
COVID-19 Recovery:
Building Future Pandemic
Preparedness and
Understanding Citizen
Engagement in the G7

Principles of Building Trust: Engaging Disenfranchised Communities Across the G7 in COVID-19 Vaccine Campaigns

September 2022

Elizabeth Storer

Iliana Sarafian

About the authors

This report presents summary findings from the *Ethnographies of Disengagement: Understanding Vaccine Rejection in Chronically Neglected Communities across the G7* research project. This research project is led by Principal Investigator Dr Elizabeth Storer (Firoz Lalji Institute for Africa, London School of Economics and Political Science), and co-investigators Dr Iliana Sarafian (Firoz Lalji Institute for Africa, London School of Economics and Political Science) and Dr Naomi Pendle (Department of International Development, University of Bath). Additional research contributions feature from Costanza Torre (Firoz Lalji Institute for Africa, London School of Economics and Political Science), Sara Vallerani (Theoretical and Applied Social Research, University of Roma Tre), Malith Kur (Faculty of Religious Studies, McGill University) and Dr Eloisa Franchi (Rainbow 4 Africa).

Elizabeth Storer and Iliana Sarafian compiled this report. Costanza Torre led the research and drafted the chapter on 'People on the Move' in Italy. Sara Vallerani and Costanza Torre drafted the chapter on undocumented migrants in Rome. Naomi Pendle and Malith Kur drafted the chapter on South Sudanese Diaspora in Canada. Dr Eloisa Franchi and Dr Benjamin Morris reviewed this report prior to submission.

Acknowledgements

The *Ethnographies of Disengagement* project was generously supported by the British Academy COVID-19 Recovery: G7 Research Grant (COVG7210058). The research benefitted from institutional support from the Firoz Lalji Institute, London School of Economics, as well as intellectual collaboration from the LSE Department of Anthropology, LSE Behavioural Lab, and the EU Horizon PERISCOPE (*Pan-European Response to the Impacts of COVID-19 and Future Pandemics and Epidemics*) project. The authors additionally acknowledge the active participation of a host of organisations, as well as communities – both settled and mobile – across Italy and Canada.

About COVID-19 Recovery: Building Future Pandemic Preparedness and Understanding Citizen Engagement in the G7

The programme aims to facilitate global and interconnected learning about the contexts, causes and factors leading to vaccine engagement. Through the programme, the Academy has awarded funding to seven research projects exploring vaccine engagement in Canada, France, Germany, Italy, Japan and the UK. The programme, which was funded by the UK's Department for Business, Energy and Industrial Strategy, builds on a series of statements developed in partnership with humanities and social sciences bodies across G7 countries. The Academy has supported another series of projects focused on the USA and UK.

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1.0 Introduction to the research

This report is written as G7 countries increasingly recognise COVID-19 as an endemic threat, and embark on discussions of long-term management in a post-emergency world.¹ Within G7 countries, since their arrival in mid-2021, COVID-19 vaccination campaigns have been promoted as the cornerstone of transitions to well-being and national recovery. Delivered through ‘top-down’ initiatives and designed around principles of uniformity and compliance, vaccine uptake in many countries has been coupled with legislation that links the rights to work, travel and access spaces, to proof of immunity.²

Yet amid efforts to regulate vaccination status, “vaccine hesitancy” persists in certain sub-groups of the population.³ What has emerged is a divergence between policymaking rhetoric and orientations towards vaccines on the ground. At present, many ordinary citizens view vaccines not just in terms of health and safety, but in relation to governance and to access of freedom and movement. Moreover, for disenfranchised groups, vaccination campaigns have often served to amplify prior tensions and fears of state authority. Over the past year, political discourses in G7 countries have come to regularly distinguish between vaccinated and unvaccinated members of the population.⁴ Diverse attitudes are side-lined, and ‘hesitant’ individuals or ‘anti-vaxxers’ are blamed for seemingly ill-informed decision making that presents a risk to post-pandemic recovery among the majority population.⁵

Our study recognises the implications of this complex divergence. The “Ethnographies of (Dis)Engagement” research project explores orientations towards COVID-19 vaccinations among some of the communities considered the hardest-to-reach across G7 countries. The project presents evidence from Roma populations, undocumented migrants and members of the African diaspora in Italy and Canada. Belying the significant diversity within and between these groups, policymakers have increasingly labelled these communities as “vaccine hesitant”.⁶ Yet ‘Ethnographies of (Dis)Engagement’ seeks to examine the experiences of these groups in detail, to understand vaccine orientations through qualitative research.

- 1 Katzourakis, A. (2022). COVID-19: endemic doesn't mean harmless, *Nature* 601, 485, doi: <https://doi.org/10.1038/d41586-022-00155-x>;
- 2 Torjesen, I. (2021). Covid-19 will become endemic but with decreased potency over time, scientists believe *BMJ*; 372 :n494 doi:10.1136/bmj.n494
- 3 Institute for Community Studies. (2021) Understanding vaccine hesitancy through communities of place: Abridged Report. 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>
- 4 Karafillakis E, Van Damme P, Hendrickx G, Larson HJ. COVID-19 in Europe: new challenges for addressing vaccine hesitancy. *Lancet*. 2022 Feb 19;399(10326):699-701. doi: 10.1016/S0140-6736(22)00150-7. Epub 2022 Feb 3. PMID: 35123665; PMCID: PMC8813064
- 5 The 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>
- 6 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>
- 7 Holt, E. (2021) COVID-19 Vaccinations among Roma Populations in Europe, *Lancet*, Vol.2, Issue 7, E289, July 2021. DOI: [https://doi.org/10.1016/s2666-5247\(21\)00155-5](https://doi.org/10.1016/s2666-5247(21)00155-5), 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

This research is structured around four main aims:

1. To produce an understanding of the historical and contemporary contexts that lead to vaccine disengagement in specific communities across the G7. Through deep explorations of specific contexts, we seek to reverse chronic blind spots in national COVID-19 response and vaccination campaigns.
2. To produce community-specific recommendations for health interventions, including how to enhance understandings of whom (dis)engaged communities do trust, in order to facilitate vaccine engagement across G7 countries.
3. To make these findings translatable to future pandemics, or to broader engagement of disenfranchised 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 that have dominated academic analyses of COVID-19 impacts.

The research was based on ethnographic methods conducted in Italy and Canada between November 2021 and January 2022, consisting primarily of semi-structured interviews and focus groups with respective communities and policymakers. Further observations were conducted in Roma settlements near Rome, refugees along Italy's Alpine border, and migrant houses in Rome. Following our data collection and analysis, our findings were validated through dialogic editing workshops with policy-makers, community leaders and academics in early 2022.⁷

⁷ For an extended description of sites and methods, see Annex, Principles of Building Trust: Engaging Disenfranchised Communities across the G7 in COVID-19 vaccine campaigns, British Academy (Longform) Impact Report, forthcoming

2.0 Conceptual approach

Alongside their significance as measures to contain COVID-19, vaccine mandates have been lauded as tools for rebuilding trust in the state and the healthcare system following the disruptions wrought by lockdowns.⁸ Yet we contend that to understand relationships between the administration of vaccines and public trust, it is important to first engage critically with historical and contemporary relationships between local communities, the state and healthcare actors. On the one hand, this approach builds on emergent literature that notes the key role local communities play both in initial pandemic responses and in post-pandemic recovery. On the other hand, this approach enables us to document the swiftly-evolving landscape of policy-making that now involves the twinning of vaccines with restrictions on unvaccinated people.

Indeed, vaccine campaigns that initially relied on voluntary consent have become increasingly linked to bureaucratic instruments that require proof of vaccination. In Italy, for example, following legislation that entered into force 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.⁹

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-regulated transportation sectors, to be vaccinated. Provinces and territories have responded in a variety of ways, including expanding the categories of those who must 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 (who do not or may not work from home), vaccination is either compulsory or is perceived to be.

Both of these countries have reported relatively high rates of national vaccination. As of the end of February 2022, over 83.38 percent of Canadians have been vaccinated.¹⁰ Italy has reported slightly lower rates of 79.7% of its population.¹¹ Yet these statistics bely both intense variation within and continuing resistance from particular sectors of the population. Key recent studies indicate that efforts to police vaccination through the issue of certifications and 'passports' are unlikely to boost uptake rates among groups that have expressed consistent resistance.¹²

Debates about the appropriate level of coercion in delivering vaccines are not new, and historically have been rehearsed during health emergencies.¹³ Dada et al. summarise that for COVID-19, most discussions of vaccine documentation have focused on the scientific and economic benefits of vaccines, as well as the ethical aspects of their implementation, drawing on a narrow range of historical precedents

8 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*

9 As of 6th December, the validity of COVID-19 test results which previously offered an alternative to the pass, was reduced from 72 to 48 hours. These measures are particularly significant since COVID-tests have to purchased at a cost.

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

11 Our World in Data, 'Vaccine Map', 28th February 2022. https://ourworldindata.org/covid-vaccinations?country=OWID_WRL

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>

13 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

such as Yellow Fever.¹⁴ Yet missing from these analyses is an engagement with local perceptions, and how shifting landscapes of vaccine governance interface with diverse social groups—especially groups on the margins of society. An increasingly polarised civic discourse has politicised trust in vaccinations, and made being vaccinated or unvaccinated a political identity. In this context, we contend that understanding vaccines necessarily warrants a critical engagement with those communities on the margins to gauge the socio-political lives of vaccination.¹⁵

Engaging critical communities

During previous epidemics and pandemics, including during Ebola, HIV/AIDS and Polio, there has been significant investment in integrating qualitative social science into outbreak responses.¹⁶ This integration of qualitative social science often increased over the course of the epidemic or pandemic as lessons were integrated into policy approaches. Yet throughout the COVID-19 pandemic to date, epidemiological and statistical data has dominated in policy-making. Fine and Abramson summarise that ‘big data’ has substituted for ‘deep data’.¹⁷ Qualitative studies are important, as they provide opportunities to challenge forms of top-down knowledge production and control that can marginalise communities. In response to the unevenness of COVID-19’s impacts—as well as to its varied vaccine uptake—recent studies have stressed the importance of taking local communities into consideration, an approach that qualitative studies by their nature enshrine.

One key study on “vaccine hesitancy” within selected communities in the UK and US has advocated for the recognition of the power of communities in facilitating vaccination.¹⁸ According to the Institute of Community Studies, adapting top-down strategies to the local social fabric is essential to encourage community “buy-in” for mass vaccination and health engagement. Crucially, such an approach is not simply about instrumentalising qualitative insights for top-down agendas. Instead, far from being passive recipients of top-down vaccination efforts, local communities are reconceptualised as powerful “sites of knowledge and action” within this work. In that sense, communities are not just physical sites but are spaces of deliberation, where diverse cultural, socio-economic, and socio-historic backgrounds “mediate relationships with preventative health and immunisation”.¹⁹

In a similar way, Bear et al. 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 relies.²⁰ Investing in these networks though accessing trusted local partners—including voluntary sector and religious organisations, or community champions—can be a key entry-point to encourage vaccination uptake. In contrast to universal, top-down strategies, such local social infrastructure can innovate rapidly in response to ideas on the ground. Indeed, the concept of social infrastructures has the distinct

14 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>

15 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

16 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>

17 Fine, G and Abramson, C. (2020) Ethnography in the Time of COVID-19: Vectors and the Vulnerable, online at: https://www.researchgate.net/publication/340680966_Ethnography_in_the_Time_of_COVID-19_Vectors_and_the_Vulnerable/citation/download

18 Institute for Community Studies, Understanding vaccine hesitancy through communities of place: Abridged Report

19 *Ibid*, p.1

20 Bear, L, Simpson, N, Bazambanza, C, Bowers, R, Kamal, A, Gheewala Lohiya, A, 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>, p.1

advantage of not implying a fixed network of actors, and being able to transcend notions of community delimited by space.

Bear et al. also note that the socio-economic bonds upon which the resilience of communities relies have become increasingly fragile over the duration of the pandemic. Such insights are pertinent to Italy and Canada, both of which have recorded high mortality rates and instigated stringent containment policies. Italy has been among the countries most heavily affected by COVID-19 since its onset: as of January 2022, Italy had reported 144,000 reported COVID-19 related deaths.²¹ This high mortality rate has been attributed to early underestimations on the part of the Italian government. Before a country-wide lockdown was initiated in 2021, an initial approach of locking-down only “hardest-hit” municipalities first was blamed for the rapid spread of the virus.²² The first-known case of COVID-19 in Canada arrived in late January 2020. Like other countries, Canada implemented various emergency orders to try to stop the spread: whilst the federal government did not mandate a national lockdown at the onset of the pandemic, mandatory province-wide or partial lockdowns in places such as Ontario were put into effect.

To date, the impacts of COVID-19 have been deeply uneven. Disadvantaged groups, who are disproportionately involved in certain forms of labour, or living in overcrowded or multi-generational dwellings, have registered disproportionate number of COVID-19 cases and mortality rates. At the same time, lockdowns have precipitated significant social isolation, and economic losses have compromised norms of reciprocity, sharing and support within these networks.²³ Thus whilst we agree that community engagement is essential to encourage vaccine uptake, we consider communities not as romanticised spaces of recovery but as entities profoundly reshaped by state pandemic governance. In looking to ‘flatten the curve’, policymakers have been less attentive to deleterious socio-economic effects. Moreover, the continued impacts of austerity and withdrawal of public welfare have also been overlooked.

Critically appraising community

Such insights must engage an extensive social-science scholarship that has revealed the dangers of transposing romantic ideas of coherence and solidarity onto diverse internal politics that characterise communal life.²⁴ In the context of COVID-19 recovery, 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.

Community engagement must, then, rely on a realistic assessment of communal structure and capacity. Anthropologists have long argued for a consideration of communities as transgressed by power relations, where divisions of class, gender, race, ethnicity, age, and belief intersect to structure the relative power and status of community members. New categories of viral risk, based on co-morbidity and age, have supplemented prior political matrices of vulnerability. Rather than existing as homogenous and stable entities, communities have long been understood to

21 Worldometer Resource Center. (2021). World Countries: Italy. Available online at: <https://www.worldometers.info/coronavirus/country/italy/>

22 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>

23 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>

24 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>

be spaces of boundary-making, whereby contours of inclusion and exclusion are continually redrawn. Fundamentally, understanding these shifting contours makes for a more realistic mapping of legitimate entry points for external collaboration. This politics of power and differential vulnerability matters, finally, because it structures deliberations whereby individuals make decisions about vaccines within their social world. This world is not defined by spatial limits, but instead integrates offline/online flows of information. Whilst this structure could be attributed to the influence of the “infodemic”, we found it important that information was trusted precisely because it was offered and mediated through family members. Intimacy and trust remain inherently related, and social infrastructures, though stretched across virtual and physical space, have continued to function as support mechanisms.

Communities and public authorities

Revisions to the concept of community also require countering the notion of communities as depoliticised entities. 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 arm 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.²⁵

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 enforcement of COVID-19 containment: throughout G7 countries, health policies have often been enacted concurrently with discriminatory state policies to police both settlement and citizenship.

Finally, a 2021 British Academy report notes the multiple dimensions of well-being that have been affected by the COVID-19 pandemic.²⁶ This research highlighted how the dominant frame of COVID-19 as a health crisis disguised its social, economic and cultural impacts. We contend that any approach to rebuild trust between disenfranchised groups and the state must adapt a generous definition of pandemic “harms”, and be centred on achieving social justice. When social justice mandates are pursued, we have found evidence for optimism, as such priorities lead to increased community buy-in among otherwise sceptical or reluctant populations.

25 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)

26 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/>

3.0 The evidence base

In this section, we provide a brief summary of our four case studies, as well as policy recommendations for each.

3.1 Fears of COVID-19 governance: Findings from undocumented migrants in Rome, Italy

Among undocumented migrants living in Rome, we found that perceptions of COVID-19 vaccines were deeply entangled with notions of vaccine governance.

Migrants' negotiations with COVID-19 take place within the framework of national responses to control the virus and to administer vaccinations. Whilst many of our interlocutors had received a vaccine, their decisions to do so were made under duress, most often after their employers asked for Green Pass certification.

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 African nations.²⁷ Living without citizenship or formal claims to state welfare, migrants in this category have been difficult to access—thus while existing data does indicate that the clinical and socio-economic burdens of the pandemic has been significantly heavier upon migrant groups in Italy, research on these issues remains scarce.²⁸

Undocumented individuals experience significant barriers in accessing public health services

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

In Italy, undocumented individuals need a code known as the STP (Temporarily Present Foreigner) code in order to access health services. The STP code gives access to some health services for undocumented people from non-EU countries, and should in theory grant access to vaccination as well. In the first few months of the vaccination campaign, however, there was a lack of clear, timely institutional communication on how people with STP codes could access the vaccine and obtain the Green Pass. This was combined with a lack of communication even on the existence of the STP code and its use for accessing public services—including health services outside of the Emergency Room, which remains the main referral point for many.

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

28 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

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 frequent. 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 migrants in Italy are employed in illegal work across exploitative sectors, have limited access to basic welfare services, and are denied their fundamental rights.²⁹ In 2020, at least 207,000 requests for regularisation of undocumented individuals working in illegal conditions were filed, however, actual figures are likely much higher and do not appear in any formal estimate.³⁰

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 undocumented migrant relayed: *“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”*.

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 regularisation of work conditions of their undocumented employees. 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.

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. As one inhabitant of a housing association in Viale delle Province explained, *“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.”*

Furthermore, while a Green Pass certificate should be automatically issued following vaccination, in many cases months-long delays in its reception occurred. Such delays were due to several different reasons, namely administrative holdups, confusion regarding the procedures to download it, or spelling mistakes in the person's name. As a consequence, many vaccinated workers had to pay for COVID-19 tests (which

29 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>.

30 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>. 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>

cost a minimum of €15 at local pharmacies) several times a week while waiting for the Green Pass; when unable or unwilling to, these workers lost their jobs.

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 was 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 at the end of 2021.

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 organisations, activist organisations and health clinics to improve access to public services and implement clear, effective messaging about access to care. These 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 be reported to the authorities upon accessing public services. To ensure the greatest reach, such 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.

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. Health information should explicitly include guidance regarding vaccine brands not administered in Italy, e.g. the Sputnik vaccine. 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. 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 regularisation 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). Moreover, integrated policies aimed at tackling illegal work and exploitation should be strengthened. To ensure the greatest equity, migrant-led and workers' organisations should be closely involved in all parts of the design and implementation of this process.

Summary

Among undocumented migrants, 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.

3.2 Prioritising mobility: ‘People on the move’ at the Italian alpine border

Italy has long been a transit country for undocumented individuals trying to reach other European countries. We conducted research with interlocutors predominantly travelling from Afghanistan and sub-Saharan African countries, on trips lasting from forty-five days to as many as several years.

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. 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 certain vaccine brands were not recognised by the Italian state as offering immunity.

Mobility restrictions and migrants’ passage through Europe

Migrants have been disproportionately impacted by restrictions to mobility such as increased border policing and forms of control, as well as surveillance and containment that have accompanied COVID-19.³¹ In 2020, migration came to an almost complete halt. But by 2021, rates of migration on the Central Mediterranean route had increased once again: as lockdowns eased, the reported number of migrants increased.

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.³²

The high mountains and the often extreme weather conditions make the journey a dangerous and potentially deadly one, especially during winter. In addition, repeated push-backs by the French police mean that people frequently attempt the crossing several times before succeeding. Indeed, several people have died during the journey in recent years, and the outrage that followed these incidents has resulted in extended networks of solidarities emerging on both sides of the border. The safehouse in Oulx, where this research was conducted, is one of the main referral points in the region.

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

32 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.

Constructing health borders through COVID-19 bureaucracy

Contrary to the narrative that sees undocumented migrants as generally unvaccinated or reluctant to vaccination, we found that many of the people that were passing through the safehouse in Oulx 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 routes. 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. This interaction should not be understood as downplaying the health consequences of COVID-19; indeed, our informants were often clearly aware of the 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' 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 2016.³³

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 an attempted border crossing results in rejection, these encounters include intimidation, verbal and physical abuse. These interactions heavily inform migrants' decisions regarding vaccination.

'Health Nationalisms'. Following the 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 of discouraging them from continuing their journey. In some cases, these incidents were accompanied by acts of police brutality such as intimidation and physical violence.

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

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. These support workers also reported instances in which migrants who were traveling by bus (minimising 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).

While most participants who had received a vaccination described their decision as largely voluntary and motivated 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.

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). 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 recognise 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.

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 refusing vaccination showed a 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 considerations regarding established and common side-effects of the vaccine: chief among them, physical weakness. 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.

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.

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. 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. COVID-19 testing and the issuing of Green Pass certificates should become freely and widely accessible to facilitate mobility. The availability of testing should follow fast and continuous policy changes and mobility restrictions of relevant contiguous regions and countries (e.g., Italy and France). Mobile groups may be seen as presenting greater difficulties in administering vaccines requiring repeated doses and boosters. Ultimately, for the most effective outcomes at present, it may be 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.

Engage with trusted intermediaries. Our findings identified solidarity infrastructures that engaged migrants and became trusted bearers of information. Within these networks, however, notions of vaccination often reflected mistrust of the Italian state, and as such, volunteers were not necessarily 'pro-vax'. 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.

Summary

Among 'people on the move' in northern Italy, diverse orientations towards COVID-19 vaccines 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.

3.3 Reactivating histories of blame: Roma and Sinti communities in Italy

Among Roma people, the barriers to vaccine uptake originate from a complex and ongoing experience of disadvantage and 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 a revised starting point for engagement with Roma communities: namely, the entanglements of pre-existing inequalities with the new forms of marginalisation induced by the pandemic.

Historical context

Understanding vaccine uptake among Roma groups requires an awareness of previous regimes of social inequality and discrimination. To date, despite having lived in Italy for the last six centuries, Roma and Sinti peoples have been largely viewed as “outsiders.”³⁴ During the wars of the 1990s, waves of Roma from former Yugoslavia sought refuge in nearby Italy.³⁵ More 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”.³⁶

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 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.³⁷ In such policies, nomadism is not only regarded as a lifestyle, but a socially-deviant trait, resulting in anti-Gypsyism and communal stigmatisation.³⁸

Known by the derogatory term ‘zingari’, some Roma live in ‘nomad camps’ (*campi nomadi*) or shantytowns (also called ‘villages’), usually on the outskirts of cities. The construction of such camps is the legacy of local and regional regulations passed from 1984 to 1992, when local authorities offered these settlements as a temporary housing solution for migrants. This temporary solution, however, has become semi-permanent. Both formal and informal camps of today are characterised by poverty, unemployment and precarious work in the informal economy, and inadequate access to healthcare and education. Moreover, the pandemic has had devastating effects on Roma groups in Italy and elsewhere.³⁹

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

35 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.

36 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.

37 EU FRA. 2020. ‘Coronavirus Pandemic in the EU - Impact on Roma and Travellers’

38 Solimene, M. 2018. ‘Romani (Im)Mobility, Between Camps, Evictions and Ambivalent Repressions of “Nomads” in the Eternal City’, *Nomadic Peoples* 22(1): 65-82. 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)

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

Lockdowns and the proliferation of bureaucracy

Prior to the pandemic, Roma settlements (formal and informal) were already seen as spaces threatening majority Italian society and its values. The perceived illegality of the camps had long caused frequent police visits, reinforcing the social and physical boundaries between camp dwellers and the rest of the population.⁴⁰

During the pandemic, however, this previously-established ‘biopolitical control’ cemented views of Roma people as a public health threat.⁴¹ 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.⁴²

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. In both formal and informal settlements, Roma inhabitants struggled to access food, medication, education, and mainstream services. Reliance on kinship support and solidarity increased, although as resources depleted over time, reciprocity became less prominent. While mutual support and close social infrastructure proved lifesaving factors, depletion of the limited resources available to Roma households created further vulnerability and poverty. Moreover, 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.

“Vaccine hesitancy” versus “Vaccine uptake barriers”

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. We found a variety of themes on the barriers to vaccine uptake.

Doubts towards vaccine efficacy and safety, and fear of side effects were the most common themes 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.

40 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>

41 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.

42 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.

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 was the vaccination effort taking place concurrently 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 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 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 it to ensure 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’ choices: *‘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.

Policy recommendations

The below recommendations represent entry points for building trust, but it is important to note that they are not an exhaustive list. Rather, they 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 experiences 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. Faith leaders and networks 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.

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 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.

3.4 Connections to 'home': COVID-19 among South Sudanese Canadians

During the 1990s, as the Sudanese government battled a South Sudanese-led armed opposition, thousands of South Sudanese sought refuge in Canada. Many who came to Canada decades ago did so through scholarships, resettlement schemes or family links, but after years of residence, their opportunities in Canada and South Sudan are still being navigated.

The South Sudanese Canadians within this study often perform precarious jobs that require continual cross-province movement. Many, moreover, experienced deepening levels of poverty throughout the pandemic. At the same time, conditions of suffering have served to revive traumatic past experiences, such as exposure to political repression and social isolation during the long years of the second Sudanese civil war. It is this frame of socio-economic trauma, past and present, that provides the reference point for accepting vaccines.

Whilst many South Sudanese Canadians have accepted a vaccine, this was largely to fulfil demands of government regulation. Members of the diaspora receive conflicting information from relatives at home and are regularly in contact with other members through Facebook and Whatsapp. Yet conflicting health information produces confusion about the efficacy and side-effects of the vaccine, and when individuals feel pressured to accept a vaccine, this often serves to foster mistrust in the Canadian state.

Histories of distrust, fear and diaspora knowledge exchange

Historic reasons for distrust. South Sudanese community leaders we interviewed referred to 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.⁴³ Both before and after World War II, a massive global infrastructure of vaccinology was also implemented by European colonial authorities in Africa.⁴⁴ Those public health measures were defined by imperial states using force to compel Africans to accept vaccines. As Jessica Pearson-Patel has shown, the purpose of such vaccination campaigns was to protect European colonial officials from contracting diseases from local people, suggesting that helping Africans was not their true aim.⁴⁵

43 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)

44 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/>.

45 *ibid.*

Africans still recall these unethical colonial experiments, which are partly responsible for the current mistrust of vaccines. During COVID-19 vaccination campaigns, this distrust was exacerbated in some parts of Africa once the first COVAX vaccines arrived on the continent: certain European leaders had rejected these same vaccines, which created a perception of the dumping of dangerous vaccines in Africa.⁴⁶ 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. In the course of our ethnography, we found that members of the diaspora regularly shared these fears on the online platforms discussed above.

By now, however, South Sudanese community and church leaders in Canada have largely encouraged their members to follow Canadian public health guidelines, as more leaders have spoken publicly about the dangers associated with COVID-19. Additionally, these leaders have advised community members to take the available vaccines, believing their efforts will reduce the rate of infection among South Sudanese Canadians.

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 in order to keep their jobs. In other contexts, gender perceptions played a key role: during discussions in London (Ontario), one community leader described men receiving the vaccine as equivalent to their 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 was seen as an act undertaken for family and community. Likewise, the vaccine was seen as having grave risks, but receiving it was a service to the family as men could then still maintain an income.

Diaspora and routes for knowledge exchange. Even in diaspora, South Sudanese Canadians remain part of epistemic communities back in South Sudan, sharing knowledge and ideas through phones and social media. Some of our interlocutors in Canada attested that they had received calls from relatives and friends in South Sudan, advising them to reject the vaccines. As noted above, social media has made it easy to share information (including misinformation) about the COVID-19 vaccine in different parts of the world and across global communities. Like many communities, the South Sudanese first heard about COVID-19 in 2019 through social media and were informed about the vaccine rollout in late 2020.

Many South Sudanese are members of Whatsapp groups and Facebook pages that link them to discussions in South Sudan on a daily basis. For example, in January 2022, during a violent incident in Jonglei State (South Sudan), South Sudanese in London (Ontario) were receiving live-updates and analysis via friends on Whatsapp about the situation. These Whatsapp groups have also hosted debates about COVID-19 and vaccinations, reinforcing people's social and epistemic links to South Sudan, which maintains a strong influence upon these Canadian communities.

Within the diaspora, other factors also influence South Sudanese Canadians' notions of the vaccine. Four key sub-factors also played a role: widespread poverty limited respondents' access to multiple news sources; lack of education and time (particularly for single mothers) limited their ability to parse information; fringe religious beliefs at times supplanted biomedical evidence for vaccine safety; and errant notions of the vaccines' effect on fertility diminished uptake among both men and women.⁴⁷

46 Robinson, A. 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>.

47 All these factors are explored in more detail in the full impact report.

Reasons for vaccine reluctance

Our study found that the vaccination rate is high among South Sudanese Canadians, but that they rarely accepted 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 remain concerned about their long-term side effects on their health.

Three key reasons for reluctance characterise this community's response, but it is important to note that 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. Our interlocutors suggest, moreover, that unvaccinated South Sudanese Canadians include men, women and youths. Indeed, a leading member of a women's group we interviewed in Winnipeg emphasised the reluctance among young people to get the jab.

A COVID-19 response designed for others. Many South Sudanese Canadians expressed general support for the Canadian government, and the freedom and welfare it provided. Our informants also expressed trust in doctors and health services they have experienced in Canada. 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 share their priorities for communal togetherness and economic mobility. Pre-vaccination measures sowed distrust of the government's policies, which would later have an impact when vaccines were finally rolled out.

Social connections not prioritised. One major reason for South Sudanese concern over the Canadian government's COVID-19 restrictions was their impact on social interactions. South Sudanese living in Canada often remain socially reliant upon and connected to communities of their fellow nationals, namely exiled communities that have reformed 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 just for individual security but for social and emotional well-being.

Trust in government and public health authorities. Although most South Sudanese Canadians perceive the benefits of the vaccines and have faith in Canada's health services and providers, they do not want to be among the first to get vaccinated. When the Canadian government announced the rollout, most South Sudanese Canadians decided to wait and see how the vaccines would work.

Policy recommendations

To engage the South Sudanese community in particular, and other diasporic communities, we identified four key recommendations for policymakers to pursue.

Engaging grassroots leaders. 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.

Engaging women. The government of Canada should also 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.

Address medical racism. 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. Community champions, including women's groups, can be central figures in encouraging dialogue with respect to historical legacies and scientific evidence.

Pathways to psycho-social support. Alongside offering vaccine information, it is important to signpost South Sudanese Canadians to welfare services, specifically psycho-social assistance. The experiences of COVID-19 restrictions have the potential to reactivate prior memories of repression of war, so it is doubly important to offer counselling outlets, rather than depend on community structures alone, to manage and treat the reactivation of past trauma.

4.0 Moving from evidence to policy: Five overarching principles

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 identified potential entry points to rebuild trust in the healthcare system.

Departing from our appreciation of diversity and internal deliberation within communities, we contend that wider frames of well-being (i.e. beyond targets of health benefits or information dissemination) should be the basis for such equitable policymaking. The following five principles emerge from learning derived from experiences within our research groups.

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. Moreover, gender divisions in decision-making regarding health should be factored into the consideration of entry points for engagement.

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

Design community-based policies inclusive of citizenship, movement and economic survival

Lockdowns and/or the securitisation 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 quarantines. Among communities on the margins of state provision, such policies have created deeper economic uncertainty 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 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 prioritising 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.

Consider local and 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 dismantle the bureaucratic rigidity that poses barriers to vaccine participation and social justice. One 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 uptake, in the longer-term, advocacy must be embarked around structural marginalisation to remedy the significant disjuncture between aims of healthcare providers and the perception of these aims among disenfranchised populations.

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.

Expanding intellectual frameworks underpinning vaccine delivery

The framework of “vaccine hesitancy” provides only a partial tool to understand longstanding inequalities and 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 of socio-economic and political inequalities that inform people’s choices, which must be addressed through interventions beyond emergencies and coercion. Beyond the semantics of the use of an alternative language, it is useful to contrast the notion of vaccine barriers with the practice of 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 policymaking. These perspectives must be accommodated not as an ‘add-on’ to epidemiological research, but integrated into the theoretical development and practical delivery of vaccine campaigns.

Without community buy-in, vaccine campaigns will remain engines of mistrust, fostering misinformation and conspiracy theories. At the policy level, moreover, collapsing communities into homogenous units will only intensify the stigma and blame for those deemed non-compliant.⁴⁸ Such concerns are particularly pertinent in the context of nationalist tones that have emerged in recent political discourse: in G7 countries, getting vaccinated is increasingly equated to a civic duty to protect the nation within the public sphere, with particular risks for minority groups who refuse to do so.⁴⁹ Taking the above measures is a necessary prerequisite to avoid deepening the discrimination experienced by disenfranchised groups.

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Published September 2022

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To cite this report: British Academy (2022), *Principles of Building Trust: Engaging Disenfranchised Communities Across the G7 in COVID-19 Vaccine Campaigns*, The British Academy, London

doi.org/10.5871/c19-recoveryg7/ES

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