



PARTICIPATORY METHODS: THE INCLUSION OF UNDOCUMENTED MIGRANTS IN HEALTHCARE AND BEYOND



PLATFORM FOR INTERNATIONAL COOPERATION ON
UNDOCUMENTED MIGRANTS

This report was authored by Dastan Salehi, PICUM Advocacy Officer and edited by Michele LeVoy, PICUM Director. We gratefully acknowledge the valuable research support of Manuela De Koster and Shabnam Khezri, PICUM Advocacy Trainees, Alyna Smith, PICUM Deputy Director, as well as the contributions of Hanna Scott, lawyer and graduate student at Linköping University and PICUM members the European AIDS Treatment Group (EATG), European Sex Workers Rights Alliance (ESWA), Focus on Labour Exploitation (FLEX), and Maisha e.V. of their insight and experience on putting participatory approaches into practice.

This publication was made possible with kind support from:



Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Union Programme for Employment and Social Innovation "EaSI" (2021-2027). Neither the European Union nor the granting authority can be held responsible for them.



**OPEN SOCIETY
FOUNDATIONS**

SIGRID RAUSING TRUST

Cover photo: ©Seventyfour - Adobe Stock
Page 2: ©Rawpixel.com - Adobe Stock

CONTENTS

| | |
|--|-----------|
| INTRODUCTION | 2 |
| WHAT ARE PARTICIPATORY METHODS? | 3 |
| Background..... | 3 |
| Social justice in an intersectional era..... | 3 |
| Participation and inclusion as justice..... | 4 |
| Participatory Health Research..... | 4 |
| Challenges..... | 6 |
| Outcome expectation..... | 6 |
| Recruitment and remuneration..... | 6 |
| Positionality and power dynamics..... | 7 |
| Participatory Health Service Delivery..... | 8 |
| Phases of involvement - inception, design and implementation..... | 9 |
| Phases of involvement - evaluation and focus groups..... | 9 |
| PARTICIPATORY METHODS: EXAMPLES OF LOCAL PRACTICE | 10 |
| Delivery of health care and community engagement in Frankfurt, Germany..... | 10 |
| Feminist participatory action research focused on the experience of migrant women advocacy in London, United Kingdom..... | 11 |
| Applying participatory methods to comparative research to understand sex workers' treatment by police across multiple countries..... | 11 |
| People-centred research for improved prevention and treatment of HIV in Europe..... | 12 |
| Understanding the experience of young people with insecure residence status with violence and protection in Sweden..... | 13 |
| A WAY FORWARD | 15 |

INTRODUCTION

The briefing looks at participatory research methods in the research, and delivery of health care services as well as how that might apply to organisations supporting undocumented migrants, including on advocacy, communications, and governance. By drawing lessons from other fields, the paper hopes to reflect on what lessons may be learned for those who deliver services to undocumented migrants.

This briefing note does not intend to be exhaustive or to resolve the debates around the inclusion and participation of undocumented people in the work of organisations. Rather, it hopes to stimulate discussion and reflection for civil society organisations and migrant-led organisations about how to advance this objective. It recognises the tremendous diversity and different contexts in these organisations operate and the different capacities and viewpoints and that there will be divergent perspectives on this topic.



WHAT ARE PARTICIPATORY METHODS?

In simple terms, participatory research aims to meaningfully engage people and communities who are not necessarily trained in research methods but belong to groups of people who are the focus of the research¹.

Participatory research includes research designs, methods, and frameworks that use systematic inquiry in direct collaboration with those affected by an issue being studied for the purpose of action or change².

Concerning undocumented migrants, participatory methods in the context of the delivery of community-based services can be understood as the active involvement of undocumented migrants in decision-making, implementation, management and evaluation of policies, programmes, and services³. Participatory research represents a distinct research paradigm in which research is done collaboratively with the individuals whose lived experiences and actions are the subject of study, as active partners who share power and influence over research processes and outcomes⁴.

Background

Social justice in an intersectional era

The struggle for undocumented peoples' rights cannot be separated from broader social justice movements. The COVID-19 pandemic exposed and exacerbated inequalities that run deep in our societies, especially around who is able to access health care, work in safe and decent jobs, and be protected from financial shocks.

The movement to support undocumented migrants and their rights has always necessarily been intersectional. In addition to discussing double standards in the treatment of migrants based on systemic discrimination, alliances have increasingly been forged with organisations and networks working on criminal justice, on racial justice, on sex workers' rights, digital rights, and the fight against poverty.

Our efforts to achieve social justice for undocumented people and those with insecure residence status is not separate from efforts to dismantle racism, LGBTQI+phobia, sexism, classism. All of these efforts must be viewed within a common struggle for a more just society. Working in silos cannot achieve lasting change but joining forces across movements can.

- 1 Vaughn, L. M., & Jacquez, F. (2020). Participatory Research Methods – Choice Points in the Research Process. *Journal of Participatory Research Methods*, 1(1). <https://doi.org/10.35844/001c.13244>
- 2 Vaughn, L. M., & Jacquez, F. (2020). Participatory Research Methods – Choice Points in the Research Process. *Journal of Participatory Research Methods*, 1(1). <https://doi.org/10.35844/001c.13244>
- 3 Sachs JD. *Investing in Development: a Practical Plan to Achieve the UN Millennium Goals: a Report to the UN Director-General*. London: Earthscan; 2005.
- 4 Rustage K, et al. *BMJ Open* 2021;11:e053678. doi:10.1136/bmjopen-2021-053678

While every movement has its own specificities, the realisation of an equal society requires us to work together against oppression and towards a common vision of a more just society. Importantly, it also requires creating a space where undocumented people have a voice in the future of this struggle.

Participation and inclusion as a matter of justice

In this context, refugee and migrants' rights organisations are looking for ways to increase the involvement and participation of refugees and migrants in all aspects of their work. Refugee- and migrant-led organisations have proliferated across Europe in recent years, claiming a space for themselves in the advocacy of their rights.

The disability-rights movement has long championed the idea of community-involvement most notably recognised through the slogan, "nothing about us, without us", with other sectors, such as the HIV/AIDS advocacy movement and the LGBTIQ+ movements also adopting this slogan.

PICUM recognises the growing need for the inclusion and representation of undocumented people in all areas of its work. PICUM's [Strategic Plan 2021 – 2025](#) states that the organisation will strive to work "for the participation of undocumented migrants in society and PICUM itself"⁵. To that end, PICUM will work toward achieving the following outcomes by the end of the strategic period:

- Strengthen undocumented migrants' self-representation by supporting and lifting up migrant-led initiatives, lived experiences and calls for change
- Increase the participation of undocumented migrants across the work of the organisation
- Increased understanding and use of participatory research methods involving undocumented migrants and migrants' rights organisations.

Participatory Health Research

Participatory health research stems from a broader research methodology known as "participatory action research" and can be defined as an approach to research in which researchers and research participants work together to examine a social issue with a view to improving the situation. It is broadly understood to be an umbrella term with a diverse variety of research methodologies and varying levels of participation. Research is not done "on" a specific target population, but together "with" them⁶.

At its core, lies principles of democracy, which seek to increase the voice of those who are currently left outside of the system. In 1969, Sherry Arnstein wrote that "participation of the governed in their government is, in theory, the cornerstone of democracy"⁷. She continues by stating that "Citizen participation is a categorical term for citizen power. It is the redistribution of power that enables the...presently excluded from the political and economic processes, to be deliberately included in the future." In a recent special issue of the academic journal *Migration Letters*, authors Mata-Codesal et al argue that although Arnstein made this assertion of participation in government and local policies, "it is fully relevant to the current analysis of the (non) participation of (non) citizens in supranational, national or local policies governing international migrations."⁸

Participatory action research in the field of research on undocumented migrants therefore has three underlying elements:

1. It is rooted in principles of social justice, equality and intersectionality.
2. It is a collaborative effort between researchers and research-subjects, aiming to bridge the dichotomy between the two through meaningful collaboration.
3. As the name suggests, it is action oriented. Research is carried out for a specific change-focused purpose.

5 PICUM, [Strategic Plan 2021-2025](#).

6 ICHPR (2013) [position paper 1. Definition of participatory health research](#).

7 Arnstein, S.R., (1969) A Ladder of Citizen Participation, *Journal of the American Institute of Planners*, 35:4, 216-224, DOI: 10.1080/01944366908977225

8 Mata-Codesal, D., Kloetzer, L., & Maiztegui-Oñate, C. (2020). Editorial: Strengths, Risks and Limits of Doing Participatory Research in Migration Studies. *Migration Letters*, 17(2), 201-210. <https://doi.org/10.33182/ml.v17i2.934>

Participatory health research can be a tool to address some of the inequities in health delivery and in health outcomes between undocumented migrants and the general population. Most health services and interventions are based on research and data generated from the general population and may therefore not be suitable for the needs of undocumented people⁹. Participatory research can therefore be a useful tool in allowing undocumented migrants and migrants more broadly to have a say in shaping research priorities as well as health interventions.

Participatory research origins are firmly rooted in increasing social justice, and the promotion of doing research with, not on or about individuals and communities, particularly those that are disadvantaged¹⁰. It recognises that the legacies of postcolonialism, structural inequality and unequal access to political decision-making have resulted in the marginalization and exclusion of key sectors of the

population on important aspects of service delivery and activism that potentially affect their lives. The aim is to empower otherwise marginalized or socially excluded communities to enact social change.

Participatory methods can therefore be an effective tool in reaffirming the commitment of NGOs and community-based service providers to social justice and to redressing this imbalance and marginalization. At its roots lie the desire to empower marginalized communities and ensuring that they have the possibility to participate in processes that impact their lives. This can potentially have a positive and empowering impact on undocumented people and their communities¹¹.

Participatory health research also has other potential benefits, including producing stronger research findings¹² informed by and relevant to local contexts, which can be adopted in community and non-academic settings¹³.

A research project in Ireland¹⁴ used participatory methods to improve the participation of “hard-to-reach” migrant groups (including undocumented migrants) in the development of guidelines to improve communication with primary health providers. The communication gap was understood to include language discordance, cultural differences as well as social exclusion.

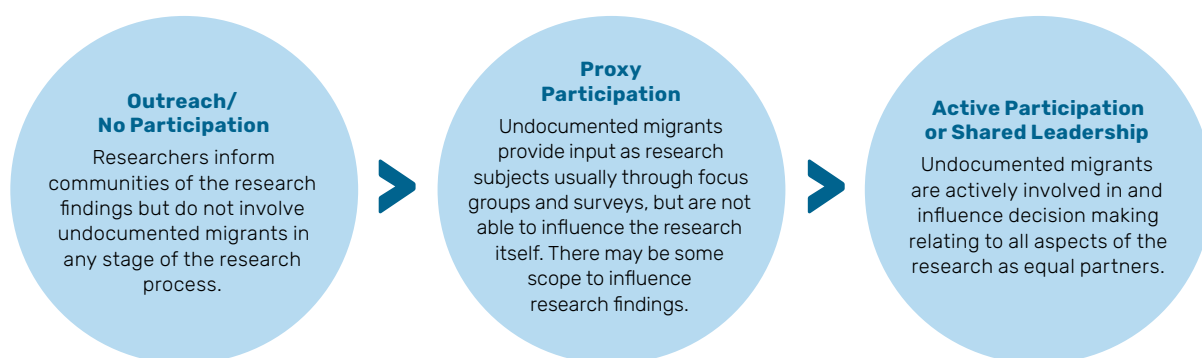
To bridge this gap, the researchers worked with seven migrants from local communities, who received training in participatory research methods. Through their networks and training, these seven people recruited 51 “hard-to-reach” migrants from their communities to take part in this participatory research project to improve the communication gap.

The study found that participatory health research was a powerful tool to ensuring that primary healthcare was fit-for-purpose in local communities, enabling these normally excluded groups to meaningfully engage and contribute to academic research. They conclude that participatory research methods have “the potential to become a ‘standard’ or generic approach in building community-based primary health care,” as well as the potential to include the perspectives and needs of excluded populations in research and health care delivery.

- 9 Redwood S, Gill PS. Under-representation of minority ethnic groups in research--call for action. *Br J Gen Pract*. 2013 Jul;63(612):342-3. doi: 10.3399/bjgp13X668456. PMID: 23834862; PMCID: PMC3693777.
- 10 Macaulay AC. Participatory research: what is the history? Has the purpose changed? *Fam Pract* 2017;34:256-8.
- 11 Reason, P., & Torbert, W. (2001). The action turn: Toward a transformational social science. *Concepts and Transformation International Journal of Action Research and Organizational Renewal*, 6(1), 1-37. <https://doi.org/10.1075/cat.6.1.02rea>
- 12 Balazs, C. L., & Morello-Frosch, R. (2013). The three Rs: How community-based participatory research strengthens the rigor, relevance, and reach of science. *Environmental Justice*, 6(1), 9-16. <https://doi.org/10.1089/env.2012.0017>
- 13 Bush, P. L., Pluye, P., Loignon, C., Granikov, V., Wright, M. T., Pelletier, J.-F., Bartlett-Esquilant, G., Macaulay, A. C., Haggerty, J., Parry, S., & Repchinsky, C. (2017). Organizational participatory research: A systematic mixed studies review exposing its extra benefits and the key factors associated with them. *Implementation Science*, 12(1). <https://doi.org/10.1186/s13012-017-0648-y>
- 14 O'Reilly-de Brún, M., de Brún, T., Okonkwo, E. et al. Using Participatory Learning & Action research to access and engage with 'hard to reach' migrants in primary healthcare research. *BMC Health Serv Res* 16, 25 (2015). <https://doi.org/10.1186/s12913-015-1247-8>

It is important to stress that not all “participation” is the same. There are different ways to conceptualise forms of participation, but participation broadly exists on a spectrum^{15,16}. Different types of participation serve different research purposes and one type of research is not inherently better than another. It is

important for organisations and researchers carrying out work with undocumented migrants to be aware of these different levels of participation. At worst, participation can become tokenistic and be reduced to tick-box exercises.



Challenges

Participatory methods and inclusion of undocumented people is not without pitfalls, risks and challenges. Organisations wishing to engage in this type of work should be aware of the potential risks associated with this to safeguard the wellbeing of their populations as well as to ensure that participation is meaningful and empowering. Participatory research blurs traditional role divisions in the research process, introducing the researcher to potentially new academic, practical and ethical dilemmas.

help empower undocumented migrants in shaping research outcomes based on their own input.

However, as participatory research is intended to be action oriented, it can also garner expectations of real-life benefits through societal change as a result of the research. The potentially modest impact of research due to the limited control that participants have in key political decisions around migration is a concern that many feel when carrying out participatory health research¹⁸.

Outcome expectation

Researchers and NGOs who have engaged in participatory approaches to research generally refer to the positive benefits in including migrant communities in their research both for the migrants themselves and in enhancing the quality of the research outputs¹⁷. However, managing the expectations of those involved in research can be a very real challenge, especially when working with socially marginalized groups who struggle to realise their rights, such as undocumented migrants. Engaging in participatory research can

Recruitment and remuneration

It is not uncommon to provide compensation and remuneration for research participants who engage in participatory research. There are very good ethical arguments for remunerating people with lived experience for dedicating their spare time to research. This can be especially relevant when asking undocumented people to participate in this type of research, as they often occupy low-wage sectors with difficult and unpredictable work hours and unsteady

15 Vaughn, L. M., & Jacquez, F. (2020). Participatory Research Methods – Choice Points in the Research Process. *Journal of Participatory Research Methods*, 1(1). <https://doi.org/10.35844/001c.13244>

16 Rustage K, et al. *BMJ Open* 2021;11:e053678. doi:10.1136/bmjopen-2021-053678

17 Rustage K, et al. *BMJ Open* 2021;11:e053678. doi:10.1136/bmjopen-2021-053678

18 Cawston PG, Mercer SW, Barbour RS. Involving deprived communities in improving the quality of primary care services: does participatory action research work? *BMC Health Serv Res*. 2007;7:88.

incomes. However, this poses a specific challenge in terms of creating incentives for those who choose to participate in research.

In addition, power relations within participants groups can also skew research findings. For instance, one of the frequently stressed challenges of carrying out participatory health research is if only the most vocal or most senior people participating dominate the input to and analysis of the research¹⁹. For researchers wanting to engage in this type of research with undocumented migrants, they often have to go through local organisations as interlocutors. This should trigger reflections around which voices are included as well as how representative those voices may be in the research outcome. The absence of reflection on this aspect can lead to risks that existing power imbalances are reinforced or exacerbated within communities²⁰.

It is important to note on the issue of representativeness that this should not be used to undermine efforts to be more inclusive. A report on migrant-led advocacy by the European Programme on Integration and Migration (EPIM) notes that not being considered 'representative enough' is often used by mainstream civil society organisations and policymakers to challenge the legitimacy of migrant-led organisations. However, the report notes,

"In reality, and since it is near impossible for any organisation to be truly representative of all migrants, this act of questioning legitimacy instead intends to delegitimise the voices of migrant advocates, and ensure non-migrant experts become the only trustworthy voices in the political space. Instead of questioning the legitimacy of migrant advocates, mainstream civil society organisations (CSOs) and policymakers should focus on engaging them to create more inclusive policymaking that reflects the lived experiences of affected populations²¹."

Whilst it is important for researchers and advocates to be conscious of potential power dynamics withing groups and communities, this should not be used as a prima facie justification from seeking to increase representation in research and in advocacy.

Positionality and power dynamics

Under participatory health research, there is a proactive attempt to remove power imbalances between researcher and research subjects. When done effectively, participatory health research should actively be involved in shaping the research question, carrying out the research and data collection, as well as in the analysis of the results and dissemination of the research. They should be meaningfully and equally involved in all phases of the research.

Attempting to erode the inequalities between the two does not, however, mean that it is possible to remove them entirely. The situation of social, legal and economic marginalisation that undocumented people find themselves in mean that there will always exist in asymmetry between the two, and researchers should be aware of this at all times.

There may be ethical concerns around asking someone who is struggling to earn a living to take part in research (remunerated or otherwise). Undocumented people may not benefit personally from the outcome of a publication, but the researchers will benefit from being able to author academic research. This is the case even when undocumented people can be included as co-authors in the publication.

Finally, it is important to include strong safeguards for undocumented participants who may be taking part in this type of research. As always, there are risks associated with undocumented people engaging in research and activism, as it can bring public attention to them and their status. This should include very robust informed consent procedures.

19 ICPHR Position Paper 1. [What is participatory health research?](#) 2013, Berlin: International Collaboration for Participatory Health Research.

20 Guta A, Flicker S, Roche B. Governing through community allegiance: a qualitative examination of peer research in community-based participatory research. *Crit Public Health*. 2013 Dec;23(4):432-451. doi: 10.1080/09581596.2012.761675. Epub 2013 Jan 11. PMID: 24273389; PMCID: PMC3827674.

21 European Programme on Integration and Migration (EPIM), 2021. [Migrant-Led Advocacy Across Europe Challenges and Opportunities](#)

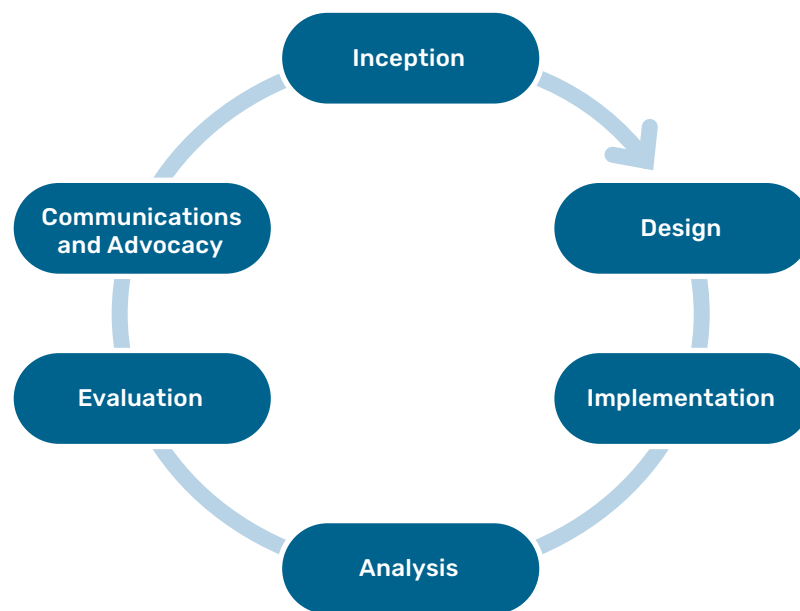
Participatory Health Service Delivery

For community-level organisations who provide health services to socially excluded groups, including undocumented migrants, in Europe there is a growing interest in increasing the involvement of migrants in decision-making. Participatory methods can be a useful lens to stimulate, learn and explore ways in which undocumented people can participate in, inform and help design health interventions that directly impact them.

Participatory methods in health service delivery differs from research in that its final objective is to practically inform and improve the delivery of services for specific groups. This is usually done through focus groups with service-users or patient groups but can also take the form of specific participatory research projects.

Phases of involvement

1. **Inception** – are undocumented people involved in the planning/thinking of service delivery?
2. **Design** – are undocumented people involved in the design phase of the service?
3. **Implementation** – are undocumented people involved in the implementation of the service?
4. **Analysis** – are undocumented people involved in analysing the outcomes of the service?
5. **Evaluation** – are undocumented people involved in the evaluation of the service?
6. **Communication, advocacy and activism** – are undocumented people involved in communicating the results and in any potential advocacy around service delivery needs?



Phases of involvement - inception, design and implementation

Involving undocumented people in the inception and design of health interventions can help ensure that their needs are met and that barriers that limit their access to services are addressed²².

A project in the state of Hawai'i in the United States of America increased the use of mammography screenings for Micronesian immigrant women²³. The project used community-based participatory research methods to raise awareness of cancer prevention among the migrant women. The researchers worked collaboratively with a community-based civil society organisation who provided services to the target population. In a participatory approach, they asked questions pertaining to what the main health concerns were as well as the main barriers and what cultural strengths the group had which could help improve health outcomes.

The focus groups themselves identified breast cancer as a leading concern. The women mentioned because there were limited resources for and a lack of knowledge of cancer among their community, many women were diagnosed late. The women therefore recommended that breast cancer education be provided to all members of their community to overcome this. They also identified "champions" in their community who could serve as one-on-one peer educators and to support the women navigate the health system. The research project yielded positive results in screening uptakes but also had other benefits such as instilling new skills in community members.

For organisations working with undocumented migrants, there are many principles from this project that can potentially be meaningful and impactful. Of course, the regulatory framework governing access to health care services as well as practical barriers to

health care, present specific challenges to this goal. However, working with specific migrant groups and community-based organisations to identify the most pressing health needs and working collaboratively to design and implement a successful programme of intervention is something that can potentially be replicable in a context working with undocumented migrants.

Phases of involvement - evaluation and focus groups

Focus groups are qualitative data collection methodology in which a researcher moderates a small group of people to gain insight, feedback interpretation on a critical appraisal of specific parameters²⁴. As a method, it is easy to adapt, requires relatively few resources and can complement other forms of data collection such as surveys, questionnaires and interviews²⁵.

Focus groups can therefore be a very useful method for service providers delivering healthcare services to undocumented migrants. They are inherently participatory as they have the potential to serve as a dynamic forum to stimulate discussion, engagement, empowerment, inclusion and community building. Focus groups can be particularly useful in the evaluation phase (see above) as health service providers, together with the groups they serve, can gain first-hand insight into whether their services are yielding desirable outcomes and how they can be improved.

There are elements of focus group discussions that are inherently participatory. Despite these inherently participatory elements, to be truly participatory, focus groups should be considered a tool as a part of a larger strategy that seeks to include, empower and involve undocumented people meaningfully in the work of the organisation.

22 Nobody Left Outside Initiative, 2020. [NLO Service Design Checklist Guidance Document](#).

23 Aitaoto N, Braun KL, Estrella J, Epeluk A, Tsark J. Design and results of a culturally tailored cancer outreach project by and for Micronesian women. *Prev Chronic Dis*. 2012;9:E82. doi: 10.5888/pcd9.100262. Epub 2012 Apr 5. PMID: 22480611; PMCID: PMC3396555.

24 Bloor M, Frankland J, Thomas M, Robson K (eds) (2001) *Focus groups in social research*. Sage, Thousand Oaks

25 Longhurst R (2010) *Semi-structured interviews and focus groups*. In: Clifford N et al (eds) *Key methods in geography*. Sage, London

PARTICIPATORY METHODS: EXAMPLES OF LOCAL PRACTICE

As a complement to the analysis set out in Part I, this section presents five examples of practices from different countries and contexts, all of which directly and intentionally involve undocumented people or people with insecure residence status at multiple stages of the research process. In some cases, this research is scholarly; in others, it feeds into the design or redesign of services or into advocacy to improve existing policies that negatively impact affected communities. They are based on accounts from individuals from European networks, national organisations and academia, drawing on their current work and practice and provide an illustration of how participatory methods can be applied in different settings to co-create knowledge that centres involvement of and benefit to communities.



Delivery of health care and community engagement in Frankfurt, Germany

Maisha e.V. was established in 1996 to support African women in navigating their dealings with authorities and institutions in Germany. Today it provides support to women on issues related to asylum, health promotion and awareness, integration, migration, entrepreneurship, education and family, and runs a health clinic in partnership with the City of Frankfurt for people without health insurance.

Maisha defines participatory research as research where both participants and researchers are open to each other's questions and observations, and where the opinions, questions and observations of both parties are respected. The design and delivery of health services is community-led when the health needs of the community are acknowledged and respected and when its members are seen as subjects, rather than objects of health services. The community must be on-board with such an initiative from the outset.

In recent years, Maisha has introduced various community surveys to understand where its community stands on key issues, such as sexually transmitted infections and myths and facts on COVID-19. The community was involved in developing the design and content of these surveys.

Maisha's experience in working with undocumented people has highlighted the importance of not minimising their fears and concerns and respecting their wishes, especially those for anonymity. It is key to show participants that their involvement is welcomed and respected, and that they are not there to make up numbers. Undocumented people's ability to reach a meeting location should not be taken for granted. Financial needs to cover transport costs should be discussed with participants and travel distances to reach meetings should ideally be small. Likewise, Maisha advises to be mindful of participants' time and their need to leave at particular moments because of other responsibilities. Therefore, participants should be involved in determining a good time to meet, and agendas should be kept short.

Feminist participatory action research focused on the experience of migrant women advocacy in London, United Kingdom

Focus on Labour Exploitation (FLEX) was founded in 2013 in the UK as a research and policy organisation working to end exploitation in the workplace. For FLEX, participatory research should ensure that the experiences, knowledge and perspectives of the group or community that is being researched are not only acknowledged but form the foundation for the research. It should be community-led and aim to empower those most affected by an issue. Therefore, it facilitates the generation of knowledge that can bring about societal change. Practically, FLEX has done this by using a Feminist Participatory Action Research Approach, which has included focusing on the experiences of women and other minoritised as well as traditionally 'othered' groups, with the aim of highlighting and challenging intersecting forms of oppression, like poverty, racism, and gender inequality.

Similar to FLEX's approach to participatory research, community-led design and delivery of health services is understood to include the experiences and perspectives of the groups that use these services. These groups should meaningfully be able to give input at every stage of the design and delivery of the services. FLEX research projects that have had a participatory approach include a set of (conceptual) guides on participatory and feminist participatory action research (FPAR)²⁶ and several reports.²⁷

The "illegal working offence" provision under the UK's Immigration Act 2016²⁸ makes it unlawful to employ someone you know or have "reasonable cause to believe" does not have the right to work in the United Kingdom. Therefore, one of FLEX's challenges in conducting participatory research has been the inability to recruit irregular or undocumented migrant workers as peer researchers.

Applying participatory methods to comparative research to understand sex workers' treatment by police across multiple countries

The **European Sex Workers Rights Alliance (ESWA)** is a network of more than 100 organisations across 30 countries in Europe and Central Asia and advocates for the rights of sex workers. ESWA defines participatory methods as those that intentionally include - and ideally are led by - the people and groups who will be most affected by the outcomes of the project. The methodology recognises that it is the communities themselves that are the experts and does not assume that the researchers/service providers in question are the authority voice on the project topic.

Participatory methods implies that the community in which the research takes place has a meaningful stake in affecting the research design, data collection process and analysis. The community's needs are listened to and prioritised in the research, and the implications of the research results have been considered with the community members themselves. Meaningful involvement of community members at all steps of the design and delivery process means that community members hold power in making key decisions for the design and delivery of health services.

ESWA is conducting new research on how sex workers are treated when they come into contact with police. The project uses a Feminist Participatory Action Research (FPAR) framework, which is defined as research for change, and led by the community. Implementation of this FPAR framework involves ESWA consulting its members via community focus groups on best research practices; funding 10 of the 12 organisations involved in the project, the majority of whom are sex-worked led organisations; conducting 240 interviews in 11 countries, with interviews conducted by sex workers themselves; conducting a three-day research training workshop to train sex

26 See, e.g., FLEX (2018) ["Researching Labour Exploitation: Guide to Research with Hard-to-reach Migrant Workers in the UK"](#) and FLEX (2021), ["Experts by Experience: Conducting Feminist Participatory Action Research with Workers in High-Risk Sectors"](#).

27 See, e.g., FLEX (2022), ["The vulnerability of paid migrant live-in care workers in London to modern slavery"](#), FLEX (2021) ["Assessment of the risks of human trafficking for forced labour on the UK Seasonal Workers Pilot"](#), and FLEX (2021), ["The gig is up": Participatory Research with Couriers in the UK App-Based Delivery Sector"](#).

28 See [Penalties for employing illegal workers - GOV.UK \(www.gov.uk\)](#).

workers in how to conduct FPAR research, where the final decision about the scope of the research project was decided by the sub-granted members; producing several research resources to support the sex working organisations involved in the project; providing data collection tools and setting up a group chat where those involved in the project can share their experiences; hosting fortnightly drop-in sessions with ESWA's research officer, which the organisations can attend if they have any issues throughout the project; and holding a focus group with the sub-contracted organisations to discuss preliminary research findings.

For undocumented people, a separation between the project and the police and other authorities must be made both explicitly (in the form of written and verbal statements), and implicitly. This can be achieved by ensuring that community members are able to trust the individuals who are carrying out the participatory approaches, as well as establishing a working relationship with the communities that will be affected by the project. Transparency is key, being honest about limitations or any conflicts of interest. A focus group was run with community members before the research was carried out, so that the issues of the community can be addressed. It is also critical to give community members a stake in all stages of the project. Sub-granting was carried out for community members to support their contribution to the design, implementation, and evaluation of the project.



People-centred research for improved prevention and treatment of HIV in Europe

The **European AIDS Treatment Group (EATG)** is a patient-led organisation that advocates for the rights and interest of people living with or affected by HIV/AIDS and related co-infections. They see participatory services as having communities involved in the planning, coordination, implementation, and evaluation of health services. In the case of research,

participation is possible to differing degrees and at different stages of a research process. In some cases, the community is involved from the beginning and throughout the process, from suggesting research ideas to being part of the research team and working with a researcher. In other cases, the involvement needs to be encouraged and built.

EATG is currently working on a participatory and community-led project called SCOPE,²⁹ which focuses on community-specific preferences around HIV prevention. There are different steps within this project in which the community is involved. A community expert group guides the project and priorities are defined based on their guidance. The expert group is made up of people from different unique population groups that EATG wants to work with. The expert group members are paid for their time and help EATG connect with other partner organisations and individuals to participate in their activities.

Two pieces of research are conducted as part of this project. First, research on the community consensus on the definition of combination prevention for HIV as well as an agreement on the key indicators for an effective monitoring of combination prevention. These indicators are population-specific and highlight the variety of needs in each population. They will also have a survey for people who are working in community-based organisations in relation to HIV and HIV prevention. Ideally, they want to develop a tool that will be applied for future community-led monitoring of prevention services. Second, they aim to launch a new research project and to build research capacity among peer advocates or peer workers.

EATG is collaborating with Coalition Plus³⁰ to provide training for EATG peer researchers on the protocols and approach to research. The research aims to be intersectional and open to diverse communities. Each community of expert group is composed of several smaller communities within that group. For instance, the community of sex workers includes transmasculine men from migrant backgrounds from sub-Saharan Africa. People from different contexts are involved and the idea is that the communities will lead the research and produce data that is relevant for them. The data can later be used for advocacy purposes.

29 See [The SCOPE Project](#).

30 See [Coalition PLUS - Ensemble, construisons un monde sans sida, ni hépatites](#).

Other examples of participatory approaches that EATG has used include a survey conducted at the beginning of the COVID-19 pandemic to understand the impact of COVID on the populations they work with. EATG worked with task groups from members of different populations to help them design the survey and disseminate the survey within their respective networks, with the aim of portraying people's perceptions and experiences of the pandemic. EATG also participated in another project, EmERGE,³¹ on digital health where they worked with a local focal point from the community to organise the different user groups of a local clinic to provide feedback on the design of the intervention. This was important as some of the issues of the community are sensitive, and the users need to be safe from stigma or discrimination when they are using an app associated with HIV. The findings were used to determine the type of services, beyond tele-consultation or getting test results, that the community wanted as part of the app being developed. The community and the user groups were involved in designing the intervention and its evaluation.

When undertaking participatory approaches, it is important to recognise that ensuring proper consultation with communities and outreach to various populations takes a considerable amount of time, and that this needs to be accounted for at every step of the project. It is important to work with a network who can share the call for participation with their contacts and even encourage their colleagues, friends, or peers to apply. The consideration of time is not only in relation to EATG or the organisation of facilitating and guiding the process; it is important to recognise the investment of the time of participating community expert groups and researchers, who are asked to make the time to be available for the tasks.

Another consideration is in relation to compensation and payment. People from the communities EATG works with are often already in a precarious financial situation and are asked to do something as part of the research project that may prevent them from working, given the time investment. In some national contexts there may be challenges around paying undocumented people, or there may be specific

considerations for those who need to register as a freelance worker to be able to collaborate or give consultations on their research.

Working with communities can be unpredictable in some cases. It may be that people cannot find the time in their day to day lives to be available for the project, to do the work, or to respond to emails. With an undocumented person it may be that they are forced to leave the country and are no longer able to participate. This is a risk that should be accepted when working with communities and it is important to think of an alternative plan in such cases.

It is crucial to avoid tokenism and to work towards meaningful participation from varied perspectives, including service providers, researchers, and people with lived experience of the issues.

Understanding the experience of young people with insecure residence status with violence and protection in Sweden

Hanna Scott is a lawyer and doctoral student at Linköping University. Her doctoral research explores lived experiences of different forms of legal, administrative and interpersonal violence and strategies for navigating informal and formal protection, justice and reparation amongst young people who have sought refuge in Sweden.³²

Hanna's study is inspired by participatory action research methods and draws on a wide range of empirical mixed-method materials, including in-depth interviews, a survey and participatory observations at four different migrant support organisations. During her fieldwork, she made weekly visits to these sites, spent time with visitors, often sharing meals while engaging in informal conversations, or simply observing. She has involved research participants in different ways and at different stages of the research process. This has been achieved by introducing elements of co-designing materials as well as the co-creation of knowledge with research participants.

31 See EATG, [EmERGE](#).

32 Her work examines how young people who have sought refuge in Sweden reason around whether or not to turn to the police for help when subjected to violence in situations characterised by extreme welfare and migration law uncertainty. By examining young people's experiences of non-protection from criminalised violence, other forms of state violence, emerge and become part of the continuum of violence experienced by young people seeking asylum.

Participatory research elements are present both in the design of the study and in its implementation. Hanna's study is inspired by a desire to address the challenges of protection posed by real life cases of undocumented young victims of crime. The formulation of research questions was inspired by the challenges she encountered in her own practice as a lawyer working with young people seeking asylum. In developing the survey, she consulted with several young migrants and staff at different migrant support organisations to be able to include relevant questions and wording. She found that it could be a challenge to find a "common language" to talk about violence (or other sensitive topics) with young people, whether in migration or not.

Participatory research also means that empirical material is co-produced rather than collected. Hanna's empirical data includes co-produced material such as two sound documentaries in which research participants narrate their experiences of criminal victimisation and help-seeking while she provides an account of the relevant legal frameworks. These documentaries were produced by a migrant support organisation and are also used as training and capacity building tools for staff.

Hanna's research project is designed as a participatory activist research project where the sharing of knowledge of and about the law – and of rights – is central. She has asked herself the question "How can I as a researcher be sure that what I propose to 'give back' is 'what is needed'?" The mainstay of her fieldwork was carried out at a time when many changes to the Swedish migration law were enacted and there was a shortage of information about the effect of these changes on migrants' lives. In the field, she uses her experience as a lawyer to provide legal advice and information, holding workshops with migrants and training staff. This commitment to sharing information about rights and the law builds on the idea that law can be practiced not just by lawyers and that access to legal information should be increased so that young migrants can better navigate the law.

There are many ethical considerations when doing research with young people in migration, many of whom are living with precarious permits or undocumented at risk of deportation and detention.³³ Informed consent must be secured continuously in fieldwork and safe spaces assured.

33 For a discussion of some of the ethical and methodological challenges of her research, see H. Scott (2022), "[Survival over safety: non-reporting of criminalised violence by young migrants excluded from protection](https://doi.org/10.1080/1369183X.2022.2099362)", *Journal of Ethnic and Migration Studies*, DOI: 10.1080/1369183X.2022.2099362.

A WAY FORWARD

Research priorities on migrant health are still overwhelmingly shaped by academics, policy makers and clinicians, with only sporadic and infrequent inclusion of migrants. For undocumented migrants, this may be even more complicated by the barriers that arise from precarious residence status, leading to lack of trust and difficulty in meaningful participation.

Participatory methods in health research and service delivery have the potential to influence other aspects of the movement to support undocumented migrants in Europe. There is a growing recognition of the need to include the voices, input and views of undocumented people in meaningful ways across advocacy, communications and governance.

One of the key challenges stems from a lack of a common framework or understanding over what “participation” means and looks like in practical terms. As many researchers have noted, there can be no “best practice” for participation, as it is all heavily contextualised and rooted in the specific socio-cultural contexts³⁴. Expectations of how to increase the participation and inclusion of undocumented

people therefore necessarily differ, as they come from different contexts and perspectives.

Participatory health research and the inclusion of undocumented people more broadly has the potential to force decision-makers to rethink of undocumented people as passively affected by policies and rather as proactive and engaged agents of change. This can be an important way to counter the toxic narratives that often dominate debates.

Increasing the participation of undocumented people in research, health care services and beyond can serve as a way to combat harmful stereotypes, empower undocumented people as actors of change and redress their exclusion in policy-making spaces. Participatory methods are not the only solution to the current challenges undocumented people face in Europe. They are, however, a powerful way in which NGOs, community-led initiatives and undocumented people themselves can come together and look for innovative ways to tackle structural discrimination and social exclusion.

34 Roura M, Dias S, LeMaster JW, MacFarlane A. Participatory health research with migrants: Opportunities, challenges, and way forwards. *Health Expect*. 2021;24:188–197. <https://doi.org/10.1111/hex.13201>



PLATFORM FOR INTERNATIONAL COOPERATION ON
UNDOCUMENTED MIGRANTS

Rue du Congres / Congresstraat 37-41
1000 Brussels

Belgium

Tel: +32 2 883 68 12

info@picum.org

www.picum.org