Principles of Building Trust: Engaging Disenfranchised Communities across the G7 in COVID-19 vaccine campaigns

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Graffiti on a wall in Oulx, Italy reads "Bon Voyage". Image Credit: Costanza Torre

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Executive Summary

Since the onset of the COVID-19 pandemic, global society has undergone extraordinary changes. Whilst this crisis has often been described as a “great leveller”, it is now well-documented that the effects of this period – both in terms of health outcomes and wider social, economic, and political disruptions – have been deeply uneven, particularly for communities on societal margins.[1] Yet across G7 countries, emergency approaches by governments to administer COVID-19 vaccines have largely focused on achieving mass vaccination targets through rollouts based on the principles of uniformity, compliance and service-provision, rather than the principle of adaptation to specific local environments.[2]

This report results from research conducted under the project 'Ethnographies of (Dis)Engagement', which explored orientations towards COVID-19 vaccinations among some of the communities considered the hardest to reach across G7 countries. Supported by the British Academy COVID-19 Recovery: G7 Research Programme (COVG7210058), this project presents evidence from undocumented migrants, Roma communities, and members of the African diaspora, focusing on communities in Italy and Canada. Whilst ethnically, geographically, and socio-economically diverse, these groups are understood to have expressed consistent resistance to COVID-19 vaccination and to be “vaccine hesitant”. Indeed, the highly limited data that does exist reports some of the lowest vaccination rates among these groups not just in the G7 but across the world.[3]

Moreover, there is little qualitative research investigating how these “vaccine hesitant” (or so perceived) groups understand either COVID-19 vaccines or the agents of the health system

[1] Almeida, V; Barrios, S.; Christl, M; Poli, S.D.; Tumino, A; Wielen, W.V.D. (2021). The impact of COVID-19 on households´ income in the EU, The Journal of Economic Inequality (2021) 19:413–431, https://doi.org/10.1007/s10888-021-09485-8. Darvas, Zsolt M. (2021) : The unequal inequality impact of the COVID-19 pandemic, Bruegel Working Paper, No. 2021/06, Bruegel, Brussels. Patel, J. A., Nielsen, F., Badiani, A. A., Assi, S., Unadkat, V. A., Patel, B., Ravindrane, R., & Wardle, H. (2020). Poverty, inequality and COVID-19: the forgotten vulnerable. *Public health*, *183*, 110–111. https://doi.org/10.1016/j.puhe.2020.05.006

[2] Institute for Community Studies. (2021). Understanding vaccine hesitancy through communities of place: Abridged Report. Available online at: https://icstudies.org.uk/repository/understanding-vaccine-hesitancy-through-communities-place

[3] Holt, E. (2021) COVID-19 Vaccinations among Roma Populations in Europe,The Lancet, Vol.2, Issue 7, E289, July 2021. DOI: https://doi.org/10.1016/s2666-5247(21)00155-5; Iyengar KP, Vaishya R, Jain VK, et al BAME community hesitancy in the UK for COVID-19 vaccine: suggested solutions Postgraduate Medical Journal Published Online First: 29 March 2021. doi: 10.1136/postgradmedj-2021-139957; Razai M S, Osama T, McKechnie D G J, Majeed A. Covid-19 vaccine hesitancy among ethnic minority groups BMJ 2021; 372: n513 doi:10.1136/bmj.n513

or state delivering them.[4] Within G7 countries, many social groups continue to doubt, resist and fear the vaccines. With medical and social research thus far primarily concerned with increasing vaccination uptakes, this report identifies a need for research approaches that trace and historicise community-based concepts of vaccination and of the pandemic at large. To date, this type of evidence has been side-lined in governmental and EU decision-making in favour of centralised approaches informed by epidemiological evidence.

This report builds on the growing literature that illuminates pandemic inequalities and community-based approaches to care (including quantitative approaches), while supplementing existing approaches with granular analysis of how communities perceive and access routine health and social care. Thus, one of the primary aims of 'Ethnographies of (Dis)Engagement' is to raise the profile of ethnography in shaping a post-COVID world, whilst at the same time complementing and challenging epidemiological models for the benefit of placing community-centred approaches at the core of research and policy discourse.

Fundamentally, to understand the diversity of responses to COVID-19 vaccines, it is vital to construct understandings within the frames of the lived experience of individuals and collectives. Accordingly, this report argues that a key starting point is the critical appraisal of the concept of *community* itself. Rather than existing as a homogenous and stable entity, communities have increasingly been understood to be spaces of boundary making, whereby contours of inclusion and exclusion are continually redrawn.[5] Similarly, this research reveals the need to push against ideas of communities defined by spatial limits. Communities are themselves political entities, which are constantly reshaped by policies even under normal circumstances, but which under the effects and impacts of pandemic governance can be even more so.

Advocating for a community-centred approach to vaccination, this report proposes the following five key policy-making principles:

First, it urges for continued attention to the **role of places and communities in delivering vaccine strategies**. We recognise that significant community outreach and research affecting decision-making within particular places can produce an evidence base to document spatial divergences in negotiating COVID-19 vaccine rollouts. In contrast to universal, top-down strategies, local social infrastructures often innovate rapidly in response to ideas on the

[4] Dada, S., Battles, H., Pilbeam, C. *et al.* Learning from the past and present: social science implications for COVID-19 immunity-based documentation. *Humanit Soc Sci Commun* **8,** 219 (2021). https://doi.org/10.1057/s41599-021-00898-4

[5] Anderson, B. 1983. Imagined Communities: Reflections on the Origins and Spread of Nationalism. London: Verso.

ground. Engaging community champions, faith leaders, health mediators, elders and gatekeepers all fosters change in vaccine uptake. This mapping of community structures is crucial for tapping into local mediators or networks of support who serve as nodes of legitimization in communities. Yet we regularly found that whilst these structures are vital to welfare and survival in places where mistrust of the state is high, norms of reciprocity, trust and sharing have been deeply compromised by the sustained withdrawal of state welfare in general, as well as the impacts of COVID-19 specifically. Thus, engagement and investment in communities is central to sustaining this important grassroots work.

Second, we show that **community-based policies must account for the specific dynamics of citizenship, movement and economic survival.** In particular, this research uncovered structural barriers towards COVID-19 vaccines administered within a nationalistic framework. Those without national IDs, for example, could not access vaccines, or people feared to access mainstream health facilities. With COVID-19 primarily treated as a medical crisis by scientific experts and policymakers, for the communities in this research the pandemic has also ushered in threats to their tenure, citizenship, security and stability, threats that pandemic containment policies have both created and exacerbated. We found that communities largely opted to take vaccines not on the basis of health-related evidence, but on the basis of movement, work and livelihood. These wider quests to self-secure must be considered alongside health insecurities: health messaging is indissoluble from the specific physical, psychosocial and mobility needs of communities. To build trust and to encourage engagement with vaccine programmes, it is important to simultaneously offer advice or links to advocacy with regards to eviction or asylum claims.

Third, this report notes that policymakers must take into account **local and historically-rooted perceptions of the state and public authorities**. For many of our research interlocutors, vaccine campaigns represented an extension of state authority, and entailing not just bureaucracy but forms of surveillance and policing that affect their everyday lives. Our interlocutors expressed significant past and present fears of state authorities, including health facilities. Pandemic governance (including vaccination) passes through health authorities, but also through representatives of police, border, transport and other state agencies—hence public health strategies that employ varying degrees of coercion risk confirming and exacerbating prior fears and mistrust of government authorities. State approaches to combating the pandemic often illustrate bureaucratic rigidity, posing barriers to vaccine participation and social justice. It is therefore critical to consider the changing political terrain on which vaccinations are delivered, and how state and health authorities are perceived “from below”. Crucially, many of our interlocutors have experienced COVID-19 governance not as

“exceptional” but rather as connected to forms of surveillance, policing or incarceration as a routinised part of everyday life.

Fourth, this report questions ideas about trust built through COVID-19 vaccination policies. For the communities engaged in this research, vaccination rollouts were understood to be an intervention both of health and governance. As such, vaccines were often framed in terms of coercion, deception or the denial of individual freedoms. Often, our interlocutors opted to receive a COVID-19 vaccine but regarded it as a decision made under duress. As such, whilst punitive approaches to delivering vaccinations may register as a statistical success, on the ground, such an approach can generate deep mistrust. Across marginalised communities, this quandary presents further barriers to be overcome in the post-COVID world. In response, we propose the principle of **engaging in community dialogue and participation**. Rather than simply rejecting vaccines, our interlocutors engaged in complex deliberative conversations with our researchers as to the relevance of vaccines within the prospects and constraints of their socio-economic lives. Through tapping intro trusted local mediators, we found it is critical for health workers to engage in process-based, nuanced encounters with members of marginalised communities, in order to foster trust.

Fifth, taken together, our findings point to an **understanding of vaccine resistance beyond vaccine hesitancy**. Given the context of collective discrimination, this report contends that the framework of vaccine “hesitancy”—rooted as it is in individual decision-making—provides only a partial tool to understand longstanding vulnerabilities and contemporary forms of dispossession that affect orientations towards vaccination in these research communities. Instead, this report advocates for a focus on structural barriers, rather than on vaccine hesitancy**.** As an alternative language, it is useful to consider vaccine ‘barriers’ against laying blame upon and locating reluctance in the individual. Accordingly, this research considers the structural elements that both inform people’s choices and address interventions beyond emergencies and coercion. Without community buy-in, vaccine campaigns can be powerful engines of mistrust, fostering misinformation, conspiracy theories, and more.

Finally, the report also provides evidence for optimism when community-centred approaches are pursued. Utilising established infrastructures of kinship, communal solidarity and activist networks, while engaging local health authorities to make their work transparent and legible, can produce profound results— especially when these approaches are kept discrete from the contradictory meshwork of state policies. Ultimately such approaches can offer gains that far transcend the achievement of target metrics: given the heterogeneity of the populations studied, this recognition of individual and communal quests to achieve equitable health goals can yield broader conceptions of dignity, well-being and social justice.

Summary of Terms

Activist Networks	Networks of anarchists and political organisers in Italy
Community	Collective social group connected by shared identifies and socio-cultural experiences, and not (necessarily) bound by geographical limits
Experience-Centred Policy	Policy that is respectful of legacies of discrimination experienced by vulnerable groups, and reflects their input and participation in its development
Lifeworlds	The social, cultural and political frames of experience that formed the ontology of our interlocutors
People on the Move	Migrants transiting through Italy, i.e. those seeking to pass through, rather than settle. This was the term commonly used within the solidarity infrastructures assisting migrants
Solidarity Infrastructures	Networks of volunteers, NGO-workers and civil society members involved in supporting migrants in Italy. Though at times activist networks also participated in solidarity networks, the two forms of locally-based assistance were discrete
Structural Violence	Discrimination in an institution or social structure that prevents individuals from meeting their needs
Structural Barriers	The historical and contemporary factors that complicate participation in vaccination
Undocumented Migrants	Migrants who are present in Italy without formal citizenship. Within this research, this term is used to refer to both “settled” migrant communities, who are working informally in Italy’s cities, and to “people on the move” (see above)
Vaccine Hesitancy	According to the WHO, “a delay in acceptance or refusal of safe vaccines despite availability of vaccine services”
Vaccine Resistance	Overt participation in anti-vaccine activities, e.g. protest

1. Understanding the impact of COVID-19 on disenfranchised communities in the G7 countries

1.1 Introduction and Overview

This report is written at a point when G7 countries are increasingly recognising COVID-19 to be an endemic threat and are embarking on discussions of reconstruction in a post-emergency world.[6] Yet such notions of recovery pose a problematic metanarrative, as reparative frameworks continue to exclude those communities who are most likely to be exposed to the long-term impacts of COVID-19. Against the backdrop of wealthier countries hoarding vaccines at the expense of poorer ones, of pharmaceutical companies limiting access to vaccine patents, and a large share of the world still struggling with new outbreaks and variants, viable, equitable scripts of post-pandemic recovery remain elusive.

Within G7 countries COVID-19 vaccines are promoted as the cornerstone of transitions to national recovery, yet state approaches to coordinating vaccines have differed widely. To date, government-led approaches to administer vaccines have largely been informed by, and delivered through, "top-down" initiatives.[7] As is often the case in vaccine campaigns, the roll-out of COVID-19 vaccines has been designed around principles of uniformity, compliance and service-provision, rather than adaptation to specific local environments. At their core, these campaigns have assumed that centralised government planning is the most efficient and effective way to achieve mass immunisation and herd immunity.

In Italy and Canada, where this research is based, high rates of vaccination uptake have been reported. As of this writing, in Italy over 88% of enumerated citizens (above 12) have received two shots of COVID-19 vaccination. In Canada, this figure stands at 79.3% of the population. Yet vaccine uptake has remained markedly uneven across social groups, and reluctance and resistance persist in specific communities: recent large-scale surveys have highlighted intense disparity in vaccine uptake between socio-demographic groups in Europe.[8]

Alongside their significance as viral containment measures, vaccine mandates have been portrayed as tools for rebuilding trust in the state and in healthcare systems, in the aftermath

[6] Katzourakis, A. (2022), COVID-19: endemic doesn't mean harmless, Nature 601, 485, doi: https://doi.org/10.1038/d41586-022-00155-x; Torjesen, I. (2021), Covid-19 will become endemic but with decreased potency over time, scientists believe BMJ; 372 :n494 doi:10.1136/bmj.n494

[7] Institute for Community Studies, Understanding vaccine hesitancy through communities of place: Abridged Report. 2021

[8] de Figueiredo, Alexandre and Larson, Heidi J. (2021) Exploratory study of the global intent to accept COVID-19 vaccinations. Communications Medicine, 1 (1). DOI: https://doi.org/10.1038/s43856-021-00027-x

of the deep disruption of national lockdowns that began in early 2020.[9] Changing orientations towards COVID-19 vaccines are not, however, necessarily reflective of civic trust in the process of repair. Rather, in G7 countries the acceptance of vaccines is more accurately tied to changing techniques of their administration.[10]

In both Italy and Canada, vaccine campaigns that initially relied on voluntary compliance have been increasingly linked to restrictive measures for the unvaccinated. in the past year, proof of vaccination has become yoked to previously unfettered rights: in Italy, for example, following legislation passed in 1st July 2021 vaccination has led to the issuance of Green Passes which are now required to work or to access long-distance transport. This shifting logic of vaccine governance has impacted disenfranchised communities in key ways: not only can these policies intensify border issues and stoke social tensions between those for and against vaccination, but moreover some social groups continue to doubt, fear and organise resistance against vaccines altogether.

Historically, debates about the appropriate level of coercion in delivering vaccines are not new to health emergencies.[11] Studies also indicate that efforts to police uptake through the issuance of vaccine certifications and passports are unlikely to boost rates among groups who have expressed consistent resistance.[12] Yet significant gaps remain in our understanding of how disenfranchised communities react to changing regimes of vaccine government: as pandemic responses have evolved almost from the very beginning of the outbreak (and indeed, continue to evolve), such insights are critical to achieving health equities in the populace. Furthermore, there have been no attempts to map how trust relationships within disenfranchised communities, and between such communities, the state and the healthcare system, are affected by these shifts in policy. This report seeks to fill those gaps.

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[9] Cadeddu, Chiara, Martina Sapienza, Carolina Castagna, Luca Regazzi, Andrea Paladini, Walter Ricciardi, and Aldo Rosano. 2021. "Vaccine Hesitancy and Trust in the Scientific Community in Italy: Comparative Analysis from Two Recent Surveys" *Vaccines* 9, no. 10: 1206. https://doi.org/10.3390/vaccines9101206. Moucheraud, C.; Guo, H.; and Macinko, J. (2021) Trust In Governments And Health Workers Low Globally, Influencing Attitudes Toward Health Information, Vaccines

[10] Dada, S., Battles, H., Pilbeam, C. *et al.* Learning from the past and present: social science implications for COVID-19 immunity-based documentation. *Humanit Soc Sci Commun* **8,** 219 (2021). https://doi.org/10.1057/s41599-021-00898-4

[11] Porter, D., & Porter, R. (1988). The politics of prevention: Anti-vaccinationism and public health in nineteenth-century England. *Medical History, 32*(3), 231-252. doi:10.1017/S0025727300048225

[12] de Figueiredo, Alexandre; Larson, Heidi J; Reicher, Stephen D; (2021) *The potential impact of vaccine passports on inclination to accept COVID-19 vaccinations in the United Kingdom: Evidence from a large cross-sectional survey and modelling study*. EClinicalMedicine, 40. p. 101109. ISSN 2589-5370 DOI: https://doi.org/10.1016/j.eclinm.2021.101109

1.2. Research Communities and Contexts: Four Case Studies

To understand our case studies, it is important to gauge the shifting contours of national vaccine policies. Since the onset of COVID-19 in early 2020, Italy was amongst the countries most heavily affected both within and beyond the G7. As of 2nd March 2022, Italy had reported 155,000 COVID-19-related deaths.[13] High mortality rates have been attributed to early underestimations on the part of the Italian government: before a country-wide lockdown was initiated in March 2020, the initial approach of locking-down only "hardest-hit" municipalities first was blamed for the spread of the virus.[14]Across Italy's regions, the COVID-19 response has been markedly uneven as well, reflecting differential regional reliance on hospitals and/or community health structures, as well as differential investment in health systems. These imbalances have only catalysed resistance to vaccination, such as the controversy surrounding the Green Passes noted in the Executive Summary.

The first-known case of COVID-19 in Canada arrived in late January 2020. On the 23rd March 2020, Canadian residents we asked to voluntarily 'go home and stay home'. Like other countries, Canada implemented various emergency orders and laws to stop the spread of COVID-19, however the country did not mandate a national lockdown at the start of the pandemic. Instead, individual provinces and territories had the autonomy to decide. Restrictions included mandatory province-wide or partial lockdowns in places such as Ontario, as well as limits to public gatherings and periods of compulsory mask wearing.[15]

In both countries, vaccine policies which initially relied upon voluntary participation have shifted towards regulating movement of unvaccinated persons. In Italy, through legislation which became effective on 1st July 2021, COVID—19 vaccination is now linked to a Green Pass, which affords the right to work, travel and access commercial premises. As of 6th December 2021, the validity of COVID-19 test results which previously offered an alternative to the pass, was reduced from 72 to 48 hours.

In Canada, vaccines are not compulsory by law for Canadian citizens, though the federal government mandated its employees and some others, such as those who work in federally

[13] Worldometer Resource Center. (2021). World Countries: Italy. Available online at: https://www.worldometers.info/coronavirus/country/italy/

[14] Falkenbach, M., & Caiani, M. (2021). Italy's Response to COVID-19. In Coronavirus Politics: The Comparative Politics and Policy of COVID-19. University of Michigan Press. https://doi.org/10.3998/mpub.11927713

[15] Canadian Institute for Health Information. (2021) COVID-19 intervention timeline in Canada [Online]. Available at COVID-19 intervention timeline in Canada. Canadian Institute for Health Information. 2021. URL: https://www.cihi.ca/en/covid-19-intervention-timeline-in-canada.

regulated transportation sectors to be vaccinated. Provinces and territories have done a variety to things, but this has often included extending the lists of those who have to be vaccinated and making it a legal obligation for private employees to have a policy on vaccinations. Ontario, for example, has made it widely compulsory. For those who must travel to workplaces, vaccination is either compulsory, or is perceived to be necessary.

In the following section, we provide a brief summary of the effects of COVID-19 on our research communities. We begin by illustrating how the pandemic has deepened structural barriers to well-being among these groups. As our research shows, orientations towards vaccine are perceived as layered with pre-existing experiences of marginalisation which have been amplified by COVID-19 restrictions.

Undocumented Migrants and 'People on the Move' in Rome and Turin, Italy

Approximately 500,000 to 600,000 undocumented migrants currently live in Italy, arriving from numerous countries of origin but presently arriving from Afghanistan and sub-Saharan Africa countries.[16] Living without citizenship or formal claims to state welfare, migrants in this category have been particularly difficult to access—thus while existing data does indicate that the clinical and socio-economic burden of the pandemic has been significantly heavier upon migrant groups in Italy[17], research on these issues remains scarce. Undocumented migrants have been also largely forgotten by public health policies developed in response to COVID-19, to the point that they have often been referred to in public discourse as the "invisibles" of the pandemic.

In addition to the everyday challenges that undocumented migrants face, the pandemic has allowed many countries to halt bureaucratic processes involving people on the move.[18] In Italy, not only were 76% of asylum requests rejected in 2020, compared to 65% in 2019, but data processing procedures for asylum requests and regularization of undocumented migrants were severely delayed as well .[19] Other challenges for such migrants persist, such as living in

[16] Fondazione ISMU (2021), Ventiseiesimo Rapporto sulle migrazioni 2020. Available online: http://ojs.francoangeli.it/_omp/index.php/oa/catalog/book/633

[17] Fiorini, G., Rigamonti, A.E., Galanopoulos, C., Adamoli, M., Ciriaco, E., Franchi, M., Genovese, E., Corrao, G., Cella, S.G. (2020), Undocumented migrants during the COVID-19 pandemic: socio-economic determinants, clinical features and pharmacological treatment*, J Public Health Res*., Vol. 27, Issue 9(4) DOI: 10.4081/jphr.2020.1852

[18] Tazzioli, M. (2021), A "Passport to Freedom"? COVID-19 and the Re-bordering of the World, *European Journal of Risk Regulation*, Vol. 12, pp. 355–361, DOI:10.1017/err.2021.

[19] ANSAmed (2021), Migranti: Ocse, richieste asilo Italia calano del 39,4% nel 2020. Published on 28/10/2021. Available online: https://www.ansamed.info/ansamed/it/notizie/stati/italia/2021/10/28/migranti-ocse-richieste-asilo-italia-calano-del-394-nel-2020_26681ade-0f46-4abf-8a43-18c03dca45af.html

overcrowded accommodation[20] and working in exploitative, even precarious sectors in which working from home is not permitted and physical proximity to other people is required.[21] The COVID-19 pandemic has thus exposed and exacerbated pre-existing inequalities for those who were already living under conditions of great uncertainty and instability.[22]

To investigate migrants' perceptions of and attitudes towards vaccination against COVID-19, this research focused on two distinct but related case studies: the city of Rome and the Alpine province of Turin, particularly the municipality of Oulx. Whilst migrants in Rome could largely be characterised as" settled", and were actively seeking to survive in the city, in Oulx, "people on the move" were seeking to cross the border into France. Their primary motivation was to pass through Italy without encountering the authorities, in order to seek asylum elsewhere in the UK, France, Germany or Switzerland.

For contextual clarity, we refer to our participants as "undocumented migrants" and "people on the move" in accordance with the UN working definition as:

> migrants in irregular situations, migrant workers with precarious livelihoods, or working in the informal economy, victims of trafficking in persons as well as people fleeing their homes because of persecution, war, violence, human rights violations or disaster, whether within their own countries — internally displaced persons (IDPs) — or across international borders — refugees and asylum-seekers.[23]

We do so seeking to bring conditions of precariousness and uncertainty to the fore, as well as attention to the frequent re-routing and continuous pragmatic adjustments which characterise migrant trips.[24]

Roma Communities in Italy

For Roma communities, Europe's largest and youngest ethnic minority, the COVID-19 pandemic has been particularly challenging. Estimates suggest that up to 12 million Roma

[20] Mukumbang, F. C. (2020). Are asylum seekers, refugees and foreign migrants considered in the COVID-19 vaccine discourse?. *BMJ global health*, *5*(11), e004085

[21] Burström B.,Tao, W. (2020) Social determinants of health and inequalities in COVID-19, *European Journal of Public Health*, Vol. 30, Issue 4, pp. 617 618, DOI: https://doi.org/10.1093/eurpub/ckaa095

[22] Wang, Z., & Tang, K. (2020). Combating COVID-19: health equity matters. *Nature medicine, 26*(4), 458-458. Bambra, C., Riordan, R., Ford, J., & Matthews, F. (2020) "The COVID-19 pandemic and health inequalities". *J Epidemiol Community Health*, 74(11), 964-968. Doi: http://dx.doi.org/10.1136/jech-2020-214401

[23] IOM. (2020). World Migration Report, online at: https://www.un.org/sites/un2.un.org/files/wmr_2020.pdf :p2)

[24] Schapendonk, J., van Liempt, I., Schwarz, I., & Steel, G. (2020). Re-routing migration geographies: Migrants, trajectories and mobility regimes. *Geoforum*, *116*, 211-216

currently live in Europe (Council of Europe, 2020) Yet there is no official data on vaccine uptake, rates of infections, hospitalisations, or deaths among European Roma populations.[25] Despite their diversity and longstanding presence in Europe, Roma communities suffer higher rates of poverty, deprivation, and marginalisation than their non-Roma counterparts; regrettably, the enormity of the COVID-19 crisis has brought only further economic deprivation and structural violence in the daily lives of many Roma.

In Italy, Roma "camps" (known as "villages" in official documents) are characterised by poverty, unemployment, precarious work in the informal economy, lack of adequate housing and accommodation as well as interrupted access to education for Roma children due to impending evictions(EU FRA, 2020)—factors all exacerbated by the pandemic. The securitisation of lockdowns by the Italian state have, moreover, been understood by many Roma as part of a continued legacy of discrimination. On account of their perceived reluctance to accept vaccines, Roma have been portrayed in public discourse as a threat to public health, reinforcing prejudice against them. Recent non-inclusive COVID-19 policy responses, coupled with previous histories of exclusion and social inequality, have diminished Roma trust in government initiatives and vaccine participation.

At present, discussions on Roma responses to COVID-19 pertain largely to the macro-level domains of the state. Yet far less is known about individual or communal responses to the pandemic within Roma groups: how Roma peoples have tried to stay safe, for example, and whose public health advice they have trusted. While the focus of this research is on Roma camps in the city of Rome, the insights gathered here aim to be relevant to Roma populations across Europe and the G7.

South Sudanese Diaspora Communities in Montreal, Canada

Our fourth case study explores these orientations among South Sudanese Canadians, who emigrated from South Sudan during decades of civil war. There is no existing data with regards to rates of COVID-19 vaccination among these groups. Many were initially refugees in East or North Africa and came to Canada through a government resettlement program in the mid-1990s. Today, many first-generation South Sudanese Canadian families live in social housing complexes, which are often congested, poverty-stricken areas in large cities. They have continued to face challenges of accessing employment and improving their

[25] Holt, E. (2021) COVID-19 Vaccinations among Roma Populations in Europe. The Lancet, Vol.2, Issue 7, E289, July 2021. DOI: https://doi.org/10.1016/s2666-5247(21)00155-5

economic mobility; as such, many have low incomes, and rely on government social transfers to make ends meet.

Previous research on COVID-19 in South Sudan has shown the significance of diaspora networks in shaping people's responses to COVID-19 advice, revealing significant reverse information flows and relations of trust.[26] Public authorities in South Sudan, through diaspora networks and social media, appeared to be shaping public health behaviour and levels of trust in vaccines among the South Sudanese diasporas in G7 countries. South Sudan remains home to a multiplicity of actors that people trust with their public health (including those who are bio-medically trained, as well as local healers), and their advice has appeared to have a global reach.

In this case study, we examine the relationship between public authorities and trust in transnational diasporic networks, with a particular focus on how health authorities in countries of origin impact understandings of COVID-19 prevention and vaccine uptake among the diaspora in the G7. One key factor in this case study is technology: in Canada, South Sudanese networks are often geographically concentrated while remaining globally connected through new and emergent digital platforms.

1.3. The “Ethnographies of (Dis)Engagement” Project and Report Structure

“Ethnographies of (Dis)Engagement” explores orientations towards COVID-19 vaccinations among some of the communities considered the most hard to reach across G7 countries: undocumented migrants, Roma communities, and members of the African diaspora, focusing on these communities in Italy and Canada. Whilst diverse, these groups are understood to have expressed consistent resistance, or hesitancy, to COVID-19 vaccination, and as noted above, the limited data that does exist reports some of the lowest vaccination rates not only in the G7 but across the world.

Research is structured around four main aims:

1) Produce an understanding of the historical and contemporary contexts which lead to vaccine disengagement in specific communities across the G7. Through deep engagements with particular contexts, we seek to reverse chronic blind spots in the national COVID-19 response and vaccination campaigns.

[26] Robinson, A. Justin, P. Pendle, N, Ahimbisibwe, L, Biel,C., Dang, L. Tong, B. Gew, C. Mabu, R. Mou, N. and Peter, U. “This is your disease”, FLIA and FCDO. Available online: https://www.lse.ac.uk/africa/assets/Documents/Research-reports/LSE-Report-Dynamics-of-Covid-19-in-South-Sudan.pdf

2) To produce community-specific recommendations for health interventions, including how to enhance understandings of who (dis)engaged communities do trust, in order to facilitate vaccine engagement across G7 countries.
3) To make findings translatable to future pandemics, or broader engagement of communities with national health care systems.
4) To raise the profile of ethnography in shaping a post-COVID world, in so doing complementing and challenging epidemiological models which have dominated academic analyses of COVID-19 impacts.

The following chapters present the evidence collected against the aims of this report. The report is structured as follows:

- **Chapter 2** reviews the literature on community-based approaches to vaccination.
- **Chapter 3** presents evidence on vaccine attitudes among undocumented migrants in Rome, highlighting difficult issues of pandemic governance in particular.
- **Chapter 4** explores those same attitudes among undocumented migrants in the Italian province of Turin, on the border with France.
- **Chapter 5** presents evidence from Roma communities in Rome, Milan and Catania. It emphasises the diversity of these settlements, as well as the contradictory state policies that manifested concurrently with the rollout of vaccines.
- **Chapter 6** presents evidence from the African diaspora in Canada, illuminating how South Sudanese migrants often trust kinship networks over medical authorities.
- **Chapter 7** presents cross-cutting findings from each of the research sites.
- **Chapter 8** provides the overarching principles for moving from evidence to policy, based on the findings of the previous chapters.

  Annex: Details of the methodological encounters in this study can be found in the Grounded in the specific contexts of the researched communities, we note the different approaches deployed across the settings.

2. Engaging Disenfranchised Communities: A Review of the Literature

2.1 An Antidote: Harnessing Communities?

Recent studies have suggested that rather than enforce compliance through punitive measures, health authorities should target vaccine-hesitant communities with tailored approaches and communication strategies. Examining vaccine hesitancy in the UK and US, for example, the Institute of Community Studies (ICS) has advocated for recognition of the power of communities in facilitating vaccination.[27] Adapting top-down strategies to the local social fabric has been essential to encourage community "buy-in" for mass vaccination and health engagement. Far from being passive recipients of top-down approaches, the ICS argues, local communities are powerful "sites of knowledge and action"[28] . Crucially, communities are not just physical sites, but spaces of diversity and deliberation where diverse cultural, socio-economic, and socio-historic backgrounds "mediate relationships with preventative health and immunisation" (ibid).

In a similar way, other authors highlight the importance of "social infrastructures", the "networks of kinship and care within and between families, friends, and communities" upon which post-pandemic economic and social recovery depend.[29] Investing in these networks though trusted local partners—including voluntary sector workers, religious organisations or 'community champions'—has been a key means of encouraging vaccination uptake. Being embedded in local networks, such local actors possess legitimacy since they have endured the pandemic alongside those who have been most impacted by it. The concept of social infrastructures has the distinct advantage of being both unfettered by spatial limitations, and of nurturing connection between distanced actors, a point we return to below.

Among groups for whom mistrust of the state is high, whether from historic or contemporary marginalisation, a sense of community and social connections are often foundational to survival. Without sustained state support, networks between kin have fostered alternative

[27] Institute for Community Studies, Understanding vaccine hesitancy through communities of place: Abridged Report. 2021

[28] ibid

[29] Bear, L.; Simpson, N.; , Bazambanza, C.;, Bowers, R.;, Kamal, A.;, , Anishka, G.L.; Pearson, A.;, Vieira, J.; , Watt, C and Wuerth, M. (2021) *Social infrastructures for the post-Covid recovery in the UK.* . Department of Anthropology, London School of Economics and Political Science, London, UK. http://eprints.lse.ac.uk/id/eprint/111011

safety nets: in an oft-cited work that theorises “social capital”, Putnam has outlined the contrasting texture of this social infrastructure across Italy.[30] When state provision cannot be relied upon, trust relationships are constructed closer to home.

Throughout the waves of the COVID-19 pandemic and its associated restrictions, family and kin have proved an important source of care and sustenance in disadvantaged communities, when state welfare or furlough have been insufficient or absent, or when that absence has produced particular types of risk and vulnerability. These risks have included greater exposure to the virus, when ethnic minorities have been disproportionately involved in certain types of work or living in overcrowded dwellings, resulting in higher rates of infection and mortality. The economic losses precipitated by containment policies have furthermore compromised norms of reciprocity, sharing and support within these networks—thus whilst social infrastructures have proven essential in surviving the pandemic for marginalised communities in Europe, the very fabric of these systems is increasingly fragile.

2.2 Towards Granular Approaches to Community

Whilst influential studies have documented the role of communities in promoting vaccination uptake, the dominant ways of outlining vaccine orientations have tended to erase social differentiation and focus on individual choice. Among numerous groups, vaccine hesitancy has emerged as the key conceptual frame to encapsulate both reluctance and resistance to vaccines.[31] Identified in 2019 by the World Health Organization as one of the main threats to global health security, the WHO defines vaccine hesitancy as a “delay in acceptance or refusal of safe vaccines despite availability of vaccine services.” Whilst the notion of vaccine hesitancy long pre-dates the COVID-19 pandemic, such discourses are now characterised by accounts of individuals making rational decisions in the context of imperfect information.[32]

Recent studies have furthermore linked COVID-19 vaccine hesitancy to the ‘‘infodemic”, defined as a parallel realm of misinformation and disinformation regarding the existence and origin of, conspiracies about, and potential cures and prevention methods for COVID-19.[33] Quantitative analysis has dominated the analysis of this realm, with interventions largely

[30] Putnam, R. (1993), Making Democracy Work: Civic Traditions in Modern Italy, Princeton University Press

[31] Verger P and Dubé E. Restoring confidence in vaccines in the COVID-19 era, expert review of vaccines, 2020; 19(11):991-3

[32] Dubé, E., Laberge, C., Guay, M., Bramadat, P., Roy, R., & Bettinger, J. (2013). Vaccine hesitancy: an overview. *Human vaccines & immunotherapeutics*, *9*(8), 1763–1773. https://doi.org/10.4161/hv.24657

[33] World Health Organization. Infodemic. 2022. https://www.who.int/health-topics/infodemic

focused on developing relevant communication and public health messaging to dispel misinformation.[34]

Whilst these approaches offer a sense of the scale and texture of vaccine resistance, the social processes through which groups deliberate and assess COVID-19 vaccines remain markedly understudied. This is partly due to the necessary adjustments to ethnographic methods and participant observation under social distancing restrictions. Yet equally, there is a risk that diverse attitudes regarding vaccines are conflated, with marginalised groups labelled as "anti-vaxxers" in public and policy discourses. As Durand and Cunha have noted, "what vaccination advocates label as 'refusal' or 'resistance' are multifaceted opinions and attitudes. Their diverse motivations and expressions cannot all be reduced to ignorance, irrationality, irresponsibility" (2020, p.260).[35]

Indeed, such thinking was integral to the formation of vaccine hesitancy prior to COVID-19, when a lively debate between scholars of public health sought to develop and refine models for the concept. These models, emerging in the 2000s, sought to classify between different types of vaccine "resisters", as well as different modes of acceptance. The impression of hesitancy gained from this picture arrives as both a spectrum and a struggle over precise conceptual definitions. Multiple overlapping models of vaccine hesitancy based on individual choices were the result of a "complex interaction of different social, cultural, political and personal factors".[36]

Observations such as this are bolstered by a body of social-science literature that emphases the wider sociocultural context underpinning individual vaccination choices in epidemic and pandemic contexts. Research into Ebola, Polio, and Hepatitis-B has highlighted that decisions to reject vaccinations are not just individually determined, but socially mediated. Ultimately, factors beyond the individual—including experiences with the state, health authorities, and prior epidemics, as well as kinship connections and neighbourly experiences—deeply affect attitudes towards vaccines. This report seeks to illuminate those factors more fully.

[34] Bunker, D. Who do you trust? The digital destruction of shared situational awareness and the COVID-19 infodemic, International Journal of Information Management, Volume 55, 2020, 102201, https://doi.org/10.1016/j.ijinfomgt.2020.102201

[35] Durand, J. Y., & Cunha, M. I. (2020). 'To all the anti-vaxxers out there…': ethnography of the public controversy about vaccination in the time of COVID-19. *Social anthropology : the journal of the European Association of Social Anthropologists = Anthropologie sociale*, 10.1111/1469-8676.12805. Advance online publication. https://doi.org/10.1111/1469-8676.12805

[36] Dubé, E., Laberge, C., Guay, M., Bramadat, P., Roy, R., & Bettinger, J. (2013). Vaccine hesitancy: an overview. *Human vaccines & immunotherapeutics*, *9*(8), 1763–1773. https://doi.org/10.4161/hv.24657

In contrast to previous pandemics, very little research investigates how vaccine-hesitant (or so perceived) groups understand COVID-19 vaccines or understands the agents of the health system or state delivering them. With most efforts largely concerned thus far with increasing vaccination uptakes, we see the need for research that traces and historicises these groups' understandings of vaccination and of the pandemic at large. We contend that these approaches should seek to complicate the assumptions often made about these marginalised groups, and push back against the means by which they have been rendered invisible by state and public health policies during the peak of the pandemic.

Finally, we contend that these approaches must be based on "social listening": that researchers must build understandings of COVID-19 vaccines from the associated frames within communities' "lifeworlds".[37] Following Jackson, we define lifeworlds to be an individual's subjective construction of reality, through which they pursue practical means to create viable lives and build solidarity with others. Lifeworlds invoke imaginative as well as political dimensions of experience but have the advantage of alluding to modes of being which are more dynamic than suggested by terms such as "culture".[38] At heart, to accurately understand responses to COVID-19 vaccines, it is important to identify and employ the frames of lived experience known to individuals and collectives themselves. Accordingly, we suggest that the central starting point is the critical appraisal of the concept of *community* itself.

2.3 Critically Appraising Community

Whilst the power of communities to encourage particular types of decision-making is long recognised, we suggest that for many policymakers, communities continue to be imagined as spatially bound recipients of top-down interventions. An extensive body of social science research has revealed the dangers in transposing romantic ideas of coherence and solidarity onto diverse internal politics that characterise communal life.[39] In the context of COVID-19 recovery, overly simplistic notions of community occlude the analysis of complex realities and dynamism which scholars have shown is fundamental to the ability of community champions to influence health-seeking practices.

[37] Jackson, M. (2012) Lifeworlds: Essays in Existential Anthropology. University of Chicago Press.

[38] Fairhead, J. (2016). Understanding Social Resistance to the Ebola Response in the Forest Region of the Republic of Guinea: An Anthropological Perspective. *African Studies Review, 59*(3), 7-31. doi:10.1017/asr.2016.87

[39] Wilkinson A, Parker M, Martineau F, Leach M. 2017 Engaging 'communities': anthropological insights from the West African Ebola epidemic. Phil. Trans. R. Soc. B 372: 20160305. http://dx.doi.org/10.1098/rstb.2016.0305

Moreover, research has shown that collapsing communities into distinct units easily yields stigma and blame for those deemed non-compliant.[40] UK policymakers, for example, rather than tackling vulnerabilities created through economic policies, participated in blaming particular social groups—including black and ethnic minority groups and young people forced to work throughout the pandemic—for the spread of the virus.[41] Such concerns are particularly pertinent in the context of vaccine rollout campaigns that have acquired a distinctly nationalist tone. In political discourses across G7 countries, receiving a COVID-19 vaccine has become increasingly moralised, with vaccination equated to a national civic duty: to be vaccinated is to protect society.

Community engagement must then rely on a realistic assessment of community structure and capacity. Anthropologists have long argued for a consideration of communities as transgressed by power relations, where aspects of class, gender, race, ethnicity, age, and belief intersect to structure the relative influence and status of community members. Rather than existing as homogenous and stable entities, communities have long been understood to be spaces of boundary-making, whereby contours of inclusion and exclusion are continually redrawn—under COVID-19, for example, new categories of risk based on co-morbidity and age have supplemented the prior politics of vulnerability. Understanding these shifting contours enables a more realistic mapping of legitimate entry points for external collaboration.

This politics of power and vulnerability matters, finally, since it structures deliberations and decisions whereby individuals make decisions about vaccines within their social world. This world is not defined by spatial limits: migrants and diasporic populations, for example, often tap into transnational networks of health information. Whilst this reframing could be attributed to the influence of the "infodemic", we have found that information is trusted precisely because it is mediated through networks of close association, such as family members. Intimacy and

[40] Lancet Regional Health – Europe. (2022) The Vaccinated and unvaccinated need to coexist with tolerance and respect, Volume 12, 100326, https://doi.org/10.1016/j.lanepe.2022.100326. Bear, L.;, Simpson, N.; , Bazambanza, C.;, Bowers, R.;, Kamal, A.;, , Anishka, G.L.; Pearson, A.;, Vieira, J.; , Watt, C and Wuerth, M. (2021) *Social infrastructures for the post-Covid recovery in the UK.* . Department of Anthropology, London School of Economics and Political Science, London, UK. http://eprints.lse.ac.uk/id/eprint/111011

[41]Pearson, A.; Wuerth, M.; Simpson, N.; and Bear, L.(2021). Building communities in isolation: how COVID regulations have impacted society, LSE COVID-19 Blog, online at https://www.lse.ac.uk/research/research-for-the-world/society/building-communities-in-isolation-how-covid-regulations-have-impacted-society.
https://www.lse.ac.uk/research/research-for-the-world/society/building-communities-in-isolation-how-covid-regulations-have-impacted-society; Independent SAGE Report 33, January 28th 2021, COVID-19: Racialised stigma and inequalities: Recommendations for promoting social cohesion, online at: https://www.independentsage.org/wp-content/uploads/2021/01/Stigma-and-Inequalities_16-12-20_D6.pdf

trust remain inherently related, and social infrastructures, though stretched across virtual and physical space, have continued to function as key support mechanisms.

2.4 Communities and Public Authority

Revisions to the concept of community also require countering the notion of communities as depoliticised entities. The communities of migrants engaged in this research were governed populations, whose spatial location was affected by movement restrictions and resource limits. Roma settlements, for example, often developed because social stigma forced them to city margins; here, co-existence was not merely a function of shared identity, but of histories of inequality and state biopolitics.

Indeed, for many of our interlocutors, COVID-19 vaccines were understood in terms of state authority, and community responses to vaccines were thus deeply affected by negative, often fearful perceptions of state police and bureaucracy. The issuance of COVID-19 documents, moreover, has vested unprecedented regulation in a new cadre of transport authorities, food vendors and hoteliers: our interlocutors thus tended to view vaccine campaigns as an extension of the forms of surveillance and policing that affect their everyday lives.

Far from being seen as a neutral intervention to improve well-being, enforced vaccinations can be viewed as an extension of state oppression and political control. Decisions to refuse a vaccine are thus political choices embedded in structural disempowerment, serving often as an articulation of mistrust of the state and reaction to discrimination.[42]

We contend it is important to consider the changing political terrain over which vaccinations are delivered, and how state and health authorities are perceived “from below”. Specifically, it is critical to understand marginalised communities as agents of political subjectivity and activity. For people on the margins, state control has long been feared as inimical to well-being: as evidenced by the Black Lives Matter movement that arose following the death of George Floyd, law enforcement arms of the state have been a source of insecurity rather than protection for many minority groups. Such trends have been inflamed by the policing and enforcement of COVID-19 containment: throughout G7 countries, health policies have often

[42] Closser S, Rosenthal A, Maes K, Justice J, Cox K, Omidian PA, Mohammed IZ, Dukku AM, Koon AD, Nyirazinyoye L. The Global Context of Vaccine Refusal: Insights from a Systematic Comparative Ethnography of the Global Polio Eradication Initiative. Med Anthropol Q. 2016 Sep;30(3):321-41. doi: 10.1111/maq.12254. Epub 2016 Jan 27. PMID: 26818631; Hrynick, T., Ripoll, S., and Schmidt-Sane, M. (2020) ‘Rapid Review: Vaccine Hesitancy and Building Confidence in COVID-19 Vaccination’, Briefing, Brighton: Social Science in Humanitarian Action (SSHAP)

been enacted in simultaneity with discriminatory state policies to police both settlement and citizenship.

2.5 Towards Well-Being and Social Justice

A 2021 British Academy report notes the multiple dimensions of well-being that have been affected by the COVID-19 pandemic.[43] This research showed how the dominant framing of COVID-19 as a health crisis disguised its social, economic and cultural impacts. Policies of national response—particularly lockdowns and movement restrictions—have engendered wider struggles, as in seeking to 'flatten the curve' policymakers have been less attentive to deleterious socio-economic effects. The continued impact of austerity and the withdrawal of public welfare have also been overlooked.

We contend that any attempt to rebuild trust between disenfranchised groups and the state must adapt a generous definition of pandemic "harms" and be centred on achieving social justice. Policymakers do recognise the deep implication of community-state interactions: fears of state bureaucracy among those who do not possess full citizenship in their country of residence may produce reluctance to engage with state infrastructures administering vaccines. We suggest that for policymaking to be truly equitable, wider struggles for human security and rights must be considered.

We maintain furthermore that to build trust, interventions must address legacies of discrimination, including past adverse interventions, that underlie perceptions of COVID-19 vaccines. Limited research has urged the acknowledgement of injustices directly linked to health interventions. For example, low COVID-19 vaccination rates among black populations in the US stem from decades of medical racism.[44] Memories of the deceptions and horrors of the Tuskegee trials have been revived in relation to COVID-19 vaccines. Only by acknowledging these past abuses and addressing them first-hand can present attempts at meeting public health targets find any hope of success. For when social justice mandates are pursued, we have also found evidence for optimism within our research. Without community buy-in, vaccine campaigns can be architects of mistrust, in themselves fostering misinformation and conspiracy theories.

[43] British Academy, (2021), The COVID Decade: understanding the long-term societal impacts of COVID-19, online at: https://www.thebritishacademy.ac.uk/publications/covid-decade-understanding-the-long-term-societal-impacts-of-covid-19/

[44] Mondal, A. (2021). The importance of community engagement on COVID-19 vaccination strategy: Lessons from two California pilot programs, The Lancet, Commentary, online at: https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00034-1/fulltext

3. Governance of COVID-19: Evidence from Undocumented Migrants in Rome

3.1 Introduction

This chapter presents the attitudes of undocumented migrants towards COVID-19 vaccination in the Italian capital city of Rome.[45] Our research found that perceptions of vaccines were deeply entangled with notions of vaccine governance.

In Italy in December 2020 the initial formulation of the vaccine rollout used citizenship as the basis for eligibility for a vaccine, with a National Insurance Number required to book an appointment. In the first months of vaccination efforts between January and July 2021, migrants without papers, lacking such a number, were structurally excluded from the campaigns .[46]Only in September 2021, vaccination became accessible to undocumented individuals and other groups without formal citizenship. Many undocumented people were unaware of such changes during fieldwork.

Yet, simultaneously, this research tapped into a network of activist associations and clinics whom migrants trusted, and regularly accessed for care. Rome represents a valuable case study by virtue of the multiplicity of state and non-state actors offering health services and vaccination to undocumented individuals.

3.2 Findings

Barriers to public health services

In everyday life, undocumented individuals face structural barriers to accessing public health services. This pre-existing reluctance to access healthcare had a significant impact on migrants' interpretation of, and willingness to engage with, the vaccination campaign, even when vaccines did become available to them in September 2021. Among the chief obstacles for these communities is the fear of being reported: as one interviewee recounted,

> *"I decided to call Nonna Roma because I didn't know how to access the vaccines. But I have some friends who were really afraid to go to the health services because they had no documents. They were afraid of being reported, of having problems. And even today they don't have the STP code and prefer to stay like that."*

[45] This chapter reflects research conducted by Sara Vallerani, Roma Tre University

[46] Matteini C., 2020. Irregolari e homeless: gli invisibili del vaccino. Retrieved from: https://www.fondazioneveronesi.it/magazine/articoli/da-non-perdere/irregolari-e-homeless-gli-invisibili-del-vaccino#section-3

(Undocumented migrant)

In Italy, vaccinations are booked through a regional online registration platform. This platform requires entering a National Insurance Number, to which proof of vaccination and the issuance of an EU Digital Covid Certificate (hereafter Green Pass) are linked. For Italian citizens, this process takes only a short time, booking is relatively simple, and the Green Pass certification is usually available by the day after vaccination. Yet undocumented migrants, lacking a National Insurance Number, are unable to register on the platform, and hence unable to obtain either a COVID-19 vaccination or a Green Pass certificate.

> *"I have been working on the vaccination campaign for months; as a public service we have not stopped in order to ensure vaccination. We have sent several complaints to the regional government regarding this issue of booking of people without National Insurance Numbers.*
>
> *We have never understood the reason for the decision to making it impossible to register without documents. It is an unreasonable decision, but it is so important that it is not an accident. It is no longer possible to say 'I didn't think of it'."*
>
> *(Health worker, Asl Roma 1)*

Undocumented individuals need a code known as the STP (Temporarily Present Foreigner) code in order to access health services. The STP code grants access to some health services for undocumented people from non-EU countries, and was in theory supposed to grant access to vaccination as well. However, during the vaccination campaign there was a lack of clear, timely institutional communication on how people with the STP code could register for a vaccine or Green Pass, especially in the first months of availability. This confusion was combined with a lack of communication and knowledge on the existence of the STP code and its use in accessing public services, including healthcare outside of the Emergency Room, which remains the main referral point for many.

> *"I've been living in Rome for ten years, I don't have any documents. I had never heard of the STP code until I was vaccinated, that's when I had to get it and now I have it. But before that, nothing, and neither did my friends. [...] Usually, if I had a health problem I would go to the emergency room."*
>
> *(Undocumented person)*
>
> *"The fact that so many people obtained a STP code to vaccinate themselves must indicate to the health authorities that it [the STP code] was a previously unknown tool."*
>
> *(Health worker, Asl Roma 1)*

Undocumented migrants often arrive in Italy after a long journey from their country of origin. At times, our interlocutors were vaccinated at some point during their journey; however, vaccines that were obtained outside the EU (Philippines, Indonesia, Turkey, Russia, etc.) were often not recognised. This was particularly the case for Filipino migrants who had received the

Chinese vaccine, or migrants from Eastern Europe, who had received the Sputnik vaccine. This rejection of foreign vaccines led to a lack of an Italian vaccination certificate and/or Green Pass, compounded by the fact that obtaining a new vaccination is considered inadvisable for medical reasons.

Vaccine Governance and Systemic Vulnerabilities

For undocumented migrants in Rome, governance of COVID-19, rather than fear of contracting the virus, has become central to their lives. Among our interlocutors, COVID-19 vaccination pertained more to the Green Pass certification than to any other factor, as following recent legislation. A Green Pass has become mandatory for any form of employment, and inspections among the general population are a frequent occurrence. Workers can obtain a Green Pass either through vaccination or proof of a negative COVID-19 test (whose validity was recently reduced from 72 to 24 hours). Often, undocumented individuals and people on the move in Italy are employed in illegal work across exploitative sectors, have limited access to basic welfare services, and are denied their fundamental rights.[47] In 2020, at least 207,000 requests for regularization of undocumented individuals working in illegal conditions were filed[48]; however, actual figures are likely much higher and do not appear in any formal estimate.[49]

Despite the lack of legal contracts, benefits, social protection and health coverage, employers of undocumented people often require a Green Pass for job continuity, no matter whether the work is illegal or even dangerous. As one interviewee said:

> *"I work in a cleaning company [...] and they ask me for my Green Pass, like in a clothes shop. I don't have the contract and I don't have the documents, I have to carry the Green Pass with me, they ask for it every day. Otherwise they don't let me in and send me away without a job".*
>
> *(Undocumented migrant)*

This was also reportedly one of the main points that health workers used to convince undocumented individuals to receive a COVID-19 vaccine, as one health worker attested:

[47]Sanfelici M. (2020), The Impact of the COVID-19 Crisis on Marginal Migrant Populations in Italy, *American Behavioral Scientist*. Vol. 65(10), pp. 1323-1341. DOI: 10.1177/00027642211000413. OECD (2021), International Migration Outlook 2021, OECD Publishing, Paris, DOI: https://doi.org/10.1787/29f23e9d-en.

[48] PICUM. (2020). Regularising Undocumented People in Response to the COVID-19 pandemic, blog post, online at: https://picum.org/regularising-undocumented-people-in-response-to-the-covid-19-pandemic,

[49]Cortignani, R., Carulli, G., Dono, G. (2020). COVID-19 and labour in agriculture: Economic and productive impacts in an agricultural area of the Mediterranean. *Italian Journal of Agronomy*, Vol. *15*(2), pp. 172–181. DOI: https://doi.org/10.4081/ija.2020.1653

> *"We used to use the Green Pass as an incentive to vaccination. […] To convince them* [undocumented individuals] *we used to say «without it you won't be able to work». That's how we would convince them, and a lot of people got vaccinated for that reason, not for anything else. Because if you have children at school and you have to work, how do you do it? The Green Pass was a kind of «blackmail», honestly. It pains me to admit it because I think vaccination is the most important public health measure. A serious state has to take responsibility for vaccines, not only for the Green Pass, otherwise it becomes like this and people decide to vaccinate for work and not for their health."*
>
> *(Health worker, Asl Roma 1)*

As undocumented workers in illegal employment are vulnerable to being blackmailed by employers—for fear of losing their job and/or being reported to the authorities—many have been forced to obtain vaccination to ensure their livelihoods.

Conversely, for employers who fear being fined by regulatory bodies, Green Pass certifications seem to have become more urgent than the regularization of work conditions of their undocumented employees. As one volunteer reported:

> *"One day we received a phone call directly from an employer to book the vaccine for the domestic worker who worked for him. She had no contract and we found out that she did not want to be vaccinated. Despite this, the employer called us instead of her and had no problem saying that she had no contract."*
>
> *(Volunteer of Nonna Roma Association)*

Not only do such practices normalise illegal and precarious employment, they also shift responsibility onto individual workers already facing exploitative conditions. In this sense, Green Pass certifications have become an instrument not of public safety but of coercion.

Furthermore, while a Green Pass certificate should be automatically issued following vaccination, in many cases extensive delays in its reception occurred. Such delays were due to different reasons, such as administrative holdups, confusion regarding the procedures to download it, or spelling mistakes in the person's name. As a result, many vaccinated workers were forced to pay for COVID-19 tests (which cost a minimum of €15 at local pharmacies) several times a week while waiting for their Green Pass; when unable or unwilling to do so, those workers lost their jobs. As one health worker reported:

> *"You can't imagine how angry the Kurdish people were. We went to administer thevaccines and then the Green Passes didn't arrive. They got angry with us and said 'What happened to our certifications? We need to work!'".*
>
> *(Health worker, Asl Roma 1)*

Attitudes towards and perceptions of COVID-19 vaccine

Interviews with undocumented individuals reveal that attitudes towards COVID-19 vaccination are frequently characterised by frustration, anxiety, and a widespread feeling of having been coerced to obtain one.

> *"I decided to get vaccinated for the Green Pass because everyone asked for it in every space. I wasn't afraid of the disease, but I was afraid of the bureaucracy, and the Italian State becomes more discriminatory and racist all the time. I think that Green Pass is an instrument for exclusion."*
>
> *(Inhabitant of a housing occupation Viale delle Province)*

For both vaccinated and unvaccinated individuals, feelings of frustration and coercion were exacerbated by the difficulty of choosing which vaccine to receive at a time in which alarmist news about dangerous side-effects of the AstraZeneca vaccine were widely circulating. Moreover, the deep mistrust of official and institutional news channels spreading information on vaccination, was exacerbated by the discourses of the No Vax and No Green Pass protest movements taking place in the end of 2021..

In light of these findings, it is necessary to consider whether and how the vaccination campaign fosters mistrust in the state. Italian public health policies and interventions have often disregarded the health of undocumented migrants; while the vaccination campaign was a step towards addressing these issues, its efforts nevertheless resulted in frequent instances of coercion. The violence perpetuated in this way was not acknowledged, nor was it considered in the policy design and implementation process. A narrow focus on vaccine targets as an end thus disguises the multi-dimensional relations between vaccination and trust. These relations can only be properly addressed if structural interventions work beyond periods of emergency and do not lead to imposition or coercion. Otherwise, the risk persists that vaccines could come at the cost of discouraging future engagement with the healthcare system and local government.

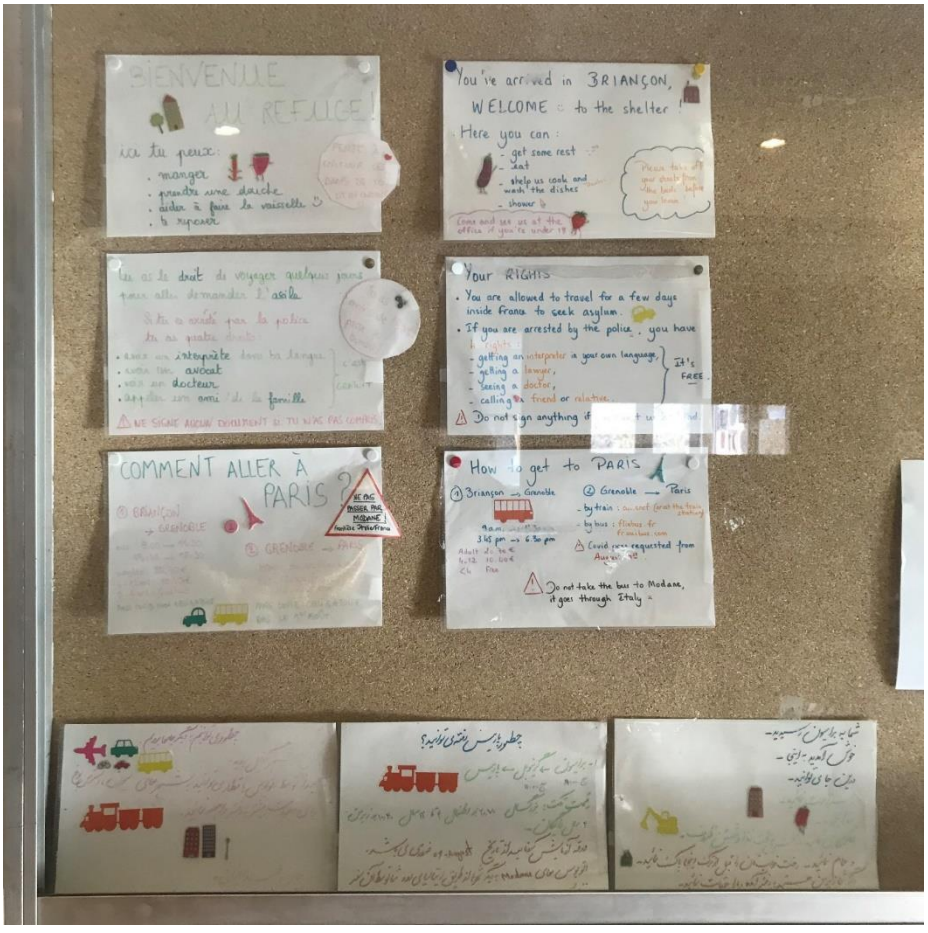
3.3 Policy recommendations

These findings provide actionable insights in securing the health of undocumented individuals. Given the ongoing nature of the pandemic and the continuous introduction of new policies, it is critical to prioritise their implementation. Such policies must ensure vaccination is not regarded as coercive intervention, and that trust in the healthcare system is not further eroded by COVID-19 response. We identify three key recommendations for policymakers today.

Equitable Approaches to Communication. To reach undocumented migrants, sound communication strategies remain a critical need. This involves carefully identifying and consulting stakeholders who have access to undocumented communities. Policymakers and

health practitioners should establish strong collaborations with migrant-led grassroots organizations, activist organisations and health clinics to improve access to public services and implement clear, effective messaging about access to care.

Communication strategies should always be constructed around people's priorities. For example, messaging regarding access to health services (including vaccination) should include explicit information on people's legal rights, in an effort to reassure undocumented individuals that they will not reported to the authorities upon accessing public services. Similarly, it is important to convey that receiving a vaccine will not infringe on a person's claims to asylum. To ensure greatest reach, such communication strategies should be developed and translated in a range of relevant languages. The regular presence of cultural mediators and translators in public health services should be ensured to improve access to services.



Signs at the safehouse Les Terrasses Solidaires in Briançon, France, inform people on the move of their rights, rules of the refuge and travel to Paris. Image Credit: Costanza Torre.

Reform access to bureaucratic systems. Information regarding the exact documentation that undocumented individuals need to access health services (e.g., the STP code) must become more widely available. This information should be advertised in spaces and clinics frequently accessed by migrants: since migrants are less likely to access government websites than other platforms, such information could also be circulated through Facebook or Whatsapp.

Health information should explicitly include guidance regarding vaccine brands not administered in Italy, e.g. the Sputnik vaccine. Ideally, a wider suite of vaccination proofs should be accepted, in view of migrant journeys that often traverse multiple countries. Moreover, Green Pass certifications should be issued immediately after vaccination, through simple and widely accessible procedures. If this is not possible, vaccinated individuals should receive clear and regular updates as to when their Green Pass will be issued.

Mitigate the exacerbation of pre-existing inequalities. Recognising that the pandemic has deepened pre-existing vulnerabilities and inequalities of undocumented individuals, the regularization of their legal status and their living and working conditions should be an even greater priority. Access to forms of social protection should be guaranteed regardless of legal status, and guaranteed nationwide (not delimited to regions or municipalities). Strong, effective and easily accessible complaint mechanisms should be reinforced in the event of harassment, violence or discrimination. Moreover, integrated policies aimed at tackling illegal work and exploitation should be strengthened. To ensure the greatest equity, migrant-led and workers' organizations should be closely involved in all parts of the design and implementation of this process.

3.4 Chapter summary

The issues of access, safety, vulnerability and equity in public health services stem from pre-existing structural problems that have long affected undocumented individuals and people on the move. These issues emerge from discriminatory migration and labour policies that foster marginalization and social exclusion, resulting in chronic inequalities and social injustice. While these policies seek to improve personal and community protection, they also risk increasing the discrimination of already marginalised groups. In this sense, a debate focused only on vaccine "hesitancy" is misleading, as it shifts responsibility onto individuals, at once drawing moral conclusions about their choices to accept or refuse vaccination and disregarding the structural elements that inform personal choices.

For these marginalised groups, state failures to identify and remedy systemic vulnerabilities fosters deep mistrust in public institutions and services. Mistrust must therefore be understood less as the basis for vaccine hesitancy, and more as an endemic condition inculcated and deepened by prior social exclusion. In order to mend this frayed political fabric, implementing migration and labour policies that focus on social protection, and reducing the inequalities faced by undocumented individuals and people on the move, must therefore be considered a key public health measure in tackling the ongoing pandemic.

4. Attitudes towards COVID-19 Vaccinations in Europe among people on the move: perspectives from the Alpine border

4.1 Introduction

Moving beyond the Roman capital, this chapter investigates the experiences of COVID-19 vaccination of people on the move in northern Italy, who were seeking to cross the border into France.[50] All the participants in this study—including recently-arrived migrants, asylum seekers and refugees—were, at the time of our research, en route to their desired country of arrival. As Italy has long been a transit country for undocumented individuals trying to reach other European countries; these participants had been traveling for varying amounts of time, from forty-five days up to several years, and many had also been briefly residing in Italy before undertaking their journey through the Alps.

While global flows of migration have persisted throughout the pandemic, little is known about these groups' attitudes towards the vaccine (WHO 2021).[51] Our evidence suggests that migrants are not necessarily vaccine-hesitant—on the contrary, many had accessed vaccines in Bosnia or Turkey, and carried their certifications with them, even if (as noted in Chapter 3), certain vaccine brands were not recognised by the Italian state as offering immunity. Overall, we found that attitudes regarding vaccines were tied primarily to the demands of strenuous journeys: migrants had accepted or rejected vaccines depending on how easily vaccines allowed them to travel, a decision-making process that took the possibility of side effects into account.

4.2 Mobility restrictions and migrants' passage through Europe

The Central and Eastern Mediterranean migration routes are among the deadliest in the world, with over 20,000 recorded deaths at sea since 2014 (Missing Migrants Project 2021). Under

[50] This chapter reflects research led by Costanza Torre, LSE, in collaboration with Sara Vallerani and Dr Elizabeth Storer.

One terminological note for clarity: though we acknowledge that reasons for migration are highly diverse, ranging from fleeing political persecution to seeking economic opportunity, for ease of reading we here use the terms 'migrants' and 'people on the move' synonymously

[51] World Health Organization, 2021, COVID-19 immunization in refugees and migrants: principles and key considerations Interim guidance 31 August 2021, available online at: https://apps.who.int/iris/bitstream/handle/10665/344793/WHO-2019-nCoV-immunization-refugees-and-migrants-2021.1-eng.pdf

pandemic governance, restrictions to mobility such as increased border policing and forms of control, surveillance, and population containment aimed at limiting movement have disproportionately impacted migrant groups.[52]

Following France's suspension of Schengen agreements in 2015, the French-Italian border has become one of the most heavily policed on the continent, especially around the coastal crossing points near the city of Ventimiglia. In this context, the Alpine route has emerged as an alternative border zone for migrants: in an attempt to elude police controls, increasing flows of migrants headed to France and other European countries have since late 2016 chosen to reroute their journey by crossing the Alps .[53]

A snowstorm in Clavière, Italy in early December 2021. Image Credit: Costanza Torre.

[52] Trubeta, S. (2021). Medicalised borders and racism in the era of humanitarianism. In *Medicalising borders* (pp. 287-309). Manchester University Press.

[53] Tazzioli, M. (2020). Towards a History of Mountain Runaways "Migrants" and the Genealogies of Mountain Rescue and Struggles. *Journal of Alpine Research| Revue de géographie alpine*, *108*, 2.

Regardless of their route of origin, for many undocumented migrants crossing the border from Italy into France represents one of the most treacherous points of their journeys. Once migrants reach the small town of Clavière, the last centre on the Italian side of the border, they have to find their own way across the mountain to the small town of Briançon, eleven kilometres into French territory. Under the pandemic, this journey has been further complicated by the fact that buses to Clavière are running only infrequently, due to the fact that several Italian bus drivers are not vaccinated against COVID-19 and hence are not in possession of the Green Pass certification that guarantees their ability to work. When buses are not running, migrants are faced with an additional thirty-four-kilometre journey by foot to the border. Overall, the journey is estimated to take at least twelve hours at minimum.

The danger of the journey across the Alps cannot be underestimated. Particularly during the winter, paths can be covered with thick snow, becoming difficult to identify. Moreover, migrants are often at risk of getting lost in their attempts to avoid French police, who have doubled the number of agents patrolling the border over the past year partly in response to increasing numbers of institutions and actors working in solidarity with the migrants

Since 2017, several people have died attempting the crossing, and in response, mobile infrastructures of solidarity have emerged within the region .[54] These include safehouses such as those in Oulx and Briançon, and small groups of *maraudeurs*, French citizens with extended knowledge of the Alpine terrain, who roam the border to rescue migrants in distress. From their beginning, these actors have been criminalised by state authorities[55] , similar to how humanitarian missions rescuing migrants lost at sea have often been heavily sanctioned.

The safehouse in Oulx, where this research was conducted, is one of the main referral points in the region. Upon their arrival in Oulx, migrants are entirely focused on the journey ahead of them. Mostly, they do not plan to stay at the safehouse for more than one night, and they spend their time preparing for the journey: eating well, resting and obtaining good quality clothes. Frequently, too, they do not know the route across the Alps and rely solely on their smartphones or on maps distributed at the rail station by volunteers, which often results in encounters with the French police and resulting push-backs on their first attempt. In general, people are aware that the crossing will entail a huge physical effort and of the possibility that they may have to attempt it more than once.

[54] Ibid.

[55] Anafe (2019) «Persona non grata. Conséquences des politiques sécuritaires et migratoires à la frontière franco-italienne», Rapport d'observations 2017-2018. Available at: http://www.anafe.org/spip.php?article520

4.3 Constructing health borders through COVID-19 bureaucracy

Contrary to the narrative that sees undocumented migrants and people on the move as generally unvaccinated or reluctant to vaccination, we found that many of the people that were passing through the safehouse in Oulx in hopes of crossing the Alpine border had indeed been vaccinated. The likelihood of having received the vaccine varied in relation to several factors. For example, family groups frequently reported having obtained vaccination, while solo travellers (the totality of which were men) more often reported not having received one. Geographical trajectories also played a role, as people that had reached Italy through the Balkan route (e.g., originating from Afghanistan, Iran, Iraq, or Kurdistan) were more likely to have obtained a vaccine than people arriving from other routes such as the North African and the Mediterranean crossings. Finally, the duration of the journey seemed to bear relevance, as people that had spent prolonged amounts of time in one or more countries along the route were more likely to have been vaccinated there. While attitudes and experiences varied within this diverse population, our research highlights a number of cross-cutting aspects that can be summarised as follows.

Vaccines as instrumental to mobility. Generally, we found that people who had been vaccinated understood their vaccination as another requirement, and often another obstacle, in their migratory journey. Frequently, people reported having felt coerced to obtain a vaccine by law enforcement. Even when decisions to receive a vaccine had been voluntary, such decisions were pragmatic, driven by mobility needs rather than health concerns, which were rarely mentioned. The wider context of people's journeys—the conditions of their country of origin and their specific migration histories—offer helpful perspective here. For example, when asked if COVID-19 had created problems in their home country, a group of young Afghan men laughed and replied: *"Only the Taliban are a big problem in Afghanistan"*. One of the men added: *"I had two cousins in the army, they were twenty and twenty-two years old. The Taliban killed both of them"*. The same group then proceeded to discuss a recent incident in which twenty-seven asylum seekers had drowned in an attempt to reach the United Kingdom.[56]

This interaction should not be understood as downplaying the health consequences of COVID-19 worldwide; indeed, our informants were often clearly aware of the health risks the virus posed. Rather, it shows that the instability and uncertainty that people are fleeing, and that equally underlie the treacherous journey to Europe, place mobility at the centre of migrants'

[56] The Guardian, 2021, Article, online at: https://www.theguardian.com/world/live/2021/nov/24/more-than-20-people-believed-to-have-died-after-refugee-boat-sinks-in-channel-latest-updates

priorities. Furthermore, for many people the journey towards Europe is characterised by social exclusion, violence and human rights abuses, with documented instances of torture in Libya, Turkey, Bosnia and Croatia, and often years of waiting in overcrowded refugee camps and reception centres. In addition to being lengthy and dangerous, the journeys are costly, and have grown exponentially in cost since the closure of the Balkan route in 2016 .[57] Our participants reported spending up to £10,000 per person to arrive in Oulx. For example, a twenty-eight-year-old Iranian man who was trying to join his wife in the UK recounted:

> *'My journey here cost a lot of money. I paid someone €5,000* [£4,157] *to take me under a truck from Iran to Turkey. The first time we were caught, so I had to pay again. My father sold his house so I could come.'* (Young Iranian man, Oulx)

Taking these wider contexts and needs into account is essential to understand these groups' attitudes and experiences of COVID-19 vaccines. When asked why they had decided to obtain vaccination, the vast majority of our respondents reported doing so to facilitate their journey, or at least in order to avoid problems with police. By the time they arrive in Oulx, people have usually had several encounters with police and border authorities; in many cases, and especially when attempted border crossing results in rejection, these encounters include intimidation, verbal and physical abuse. These interactions heavily inform migrants' decisions regarding vaccination, as one informant attested:

> *'For me, I got the vaccine in Greece, because I thought that if the police ask for vaccine certificate, at least I will have no problem.'* (Young man, Oulx)

Similarly, another informant reflected on the value of his vaccination against COVID-19:

> *'It is just another paper, it's good to have in case they* [the police] *ask for it.'* (Afghan man, Oulx)

'Health Nationalisms'. Following the heavy lockdowns of 2020, at present most European countries tie rights of mobility to the possession of a COVID-19 vaccination certificate or negative test. Several informants reported incidents in which, during attempts to cross a border along the way, border police destroyed their vaccine certificates upon pushing them back, with the clear intent to discourage them from continuing their journey. In some cases, these incidents were accompanied by acts of police brutality such as intimidation and physical violence. As one man recounted:

> *'When I arrived at the border with Croatia, the Croatian police beat me heavily in the back with the end of their guns. They asked me for papers, and they ripped my*

[57] Mandic, D. (2017). Trafficking and Syrian refugee smuggling: Evidence from the Balkan route. *Social Inclusion*.

vaccination certificate to shreds… luckily I had taken a picture of it.' (Kurdish man, Oulx)

Incidents of this kind clearly illustrate how states actively mobilise pandemic health bureaucracy to reinforce their borders in the name of "health nationalisms". Volunteers and workers at safehouses on both sides of the Alpine border were acutely aware of these dynamics; one volunteer, who has been active in solidarity activities in the region for several years, commented:

> *'Winter is always a problem, sure, but at least we are prepared for that. But this is worrying; first the buses coming less and less frequently, now this Green Pass thing… how many obstacles will be added? It all feels like new ways of not letting people pass, or making it more difficult for them. But people do pass at the end; almost everybody does.'* (Volunteer at Rifugio Fraternità Massi, Oulx)

Social and health workers also reported instances in which migrants who were traveling by bus (minimizing personal danger compared to people who crossed the border by foot) and were in possession of valid documentation to travel from Italy to France had been turned back at the border by French police, on the grounds that the COVID-19 documentation that they carried was not valid under French law (e.g. having performed an antigen test instead of a PCR test). In the words of one worker:

> *'It* [the COVID-19 vaccination / negative test certificate] *has just become yet another excuse for police to stop people. Even if they have all the papers, they will say that the test they have is not valid, or the vaccine is not the right one, and use that. And if the COVID-19 documents are fine, then they will again fall back on their papers.'* (Social worker at Les Terrasses Solidaires, Briançon)

While most participants who had received a COVID-19 vaccination described their decision as largely voluntary and motivated, as noted above, by mobility concerns, a smaller but significant portion of vaccinated people reported feeling or having been actively coerced to obtain one. These people reported that vaccination had not been so much a choice as an imposition from the state, law enforcement or other migration authority. In the words of two young men traveling together:

> *"I got it because the police told me to. I have no power; the government has power."* (Senegalese man, Oulx)

> *"There is no choice. At the reception centre they told me I had to do it. What was I supposed to do?" (Young Cameroonian man, Oulx)*

Lack of recognition of vaccines obtained outside of Europe. Just as in migratory communities in Rome, several informants in Oulx reported that their vaccination certificates were not considered valid in Europe, as they had received a vaccine not currently recognised by European medical authorities (e.g., the Chinese Sinovac or the Russian Sputnik vaccines).

> *'I did the vaccination in Turkey, two doses…but when I showed the papers for it they said it's not good. When I arrived in Slovenia I was put into quarantine for ten days.'* (Young Iranian man, Oulx)

As noted in the previous chapter, this issue is particularly problematic as it creates a bureaucratic and medical impasse with severe consequences on undocumented migrants' lives and trajectories. In countries that do not recognize certain vaccines, migrants cannot obtain a Green Pass certification that would grant them access to public transportation, therefore experiencing additional obstacles to their mobility. Nor, as noted, can they receive new vaccinations to ameliorate the issue, which are still inadvisable under current medical guidelines.

4.4 Perspectives of unvaccinated people

As is clear, individual attitudes towards and experiences of vaccination among migrants in Oulx varied greatly. By contrast, our findings regarding why people reported not wanting to receive vaccination showed a remarkably clear trend, which has significant implications for public health approaches targeted at people on the move.

A common narrative, especially prevalent among health practitioners and policymakers, identifies the lack of awareness and accurate information around COVID-19 vaccination as driving vaccine resistance. Disinformation campaigns in particular, often referred to as the "infodemic", are frequently seen as contributing to this resistance. Yet we have found that this is not always the case. Rather, the overwhelming majority of migrants in Oulx who had refused vaccination reported doing so based on pragmatic, well-informed considerations regarding established and common side-effects of the vaccine. It is important to note that these decision-making processes continue to put mobility at the fore, highlighting the need for an attentive consideration of migrants' priorities and needs in their efforts to navigate hostile policies and regimes.

Vaccine as risk of weakness: temporality and threats to the migratory journey. In light of the above factors, which weigh heavily on migrants' expectations and experiences of their journeys, concerns around physical fitness have become even more relevant to their decision-making processes around COVID-19 vaccination. Indeed, when asked why they had refused a COVID-19 vaccine, nearly all of our unvaccinated interlocutors spoke of being worried about

the impact of the side-effects on their mobility. Fears of experiencing physical weakness were particularly common among solo travellers, for whom the prospect of feeling unwell during the journey was particularly daunting. In this sense, rather than being misinformed, people were well-aware of the medical implications of the vaccine, namely the physical symptoms expected as part of the immune response. For our interlocutors these side-effects were anything but marginal, who understood them as potentially disrupting an journey that had already been challenging enough:

> *'People are worried that if they get sick* [as a consequence of the vaccine]*, they will have to stop the trip. What if I get a fever? Then I will have to stop and rest.'* (Iraqi man, Oulx)
>
> *'I don't want to take the vaccine now, because I have to pass the mountains tomorrow and I cannot be weak when I go.'* (Afghan young man, Oulx)

The specific temporality of the peri-Alpine border, specifically the brief duration of the transit through Italy, played an important role in these decisions. As noted above, migrants in Oulx receive assistance from safehouses where people stay only temporarily—usually one day for solo travellers, and a few days for family groups—rather than residing in camps where migrants can become stuck along the route, often for longer periods of time. Crucially, then, vaccine risk was understood in terms of disruptions to mobility rather than health impacts of COVID-19, which vaccines drastically reduce. It is worth noting again that these considerations did not necessarily entail lack of knowledge about the risks incurred by contracting the virus. One young man recounted:

> *'I got a phone call last week, from my mother in Dakar. She told me that my father died of COVID-19. Bur for me, I am not interested in the vaccine here, because I have heard that afterwards you will be weak. Now I can't, maybe when I arrive to France and rest.'* (Young Senegalese man, Oulx)

Finally, such fears of experiencing physical weakness must be contextualised within these groups' migratory histories. Upon reaching Italy, migrants often present with symptoms of trauma resulting from dangerous travels, long periods spent in overcrowded and unsanitary conditions in refugee camps, and even torture, abuse and intimidation at the hands of police and border authorities. The hardship endured often results in extreme physical and psychological exhaustion, which doctors at the Rifugio Fraternità Massi report observing as symptoms of bodily weariness (e.g., widespread infections, frequent injuries to legs and feet due to lack of medical care and overuse during travel), and mental distress (e.g., scars from self-harm). Such ailments incurred by previous parts of the journey only increase migrants' fears of exposing themselves to additional physical vulnerability.

Vaccine as risk of weakness: interrelations with masculinity. In some instances, concerns around physical weakness were further linked to threats to masculinity. Indeed, rumours of

vaccines causing sterility in men were common among young migrants. One young Afghan man said:

> *"I heard that it* [the vaccine] *can make you weak, and that if you are a man and take the vaccine, it can do something to you – you can become not a man…like a shemale."* (Young Afghan man, Oulx)

Again, context offers needed insight: these rumours stem from the fact that, particularly for young men traveling alone, the migratory journey often plays a major role in the construction of identity and masculinity. The search for a better life is linked to family obligations and mandates. As one young Senegalese man said:

> *"I am the first son, I have to be the man of the family and support my five sisters and one brother to go to school, because for us in Africa when you are the first son you have to support... there's your father and then there's you"* (Young Senegalese man, Oulx)

Legal professionals operating in Oulx reported several instances in which men under the age of eighteen traveling alone were extremely reluctant, when not entirely opposed, to being identified as 'minors' or 'children'—even when they were told that such definition would likely make their journey easier by entitling them to international protections not available to adults. In this sense, physical strength and fitness are critical to young men undertaking the journey to Europe, who often refuse to accept any notion that would compromise their lifeworlds. Such notions have significant implications for public health policies, as they deeply informed these migrants' choices regarding vaccination against COVID-19.

4.5 Policy Recommendations

Regulation of legal status and recognition of pre-existing inequalities. While COVID-19 restrictions have exposed economic and health inequalities, public health policies must identify and openly address the risks created by restrictions to mobility. Public health policy concerned with reaching people on the move must actively engage with the contestation of borders, and advocate for humanitarian corridors. Lack of safe passage must be understood as a health emergency in itself.

Recognising that the pandemic has deepened pre-existing vulnerabilities and inequalities of undocumented individuals, the regularization of their legal status and their living and working conditions should be an even greater priority. Access to forms of social protection should be guaranteed regardless of legal status and guaranteed nationwide (not delimited to regions or municipalities). Strong, effective and easily accessible complaint mechanisms should be reinforced in the event of harassment, violence or discrimination.

Facilitating access to services and clear communication. Communication strategies regarding vaccination and access to health services should include explicit information on people's legal rights, in order to reassure undocumented people that they will not be reported to the authorities upon accessing public services. In border areas such as Oulx, where people often refuse a vaccine in order to prioritise their journey, COVID-19 testing and the issuing of Green Pass certificates should become freely and widely accessible to facilitate mobility. Ultimately, for the most effective outcomes at present, it is necessary to adopt a "harm reduction" approach, for example to fund testing and quarantine without threat of discovery by the authorities and with minimal disruption to mobility needs and migratory journeys.

Adress shortages of professional staff. We note the limited funding available to staff in safe havens with medical personnel, such as trained doctors and nurses. Further, for maximum effectiveness, the implementation of public health policies targeting people on the move must rely on health and social workers that are already embedded in solidarity spaces and safe havens. The presence of cultural mediators and translators in public health services, safehouses and solidarity infrastructures should be ensured to improve access to services.

4.6 Chapter Summary

This chapter has presented findings from 'people on the move' in northern Italy, documenting diverse orientations towards COVID-19 vaccines within this demographic that are often dictated by the specific stop-over points of migrants. In detailing the treacherous journeys migrants take over the Alpine mountains, we highlighted the disjuncture between risks of infection, concerns regarding the demands of movement, and fear of the state authorities. In general, prerogatives of movement rather than health concerns dominated decision-making processes.

Importantly, these findings identified solidarity infrastructures that engaged migrants and became trusted bearers of information. We note, however, that within these networks, notions of vaccination often reflected mistrust of the Italian state, and as such, volunteers were not necessarily 'pro-vax'. Mobile groups may be seen as presenting greater difficulties in administering vaccines requiring repeated doses and boosters. Rather than stigmatising migrants, however, it is important to understand and take seriously the priorities that guide their decision-making processes and attempt to engage these groups and individuals through trusted networks already in place.

5. Exclusion and Stigma: Evidence from Italy's Roma Communities

5.1. Introduction

This chapter explores the role of three main factors—structural discrimination, negative encounters with the state, and trust in public authorities—in producing attitudes towards COVID-19 vaccines among Roma groups in Rome, Milan and Catania.[58] Among Roma people, the barriers to vaccine uptake originate from a complex and ongoing experience of disadvantage and a communal struggle for survival. Critically, these findings indicate that contradictions in state pandemic response coupled with continuous forms of exclusion can increase Roma mistrust in government initiatives and prevent vaccine participation. To redress this damage, public health research, policy and practice must consider the entanglements of pre-existing inequalities with the new forms of marginalisation induced by the pandemic as a starting point for engagement with Roma communities.

5.2 Historical Context

Vaccine uptake among Roma groups cannot be fully understood without referring to previous regimes of social inequality and discrimination. To date, Roma and Sinti peoples have been largely viewed as "outsiders" although they have lived in Italy for the last six centuries.[59] During the wars of the 1990s, waves of Roma from former Yugoslavia migrated and sought refuge in nearby Italy.[60] Most recently, following the collapse of the communist regimes in Eastern Europe and the enlargement of the EU, new waves of Roma from these regions migrated to Italy primarily for economic purposes. Although Italy has one of the lowest share of Roma and Sinti populations in Europe, these recent waves of immigration have made Roma more visible in public discourse and turned them into a "public enemy".[61]

Between 140,000 and 160,000 Roma and Sinti live in Italy, although this number remains an estimate, as Roma are not one homogeneous community group nor are they recognised as an Italian minority in policy and national statistics. Recently, the public fear of Roma migration

[58] This chapter reflects research led and conducted by Dr Iliana Sarafian, LSE.

[59] Piesere, L. 2004. *I Rom d'Europa. Una Storia Moderna*. Rome-Bari: Laterza.

[60] Fraser, A. 1992. *The Gypsies*. Oxford: Blackwell. Sigona, N. 2008. The 'Latest' Public Enemy: Romanian Roma in Italy. The Case Studies of Milan, Bologna, Rome and Naples. Milan: Deakin Research.

[61] Clough Marinaro, I., and N. Sigona. 2011. 'Introduction Anti-Gypsyism and the Politics of Exclusion: Roma and Sinti in Contemporary Italy', *Journal of Modern Italian Studies* 16(5): 583–9.

has become apparent in political discourses through the so-called 'Nomad Emergency' policies (although few Roma in Italy are nomadic today) that have resulted in xenophobia and discrimination, including targeting Roma in racially-motivated attacks and evictions.[62] In such policies, nomadism is not only regarded as a lifestyle, but is considered as a socially-deviant Roma trait[63] resulting in anti-Gypsyism[64] and communal stigmatisation.

Image of a Roma Camp, Italy. Image Credit: Iliana Sarafian

Known by the derogatory term 'zingari', some Roma live in 'nomad camps' (*campi nomadi*) or shantytowns (also called 'villages'), usually in the outskirts of cities. The construction of such camps is the legacy of local and regional regulations between 1984 to 1992 when these settlements were offered by local authorities as a temporary housing solution for migrants. This temporary solution, however, has become semi-permanent. Both formal and informal camps of today are characterized by poverty, unemployment and precarious work in the

[62] EU FRA. 2020. 'Coronavirus Pandemic in the EU - Impact on Roma and Travellers'

[63] Solimene, M. 2018. 'Romani (Im)Mobility, Between Camps, Evictions and Ambivalent Repressions of "Nomads" in the Eternal City', *Nomadic Peoples* 22(1): 65–82.

[64] The European Commission against Racism and Intolerance (ECRI) at the Council of Europe defines anti-Gypsyism as "a specific form of racism, an ideology founded on racial superiority, a form of dehumanisation and institutional racism nurtured by historical discrimination, which is expressed, among others, by violence, hate speech, exploitation, stigmatisation and the most blatant kind of discrimination" ((ECRI – General Policy Recommendation No. 13 on combating anti-Gypsyism and discrimination against Roma, June 2011)

informal economy, and inadequate access to healthcare and education. Moreover, the pandemic has had devastating effects on Roma groups in Italy and elsewhere.[65] Due to the marginalisation and demonization they experience, the Roma risk being disregarded by public health initiatives and policymakers. This case study thus contends that current policy practices should consider previous and present dispositions with a twofold aim: first, to mitigate the increased vulnerability of Roma communities, and second, to provide solutions based on communal participation.

5.3 Lockdowns and the Proliferation of Bureaucracy

In March 2020, seeking to halt the spread of the pandemic, the Italian prime minister Giuseppe Conte signed a decree implementing a strict lockdown across Italy. Seen as spaces of contagion, the securitization of Roma camps increased.[66] Yet the presence of police at the entrances of their camps was not a new occurrence for camp dwellers. Prior to the pandemic, formal and informal Roma settlements were already seen as spaces threatening majority Italian society and its values. The perceived illegality and informality of the camps had long caused frequent police visits, reinforcing the social and physical boundaries between camp dwellers and the rest of the population.[67]

[65] Korunovska, N. and Jovanovic, Z. (2020) *Roma in the COVID-19 Crisis:*, Open Society Foundations.

[66] Stasolla, P. and Vitale, T. (2020) '#IStayCamp. Health Conditions, Food Deprivation and Solidarity Problems in the First Days of Lockdown in the Roma Villages of Rome', *metropolis.org* [Online]. https://metropolitics.org/IStayCamp-Health-Conditions-Food-Deprivation-and-Solidarity-Problems-in-the.html.

[67] Marinaro, I. C. and Solimene, M. (2020) 'Navigating the (in)formal city: Roma, urban life and governance in Rome', *Cities*, vol. 96, p. 102402 [Online]. DOI: https://doi.org/10.1016/j.cities.2019.102402

Removal of a Dwelling from an Italian Roma Camp. Image Credit: Iliana Sarafian.

During the pandemic, however, this previously-established 'biopolitical control' cemented views of Roma people as a public health threat.[68] A further dimension of public imagery joined the perceived illegality of Roma lives, where the physical characteristics of contagiousness intermeshed with long-standing prejudice. As in other European countries, lockdowns for Roma peoples entailed the state securitisation on a neighbourhood and community (ethnicity) level rather than on an individual (citizen) basis. [69]

This control over movement ensured that Roma people who were employed in the informal sector or in manual and essential jobs were disproportionately affected by the lockdown. All our respondents suffered negative socio-economic impacts largely due to employment in low-paid, temporary, and precarious work, often falling into deeper poverty or debt. When, for example, a Bulgarian Roma woman in Catania working as an informal carer for the elderly fell ill, she resorted to taking out a loan to cover the out-of-pocket hospital costs due to her restricted access to medical care and income. In both formal and informal settlements, Roma inhabitants struggled to access food, medication, education, and mainstream services.

[68] Clough Marinaro, I. (2009) 'Between surveillance and exile: Biopolitics and the Roma in Italy', *Bulletin of Italian Politics*, vol. 1, no. 2, pp. 265–287.

[69] EU FRA (2020) 'Coronavirus Pandemic in the EU - Impact on Roma and Travellers', European Union Fundamental Rights Agency; Korunovska, N. and Jovanovic, Z. (2020) *Roma in the COVID-19 Crisis:*, Open Society Foundations.

Reliance on kinship support and solidarity increased, although as resources depleted over time, reciprocity became less prominent. While mutual support and close social infrastructure were lifesaving factors, depletion of the limited resources available to Roma households created further vulnerability and poverty. An elderly leader in a Roma community in Milan expressed the following:

> *'I used all of my savings, everything, for my family and friends. On the one hand, we were not contracting the virus because we were not allowed to go out of the settlement which is far from the central places in the city—but on the other hand, we could not go to the market to sell and earn money to feed ourselves. [It was] an impossible situation.'*

Education for Roma children, already sporadic prior to the pandemic, became inaccessible due to the lack of technological/internet access and school supplies in Roma settlements under lockdown. In the words of one Roma woman in Rome: '*My child didn't have a computer at home to be able to access online classes, indeed school wasn't on our minds at a time when we struggled to feed ourselves*'. In due course local authorities across Italy did provide food vouchers for disadvantaged communities, but this measure did not include Roma living in informal settlements who required official registration.[70] Moreover, emergency COVID-19 isolation policies were predicated on the assumption that all individuals had access to basic sanitary conditions such as drinking water and adequate accommodation. However, public health messages urging social distancing and sanitation had no relevance for the occupants of Roma camps. As one respondent in Rome explained: '*Keeping away from each other was impossible. Washing your hands every time you go out or staying at home did not mean much to those of us who live in a camp without drinking water or who live in a room with all members of your family'.*

Despite the ease of access and availability of vaccines in Italy at the time of the research, Roma communities expressed mistrust due to their considerable past and present experiences of living in strained relationships with the state. Indeed, state approaches to tackling the pandemic illustrate both the proliferation of bureaucracy and the subsequent policy contradictions posing as barriers to vaccine participation and social justice.

5.4 "Vaccine Hesitancy" versus "Vaccine Uptake Barriers"

Although there is a lack of official data regarding vaccine uptake, infection rates, hospitalisations, and deaths among European Roma populations, anecdotal evidence

[70] EU FRA (2020) 'Coronavirus Pandemic in the EU - Impact on Roma and Travellers', European Union Fundamental Rights Agency.

suggests a lower vaccination participation among these diverse groups.[71] In our encounters with Roma peoples, whose responses we quote in-line in this section, we found a variety of themes on the barriers to vaccine uptake:

Doubts towards vaccine efficacy, safety and fear of side effects was the most common theme in respondents' narratives. '*I fear the side-effects of the vaccine. I want more information. People die because of these vaccines.'* In addition, the belief that the speed with which the vaccine was developed heightened safety concerns. *'They made it too quickly, I don't know what I will be injecting in my body'*. Timing ('*I will wait for some time'*) was also considered by participants who were not necessarily refusing but delaying vaccination.

Mistrust in government due to 'state of emergency' policies contradicting everyday experiences of inequality. *'We, Roma, are such a target, I don't trust any of them* (meaning government). *They want to give me the vaccine while taking the only home I know and giving me no support'.* The ease of access to vaccination contrasted with prejudice and the lack of state socio-economic support represented a significant contradiction for our respondents, and became a major source of mistrust toward the vaccination campaign. One such example of policy contradiction were the vaccination efforts taking place simultaneously with evictions in a Roma camp.

COVID-19 risk versus socio-economic precarity. The everyday inequalities our participants suffered—such as poverty, discrimination, and lack of access to education and healthcare—were not side-lined by the onset of the pandemic. Rather, these aspects of precarity remained central to the livelihoods of many who considered the risk of COVID-19 '*as another difficulty that needed to be had'* in addition to what they were already experiencing. To many respondents, the risk of COVID-19 was marginal in comparison to socio-economic survival, often summarised as follows: '*I either die of COVID-19 or of hunger'*. Moreover, social restrictions and isolation disrupted the communal networks linking Roma households, preventing them from meeting essential needs. '*How could I help my sister who is disabled and lives in another camp? People like her are left to die.*'

Lack of community participants in vaccine campaigns. The vaccination process was seen as '*solely belonging to the non-Roma*'. In other words, engagement of public health professionals with Roma community gatekeepers and support workers, religious leaders and

[71] Holt, E. (2021) 'COVID-19 vaccination among Roma populations in Europe', *The Lancet Microbe*, Elsevier, vol. 2, no. 7, p. e289 [Online]. DOI: 10.1016/S2666-5247(21)00155-5.

role models was conspicuously absent, an absence that bred mistrust towards health professionals and state initiatives.

Lack of health records and health insurance. Due to their status as informal workers, some of our participants were not covered by social welfare or health insurance, and remained ineligible for any social aid. For these participants, the precariousness of informal work meant that they were forced to rely on communal solidarity and mutual support, which was often limited. The lack of health records furthermore ensured that their interaction with public health services, and their access to information about vaccination, remained limited.

Vaccine mandates and resistance to vaccination. As noted earlier in this report, in 2021 the Italian government approved strict measures of pandemic governance, including mandating the 'Green Pass' as a proof of vaccination, a recent recovery from COVID-19 or a negative COVID-19 test. Contravening these rules warranted fines and restricted access to public facilities—yet such rules were a reminder of historical events of mistreatment of Roma and Sinti communities. '*The Nazis killed our people in the concentration camps in the same way, what can stop people from doing the same now?'* Moreover, our respondents who were vaccinated were not necessarily in favour of vaccination and had chosen to receive the vaccine for access to employment. '*I need the vaccine for my job, but I don't believe in the COVID-19 vaccination'*. In other cases, scepticism by medical professionals themselves influenced our respondents' choice: '*My doctor tells me she wouldn't have taken the vaccine if it wasn't for her job, so why should I take the vaccine?*'

Misinformation and social media. All our participants had access to social media platforms, and over half of them shared their exposure to online materials labelling the pandemic as a hoax or as a tool for population control by politicians and celebrities.

5.5 Policy Recommendations

The below recommendations represent entry points for building trust are not an exhaustive list, and should complement policy recommendations regarding the overall social inclusion of Roma communities in Europe, both prior to and during the ongoing pandemic.

Focus on communal views and Roma participation. While numerous efforts have sought to mitigate the spread of COVID-19, little research has focused on communal views and concerns throughout the pandemic. As well as looking at the barriers to vaccine uptake among Roma populations, this research illuminates the relationships of trust within communities and their impact on vaccine uptake, relationships we urge policymakers to consider. Bearing in

mind the heterogeneity of Roma communities, approaches to addressing vaccine participation may require varying strategies of communal engagement.

Address trust through community-based approaches. We found that the sites of greatest trust rested within family and communal relationships, where family consisted of relatives living in close proximity or sharing accommodation (in portacabins, trailers, make-shift constructions or apartment flats). Households we encountered tended to be larger than the nuclear family unit, and consisted of a higher number of young children; while overcrowding in Roma settlements has been seen as a health risk, the reasons behind this tendency (apart from being the only available state provision) are rarely considered as a communal strategy for survival and mutual support. Yet in environments where employment, accommodation, and health access are restricted, these kinship structures and patterns of household formation represent key communal strategies for tackling poverty and ensuring socio-economic and cultural survival. This mutuality predicates conditions of trust in which members share information and attitudes towards vaccination, resulting in pro- or against choices.

Understand pre-existing inequalities and discrimination. Against the backdrop of historical injustices, trust can be challenging to build. Roma mistrust towards vaccine campaigns intersects with their resentment of punitive public measures, most recently the lockdowns implemented on the scale of entire settlements, not individual households. Reconsideration of the 'mass', even arbitrary nature of quarantine is crucial, and such measures must account for the needs of the affected populations such as access to amenities and services, aid, healthcare, education and employment.

Work with trusted individuals and community structures. Involving trusted community champions often falls outside existing public health practice, highlighting the need to evaluate the effectiveness of outreach strategies. Yet our respondents did trust community champions and leaders who fostered change. For example, the availability of a Roma health mediator (supported by a non-governmental organisation) in a settlement in Rome resulted in higher vaccination rates among that community. Religious leaders and faith-based circles also played a part, as discussions in church and communal gatherings reflected on how religious beliefs intersected with vaccination. Community members respected Roma elders' authority, and the drive to protect the elderly increased vaccination uptake in Roma households.

Support community organisations. Non-profit and faith-based organisations at the local level require consistent access to training and funding to meet the diverse needs of Roma communities. Importantly, Roma communities themselves should have a role in prioritizing and co-producing solutions.

Build on established trust with medical personnel. General practitioners are more likely to be viewed as credible messengers by Roma people if they have an established relationship with Roma patients. One Roma woman in Catania shared: *'She* (the GP) *listens to me with respect, and she is always supportive. She helped me to make a decision about the vaccine by explaining how it works'.* A key component to increasing vaccine uptake would be the authoring of culturally-tailored and accessible information about the vaccines, including their benefits and side-effects. Medical personnel who already treat Roma peoples can play a unique and important role in this authorship.

Raise awareness among medical professionals. In order to deliver consistent, relevant messages and boost outreach efforts among Roma communities, medical personnel must understand the needs, concerns and historical inequalities the Roma face. Given uneven literacy rates, a shift toward oral forms of health messaging in addition to working with Roma champions can provide better health outcomes in general. Encouragingly, past instances of successful public health campaigns for Roma children in Italy and elsewhere have achieved higher rates of vaccination (Dyson et al., 2020), and we urge a consideration of prior successes.

Increase alternative messages on social media platforms. Within Roma households, nearly all generations frequently access digital media. The use of social media, including materials featuring Roma community members, can contravene online materials leading to misinformation and distrust in vaccination.

Generate data and research. Any policies supporting long-term solutions for building trust must improve the health and well-being of Roma communities. Public health research, policy, and engagement with Roma communities—including the entanglements of pre-existing inequalities with new forms of disadvantage—are necessary to redress disproportions in vaccine outreach and uptake.

5.6 Chapter summary

Among Roma communities, longstanding social inequality and its effects have directly impacted vaccine participation. Poverty, discrimination, and socio-economic disparity have diminished vaccine uptake among vulnerable communities. Moreover, prior disparities and structural harm can become normalised, and thus rendered invisible, in public discourses on vaccine uptake. Equitable access to public health services requires the rethinking of linear state solutions, as well as the tackling of underlying everyday realities in the lives of Roma peoples.

At present, low vaccination rates are consequences of the shortcomings of public health efforts in reaching, reassuring, and engaging vulnerable or so-called ‘hard-to-reach’ communities. Transparent public health engagement with Roma communities is key, including conveying the benefits, risks and side-effects of vaccination. Moreover, future policy interventions must account for the new inequalities and forms of marginalisation the pandemic has engendered, and must provide multi-layered solutions to the complex and age-old issues faced by Roma populations. Finally, and most importantly of all, without communal participation and resources targeted at cultural and socio-economic interventions, efforts to increase vaccine uptake and equality are likely to fail.

6. COVID-19 Among South Sudanese Canadians

6.1 Introduction

In 1990s, as the Sudanese government battled a South Sudanese-led armed opposition, thousands of South Sudanese sought refuge in Canada.[72] Many of these refugees had first-hand wartime experiences and had initially sought shelter in camps in East Africa. Those who accessed Canada did so through scholarships, resettlement schemes or later, through family links. The South Sudanese respondents we spoke to for this research described how they were still on a 'journey to build life here in Canada'.

The South Sudanese Canadians within this study often perform precarious jobs throughout Canada, frequently moving from one province to another for job opportunities. Lines of work have been significantly disrupted by COVID-19 restrictions, and many have experienced deepening levels of poverty throughout the pandemic. Simultaneously, conditions of suffering, and movement restriction created by COVID-19 served to revive traumatic past experiences, such as exposure to various deadly diseases, hunger, economic deprivation, political repression and social isolation. Memories of past experiences of repressive government regimes and various rebel authorities during the long years of the second Sudanese civil war surfaced during the pandemic. It is this frame of socio-economic trauma, past and present, that provides the reference point for accepting or rejecting COVID-19 vaccinations.

6.2 Communal Perspectives: Histories of distrust, fear and diaspora knowledge exchange

Historic reasons for distrust in government initiatives. South Sudanese community leaders narrated historical incidents when Africans were exposed to numerous unethical medical trials or procedures, which in some parts of Africa has eroded faith in pharmaceutical companies. Unsurprisingly, this erosion has also created general distrust in vaccines.[73] Both before and after World War II, a massive global infrastructure of vaccinology was also

[72] This chapter reflects research conducted collaboratively by Dr Naomi Pendle (University of Bath) and Malith Kur (McGill University).

[73]Quinn, S., Jamison, A., Musa, D., Hilyard, K., & Freimuth, V. 'Exploring the Continuum of Vaccine Hesitancy Between African American and White Adults: Results of a Qualitative Study'. *PLOS Currents Outbreaks.,* p. Edition 1 (2016)

implemented by European colonial authorities in Africa.[74] Those public health measures were defined by imperial states using force to compel Africans to accept vaccines. The purpose of such vaccination campaigns was to protect European colonial officials from contracting diseases from local African populations.[75]

Africans still recall these unethical colonial medical experiments, which are partly responsible for the current mistrust of vaccines. During the COVID-19 vaccination campaigns, this distrust was exacerbated in some parts of Africa once the first COVAX vaccines began to arrive on the continent. Meanwhile, certain European leaders had rejected these same vaccines, which created a perception of the dumping of dangerous vaccines in Africa.[76] Some interlocutors went as far as to suggest that the coronavirus was not present in South Sudan, and that it was brought there as a pretext to introduce vaccines to control the growing African population.

Unfolding understandings of COVID-19. In South Sudan, one reason for people refusing the vaccine has been the perceived lack of threat from the virus. Initially, as COVID-19 hit global headlines in early 2020, there was widespread fear. Yet, with a lack of testing in South Sudan, COVID-19 has remained largely invisible.[77] By contrast, in Canada, South Sudanese Canadians expressed fear about coronavirus infections. At the beginning of the pandemic, these fears were high among all adult age groups, deepened by the mysteries surrounding the origin of the coronavirus. Our interviewees, particularly the younger generation of South-Sudanese Canadians, searched for information and ways to protect themselves.

The precarious nature of employment for South Sudanese Canadians as well as the areas in which they lived in—populous cities across Canada— increased the exposure to COVID-19. Many South Sudanese Canadians work in industries that do not offer the chance to work remotely. This situation generated further fears for individuals and families, related to the possibility of losing income and household livelihoods. Our discussion with a nurse in London (Ontario) captures this: *'I fear coronavirus as a frontline worker at nursing home. I may get infected and bring it to my children.'* As new variants emerged, these fears spread among the older generation too. One of the community leaders echoed his fears. *'I am a coronavirus survivor. I have become more afraid of it. The virus is mutating, and many variants are coming*

[74] Pearson-Patel. J. April 2, 2015. "A Brief History of Vaccines in Colonial Africa," Active History. https://activehistory.ca/2015/04/a-brief-history-of-vaccines-in-colonial-africa/.

[75] *ibid.*

[76]. Alice Robinson, et al. 'This your Disease: Dynamics of Local Authority and NGO Response to COVID-19 in South Sudan'. https://www.lse.ac.uk/africa/assets/Documents/Research-reports/LSE-Report-Dynamics-of-COVID-19-in-South-Sudan.pdf.

[77] *ibid*

*up and the vaccine cannot prevent infection. I do not want to experience another infection from this virus. It is scary and dangerous***.'**

The pandemic brought COVID-19-related deaths, and these were discussed across diasporic networks and where losses came to be experiences close and personal. When restrictions rendered in-person mourning at the home impossible, families hosted "open-houses" online, setting up Zoom meetings on TVs in their lounges where friends and family could join the Zoom call throughout the day in order to offer words of comfort.

Diaspora and routes for knowledge exchange. Social media enabled easy access to information (including misinformation) about the COVID-19 vaccine in different parts of the world and across global communities. Like other communities, the South Sudanese first heard about COVID-19 in 2019 through social media and were informed about the vaccine rollout in late 2020, again through social media. South Sudanese Canadians members of WhatsApp groups and Facebook pages make it possible for them to be part of discussions in South Sudan daily. Participating in these groups reinforces people's social and epistemic links to South Sudan and it also shapes their opinions about vaccination.

The reliance on information from distant epistemic communities and sources is explained through the lens of socio-economic inequality and poverty. Research participants in London (Ontario) highlighted how few South Sudanese Canadians were able to afford cable television with access to the main Canadian or international news outlets. Instead, they access news and knowledge through their phones and in their language. Knowledge from a plurality of social media online sources was then judged, discussed with friends and family, and ultimately trusted (or not).

Perceptions of vaccination violence. Our research found that a significant number of South Sudanese Canadians received vaccines in 2021. Yet many vaccinated individuals did not initially accept vaccination voluntarily—instead, they described having to receive the vaccine to keep their jobs. As one interviewee described:

> *'I was forced to take the vaccine that I did not want. That has affected me psychologically because I do not know the long-term effect of this vaccine on my health. Through government mandate, my workplace required me to take the vaccine whether I work remotely or not. It was disappointing that people did not have a choice'.*

Another discussant in London (Ontario) described vaccination as equivalent to fighting in the rebel armies in Sudan during the 1990s. During the Sudanese civil wars, male service in the rebel army entailed grave risks, but this was seen as an act for their family and community.

Likewise, the vaccine was seen as bringing risks, but receiving it was a service to the family as men could then still have an income.

Unvaccinated adults, regardless of gender, also mentioned religion and the rumours they had heard from friends and relatives (often on social media) as the primary causes for rejecting vaccines. These respondents associated both the virus and its vaccines with the Biblical 'signs of the beast', signalling the end of times. The response to the perceive vaccine violence was to have faith as they have survived war and sickness previously.

6.3 Wider considerations of vaccine reluctance

Vaccination perceived as involuntary. For many Canadians, the vaccine rollout was welcome news. However, South Sudanese Canadians, especially frontline workers, received the news reluctantly and remained cautious about accepting a COVID-19 vaccination. To date, over 83% of Canadians have been vaccinated.[78] This number includes most South Sudanese Canadians whom we interviewed across different provinces. Our case study found that the vaccination rate is high among South Sudanese Canadians, but that they did not accept the vaccines voluntarily. Rather, government mandates and proof of vaccination in workplaces compelled most of them to receive the jabs. Our informants in Ontario, Alberta, Manitoba, and Saskatchewan received full doses of the available vaccines, but they remained concerned about their long-term side effects on their health.

Exact statistics of vaccinated and unvaccinated South Sudanese Canadians are unknown. Community and religious leaders estimate the number of unvaccinated to be between 5–10% of all South Sudanese across Canada. There was a particular reluctance to get the jab among young people. Pointing to the recent breakthrough infections documented among vaccinated individuals, younger South Sudanese Canadians rejecting the vaccines argued that '*the vaccines are not working. They do not stop the virus*.'

A COVID-19 response designed for others. Research participants expressed general support for the Canadian government, in doctors and health services and the freedom and welfare it provided. From the earliest stages of the COVID-19 response, however, it became clear to many South Sudanese that the federal and provincial governments did not consider how different policies and restrictions will affect the community. These pre-vaccination measures sowed distrust of the government's policies, which later impacted vaccine roll out.

[78]Government of Canada, 'Vaccine Coverage: COVID-19 Vaccination in Canada'. Jan 21, 2022. https://health-infobase.canada.ca/COVID-19/vaccination-coverage/

Moreover, the government rarely reached out to the leaders or associations representing them.

Social connections not prioritised. One major reason for South Sudanese concern over the Canadian government's COVID-19 restrictions was the impact they had on social interactions. South Sudanese living in Canada often remain socially reliant upon and connected to communities of their fellow exiled communities that have been remade in this diasporic context. This social reliance also chimes with South Sudanese notions that the community is more important than the individual, and that belonging to a community is essential not only for individual security but for social and emotional well-being. As in many countries, the pandemic enabled the government to institute policies that required social isolation or distancing to minimise coronavirus infections, with some of the most restrictive measures implemented in urban areas such as London (Ontario) and Toronto.

Travel restrictions. The cost of travel and social restrictions acutely impacted South Sudanese living far away from other South Sudanese. As one man in Charles Town, Prince Edward Island, described '*The problem is that South Sudanese are scattered around Canada. Most of us find themselves in isolated places with few friends to talk or interact with in many cases. Loneliness is a major issue for me*'. The lack of international travel also impacted our informants' ability to spend time family abroad. Many South Sudanese in Canada have siblings and close relatives in Europe and Australia, as well as daily communication with people in South Sudan. Government restrictions directly prevented travel or made it too expensive, keeping people apart from their communities. One man put it this way:

> *The current pandemic has affected my life in many ways. It has halted my travel plans. I wanted to go to South Sudan in 2020 for the first time since I left in 1985, but the virus changed that plan. In addition, the virus has caused isolation in our community. We enjoy socializing with one another, but now, it is not possible for a number of people to gather in one place. People are afraid to carry the virus to others.*

6.7 Policy Recommendations

At present, South Sudanese Canadians live on the fringes of Canadian society, which has created a variety of social problems for them. Vulnerable groups among them struggle to find adequate resources and the correct information on important issues, with single mothers among the majority of those facing challenges and who are reluctant to receive vaccines. The COVID-19 pandemic has worsened these challenges, but Canada's federal, provincial and municipal governments can address these issues through the following:

Engaging Local Leaders and Champions. While COVID-19 continues to cause health problems, public health authorities should consider reaching out to South Sudanese community leaders, social networks and associations across Canada to partner with them. These groups can spread reliable information about the coronavirus and vaccines to their members, reducing the reliance of some individuals on social media for questionable information on managing risks, taking precautions, and general vaccine safety.

Investing in Women's Literacy. The government of Canada should invest in South Sudanese Canadian women's health literacy programmes. Women-led and women-centred community groups and networks can be essential partners in such initiatives. Women participants can be empowered to become health champions in their respective communities.

Addressing Histories of Medical Discrimination. It is important for health education to address and revisit wider legacies of medical racism. It is also important for messaging to be transparent, and to include, for example, rates of ethnic and gender participation in vaccine trials. It is essential to approach concerns of community seriously, through revisiting biomedical legacies which have resurfaced in relation to COVID-19 vaccines. It is also important to relay evolving messages regarding the safety of vaccines. Community champions, including women's groups, could be central figures in encouraging dialogue with respect to historical legacies and scientific evidence.

Signposting to Psychosocial Support Services. Alongside offering vaccine information, it is important to signpost South Sudanese Canadians to welfare services, as well as psycho-social assistance. It is important to recognise the experiences of COVID-19 as causes to reactivate prior memories of repression and war. Offering counselling outlets, rather than depending on community structures alone to manage the reactivation of past trauma.

7.0. Overall Findings: Seven Themes for Consideration

7.1. Communities, culture and inclusion

Much policy-making assumed communities as homogenous entities, as passive recipients of health messaging. Implicitly, a spatial connotation is implied – and community becomes both distinct and bound by place. For the interlocutors within this study, it was evident that community – and belonging – often transcended space. Simultaneously, throughout this research, it was clear that decision making was a *deliberative* process, unfolding conversations being mediated by the dynamics of kin, peers, elders, neighbours and community leaders. Though we found much evidence for decision-making processes in-situ, advice trusted by our interlocutors was dealt at a distance, with their views being transmitted through telephone communication and social media. On occasion, advice from quite different national contexts was integrated into people's decision making. Community reflected the transnational worlds inhabited by many of our interlocutors.

The communities engaged in this research are ethnically, geographically, and socio-economically diverse. Bearing in mind this heterogeneity, approaches to addressing vaccine participation require varying strategies and methodologies reflecting diversity and inclusion. It is particularly important, for example, to avoid conflating established Roma populations with mobile migrants. Many of our Roma interlocutors had been settled for decades, and old stigmas directed at them had colluded with new state fears that these supposedly 'nomad' yet settled populations constituted a health risk. This is why, this study does not aim to collapse diverse claims of citizenship and settlement across its research sites. Indeed, its aim is rather to present the complex matrix of experiences of vaccine uptake, acknowledging factors such as social exclusion or pre-existing histories of inequality.

Fundamentally, we advocate for a recognition of communal and individual specificities in efforts to achieve health goals, as well as wider conceptions of well-being, justice and settlement. Such efforts must include those people on the margins in community-based policies accounting for specific access to citizenship, movement, and economic survival. Ultimately, ensuring the equitable uptake of vaccination requires tailor-made interventions. Whilst we note diversity across our study sites and interlocutors, significant overlaps also arise. Among the many complex orientations and individual narratives, our research reveals commonalities in structural barriers towards COVID-19 vaccination that have served to exert further exclusion. Importantly, these cross-cutting themes emerged from the ethnographic material—i.e. our interviews, dialogues, participant observation and general engagement with

interlocutors—leading to our conclusion that policy-making should be centred on communal dialogue and inclusion.

7.2. Poverty, informality and social inequality

For “settled” migrants in Rome, the ability to work often dominated discussions of COVID-19, as did discussions of navigating the new governance and policing structures that arose during the pandemic. For migrants on the move, the need to obtain safe passage and reach safe harbour was often the most pressing concern. Thus, many male migrants who were undertaking physically demanding journeys across Alpine borders feared taking vaccines on account of exposing their bodies to additional stress. A common refrain heard at the safehouse in Oulx was that the ‘vaccine can make you weak.; Similarly, these migrants feared that side effects would delay the journey. For Roma in Milan, Rome and Catania vaccine uptake was directly influenced by economic survival and communal memories of pre-existing inequalities, discrimination and stigma. For South Sudanese Canadians, the resurfacing of hunger, economic deprivation, political repression, and social isolation brought on by the pandemic reminded them of the conflicts they had endured back in Sudan.

The pandemic only exacerbated the already-high level of poverty among the communities of our research. Whilst our study acknowledges that rumours about COVID-19 vaccines do exist, people’s calculations to accept or reject vaccines are often tied more to pragmatic decisions than to risk of infectious disease. Our respondents assessed correct and incorrect information about the vaccine but interpreted it within wider practices of movement and (for migrants) obtaining safe passage. Across our studies, research participants faced issues of competing priorities such as accessing employment, medication, food, safe passage and more. Apart from prioritising basic needs, respondents expressed fear and hesitation due to past and present interactions with the state leading to legacies of exclusion.

7.3. Trust and mistrust in government and community

Wider legacies of violence, marginality and discrimination have proliferated G7 state systems, including public health interventions. Policy contradictions such as vaccinations taking place concurrently with evictions in Italian Roma camps can erode trust in vaccination campaigns. Moreover, pre-existing disparities and structural harms can become normalised in public discourses on vaccine uptake, leading to further invisibility of marginalised peoples. In the case of mobile populations, the governance of vaccination passes fosters mistrust of public agencies that occurs within and beyond the limits of European nations.

Despite the recent focus on inclusion within global policymaking on COVID-19 vaccination, the lived experiences of the collectives within our study indicate profound, ongoing experiences of exclusion alongside vaccine rollouts. Our interlocutors often noted regular and deep mistrust of the healthcare system, and the state. Whilst these reasons are rooted in legacies of historical discrimination, contemporary practices of eviction, incarceration, containment, violent policing and other forms of restriction continue to impact all groups of the study, COVID-19 restrictions notwithstanding.

Moving beyond the immediate focus on health policies to take those concurrent measures that restrict individual freedom of residence into account, it is perhaps unsurprising that marginalised groups frequently mistrust the state. Among our interlocutors, COVID-19 vaccination is experienced as a state-led priority, not necessarily their own. Conclusively, we found a widespread disparity between present policy rhetoric of boosting trust and promoting inclusion, and the fragmented, at times even hostile experiences of receiving healthcare and state services.

7.4. Vaccination as Part of Bureaucratic Systems

Both migrant communities and longer established peoples such as the Roma and South Sudanese Canadians have experienced more border and settlement controls and state surveillance, whilst being disproportionately impacted by lockdowns and travel restrictions. Following the lockdowns of 2020, in most European countries and in Canada mobility rights have increasingly become tied to the possession of a COVID-19 vaccination certificate or negative test. Furthermore, the governance of vaccination passes through police, transport and health authorities, risks exacerbating prior fears of state agencies.

Vaccination campaigns have been interpreted in nationalistic terms. Examples such as destroying paper versions of vaccine certificates for migrants at border crossings, lack of recognition of vaccination obtained outside the EU, and/or the mandatory requirement for a possession of a Green Pass to access employment have all increased mistrust in government. Importantly, the crux of this mistrust has been the implementation of ‘one size fits all’ policies, ignoring or rejecting specificities in circumstances, that have affected people’s vaccination choices.

Barriers to accessing healthcare can also be impediments to vaccination. Lack of information about the host country’s health system (including language barriers for migrants) can exclude people from vaccine participation. Equally, mistrust built through punitive approaches to vaccination can also promote disengagement with the state and healthcare system. Some of

our participants were not covered by social welfare or health insurance due to being informal workers, hence being ineligible for social aid. Overall, our respondents' efforts to self-secure against the backdrop of limited state welfare, poverty and trauma, has underscored the many bureaucratic hurdles they must clear to sustain themselves or move onwards in their migration journey—hurdles that existed even prior to the pandemic.

7.5. Limits of "vaccine hesitancy"

Current notions of vaccine hesitancy place responsibility for accepting vaccines on individuals. Direct links have been made by epidemiologists and behavioural economists between individual decision-making, and access to correct information. Resistance to vaccines is thus commonly attributed to a lack of education or to misinformation, what the WHO has termed the "infodemic". Yet our evidence suggests that mistrust in vaccines often has less to do with misinformation than with wider frames of exclusion, discrimination and violence, as mentioned above. Contrary to the narrative that sees these communities as unvaccinated or reluctant to vaccination, we found varying rates of vaccination depending on a myriad of individual situations.

Many of our respondents who had taken vaccines to obtain a Green Pass reported high levels of coercion in the process of vaccination. Thus, whilst those people did accept a vaccine, their experience produced further mistrust in the state. Rather than assuming that accepting a vaccine equates to or creates trust, it is important to theorise the wider dynamics of trust/ mistrust that vaccination campaigns generate. For individuals, accepting a vaccine under coercive conditions could easily produce new fears as to bodily harm. When asked why they had decided to receive a vaccination, the vast majority of our respondents reported that they had done so to facilitate their journey, or to gain employment.

Historically and more recently, vaccine campaigns have often diagnosed vaccine hesitancy as an education or knowledge deficit. Whilst tackling discrimination and unequal access to education is a prerogative for communal development, including considering age and gender aspects of access to education as illustrated in our case studies, we found that viewing our research groups as hesitant due to lower education is both discriminative and potentially further marginalising. Complex factors play a role in vaccination choice, including the prioritising of socio-economic survival, addressing mistrust in government initiatives, increased communal presence and engagement in public health initiatives.

7.6. The Limits of Evidence

Despite nominal shifts towards inclusion, many hard-to-reach communities continue to be excluded from EU/G7 COVID-19 datasets. The lack of health records has meant that interaction with public health services and access to information about vaccination has remained limited. Moreover, throughout the pandemic, epidemiological models and quantitative statistics have dominated the analysis of pandemic impacts. Yet we found that there was little quantitative evidence about vaccine uptake among undocumented migrants and Roma communities in Italy and the South Sudanese diaspora across Canada.

Crucially, we also found a scarcity of qualitative data and methods, and specifically ethnographic materials, examining vaccine orientations. As vaccine hesitancy is still an emerging area of research, it requires supplementation from existing studies and a mixture of methodologies, including qualitative participatory methods. Core anthropological prerogatives to centre the ontologies of "others" must inform policymaking for it to be equitable. These approaches advocate for partnership and co-production of knowledge with marginalised and disengaged groups, rather than imposition upon them that risks further exclusion.

7.7. Communal dialogue, social infrastructure and solidarity

Relevant engagement from public health professionals greatly affects vaccination rates among our research groups. The vaccination process was seen as an "external", state-led initiative, whereby the absence of communication and engagement of public health professionals with our research groups correlated heavily with these groups' mistrust. Beyond this dynamic, a variety of activist and grassroots structures were already in the process of providing services to mobile and marginalised populations, such as the network of migrant safehouses that span the Italian/French border. Similarly, non-governmental organisations in Rome and Milan as well as faith-based groups in Catania worked with Roma to supply medicines, food and sanitary equipment during lockdowns. Diaspora networks also organised distributions among South Sudanese Canadians. Since these networks are understood as sources of assistance, it is likely that disengaged groups view them as more trustworthy than state health-care workers. In contrast to universal, top-down strategies, the local communal infrastructures were able to adjust, respond and facilitate support more swiftly than government agencies.

Elsewhere, without sustained state support, networks between kin also fostered alternative and important safety nets. Our informants often navigated informal environments in which employment, accommodation, and health access were difficult to secure. These conditions predicated high reliance on familial kinship and communal structures. As these structures were important sources of information for our interlocutors, there is a great need to understand the influence of these structures and how to access them. Community elders (such as among the Roma) also held a privileged place in encouraging particular types of health-seeking behaviour. As heads of large families, these figureheads hold significant sway in dictating conduct and dispelling misinformation. Such sway can be leveraged either in person or at a distance, as our diasporic communities in Canada show (e.g. via Whatsapp or other social media).

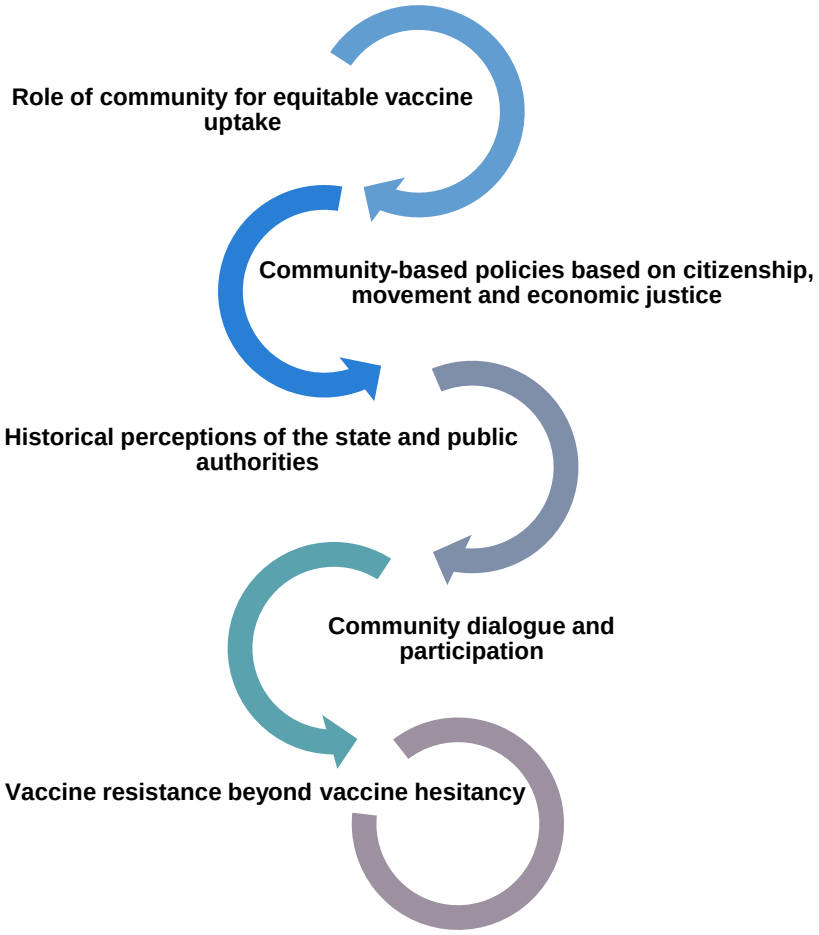
Overall, we consistently found that engaging community champions, faith leaders, health mediators, elders and gatekeepers fostered positive change in vaccine uptake. To many, strategies of mutuality and solidarity for ensuring socioeconomic and cultural survival were a lifeline during the pandemic. Such insiders and persons deeply engaged in communal life were instrumental in ameliorating the impacts of the pandemic as well as in tackling mistrust in state-led vaccination efforts.

8.0. Moving from evidence to policy: Five Overarching Principles

Bearing in mind the diversity of the populations studied in our research, as well as the context-specific recommendations each case study provides, we contend that wider frames of well-being (i.e. beyond targets of health benefits or information dissemination) should be the basis for equitable policymaking. The following four principles are based on the commonalities of vaccination experiences among our research groups, although we stress that governments must ensure that policy translates into practice, recognising population diversity.

Equitable access to vaccines requires the re-thinking of linear state solutions and the tackling of persistent everyday realities in the lives of these communities. Daunting though this task may seem, our research has also identified potential entry points to rebuild—or build for the first time—trust in the healthcare system.

Figure 2. Five principles for policymaking



8.1. Recognise the role of community for equitable vaccine uptake

Vaccination campaigns must consider historical and contemporary legacies of discrimination. Whilst this requires the rethinking of contemporary policymaking, it is essential that policy discussions elevate local community perspectives to initiate and catalyse vaccination uptake. This involves carefully identifying and mapping stakeholders who have access to undocumented communities, employing accessible information, relevant use of languages, and cultural mediators and translators to improve access to services. Engaging with community champions, faith leaders, health mediators, elders and gatekeepers—in short, pursuing a strong intentional focus on communal views and participation—can all increase awareness of vaccinations and foster trust.

In particular, this research revealed disparities in the gendering of decision making. Whilst it was often male family members who had overall authority for families at home and on the move, women often took a central role in promoting health information within communities. Within South Sudanese diaspora communities, women were actively seeking to improve health literacy, and among Rome communities, it was often women who dealt with public health officials and the general the health of the family. Such dynamics points to the need to develop entry points with community gatekeepers, but also to develop associational channels for women to participate.

Whilst we have found evidence for optimism when participation is encouraged, interventions must also recognise that community capacity has been deeply affected by state austerity coupled with the economic shocks from COVID-19 policies. Thus it is important to invest in communities, and to provide funding for community mediators and associations to perform outreach.

8.2. Design community-based policies inclusive of citizenship, movement and economic justice

It is clear that lockdowns and/or the securitization of particular sectors of society (such as migrant facilities and informal communal settlements) have had detrimental effects both on vaccine uptake and the general well-being of the communities we researched. Going forward, policies should consider the repercussions of ‘mass’, seemingly arbitrary restrictions and quarantine. Among communities on the margins of state provision, such policies have created deeper economic uncertainly and instability as well as worsening health outcomes (on account

of COVID-19 and disruption to care). In times and places where they do become necessary, such measures should be accompanied by provision of services such as access to healthcare, education and employment.

Establishing strong collaborations with local grassroots organizations and/or activist organisations to improve access to public services and implement effective communication strategies has proved instrumental in reaching the communities engaged in this research. Most importantly, these communities themselves should have a role in prioritizing and co-producing solutions and recovery plans. Taking a wider approach to well-being, it is essential to couple health interventions with wider advocacy and support in relation to asylum claims, psycho-social support, and housing services, as contexts require.

8.3. Consider historically rooted perceptions of the state and public authorities

In each of the four case studies presented in this report, pandemic governance was experienced as interwoven with forms of surveillance, policing or incarceration. Vaccine campaigns appeared as an extension of state authority and bureaucracy, whose actions to control movement and the spread of the virus inculcated fear, mistrust, histories of violence, and longstanding inequalities. Misleading notions of “building trust” or punitive or coercive approaches to vaccination can instead promote mistrust and disengagement with the state and healthcare system. Going forward, it is critical for state approaches to pandemic response to tackle bureaucratic rigidity that poses barriers to vaccine participation and social justice. A precondition for this work is for policymakers to consider the changing political terrain on which vaccinations are delivered, to illuminate how state and health authorities are perceived “from below”, and to move to remedy misleading notions of the nature of their work.

Whilst in the short-term partnering with trusted communities may provide a ‘stop-gap’ and increase vaccine up-take, in the longer term, advocacy must be embarked around structural marginalisation to remedy significant disjuncture between aims of healthcare providers and disenfranchised populations perceptions of their work.

8.4. Engage in community dialogue and participation

By engaging in complex deliberative conversations, the communities of this research connected their experiences of vaccination to wider constraints of their socio-economic lives. This fourth principle aims to build trust through community-based approaches that produce

genuine partnerships between local stakeholders and public health professionals. Throughout this report, we have shown how the framework of “vaccine hesitancy” is a limited tool to understand longstanding vulnerabilities and forms of dispossession in our research communities. If policymakers can recognise that such decisions are rooted in histories of collective discrimination, then community dialogue becomes a guiding principle that considers the structural elements informing people’s choices beyond periods of mere emergency or exigency. Without community buy-in, vaccine campaigns can become architects of mistrust, fostering misinformation and conspiracy theories, and working against their own aims of improving public health. Finally, when community-centred engagement and dialogue are prioritised, all segments of society benefit. Utilising established infrastructures of kinship, solidarity and activism, while working together with health authorities and medical providers, can produce profound results for marginalised and mainstream communities alike. Conclusively, community buy-in can change the outcomes of vaccine campaigns, to counteract mistrust and build bridges between public health and the communities at the margins of state initiatives.

8.5. Improve understanding of vaccine resistance beyond vaccine hesitancy

The framework of vaccine “hesitancy” provides only a partial tool to understand longstanding inequalities and multiple forms of disenfranchisement that affect orientations towards vaccination. We advocate for a focus on structural barriers, rather than on vaccine hesitancy**.** Importantly, it is the structural elements if socio-economic and political inequalities that inform people’s choices and these must be addressed through interventions beyond emergencies and coercion. Beyond the semantics of the use of an alternative language, it is useful to consider vaccine barriers against laying blame upon and demanding responsibility from the individual. Moving forward, it is essential for ethnographic research, co-produced and shaped by communities of interlocutors, to inform policy-making. Perspectives must be accommodated not as an ‘add-on’ to epidemiological research, but integrated into theoretical development and practical delivery, of vaccine campaigns.

A worker at Rifugio Fraternità Massi shows a map to two young Sub-Saharan African migrants. Image credit: Costanza Torre.

Annex A: Methodology

In this Annex, we give an account of the approaches and the methodologies we used to gather data in each research site as well as to engage with the wider academic field on vaccine hesitancy and marginalised populations.

1. Research Questions

Our starting point was an appreciation for the specificities of local context in shaping responses to COVID-19 vaccinations. Whilst our approach was grounded in understanding the lifeworlds of our interlocutors, two key factors shaped our research encounters: the unique contours of each community, and the networks of solidarity that surrounded and engaged our participants. Therefore, we build on the two entailing questions: How has the COVID-19 pandemic impacted our research respondents personally and as part of a community as well as whom did they trust the most during the crisis? As a result, we developed a phased research plan consisting of: literature review; fieldwork; evidence review; and consolidation and analysis.

2. Literature review

We undertook a literature review, carrying out desk research of relevant publications in addition to holding conversations with community leaders, academics, non-government organisations and policymakers to understand the main research leads and to build our evidence base. Harnessing communities, engaging with social infrastructures and networks of kinship and care transpired as the most important theoretical categories for us to engage with.

3. Fieldwork

Undocumented Migrants in Rome

Conducted by Sara Vallerani in November 2021 in Rome, this data collection was carried out through semi-structured interviews with social workers, health workers, volunteers involved in

the vaccination campaign, and with undocumented individuals. In Rome, vaccination campaigns have been characterised by a strong collaboration between the NHS and non-governmental organizations. This research required the collaboration of health authorities, NGOs and self-organised groups.

To document the vaccination campaign and the diversity of its beneficiaries, we conducted interviews with social and health workers from Azienda Sanitaria Locale (ASL) Rome 1 and Rome 2, with volunteers of the association Nonna Roma, and with activists of the housing occupation in Viale delle Province. Interviews were also conducted with undocumented migrants, whose reported countries of origin of the undocumented individuals were mainly Bangladesh, Ecuador, Venezuela, and Peru.

Participation in the research was entirely voluntary; research participants could choose between in-person and online interviews, and whether the interview was recorded. To supplement our research, we conducted additional interviews with people working in the context of the COVID-19 vaccination campaigns and policymakers.

Migrants on the Move, Turin

Taking place between 1st-9th December 2021, this research was conducted primarily in the context of the Rifugio Fraternità Massi in the border town of Oulx in northern Italy, at the foothills of the Alps. This site was selected as particularly relevant to gain insight on the perspectives of people on the move as Italy is a transit country to other destinations in Europe such as France, Germany and the United Kingdom. The Rifugio Fraternità Massi is a key stop for many people on the route, and the last well-known safehouse in the Italian peri-Alpine area where migrants can receive legal aid, medical assistance, food, shelter and mountain clothing to help with the crossing.

Researchers Costanza Torre, Sara Vallerani and Elizabeth Storer collected data through qualitative methods such as: (1) participant and non-participant observation in the activities of the Rifugio Fraternità Massi, especially where medical assistance was provided to people on the move; (2) interviews with health workers involved in vaccine and healthcare provision; and (3) interviews with migrants passing through the refuge during that time. By necessity our methods adapted to a context of hyper-mobility: migrants often spent less than a day at such refuges, and spent this time preparing for the border crossing, and acquiring information from refuge volunteers.

While the country of origin of these migrants varied greatly, the most prevalent were Afghanistan, Iran, Kurdistan, Morocco, Algeria, Guinea and Senegal. Due to the diversity of

this population, researchers conducted interviews in English, French, Italian, or, as needed, in other languages (e.g. Farsi, Arabic) with the help of a translator. Access to the site and its participants was negotiated with the organization Talità Kum managing the Rifugio Fraternità Massi, and with the medical NGO Rainbow4Africa, which maintains an important presence on site. Finally, to supplement our research, we conducted semi-structured interviews with volunteers and employees at the safehouse of Les Terrasses Solidaires in Briançon, France, which hosts migrants who have successfully crossed the Alps. This enabled us to understand contrasting regimes of COVID-19 governance on either side of the border.

Roma settlers in Rome and Milan

This research, conducted between October 2021 and January 2022, consisted of in-person participant observation and in-depth interviews, employing a 'snowball' method for reaching Roma individuals and communities living in settlements near Rome and Milan. In addition, two NGOs and one faith-based organisation provided support in contacting Roma and Sinti individuals. The necessity of social isolation increased the reliance on digital ethnography; we often reached our participants online, and most often through social media. The qualitative nature of this research was prioritised in order to collect and place Roma narratives at the centre of policymaking, adding new layers of information to predominantly quantitative epidemiological studies. Research ethics here included the provision of confidentiality for all participants, as well as all necessary health and safety measures required by the local COVID-19 rules.

Bearing in mind the heterogeneity of Roma communities, the research aimed to capture different segments of the Roma population, conducting interviews in three locations: Roma and Sinti communities in Milan (northern Italy), Roma from the former Yugoslavia in Rome (central Italy) and Bulgarian Roma economic migrants in Catania (southern Italy/Sicily). In total, forty-two people participated. Half of the participants lived in the so-called 'nomad camps' and the rest lived either in council flats or in privately-rented accommodation. Demographically, over 60% of participants were women, and the overall age range was between 13 and 72. A large share of participants relied on low-wage, informal sector employment such as carers for the elderly and children, street vendors, cleaners, drivers, and scrap-metal collectors.

Sarafian led a dialogic inquiry at two separate workshops, where participants in Rome and Milan were presented with the initial research results and the opportunity to provide input into the final findings.

African Diaspora in Canada

In late 2021 and early 2022, our team researched COVID-19 vaccine hesitancy among South Sudanese Canadians. Malith Kur and Naomi Pendle conducted qualitative studies using in-person interviews, in-depth telephone interviews, and online group discussions in different Canadian provinces. With research being conducted at the heigh of global concern regarding the omicron variant, an intended in-person methodology based on focus groups and participant observation was flexibly adapted to protect the safety of participants. As an insider within South Sudanese networks, Malith Kur facilitated access to leaders and community members. He also brings his own lived experience to bear on the case study. Following this research, Dr Naomi Pendle was involved in research projects in South Sudan, allowing connections to be made to diasporic connections "at home".

4. Evidence reviews

Dialogic Editing

From the outset, we were invested in developing ways to share our findings *together* with our interlocutors. Following the initial phase of research, dialogical editing workshops were conducted in each site. This involved lead researchers summarising the key findings of the research, as well as circulating draft outputs of publications for comments.

Stakeholder Engagement

Beyond these community-based workshops, we sought to present our findings to wider academic and policy communities. A virtual workshop hosted by FLIA on January 10th 2022, 'Vaccines at State Margins', brought together 22 scholars and activists to examine COVID-19 responses at Europe's margins. Specifically, the event focused on understanding complex attitudes to COVID-19 vaccinations and placing hesitancy and resistance in historical and contemporary context. Italy received particular emphasis, exploring activities along geographic and social borders within the country. Researchers presented data from their specific sites, and audience members were invited to consider findings in dialogue with their own research, as many participants were also engaged in research/policy activities with Roma and/or migrant communities.

We also sought to deepen the theoretical framework for our empirical findings. We did so through hosting virtual a workshop with social scientists on 10th February 2022 with a host of

qualitative specialists including geographers, anthropologists and historians. Specifically, the workshop was premised on theorising ‘trust’ in health and other contexts.

On 22nd March, we will host a collaborative workshop with LSE’s Behavioural Lab. The workshop will feature presentations from anthropologists, behavioural economists and epidemiologists, and sought to find paths to make COVID-19 policy multi-disciplinary.

5. Consolidation and analysis

After completing discussions and sets of workshops with our interlocutors and various stakeholders, we synthesised the main themes, key recommendations, and principles in the project report. We produced a series of blogs on the LSE website, and we are in the process of publishing brief and long-form papers related to our findings.

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