approaches and acknowledgements given to respondents if desired. Privileging participants is critical to disrupting hierarchies.

## ***2) H2R Because of the Researcher's Positionality and Characteristics***

*General Challenges:* H2R conditions can arise because of the aforementioned geographical distances and lack of infrastructure (an institutional misalignment), which make it hard to get to participants. Socio-cultural differences and lack of familiarity with the context could make it hard to understand each other or make it difficult to foresee fieldwork challenges. And power dynamics between researchers and participants influence levels of trust. The characteristics of researchers—and whether they are an insider or outsider—inform many of these conditions while adding complexities to them.



*who might be?* In short, the researcher's positionality matters and should be recognized (Joy et al., 2007; Ozanne and Fischer, 2012; Steinfield and Holt, 2020).

*Recognizing Harms to Researchers and Participants:* Research with H2R participants can be hard and challenging. Researching sensitive, traumatic, and/or dangerous topics can put researchers at risk for emotional, mental, spiritual and physical harm. Situations in which researchers fear for their very lives can occur. Researchers can face data burdens when having to re-read and analyze difficult data. Rarely are researchers trained in how to address these harms, yet harms do exist. Moreover, during the TCR session we recognized that there is considerable tension when working with H2R related to how researchers can join on an empathic journey or help participants advance their livelihoods without creating undue harm to the researcher or inadvertently creating a sense of dependency in which participants expect more from the researcher than what can be given. Research ethics forms may prompt scholars to consider these elements, yet there is a difference between prompting people to think about things (some which they may not even know to envision) and training researchers on what to do in these instances to ensure self-care and boundaries.

*The Role of Researchers:* When working with H2R participants, a researcher's positionality often expands beyond being a data collector and academic disseminator. It becomes about being an ally, advocate and activist. Many of the TCR scholars recognized that the voices of H2R should not be limited to academic journals but be extended and leveraged to address the conditions that cause them to be hard to reach. Doing this work is not easy and calls for additional emotional, physical, and mental labor that is not always recognized. Scholars working with H2R need to take this into account so they can build in time for the important work.

*Managing Tensions:* Being an ally, advocate and activist comes with tensions that need to be managed. Researchers may have to make hard choices in whether to work as an activist—lobbying for change—or as an ally, seeking to build bridges to powerful stakeholders. Deciding whether to form partnerships with stakeholders versus lobbying them for change is a decision that requires community involvement to make, particularly if researchers are committed to reducing hierarchies between them and those with which they work.

Researchers may also find research becomes hard to do because they face tensions when managing differing expectations of the stakeholders and institutions involved, academia, and that of research participants. For example, data ownership is typically something that universities and/or involved external stakeholders and/or researchers believe they own. Yet Indigenous methodologies and participatory methods challenge these assumptions (Carroll et al., 2020; Kukutai and Taylor,

2016). Adopting these more inclusive and decolonial ways of doing research may demand researchers take on the additional role of being an institutional entrepreneur, seeking to change structures that work against these taken-for-granted assumptions.

### 3) *H2R Because of Structural Challenges*

Structural challenges that create H2R conditions were noted from two perspectives: i) those that research participants encountered; and ii) those that researchers encountered.

*Structural Challenges Faced by Research Participants:* Socio-cultural, normative, and regulatory institutional structures, and the underlying power dynamics, contribute to H2R experiencing marketplace exclusions as well as marginality and misrecognitions in research endeavors. That is, it is not just societal elements but also academic elements that perpetuate H2R conditions. Consider researchers that may go in with a different world view (a sociocultural structural misalignment), or official statistics that homogenize individuals and that contribute to institutional data voids (e.g., a lack of data points on individuals that do not fall within the categories used), or exclusionary research practices, or misperceptions that fail to consider if participants should co-own the data. These scenarios can result in research participants feeling like they and their experiences or ways of life may be misunderstood, overlooked and exploited. Research practices need to be interrogated for these structural misalignments.

*Structural Challenges Faced by Researchers – Resistance:* A key structural element that fosters H2R conditions for researchers includes encounters of resistance. This resistance may come from organizations or stakeholders involved (academic-practitioner tensions), or emerge from normative institutions outside as well as within academia. Organizations or stakeholders may resist covering certain topics or work to silence or hide certain participants or data for fear of reputational damage. While gatekeepers were often mentioned as key to overcoming structural barriers, as aforementioned, they themselves can become a barrier by controlling and determining access to certain participants over other participants.

Often these forms of resistance are hidden from researchers and are stumbled upon over the course of the project. Resistance can be something that is hard to forecast, particularly since many research projects start off with assumptions that people have similar interests or that partnerships will remain collaborative. However, taking steps early in the project to safeguard against possible actions of resistance (e.g., a co-constructed engagement plan or a legal research agreement or contracts)

is key, particularly when doing work on sensitive topics that people may want to silence.



*Image 2.5: Structural Challenges Word Cloud.*

Resistance also comes in the form of normative pressures and dominant narratives or policies within society that can make it unsafe to do research with H2R participants (e.g., for fear of backlash against the researcher and participant). Normative pressures and dominant narratives can also appear within academia to act as a dissuasion. For example, scholars studying genders and gender expressions, or subsistence consumers, or neurodiverse people, or refugees recounted warnings that doing so could position them as too niche in academia. The very notion that doing research with H2R is niche is emblematic of the biased nature of mainstream perspectives, which often fail to recognize the rich perspectives that can be gained from H2R participants.

*Academic Culture and Practices:* Key structural challenges occur in academia, particularly with time pressures and publication expectations. The ‘publish or perish’ mantra and pressures for pre-tenured faculty or those seeking promotion to

achieve publication ‘hits’, is at odds with the time needed to establish trust and meaningful relationships with H2R consumers. These expectations are also at odds with true community, participatory research in which data ownership is shared. Gaining agreement on how data should be used is something that can take time. The academic clock undermines some of the best practices in working with H2R populations. Administrative challenges can also occur, particularly when those working with universities to handle grants or research support, cannot envision the research realities (e.g., working in a cash-based economy).

Funding biases can also limit support for doing research with H2R groups on numerous levels. They may cause grants and foundations to not see the worth in doing this sort of work. They may have timelines that do not fit with the relational engagement approach necessary. There may be restrictions that prevent or make it difficult to appropriately and timely compensate participants. They can undermine a researcher’s capacity to ensure research continuity.

These structural mechanisms can create difficulties and undermine the research projects. Addressing them, however, will require a coherent effort. A single researcher may be treated as an anomaly but having more people raise awareness of these challenges can reveal its widespread existence and the need for change.

#### ***4) H2R Because of the Data Sought***

Data sits at the core of all of these dynamics. As such, many of the themes from the prior areas bled over into this section (e.g., dependency on gatekeepers), but they were also nuanced.

*The Nuanced Challenges:* The H2R phenomena was felt in cases where the data itself was hard to reach because of different world views, having a shared lexicon, or familiarity with the context, which effects data is collected and analyzed. A lack of familiarity with context could compromise the data collection process as researchers may fail to plan appropriately. A lack of familiarity with the context and different world views or lack of shared lexicon could make the interpretation of data inaccurate. Similarly, institutional regulations or norms may not only make it difficult to access respondents but also prevent people from sharing data (e.g., about their experiences or viewpoints). Silencing can occur when institutional norms and power dynamics are not considered as evident in research with women who remain silent when men are in the room or, as aforesaid, when powerful organizations do not want topics made apparent that could cast them in a negative light.

*H2R nature of data:* Considering the H2R nature of data led to the insight that data itself could be blurred in how it is hard to reach—it could be excluded, elusive, hidden by participants, or marginalized/ing. For example, exclusion of data arises in decisions researchers make as to what should and should not be featured, but also because of a trickle-down effect in which research participants that face exclusion will not have data about them collected. The data itself faces marketplace exclusion. The elusive nature of data is evident in struggles to collect the data due to community heterogeneity, data inconsistencies, or sampling challenges. Sampling challenges includes having an unknown sampling population that requires on-the-ground pivoting to accommodate, and/or difficulties with sample volatility where participants drop out or do not stay consistently engaged. This latter was particularly problematic with longitudinal tracking as well as research on sensitive topics that may require multiple follow-ups. These conditions make it hard to ensure sufficient data is collected to reach the academic goals of saturation, validity, and reliability, and to ensure that relevant data is being collected. Being willing to evolve methodologies and diverge from research plans in order to accommodate unanticipated realities was key to overcome some of these challenges, although that divergence in itself often demands more time and effort and a recognition that data may not come in the form originally anticipated.

These conditions can cross over with data that people hold reservations in sharing about (e.g., is hidden, or as aforementioned, is silenced). Hidden or marginalizing H2R data was particularly apparent in cases that dealt with sensitive, triggering, or traumatic data or issues that were stigmatized. When collecting data researchers need to ensure that they are not retraumatizing people and are also not perpetuating stigmas. This requires deep considerations as to how to approach topics. For example, it may mean the adoption of respectful and empathetic participatory approaches in which safe and supportive space is created and participants decide how they would like to share their experiences (orally versus in writing) and what questions they feel comfortable in answering (Conolly et al., 2023). The goal is for the process of sharing to be cathartic instead of distressing. Researchers should embed reflexivity into the process and consider adopting a strength-based approach instead of a deficit-based approach. A strength-based approach calls for a recognition of people's resilience, self-determination and the assets they have in their personal or community attributes or resources, and positioning them in a more dignified way, for example, as survivors. In contrast, a deficit-based approach tends to view people as trapped and dependent, and as victims (Fogarty et al., 2018; Silverman et al., 2023). We thus encourage scholars to consider how they phrase research goals, questions and analysis so that participants are positioned in empowering versus marginalizing or disempowering ways. The words we use in addressing H2R data matter.

*Data politics:* Data is not an inert, neutral, apolitical thing. It is politically charged. Power dynamics surround it and are embedded within it (Ruppert et al., 2017). Consider the ways data has created perceptions of racialized hierarchies of humans to justify discrimination (Allen, 1994; Buolamwini, 2023) or has resulted in epistemic injustices (Kidd et al., 2017). There are thus tensions that surround it. TCR participants share how data politics may arise because of differences in perceptions as to who should own the data (particularly when adopting community participatory research approaches or working with Indigenous communities). Data politics may also arise between academics and practitioners, including NGOs, businesses and gatekeepers who want different types of data (e.g., positivists quest for quantitative data versus interpretivist quest for qualitative data) or who want certain types of data silenced. While often quantitative and qualitative data can complement each other, there is a need to also recognize that respondents have limited capacity to give before hitting research fatigue. These considerations are often lost when data decisions are made in isolation from participants.



Image 2.6: Data sought word cloud.

The jamboards also raised awareness of data politics that unfold due to differing ontological perspectives (what we accept as knowledge and consider as reality) and epistemic standpoints (what can be known and how we can know it). This is particularly relevant when working with communities and data that have typically been marginalized in research processes or that have faced epistemic injustices. Bridging this divide calls for cultural humility (Foronda et al., 2016), which in part entails a willingness for researchers to unlearn the traditional Western-centric ways we are taught to approach data collection and interpretation, and to be open to new approaches. However, translating these differing ontological and epistemic perspectives into academia may also introduce its own set of challenges. These conditions raise to the fore the need for training on data politics.

*Data Ethics:* H2R data often had ethical considerations attached to it, whether it was how it was collected (the aforementioned concerns around traumatic, trigger, sensitive or silenced data), how to compensate co-researchers involved in community participatory research, or how data is used. Data usage can be problematic when trying to balance demands from academia with the direction desired by community participants and by other organizations involved. In short, data ethics introduces tensions that are sometimes covered by research ethics, but there remains a significant portion of elements that remain uncovered. How does one go about negotiating what data should appear in publications and in what publications? How do we cast participants in publications? Do we adopt a strength-based approach or a deficit-based approach? Data and how it is used can have ripple effects beyond what we might image. Additional care needs to be taken.

### **The Key Takeaways**

Through this process, the dialogical session at TCR enabled us to interrogate how numerous elements work together to create conditions that can make consumer experiences hard to research.

A key take away is that hard to reach is not just a condition of research participants. It is a condition premised, in part, on institutional dynamics – regulatory frameworks, norms/ideals, and cultural-cognitive meanings. Institutional dynamics can incite fear, shame, or reservation due to prior epistemic injustices that cause participants to hide or be elusive. H2R characteristics may also be brought about by a mismatch between researcher and research participant as evident by distances (geographical, temporal, sociocultural, power), language barriers or neuro- and physical-diversity differences. Gatekeepers may be part of the answer to these difficulties although challenges with using gatekeepers also need to be recognized. Importantly, a question all researchers should ask is whether they should be the

ones to do the research and to tell the stories. Rarely do we stop to question whether we have the prerogative to undertake research.

This goes to the second point about the researcher's involvement. If, after questioning their involvement, scholars decide to pursue with the research, researchers should reflect on their own positionality (Joy et al., 2007; Ozanne and Fischer, 2012; Steinfield and Holt, 2020) and take steps to reduce the power dynamics between them and respondents (Corus and Ozanne, 2012; Groot et al., 2019; Kindon et al., 2010; Liao, 2006; Ozanne and Saatçioğlu, 2008). Efforts need to be made to change the relationship from a neocolonial and neoliberal one—one in which we take data and exit the field to pursue our own agendas (e.g., publications) —to a decolonial and collaborative one—one in which we start by building meaningful relationships, share in the data collection process, stay connected, and find ways to pursue mutually-beneficial agendas for all things (Thambinathan and Kinsella, 2021; Tuhiwai Smith, 2021). It also calls for better training for researchers so that they can recognize their own positionality and the potentiality of data politics, while also learning to practice self-care and boundary setting in the data collection process.

Indeed, as our fourth theme attests, data itself may be hard to collect because its nature is associated with emotionally, mentally, spiritually, and/or physically taxing experiences that affect participants and researchers. Because academia tends to be vested in its positivistic assumption that sees data as something that should be objectively treated, the subjective elements that form its collection and analysis process are often not talked about. We might write down the possible negative side effects to participants in our letters of consent, but rarely are researchers trained in how to ensure they can limit the effects of these negative side effects on participants and themselves (Kumar and Cavallaro, 2018). There is a dire need for better training so that researchers can do this important work in a way that ensures care and safety for all. Examples of this may include training on:

- The ethics of care process articulated by Tronto (2013), in which we are taught to care about (establish the need for care), care for (adopt responsibility for providing the needed care), care give (provide the care), care receive (evaluate the provision of care) and care with (practicing care for all to achieve justice, equity and freedom);
- Decolonizing methodologies that encourage “(1) exercising critical reflexivity, (2) reciprocity and respect for self-determination, (3) embracing “Other(ed)” ways of knowing, and (4) embodying a transformative praxis” (Thambinathan and Kinsella, 2021);

- Design Justice Network's (2023) principals that seek to adopt a collaborative process that centers the voices and people who are normally marginalized, and that encourages us to think differently about ownership of co-created outcomes.
- Various self-care practices—creating/leveraging support networks, doing personal reflections, exercising, pursuing hobbies or things that spart a sense of playfulness, nurturing professional and personal relationships, ensuring attentive and supportive supervisory relations (Kumar and Cavallaro, 2018)—and how to build in time to research timelines to adopt these practices.

The final point are the structural elements. Some data may be hard to collect because of structural impediments, including organizations that do not want the truth to be made know. In these cases, the researcher may find themselves in a power dynamic vortex in which they must contend with the power that institutions (organizations, government) and people (gatekeepers) hold over their access to participants and capacity to publish data, while contending with the power dynamics between themselves and research participants. How to manage power dynamics is another element we highlight as being neglected in research training seminars. We are often taught that gatekeepers are important, but we are not taught how to manage these relationships to ensure the outcome is one that is beneficially, particularly to those whose voices are often silenced. This calls for us to recognize that mutually beneficial agendas can be thwarted when there are many agendas involved. Those who often benefit are typically the ones in power. Recognizing these dynamics early on and wording data agreements in ways that can protect those who are often marginalized are key to challenging this problem. Achieving this demands academic and institutional support to rebalance power dynamics. Sharing examples of how this has been accomplished by others and partnering in research collaboration to balance institutional variances (e.g., institutions that have adequate capacity to support versus those that do not) are some steppingstones we can take.

We also recognize that academia is not free of its own agendas. Achieving mutually-beneficial agendas can be difficult because of the structural and institutional pressures placed on academics to publish or perish, particularly for pre-tenured faculty who have to get their articles into certain ranked journals within a limited time frame. We do see hope in how some institutional dynamics are pushing for change. We see this occurring in the institutions and countries that push forward research ethic guidelines that are working to prevent epistemic injustices and data violence from being carried out on Indigenous populations (AIATSIS, 2022; Dadich et al., 2019; FNIGC, 2023; Government of Canada, 2019). We thus encourage researchers to stop and question whether they are engaging in these practices:

- Are they taking data without meaningful consideration of the effects of its collection on participants and others?
- Are they stealing information and stories of others to further only their own agendas? Should they be the ones telling the story?
- Have they asked the participants if they want recognition? Are they giving recognition to participants in the research process when desired by the participants?
- Are they adopting a decolonizing process (Thambinathan and Kinsella, 2021) and ethics of care (Groot et al., 2019; Tronto, 2013) in how the data is collected, used, and disseminated?
- If they are facing structural barriers to doing this sort of work, can they form teams with others to aid in moving this work forward?

In short, we recognize that this forum has raised to the fore the fact that H2R populations are created by the conditions within which we live—historical and current, in academia and society at large. Addressing the elements that have contributed to these conditions will require a coherent effort and better training. Every researcher and practitioner, however, can make an individual choice that can work to perpetuate injustices or bring about justice for those who are considered hard to reach. The first step may be gaining knowledge. The cases in this book are one step in this direction.

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### **3. A H2R Group Facing a Hidden Problem: Families Experiencing Difficulties with Breastmilk Feeding**

*Jessica Weaver*

#### **Introduction**

The chapter provides insight into the value and challenges of insider research alongside a H2R group. It discusses research that forms the preliminary stages of a doctoral project, which grew from the researcher's personal experiences of motherhood and breastfeeding. The research seeks to pinpoint opportunities for enhancing support services and finding successful approaches to assist individuals who may be susceptible to experiencing "breastfeeding grief." This will be achieved through collaborative efforts with families in a Northern UK city who have faced challenges in their early experiences with breastfeeding.

This chapter considers the concept of "hard-to-reach" in relation to a hidden problem. It examines ethical issues linked to researcher insider/outsider status alongside dilemmas of safeguarding versus silencing. Moreover, it reflects on the challenges of involving powerful stakeholders within the research process alongside H2R groups. Finally, it considers how to prepare for the emotional impact of sensitive, insider research. The chapter concludes with some thoughts on the key learnings from the process so far.

#### **Background to the Research**

Decisions about infant feeding can be an emotive issue influenced by complex social, economic, and personal circumstances (Ayton, Tesch and Hansen, 2019; Knaak, 2010). Debate continues between those who believe breastfeeding benefits are overemphasized, both in research and public health campaigns, in a way that attributes responsibility for risk to women (Wolf, 2010), and those who feel promoting breastfeeding (and improving support for breastfeeding) is an important way to reduce both health disparities and the psychological impact of not meeting "breastfeeding goals" (Brown, 2018). This work seeks to acknowledge some of the damage caused by stigmatizing narratives (Rodgers, 2020), whilst also being concerned with the lived experience of those who want to breastfeed. Here, we focus specifically upon those whose prebirth preference was to breastfeed (use breastmilk) who go on to experience difficulties, with a particular interest in the resulting negative impact on mental wellbeing (Watkins et al., 2011; Borra, Iacovou and Sevilla 2015).

Insider research has been defined as research “... which is conducted within a social group, organization or culture of which the researcher is also a member.” (Greene, 2014, p.1). As we will go on to discuss, binary distinctions of insider/outsider can oversimplify more complex identity issues (Chavez, 2008). However, as a new mother whose preference was to breastfeed, I experienced significant difficulties within the initial days and weeks after the birth. Difficult early experiences of breastfeeding, such as pain and difficulties with latching are commonly reported in research (Carlebach and Watson, 2020) and have been linked to a reduction in breastfeeding from 81% at birth to 69% by week one (McAndrew et al., 2012). There is widespread acknowledgement of a strong link between such difficulties and experiences of trauma and “breastfeeding grief, in terms of a prolonged sense of loss (Ayton, Tesch and Hansen, 2019), particularly for those for whom breastfeeding was ultimately not possible (Brown, 2019).

The research goal was developed considering personal insights (from peers) into the variability of service support experiences, an issue echoed in research findings (Chopel et al., 2019; Thomson and Crossland, 2019), and the considerable implications for a negative impact on mental wellbeing (Watkins et al., 2011). The research aims to identify areas for improvement in support services, as well as identifying effective ways to support those at risk of experiencing “breastfeeding grief,” by working collaboratively with families in a Northern UK city<sup>15</sup> with difficult early experiences of breastmilk feeding. In this chapter, we use the term breastmilk feeding to be inclusive of the multiple uses (i.e. breastfeeding, expressing breastmilk, using donated breastmilk) and the variety of family-types (same-sex couples, single parents, trans parents, heterosexual couples) who wish to use breastmilk to feed their children. For this reason, we also wish to take a whole family approach to the research, to acknowledge the role that partners, and close family and friends play in supporting breastmilk feeding (Brown and Davies, 2014).

The decision to focus specifically on families in one city was taken due to the desire to contribute towards findings that can directly influence the practices of local services, in line with the principles of Transformative Consumer Research, which aim to enhance consumer wellbeing through research with real world impact (Mick et al., 2012). A local approach also allows for a Participatory Action Research (PAR) methodology, that fully embeds those affected within the research process (Reason and Bradbury, 2001). While democratic approaches to research enhance the potential to empower H2R groups (Barnes and Cottrell, 2012), they also present a variety of ethical considerations and challenges (Banks et al., 2013). Before going

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<sup>15</sup> The name of the city has been anonymized in accordance with research ethical requirements.

on to discuss these challenges, we first consider what we mean by hard-to-reach in this context.

### **Hard-to-Reach: A Hidden Problem**

As demonstrated across the variety of research contexts within this volume, the notion of “hard-to-reach” is a diverse and, at times, ambiguous concept (Cook, 2002). Some have called for caution around the use of the concept due to the potential to homogenize populations (Brackertz and Meredyth, 2008), compound stigma (Ellard-Gray et al., 2015), and obscure the barriers to participation caused by researchers, research institutions, and services (Flanagan and Hancock, 2010). Here we position difficult experiences of breastmilk feeding and the resulting negative impact on mental wellbeing to be a somewhat “hidden” problem, with its hidden nature rendering those affected hard-to-reach (Ellard-Gray et al., 2015).

According to Heckathorn (1997, p.174), “A population is “hidden” when no sampling frame exists and public acknowledgement of membership of the population is potentially threatening.” We consider threat in the context of stigma and distress experienced by those for whom breastmilk feeding was difficult, resulting from a perceived “failure,” which consequently contributes to suppression of the issue by those affected (Ayton et al., 2019). Public health messaging which emphasizes the benefits of breastfeeding without acknowledging the reality of the lived experience of difficulties (Knaak, 2010), is arguably a factor in exacerbating such feelings of guilt and failure (Taylor et al., 2021). Services response to such circumstances can also be silencing, such as a lack of follow-up support when breastmilk feeding does not work out (H2R services) (Borra, Iacovou and Sevilla, 2015), this issue also impacts on sampling. Societal rhetoric such as “fed is best” (challenging the idea of “breast is best”), can also be silencing as although helpful for some, for others it fails to acknowledge the experience of grief (Brown, 2018). Finally, the liminality of new parenthood can isolate people from roles and relationships previously inhabited and obscure the difficulties being faced (Tonner, 2016).

Covid exacerbated the situation for some, with disproportionately more negative experiences of breastmilk feeding reported by more deprived families, while the situation for those from more privileged families improved due to increased time, space, and privacy, which aided breastmilk feeding (Brown and Shenker, 2021). Despite an improvement for some, overall research into the impact of Covid in the UK found that only 13.5% of women surveyed who had stopped breastfeeding described themselves as ready to do so (Brown and Shenker, 2021). Despite the hidden nature of the issue, therefore, the potential for widespread experiences of

mental distress amongst this population is significant. These findings also highlight the need to better understand how intersectional experiences impact on individuals and families' experiences of breastmilk feeding and support services. In this chapter, we utilize the concept of intersectionality defined as:

“... how multiple marginalized or disadvantaged social statuses interact at the micro level of individuals' lived experience to reflect interlocking systems of privilege and oppression at the macro social structural level (e.g., racism, classism, colonialism, sexism, heterosexism, ableism)” (Alvidrez et al., 2021, p.95).

Given the evidence of disproportionate challenges for some, it is important to also consider, therefore, the impact of intersectionality in the research context, which, as we will now discuss, calls for researcher reflexivity in the development of methods to engage with H2R groups.

### **The Layers of Insider/Outsider Status and the Impact on Methods**

Approaching a hidden problem as an insider researcher is beneficial not only in identifying the issue, but also in terms of making contact and engaging with those who may feel stigmatized, allowing for a co-creation of knowledge between researcher and participant (Russo, 2016). Given a tendency for those experiencing breastmilk feeding difficulties to not access group support (Thomson and Crossland, 2019), the use of social media was required to recruit those affected by these issues to the study. Participants (co-researchers) from the city in question were, therefore, recruited online to be members of a first-stage participatory steering group (Harrison et al., 2019) (see [Image 3.1](#)).

As we can see in [Image 3.1](#), the use of animation and illustration within a recruitment video can provide a non-threatening mode of communication with potential participants (Sudbury-Riley et al., 2020). By creating an avatar which indicates the shared experiences of the researcher, there is potential to be more approachable, despite the H2R nature of the study.

### ***Heterogeneity of Experience***

Despite these potential benefits of insider status, critical reflexivity of researcher positionality and how this influences all interaction with participants remains important (Alvesson and Skoldberg, 2009). This is particularly true given the evidence that research can often compound and reproduce marginalizing societal structures experienced by H2R communities (Chalmers, 1995). The status of insider/outsider can be oversimplified, when in reality, multi-layered identities mean a researcher can be an insider in some ways and an outsider in others (Chhabra, 2020). For example, despite having difficulties breastfeeding, my

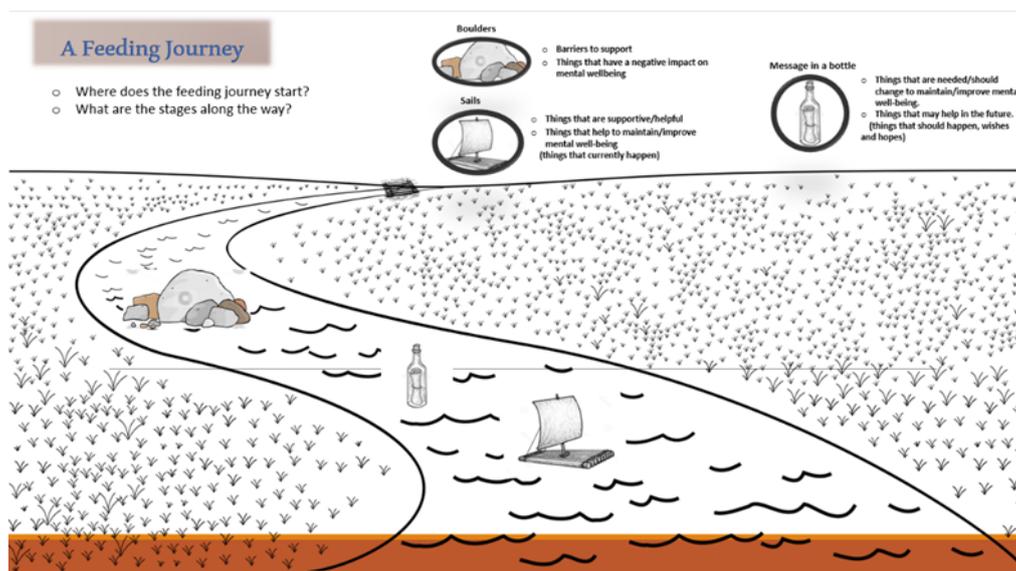
experience of support services was positive, meaning breastfeeding was ultimately possible, which helped to mitigate against prolonged mental distress. However, this is not always the case, and many families report negative experiences of support (Thomson and Crossland, 2019), alongside longer-term experiences of mental distress (Borra, Iacovou, and Sevilla, 2015). These differing experiences can create barriers to intercommunity dialogue within a H2R population, particularly due to the emotional implications of guilt and grief (Taylor et al., 2021).



*Image 3.1: Images from draft participant recruitment video.*

To help overcome barriers linked to heterogeneity of experience and taking inspiration from trauma-informed service approaches (Sweeney and Taggart, 2018), we plan to use a tool based on “the river of life” (Parker et al., 2020).

Previously used in both therapeutic and community-based participatory research settings, this tool allows for the use of a visual metaphor to aid group discussion in a less individually exposing way (Moon, 2007). The tool is to be used within steering group meetings (stage one) with the aim of collaboratively determining research priorities and goals (see Image 3.2).



*Image 3.2: Feeding journey template with group task prompts.*

When approaching a hidden and at times emotive issue, the use of tools that allow participants to talk more generally, as opposed to individually, can encourage the identification of shared knowledge, thus building group rapport and fostering peer support (McMenamin et al., 2021).

### ***Positionality, Power, and Barriers to Participation***

Reflexivity relating to further layers of positionality will also be required when taking into consideration the intersectional experiences, previously described (i.e. age, sexuality and race) that are present within a H2R group (Savin-Baden and Major, 2013). The use of participatory methods encourages shared ownership and control (Saatcioglu and Corus, 2019). This can be empowering for those who are marginalized due to both experiences of a hidden problem combined with other intersectional factors, as it allows for the co-creation of research agendas and designs that reflect their worldview (Faulkner, 2004). Nevertheless, reflexivity around my own position as a white, cohabiting mother, working within a prestigious institution, and how this may influence power dynamics is a crucial element of “anti-oppressive practice” in the research context (Dalrymple and Burke, 2019).

Reflexivity in PAR with H2R groups also means addressing any access barriers (influenced by intersectional experiences) that could prevent those affected from participating “deeply and fully” within the research process, thus allowing for “their perspectives and needs to inform solutions” (Ozanne and Saatcioglu, 2008, p.426). Practical support such as provision of expenses, meeting venues that are accessible and welcoming to parents with infants, and financial recognition of participant/co-researcher’s time and expertise are key to addressing some elements of these barriers (Knowles et al., 2021). The university policies mean that the project is constrained in providing cash payments, with access only to supermarket vouchers. Whilst there may be ethical debate regarding whether payment leads to coercion of participants (Wertheimer and Miller, 2008), it is generally accepted to be an important element of acknowledging expertise within participatory research (Bergold and Thomas, 2012). Therefore, this is a limitation of the study due to the potential to create a power imbalance between participants and the paid researcher and is illustrative of the considerable challenge of disrupting traditional research power dynamics when engaging with H2R groups (Wallcraft, Schrank and Amering, 2009). Transparency around such limitations will be important in acknowledging power disparities and allowing (potential) co-researchers to reflect on the personal risks and benefits of participation (ICPHR, 2013).

The difference between university researcher and “co-researcher” pay exposes the contrast between procedural ethics compared to the reality of ethics in practice when engaging with H2R groups (Guillemin and Gillam, 2004). We will now consider this point further in relation to dilemmas of safeguarding versus silencing H2R participants.

### **Dilemmas of Safeguarding Versus Silencing**

Research ethics protocols that include a limitation to confidentiality when there is a perceived risk of harm to, or from a participant are a common requirement, particularly in research involving “vulnerable” participants (Brady and Franklin, 2019). Whilst researchers have a duty to predict and minimize potential harm for participants, the communication of such clauses can be silencing for those participants who may have experienced, or feel at risk of experiencing, coercive interventions from services due to hidden issues such as mental distress (Gibson, Benson and Brand, 2013; Carr et al., 2019;) or domestic abuse (Bernard and Thomas, 2016). Consequently, this presents a dilemma between safeguarding H2R populations versus silencing them. This dilemma is arguably based on “ethics in practice” as opposed to “procedural ethics” (Guillemin and Gillam, 2004), in that a safeguarding protocol may satisfy an ethics committee, while having a significant impact on meaningful participation for those from H2R groups (Brady and

Franklin, 2019). Within this case study, for example, parents experiencing mental distress may feel that such safeguarding clauses are based on a ‘deficit perspective’, which assumes that their distress has the potential to cause serious harm to them or their children, thus discouraging open dialogue (Bernard, 2013).

Due to dilemmas such as this, scholars emphasize the value of considering “relationship-based” alongside “principle-based” approaches to ethics in participatory work with H2R groups (Banks et al., 2013). Relationship-based approaches allow for a more “situated research ethic,” which focuses on the “local” and “specific” as opposed to the purely “universal” (Heggen and Guillemin, 2012), thus allowing for the incorporation of the participants’ own ethical understandings (Clifford and Burke, 2009). The ethical considerations of this project are on-going. By allowing for collective dialogue around understandings of “significant harm” and avenues for appropriate support within a group agreement we aim to promote a transparent, non-judgmental forum that applies a more “situated” research ethic. A group agreement is a co-created document, that can be referred to and amended, which affirms a groups’ stated approach to a variety of practical and ethical issues anticipated within a participatory research project (Pain et al., 2012).

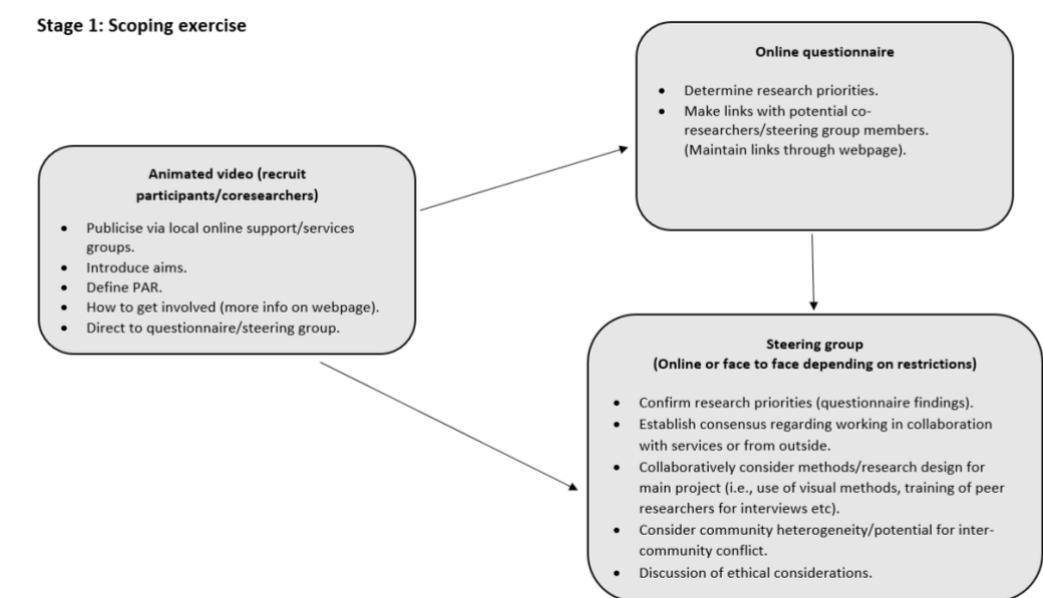
Research ethics procedures that incorporate and signpost to the safeguarding protocols of gatekeeper organizations are a common, and often effective, way to navigate the complexity of safeguarding H2R groups such as young people, for example (Farrimond, 2013). There are, however, significant factors related to power and the differing agendas of gatekeepers that also need to be addressed (Kay, 2019). We will now go on to consider this point in relation to the involvement of powerful stakeholders within the research process alongside H2R groups.

### **The Involvement of Powerful Stakeholders**

Given the research objective to effect meaningful change within local breastfeeding support services, it would seem logical perhaps to involve such stakeholders from the outset. However, engaging in collaborative research with H2R communities alongside health service providers can be challenging due to power imbalances and the potential for exacerbating barriers to service user participation (Golenya et al., 2021). Despite the potential benefits of early stakeholder participation, such as the opportunity to co-create solutions and apply co-created knowledge (Pearce et al., 2020), there is also potential for this to be a barrier to participation for those who may feel disenfranchised due to negative experiences of support from services, or experience stigma associated with a hidden problem (Turner and Beresford, 2005).

For this reason, a collaborative two-stage research design has been developed to allow those affected by this hidden problem to have control over whether services

should be involved and, if so, at what stage (see Image 3.3). By taking this collaborative approach, we hope to encourage the participation of those who feel particularly disenfranchised as a result of this hidden problem (Telford and Faulkner, 2004). As previously mentioned however, community heterogeneity of experience and opinions is likely to be a challenge in coming to a consensus over such decisions (Minkler et al., 2002), nevertheless, space for transparent dialogue on such issues are a crucial way to address barriers to participation for H2R populations.



*Image 3.3: Proposed first stage of two-staged collaborative research design.*

### **Impact on the Researcher: Preparing for Emotional Labor**

Insider research can have many emotional and professional benefits for a researcher, including as an aid in processing the researcher's own lived experiences, and to gain a deeper understanding of research identity (Johnston, 2019), as well as allowing for co-created meaning making (Tonner, 2016). However, there is also an emotional toll to insider research due to the exploration of issues of deep emotional significance to the researcher (Ross, 2017). As stated, there may be personal benefits to self-disclosure of shared experiences by the researcher (Johnston, 2019). Despite this, as noted in research by Ross (2017), who examined experiences of bisexual mothers, there is a need for reflexivity around inherent power asymmetries and decisions of self-disclosure, and whether this may add to an extra emotional burden for participants. Choosing to discuss this dilemma with participants can allow for transparency and shared reflexivity in managing such power issues

(Russo, 2016; Ross, 2017), nevertheless avenues for researcher support outside of research relationships is also important.

Research involving distressing topics can often have an impact on researchers' well-being regardless of insider/outsider status, therefore it is necessary to develop a more supportive research culture (Dickson-Swift et al., 2009; Jafari et al., 2013). A lack of consistency has been noted within emotional support for doctoral students researching sensitive topics, with an over-reliance on ad hoc, informal or peer support (Velardo and Elliott, 2021). The use of more informal debriefing mechanisms can have ethical implications in terms of the disclosure of confidential research information. Doctoral participants engaged in sensitive research within Velardo and Elliott's (2021) study, for example, spoke of the need for a "PhD Counsellor" who would be familiar with the demands of the role.

Due to my previous experience of working as a social worker within mental health services I am acutely aware of the need to allow space for supervision to aid the processing of difficult emotions that arise when witnessing and supporting others in distress (Ashley-Binge and Cousins, 2020). Despite extensive policies encouraging supervision in social work, however, barriers linked to resources mean this often does not occur (Sweifach, 2019). In preparation for the emotional labor of the research process, therefore, I have developed a reciprocal debrief arrangement with a fellow doctoral student which will form part of the ethical protocol of the study. This will overcome ethical issues of confidentiality related to less formal debrief mechanisms, whilst ensuring that a debrief conversation after each research activity is always available. Nevertheless, the requirement for a researcher-led response to this issue highlights the need for universities to develop a more consistent organizational approach, ensuring the same ethical standards applied to safeguarding participants are also employed in the provision of appropriate support for researchers and doctoral students.

## **Conclusions**

In this chapter, we have considered some of the benefits and challenges linked to insider research with a H2R group facing a hidden problem. Despite the potential benefits, which include the identification of the hidden issue, an increased approachability of the researcher, and the potential to co-create solutions, important issues of power, silencing, and reducing the impact of researching a sensitive subject matter on both participants and the researcher remain. Through a discussion of the planning stage of a doctoral project we have highlighted key insights related to ethical and practical issues of such work.

Firstly, there is need for transparency with members of the H2R community in relation to dilemmas relating to ethics and power dynamics. For example, by being transparent around the limitations of accessibility (voucher payments), dilemmas of self-disclosure by the researcher, the involvement of powerful stakeholders, and the requirements of university ethics safeguarding procedures, both researchers and members of the H2R population can engage in collaborative reflexivity to maximize participant participation, apply a more situated approach to ethics and minimize the potential for exacerbation of power asymmetries. Secondly, we have highlighted the need to remain aware of how community heterogeneity, in this case both in terms of experiences of difficulties with breastmilk feeding and support, and further intersectional experiences, can impact on group cohesion and participation. Through the use of visual metaphors such as the river of life tool, we can aim for research involving group discussion to be effective in developing a shared understanding of the hidden problem in a way that is less exposing of an individual's difficult experiences. Finally, we have emphasized the need for improved emotional support for researchers when researching sensitive subject matters, particularly for insider researchers. A planned reciprocal peer arrangement can help to navigate ethical issues and resource pressures. However, there is a clear need for a more organizational-led response to this issue to ensure that support is consistent, appropriate, and better resourced.

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## **4. Raising Refugees' Voice: Insights from H2R Refugee Informants**

*Roua Al Hanouti*

### **Introduction**

Telling refugee stories is more complicated than it seems. This chapter discusses research challenges faced while approaching refugee informants to gain insights about their life transition. The research findings presented in this chapter are part of a doctoral project conducted with Syrian refugee families settled in France. This research project was initially motivated by the personal experience of the researcher who has immigrated several times to different countries. Although there are some methodological schemes in the literature that helped to anticipate and overcome methodological difficulties, some other challenges emerged throughout this experience leading to the insights and suggestions offered in this chapter. The main aim is to provide fruitful insights to researchers approaching refugees so that it may encourage others to do research with this H2R population and increase scholarship within consumer research on this important consumer group.

Refugees present an important context to study family consumption given that it often entails vulnerability and difficulties for their lives and well-being. In fact, refugees often go through traumatic experiences, liminality, and major life transitions associated with their forced migration journey. At the same time, they can experience discrimination and harassment because of the pejorative, stereotypical image associated with refugeehood status, such as that projected in media of being socially disadvantaged and as passive victims (Wright, 2014). Moreover, refugees are not very welcomed in most European countries as they become viewed as a threat: 59% of the European population believes that refugees will increase the likelihood of terrorism in their countries (Esses et al., 2017). Studying refugee's experiences from a whole family approach, recognizing how refugees go through the immigration process as families, can contribute to an understanding of family in consumer research (Epp and Price, 2008).

### **Challenges in Approaching Refugee Respondents**

During research processes, the researcher faced several challenges in reaching refugee respondents given their "hard-to-reach" nature. This section discusses the difficulties that emerged when trying to hire this category of respondents to participate in the study.

### ***Refugeehood Stigma***

The first challenge emerged during the sample identification. It was found that people do not like to be identified or contacted as refugees because of the stigmatization associated with refugeehood. They prefer to be identified as regular migrants. In fact, due to their status and social conditions, refugees may confront unique stereotypes that other immigrants may not face. Those stereotypes are caused by several reasons: the lack of language competencies; levels of social support received; and, in some cases, association with ethnicity and religion (Baranik et al., 2017). This stigma, which is related to social exclusion, contributed to the vulnerability of research respondents and made them hard to reach. Vulnerable populations, as we discovered, are often marginalized and thus hidden, but also invisible in society.

### ***Defining the Sample of Refugees***

In finding refugees to participate in this study, the researcher looked for people who corresponded to the official definition of being a refugee, or who were classified by the government as refugees. This distinction was made because, in academic discourse, scholars often interchange terms like immigrants or ethnic minority when engaging in debates about refugees. However, as the study finds, refugees can have very different experiences than more privileged immigrants. Additionally, there is a significant body of literature devoted to categorizing and differentiating refugees from different kinds of forced migration. In order to balance these two competing dynamics—one that seeks to use a very broad term and one that further fragments this H2R group—I adopted the United Nations’ definition. According to the United Nations (1951), a refugee is “any person who is owing to a well-founded fear of being persecuted for reasons of race, religion, nationality or membership of a particular social group, or political opinion, is outside the country of his/her nationality and unable or owing to such fear, is unwilling to avail himself of the protection of that country” (Fiddian-Qasmiyeh et al., 2014).

### ***Locating and Involving Refugees***

Initially, the researcher approached refugees who introduced themselves as refugees and/or who held the status of a refugee. These connections were facilitated by a mutual acquaintance of the researcher and the refugees. However, engaging more informants required moving beyond these social networks. To do this, the researcher approached associations and public organizations who work with refugees. She also adopted a snowballing technique, contacting refugees through someone they trusted. To increase participation while avoiding the emotional impact associated with the use of the word “refugee” — given the attachment of

negative stereotypes to this term — the researcher explained the research objectives without stating directly that the study was focusing on refugees. Participants were also given incentives to participate through shopping vouchers and gift cards. These modes of compensation were key because this group is price sensitive with limited purchasing capacity (Brackertz and Meredyth, 2008), and the researcher needed to ensure we upheld their dignity by recognizing them and the time they spent during the interview.

### ***The Unwillingness to Talk***

Refugees are not only H2R as a sample population, but their very life stories and data are also H2R because they are often afraid of participating or talking about politically sensitive issues. Many refugees come from situations in which they had never had the freedom to express personal opinions and attitudes. Talking openly is thus something they are not familiar with, particularly those from Syrian culture. Research informants discussed that they were reluctant to speak about politics because of the traumatic experience they had, including the Syrian regime as they fear that citizens will be punished for their political transgression. Some respondents also have family members that remain in Syria and were thus afraid about the security of their relatives (Pearlman, 2016).

Refugee status implies a precarious situation under the law and thus any dialogue with a person who can be considered as an authority can be perceived as a threat (Ger and Sandikci, 2006). To overcome this obstacle, the researcher explained the aims of the study, and in some cases, shared and explained the interview protocol, assuring that any information related to informants would have been kept anonymous, including names and addresses, in accordance with university ethical requirements. It must also be mentioned that interview protocols and the statement of research objectives were official papers issued by the university with the official stamp, written in both English and French languages. This decision was made to accommodate participants with basic proficiency in either language, considering the difficulties involved in producing official university documents in Arabic. This approach helped to gain the trust of the respondents (Arsel, 2017).

### **Covid-19 Pandemic**

Covid-19 has changed our lives and forced us to move in to an online and remote orientation. To be able to progress in the research while respecting health restrictions, the researcher had to conduct some interviews on Zoom, a videoconferencing software. Some informants who had previously agreed to participate in the study disengaged and decided to not participate after this change,

possibly due to perceptions that a Zoom interview was less secure than in-person one. Other participants became unreachable during the pandemic.

Although virtual interviews meant that some potential participants were lost, they were a keyway to maintain relationships with those who agreed to participate regardless the shifts in research dynamics. Therefore, initial interviews were conducted despite the Covid-19 restrictions. Once these restrictions were lifted, the researcher was able to visit families and gain more insights through observations (Penaloza and Cayla, 2006) because these initial interviews allowed to establish a trusted relationship between the lead researcher and the study participants. In sum, although Covid-19 increased difficulties in accessing this population, by being flexible and by shifting goals from gathering information to first establishing a rapport, the researcher was able to maintain the involvement of some of these H2R individuals throughout the study.

### **Challenges in Obtaining Information during Interview**

In addition to the initial difficulties of locating and convincing the informants to take part in the study, the researcher encountered another series of challenges during our interviews. This was due to the potential for the stories to trigger trauma and the informants' discomfort in sharing their story with the researcher.

#### ***A Reminder of Pain***

War has had a devastating effect on these refugees' lives. In many cases, respondents lost family members during the war, which prevented them from performing the rituals of death or even saying goodbye. Moreover, they lost valuable possessions and memories, including houses, cars, and businesses. Therefore, they often avoid recalling the pain and trauma they experienced due to the psychological harm associated with these triggering experiences (Fiddian-Qasmiyeh et al., 2014).

To work through this problem, we relied on a genuine and deeply felt and communicated mode of empathy, expressing certain emotions to the respondents. The researcher emphasized how appreciative she was that they shared their stories, how it would contribute to research in this field, and how it could in turn provide them with market alternatives and market access solutions that can enhance their well-being. Importantly, she allowed respondents to be involved in the reading and editing of the transcripts, which was empowering and enhanced the reflective nature of the research (Ger and Sandikci, 2006).

#### ***Cultural and Social Restraints***

Conducting research with the (eastern) Arab community involves additional struggles and challenges. This is particularly true considering our focus on family consumption, which meant the need to involve multiple family members, notably mothers, and fathers. This approach challenged a common myth that frames refugee communities as homogenous. Usually, research, led by males, engages male respondents who participate and commit to speak and present on behalf of the whole community without paying attention to women, or to differences in the social status (Goodkind and Deacon, 2008). In our study, taking mothers into account and focusing on them in particular gave us an advantage in learning more regarding this group. However, it also resulted in difficulties given cultural-gender nuances.

Notably, convincing fathers was not an easy task primarily due to the researcher's gender. In the Syrian conservative culture, men do not feel comfortable dealing with a women researcher (Ramadan, 2016). In addition, some male respondents did not like to participate in the interview or to get involved since they consider it as women's business (Goodkind and Deacon, 2008). Thus, the researcher was faced with a situation where there was an even harder-to-reach population within an already H2R group. Despite these misgivings, she did manage to convince some fathers (male interviewees) to participate in the interviews. She did so by initially contacting mothers to request the interview, and then gradually we involved fathers, asking about their views and observations during interviews in a way that did not push them to engage beyond their comfort levels.

Previous literature well established that gender may play a complex role in studying marginalized communities (Goodkind and Deacon, 2008). Moreover, as Ger and Sandikci (2006) point out, the researcher should be sensitive to the culture of informants, and respect their beliefs, lifestyle, and attitudes. In our attempts to overcome these gendered-cultural dynamics that made men harder-to-reach, we should note that the lead researcher was familiar with the culture as she comes from a similar cultural environment. She also spoke the same language (Arabic). Moreover, spending more time with the interviewees before starting the interview, showing respect for their beliefs (Goodkind and Deacon, 2008), helped her deal with this situation. This additional time gave respondents a sense of comfort during the interview as they could see that the researcher came from the same cultural background and that she would maintain and respect the boundaries.

### **Managing Social Desirable Responding**

Stigmatized groups, like refugees, heighten concerns for socially desirable responding. We uncovered this issue during our research process, which started with exploratory research, conducting a few interviews, followed by an initial

analysis. Taking the time to look at our data revealed that there was a distortion between what the respondents declared and discussed during the interview and what the researcher observed them doing. Through the initial analysis, we connected the socially desirable responses (misrepresentations) to certain reasons. For example, some respondents, especially mothers (who were the main informants), sought to improve their image by demonstrating that they were concentrating on self-development. They declared that they were studying or were engaged in certain professional activities. With this knowledge, we flagged these topics as areas for further probing and/or as information that would have to be confirmed (or not) through other modes of data collection. The use of participatory observation, wherein the researcher engaged in familial activities and spent extended periods of time immersed with respondents, was helpful to uncover the true nature of the situation.

## **Data**

Furthermore, the data collected posed a challenge in making it accessible for other researchers to contribute to the analysis, while also ensuring that a balance between emic (consumer responses) and etic (researchers' interpretation) was achieved in reporting the findings. This challenge was due to the linguistic differences among the researchers. Thus, the data itself was, in some ways, H2R because language and translation problems added challenges to the data analysis process (Goodkind and Deacon, 2008).

The researcher conducted interviews in Arabic language, given that the majority of respondents did not speak English or French fluently. To achieve the emic-etic balance, a complex translation process ensued. It was carried out in several phases with the goal of ensuring and maintaining the original meaning. The process recognized that there is no single correct translation but that optimizing a good translation is about understanding how language has been used to localize realities. Because the researcher was the translator, she had an opportunity to observe and find intercultural meanings (Temple and Young, 2004). During interviews, the researcher observed traditional words, tried to translate and clarify with respondents, or asked for a description and verified with Google images if her understanding was correct. This step was important to ensure that emic meanings delivered by informants were not lost. When the interviews were transcribed, the researcher was in a better position to translate the words. The texts were read back and forth to make sure they looked like natural English, not like Arabic-spoken English. However, some words or descriptions were not translated because they tampered with the traditional meaning. This typology of transcription, which seeks to give voice to the H2R population, takes time.

## **Researcher's Position and Experience**

### ***Insider-Outsider Status***

As mentioned earlier, the lead researcher shares a similar cultural background with the respondents, and this has given her the advantage of being an insider. Being an insider is very important to deeply understand community knowledge and to acquire unique insights into the study that can contribute to new theories and understanding of human behavior (Chavez, 2008). This cultural background allowed the researcher to overcome some of the H2R dynamics of these respondents, resulting in her being welcomed into their homes, providing her the opportunity to extend her ethnographic study actively participating in various family activities and rituals. She was invited to family meals (dinner and lunch) and to participate with some mothers in activities for children.

The declaration of being an insider, however, is very broad because an insider might be an outsider in other situations. For example, the lead researcher was an insider because she had a similar cultural background and had immigrated several times. She was an outsider also as she had not experienced such a dramatic life transition (Guillemin and Gillam, 2004). Her outsider status meant she had to establish trust, which she did by engaging in community activities. The combination of her insider-outsider status thus allowed her to get empirical material for the research and to convince more refugees to participate in the study. However, while it strengthened the rapport with the respondents, this also came with negative implications including challenges with managing relationships and emotional and psychological harm to the researcher during the research process as explained below.

### ***Managing Relationships***

Although it was important to gain meaningful access to this H2R population, building relationships with families to gain their confidence was associated with disadvantages. Some refugees, particularly women, wanted to maintain a relationship with the researcher, especially since the interview and research process went away from the traditional format (Chaves, 2008) and took the form of a more familiar mode of engagement. Yet reconfiguring the boundaries of that relationship (even as a friend) was challenging. The researcher began to confront interference in her own life and that of her family. Sometimes she had to justify to participants her absence, limited presence in gatherings, or inability to answer telephone calls. Managing these dynamics took a lot of time and effort and added emotional labor to the work. It had to be done carefully particularly since, after leaving the field, bias could arise if researchers sever or maintain relationships with participants, impacting the interpretation process (Chavez, 2008).

### ***Emotional Impact***

In today's research expectations, ethical processes emphasize the need to preserve the well-being of the participants. As a result, the researcher's emotional well-being is often neglected (Velardo and Elliot, 2021). Indeed, before starting the research process, the researcher reviewed a number of studies done in a similar context: only few studies existed about techniques for coping with this type of contexts or how to do research with refugees after a crisis.

With little information available to prepare the lead researcher on what to expect during fieldwork, her immersion in the context of the study brought about a significant emotional impact. Listening to death stories and the experience of trauma for people who have lost livelihoods was overwhelming and resulted in a sense of frustration together with a sense of responsibility to respondents (emotional distress and guilt). There were stories of hardship, helplessness, and pain, that were profound and left an emotional impact on the researcher's life. These stories can result in emotional work and remain with us even after the completion of data collection. Indeed, the "emotional weight" of stories we encountered in the field, has its impact on the progress of the research. In certain situations, it led to emotional exhaustion, and the researcher could not progress with the research, as previously experienced by the lead researcher.

To overcome these emotional challenges, the researcher discussed these dynamics with supervisors and peers, who helped her to remain focused on the primary, positive purpose of the research (to give voice to refugees' familial experiences) and to visualize the research results. In addition, discussing these challenges with peers (who are outsiders) helped her to see the other side of the situation and capture data that was less emotionally exhausting but insightful. In addition, the lead researcher approached some experienced researchers who conducted studies with a similar category (vulnerable and marginalized) of respondents, which allowed her to benefit from their experience and advice on how to overcome these barriers. As noted by these experienced researchers, the emotional impact can contribute to the vulnerability of researchers. The nature of vulnerability depends on various aspects, such as the experience of the researcher and the context of the study. It may emerge during the early stages of the research, for example when approaching respondents and getting access to the research field, and last until the findings' presentation and beyond. A researcher's vulnerability leads to feelings of fear, guilt, and anxiety, which can affect the whole research process (Downey et al., 2016). Being prepared, while having some sort of support, from academic institutions, can really help in overcoming vulnerability outcomes. Finally, one of the researchers discussed how interactions with vulnerable consumers enhances personal reflection, by making

them aware of their own lives, capabilities, and capacity for choice, which is often taken for granted (Downey et al., 2016).

## **Conclusions**

This chapter discussed the challenges and obstacles faced by a researcher while conducting research on a H2R population of refugees and dealing with H2R data. One of the research goals was to make the experiences of refugees more visible and considered in consumer research studies. Another objective was to raise informants' concerns to public parties so that policies may be implemented that may improve their well-being and integration. However, in trying to achieve these goals, the lead researcher encountered emotional tolls and struggles, which were addressed in academic fields and research training courses. As a conclusion, it is recommended to provide emotional and psychological support for researchers, particularly at their early career stages (e.g., Ph.D. students), which can help avoid emotional harm that can occur during the research progress. Moreover, training for researchers to be better equipped to work with H2R populations should also be provided in addition to the experience and insights into how to deal with unforeseen circumstances highlighted in this chapter. This training should incorporate considerations of doing research with people who have precarious life situations, such as how to handle the complexities this may introduce into the study and how to be flexible when change is needed.

Lastly, there is a need to call for further research that is culturally sensitive and that gives recognition, voice, and dignity to consumer groups who are often H2R because marginalized. This calls for a balance between emic and etic perspectives and likely the adoption of multiple modes of data collection (e.g., interviews, participant observations) so that researchers can build empathy and trust with respondents while setting clear relationship boundaries. The principle of prioritizing the well-being of respondents should also be turned inward, extending to the well-being of the researchers themselves.

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## 5. Case Studies' Contributions

*Francesca Giliberto*

This casebook brought together contributions from authors with experience in methodological development, field-research and engagement with research populations identified as H2R. These, representing diverse global perspectives and career stages, are from diverse corners of the globe, bound by a shared commitment to amplify the voices and experiences of H2R communities within the realm of consumer research.

**Chapter 3** delves deeply into the complexities of conducting insider research with families confronting challenges related to breastfeeding. Within this domain, the emotional strain and barriers faced by those grappling with breastfeeding grief are acknowledged as a discreetly concealed issue, rendering these individuals elusive to conventional research methods. Leveraging her personal journey through motherhood and breastfeeding, Weaver's research aims to enhance support services and discern effective approaches for those susceptible to this form of grief. Weaver's work unfolds through collaborative efforts with families in a Northern UK city who have confronted early breastfeeding hurdles, complemented by the strategic use of social media to engage this particular H2R population. In her contribution, Weaver navigates the ethical dilemma of safeguarding protocols, recognizing the potential inadvertent silencing of participants who have undergone coercive interventions. Furthermore, she highlights the critical importance of researcher reflexivity, particularly in terms of positionality, and how it permeates every facet of interaction with participants, even for one with an insider status.

**Chapter 4** investigates the challenges faced when conducting research with refugee populations, specifically Syrian refugee families settled in France. With her contribution, Al Hanouti sheds light on how this particular group is hard to reach due to the stigma associated with being a refugee, as many prefer not to be identified or contacted as such. The accurate identification of individuals who qualify as refugees is often complicated by the use of confusing and interchangeable terminologies employed by academic researchers. Al Hanouti explains how many refugees are reluctant to discuss politically sensitive issues due to their traumatic experiences and fear of repercussions, further complicating the collection of pertinent research data. The chapter also underscores how conducting research with eastern Arab communities, particularly involving multiple family members, presents additional challenges due to cultural and gender nuances, which carefully need to be considered in research design and implementation. Finally, issues related

to data accessibility and translation, stemming from linguistic disparities among researchers and participants, were also identified.

Both chapters underscore the significance of reflexivity in addressing power dynamics between researchers and H2R populations. They emphasize the need for transparent dialogue on access barriers and the provision of necessary support. A noteworthy element identified pertains to the intricate nature of insider/outsider interactions, recognizing that experiences may significantly vary for different researchers and groups. While the researcher's insider-outsider status allows for a deeper understanding, it also entails emotional labor, leading to feelings of frustration, responsibility, and emotional distress. In conclusion, recommendations are put forth to provide adequate emotional and psychological support for researchers, particularly at early career stages, to process difficult emotions when researching sensitive subject matters. Additionally, training is recommended to better equip researchers for working with H2R populations. Finally, the imperative for culturally sensitive research that grants voice and dignity to marginalized consumer groups, while prioritizing the well-being of both respondents and researchers, is also emphasized.

## 6. List of Contributors

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**Daniela Alcoforado** earned her doctorate from the Federal University of Pernambuco, Brazil. She is a transformative consumer researcher focusing on consumer well-being, vulnerability, and therapeutic consumption. Recently, her work has explored the intersection of consumer behavior, the marketplace, and mental disorders, such as depression. From 2019–2021, she served as a guest researcher in Marketing at the International Psychoanalytic University Berlin. Additionally, she works as a CRM Analyst. Her research has been published in the *Journal of Consumer Marketing*, *Journal of Marketing Management*, *Advances in Consumer Research*, and other outlets.

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culture can be mobilized to address critical development issues such as poverty, inequalities, climate change and unsustainable cities. Over the past decade, she has actively engaged with global initiatives including the United Nations' Agenda 2030 and the 2015 UNESCO Policy on World Heritage and Sustainable Development. She is also an international consultant, including for the Institute of Development Studies and the British Council. Her work influences academia, policies, practices, and decision-making, inspiring responses to societal challenges. Invitations to speak at international events like UNESCO's MONDIACULT 2022 and the UN-Habitat's Smart Madinah Forum 2023 reflect her impactful research's global reach.

**Diane Holt** holds the Chair in Entrepreneurship at the University of Leeds. She has a broad focus on the role that enterprises (commercial, non-profit, social, hybrid) in both the formal and informal economy can play in sustainable development and poverty alleviation. She explores these organizations, their stakeholders and beneficiaries and various interactions with environmental and social issues especially in low-income contexts in the developing world. In particular her work explores various processes, decision making, use of innovations and strategy in such enterprises, as well as their impacts on communities and the natural world. In the case of her informal economy work this focus is on their reactive natures, their strategic gaps, links with the formal and role in livelihoods for millions in poverty.

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**Jennifer Sedgewick** is an Indigenous (Michif/Métis) and Canadian settler scholar and is currently a PhD Candidate in Marketing at the Schulich School of Business in Toronto/Tkaronto, Canada. The hard-to-reach population that she spoke to during the dialogical engagement was First Nations and Métis in Canada, which was informed by her experiences working with Dr. Gary Groot's Indigenous health research team in the Department of Community Health and Epidemiology at the University of Saskatchewan. Consistent with Indigenous methodologies and

research ethics, the research she contributed to was conducted with a combination of First Nations and Métis governments, organizations, and communities, all of which necessitated developing and maintaining authentic and reciprocal relationships.

**Katherine C. Sredl** (PhD University of Illinois at Urbana-Champaign) has impacted gender studies within marketing by theorizing and demonstrating how change in markets impacts and is impacted by consumers in their everyday life rituals and how that change is represented in social media. Sredl uses her Croatian and American identities to integrate data and challenge theory in her ethnographic research in Croatia. Her three most cited publications ask how changing portrayals of gender roles in media impacts consumption, how women respond to globalization in daily rituals, and how peace treaties (Dayton Accord) impact inter-ethnic consumer rituals in post-conflict markets. Sredl publishes in *Consumption Markets & Culture*, *Journal of Macromarketing*, and other international peer-reviewed journals, is a founding member of GENMAC (Gender, Markets & Consumers) and serves on the editorial review board of CMC, IJA, and JCIRA.

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**Jessica Weaver** developed an interest in user-led service design/delivery during her time working as a mental health social worker in the UK, due to the potential for these approaches to challenge power imbalances experienced by service users. This led to her pursuing a doctorate in Marketing at the University of Liverpool Management School, with a focus on Transformative Service Research and Transformative Consumer Research. Drawing on personal experience of motherhood and breastfeeding, Jessica's doctorate has explored difficult experiences of breastfeeding within the context of service support. Taking a participatory action research approach, this research has involved service users at all stages of the research process, with the aim of generating meaningful impact within breastfeeding and maternity services.