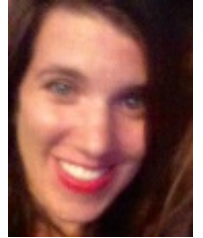


Equal parts researcher and advocate: having an impact in hard-to-reach communities

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Conducting fieldwork in hard-to-reach communities can pose significant challenges. Sarah G. Zawacki's research focuses on health in Roma migrant communities and to overcome participants' initial wariness and mistrust she constructed a data collection strategy in which she was as much a community advocate as a researcher. It is through such active involvement with hard-to-reach communities, and by placing their impressions and experiences in a wider sociocultural context, that research studies can derive most value and afford a depth of understanding of their participants not possible through interviews alone.



Having chosen to conduct my PhD research on health in Roma migrant communities, I knew from the beginning that issues of discrimination and social marginalisation would arise as key factors shaping my data collection. The term “Roma” describes an ethnic group that is believed to have migrated from India between the ninth and fourteenth centuries, with populations today concentrated in Romania, Bulgaria, Hungary and Slovakia. Within the last 25 years, large numbers of Roma have migrated to the UK from Eastern Europe, often to pursue employment prospects or to flee discrimination. In the context of centuries of harsh mistreatment, many Roma community members feel mistrust towards external institutions and show reluctance to disclose personal information to outsiders. Understanding that I would not enter into my project with participants' implicit trust, I aimed to construct a data collection strategy in which I was as much a community advocate as a researcher.

I entered the field as a complete outsider: an American who had only ever read about the Roma and certainly had no contacts within the community from which to draw a base of study participants. Yet I was seeking to learn more about health inequalities, and Roma communities' experiences of discrimination and its impacts on their health presented an extremely powerful case of the health consequences of social injustices. It moreover carried the potential to play a role in rectifying some of these inequalities, and it was with these goals that I entered the field. Understanding that trust would be paramount to effectively carrying out my research, I settled on engaging in volunteer work with Roma community organisations as a means of overcoming my outsider status and engaging the community in discussions about health.



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I am not the first researcher to employ partnerships with community organisations as a means of gaining access to the Roma community, and it was for this reason that I needed to consider my methods for establishing contact with great care. Numerous statutory representatives and researchers had by this point passed through my partner organisations, gathering perspectives from Roma community members, yet – in the view of participants – offering little sense of their impacts. As such, many Roma community members have come to view researchers with a degree of wariness, fearing their involvement in research projects will constitute nothing more than a tick-box exercise and lead to no substantial improvement in their circumstances. In order to ensure that my contact with Roma community members not only yielded rich data but also adhered to my commitment to actively work towards reducing some of the health inequalities this population faces, I realised early on that my involvement needed to stretch the boundaries of traditional participant observation. I couldn't simply be present; I also needed to be useful.

First, though, I needed to build trust with the staff members of my partner organisations, proving that my activities as a researcher would not jeopardise the relationships they have spent years building. It was vital to keep in mind that the discrimination against Roma communities throughout history shapes their perceptions of the non-Roma population, and to remember that even organisations aiming to help them do not have their implicit trust. Non-Roma advocacy workers gain the respect of the community over the course of years of productive work and proven results, and once this trust has been established, they are careful in determining the extent to which they facilitate introductions between the Roma community and representatives of external organisations. Thus, in order to represent my commitment to organisational goals, I spent nearly four months providing research support to my partner organisation – developing cultural awareness training programmes and guides for health professionals –

before coming into direct contact with Roma community members.

When I did eventually enter into the community spaces as a volunteer health advocate, it was with substantial background knowledge of Roma community organisations' role in mediating between statutory service providers and this historically marginalised group. In light of the language and communication barriers that Roma community members face in accessing health services, I stepped into an intermediary position in helping them to navigate health care systems. My work broadly took the form of making GP appointments, requesting interpreters and helping patients to understand referrals. I saw Roma individuals turned away from health services due to inability to find a suitable interpreter. I accompanied a disabled client to a meeting with a local council, where she was refused a transportation pass because she was homeless, temporarily staying with a friend and could not produce the necessary documentation. It was over the course of these experiences that I began to understand my data collection not as a one-way process, but more of an exchange between the community and myself.

My role as a volunteer health advocate gives community members a reason to talk to me about health – providing insight into a traditionally taboo subject within the Roma community. At the same time, however, [I understand that my work modifies the social environment, and my impressions are in turn moulded by my perceptions of the inequities and discrimination faced by Roma community members](#). I acknowledge as well that this model can have a substantial impact on the nature of the data I am able to collect. Health advocacy can put me in disproportionate contact with individuals who have had negative experiences of health services, which can in turn skew my analysis towards undue emphasis on barriers. In an effort to attain a higher degree of representativeness in my sampling, I use snowballing techniques as much as possible, asking all participants if they have any friends or family members who may be interested in my study. While this does not wholly eliminate the potential for bias in my sampling, it has allowed me access to a more representative cross-section of the community and to hear a wide range of perspectives on health and health services.

It is from my active involvement with Roma communities – and the subsequent contextualisation of their impressions and experiences in a wider sociocultural context – that I believe my study derives much of its strength. I am privy to striking stories of barriers to adequate health care, stories that in many contexts respondents would lack the confidence to tell. Understandably, the Roma often find it difficult to distance themselves from individual and historical experiences of prejudice and discrimination, yet when an “outsider” demonstrates consistent and prolonged commitment to the community that they will open up about their honest impressions and experiences. While being in equal parts a researcher and an advocate can sometimes seem like an impossible balancing act, it opens doors to the community, affording a depth of understanding of the Roma social world that could never have been attained through interviews alone.

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About the author

Sarah G. Zawacki is a PhD student at Durham University. Her research into Roma health arose out of a general interest in the health impacts of migration, and has since developed into a focus on the interactions between this historically marginalised group and health service institutions. Looking at the ways in which language, communication styles and cultural conceptions of health impact the experience of using health services, her work seeks to provide health professionals and policy makers with a framework for more effectively engaging with Roma communities.

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