

FOSTERING COMMUNITY KNOWLEDGE

BACKGROUND PAPER ON
**COMMUNITY-BASED HARM
REDUCTION RESEARCH**

Title

Fostering community knowledge. Background paper on community-based harm reduction research.

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Fostering Community
Knowledge

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INTRODUCTION

Communities of people who use drugs have for decades, and prior to the establishment of mainstream health services, designed and implemented some of the most effective evidence-based harm reduction interventions, such as needle-exchange programs, peer-delivered naloxone and community-based drug checking (Salazar et al., 2021). However, research collaborations between people who use drugs and academic stakeholders often remain scarce, undervalued, and misinterpreted (e.g., Simon et al., 2021). The involvement of harm reduction professionals and community members in research is often limited to serve as interviewees or a gateway to access other, often hard-to-reach participants. Consequently, community members may feel that their meaningful involvement is virtually missing, and research data results in evidence which dismisses the knowledge, experiences, and needs of the communities that are the focus of studies and hence, those who should benefit the most (Simon et al., 2021).

Evidence and research are needed to advocate for more access to and coverage of high-quality harm reduction services (e.g., Hanney et al., 2003). However, the relationship between research, policy and practice is a complex one. Consequently, it requires more efficient and functional connections between academia, street-level practitioners and communities of people who use drugs, spanning through the process of planning, designing, and conducting the research. This more collaborative approach needs also to facilitate the dissemination of results emanating from scientific studies. Partly due to requirements within the academic field, publishing in high-impact journals is often the most desired outcome for academic researchers. On the other hand, translating research findings from complex, highly abstract academic texts into relevant practical recommendations (that are understandable outside the scientific profession and more easily used by practitioners and community members) does not seem to receive enough attention.

Practitioners and community members often feel that research is detached from street-level reality and are ignorant of their challenges and needs (DPA Voices,

2022). Challenging what seems to be an unequal, unbalanced relationship between science, practice, and community would be beneficial for all parties involved (Canêdo, et al., 2022). Moving towards a more participatory and inclusive approach that values and integrates lived and living experiences, practical expertise and field knowledge can facilitate the creation of more complex and multidimensional knowledge.

Given the above, the key objective of this paper is to explore the phenomenon of meaningful community involvement, its theory and practice, barriers, and ultimately propose ways forward.

AIMS AND METHODS

This paper argues the need for inclusion in research of communities with lived experience, particularly that of people who use drugs. It aims to explore the challenges of community involvement as well as potential avenues to overcome such challenges. The specific questions that this project attempts to answer are:

What is meaningful community involvement in research?

What are the factors supporting or hindering such involvement?

This project has utilized both primary and secondary data. The study involved (1) a review of the available sources in various formats – podcasts, journal publications, commentaries, interviews, project reports; and (2) analysis of expert interviews and a focus group session. Six experts were interviewed in August-October 2022 to acquire in-depth information and discover the participants 'insider knowledge' (Wassermann, 2004). Additional information was acquired from a discussion held in the fall of 2022 during a dedicated session of the C-EHRN Expert and Member Meeting in Athens.

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THE CONCEPT AND THE CONTEXT OF MEANINGFUL INVOLVEMENT

2. The Concept and the Context of Meaningful

Notions of '*involvement*', '*engagement*', and '*participation*' are often used alongside one another with limited agreement regarding what they are meant to specify. The term '*meaningful involvement*' has been defined in a variety of ways over the years. Within the context of health care, Morrison and Dearden (2013) define it as the opposite of tokenistic involvement and assert that the ability to impact decision-making is the basis of meaningful inclusion. Meanwhile, Ocloo and Matthews (2016) describe it as an activity performed by or in collaboration with the public rather than by, about, or for them.

Further relevant concepts include '*empowerment*', with community empowerment advocated by the WHO as a key driver of population health (WHO Ottawa Charter, 1986).

For the purposes of this paper, terms '*inclusion*' and '*involvement*' will be used to encompass the notions of participation, collaboration, and engagement.

The basic condition for meaningful involvement in research is that researchers, organizations, and institutions recognize the value of the living

and lived experiences of people who use drugs. Once that recognition is in place, appropriate mechanisms need to be developed to utilize the valuable knowledge, skills, and insights of the community at hand. Such mechanisms need to ensure tokenism is avoided and instead build reciprocal relationships with people who use drugs, thus advancing truly beneficial involvement.

Community engagement in research is affected by a variety of factors that hinder or support meaningful engagement. Some examples include the way participants define their roles; the (non-) existence of protocols for accountability; and clarity regarding what is expected of them. Moreover, transparent, and consistent communication of commitments, ambitions and vision are also crucial as they can foster an environment where stakeholders from various backgrounds effectively work together for a better envisioned future. Meaningful community involvement builds collaborations in a supportive environment and requires a strong personal commitment, specific interpersonal skills, and patience (DPA Voices, 2022). The following chapter will discuss these factors.

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MEANINGFUL INVOLVEMENT: KEY CHALLENGES

Analysis of existing sources and data collected during this project identified a number of challenges hindering participation in research initiatives. Primarily, unequitable relationships between researchers and the community members have been highlighted as a key challenge. This is related to several other issues, such as unequal and paternalistic relations between the universities and the community; financial structures and mechanisms that guide university research and collaborations; and the social (as opposed to scholarly) basis of knowledge that community members bring to a collaboration.

Planning is the most crucial, yet probably most overlooked aspect of involving communities in research studies. It is the basis that can ensure meaningful collaboration with the community as it allows guaranteed involvement at all stages of research. In terms of research design, it is of key importance that the research question(s) is (are) understandable, clear in scope and significant for the community. It means that a research problem addressed should contribute to the improvement of everyday lives of community members. In practice, it seems that this aspect is often challenging as the objectives of researchers do not always align with community needs.

Moreover, measures to secure the agency and dignity of all involved participants and collaborators are often amiss. Interviewed experts emphasized that people who use drugs are rarely seen as people with valid knowledge and expertise, in a way similar to someone who acquired their knowledge through formal education in institutions (i.e., a physician). In practice, it means that often when researchers face challenges with scheduling

meetings with professionals, they tend to be understanding, patient and respectful towards interviewees' requests. In contrast, when it comes to community members, the researchers tend to not consider people who use drugs' other commitments (such as taking care of other community members, raising children or procuring drugs). Most of the time community members are not treated with dignity and respect.

COMPENSATION OF THE COMMUNITY MEMBERS

In a similar vein, one of the essential practices of respect is ensuring each community member is fairly compensated for their contributions. Although it might seem self-evident that compensating the effort, time and expertise of research participants is of key importance, anecdotal evidence shows that there is a range of challenges in this area when it comes to people who use drugs. For example, it seems that in some cases where the research budget includes funds dedicated to remunerating participants, researchers are hesitant to use cash to pay people who use drugs, justifying it with a concern that the research participants will spend the money in ways that the researchers do not approve (e.g., to purchase drugs). What can be seen is that often the decision is made to remunerate, for example, via vouchers that can be used only for very specific purposes (e.g.,

groceries, books). In extreme cases, the effort and time that community members put into a research project may even not be recognized as work at all, and they may be expected to participate driven by intrinsic motivations. Such attitudes are rooted in a prohibitionist, paternalistic mindset that moralizes and infantilizes people who use drugs, as opposed to approaching them as collaborators with an equal right to make decisions for themselves as any other contributor.

Finally, interviewed experts also highlighted that some community members are considered 'more trustworthy' than others by researchers, hence able to receive monetary compensation for their involvement. Such practices, however, do not constitute meaningful involvement, but rather are seen as paying an individual person to exploit their own community, with its expertise and unique knowledge.

NON-MATERIAL INCENTIVES

Although fair compensation is an essential part of meaningful community inclusion in research, the experts emphasized the need for incentivizing participation in other ways as well. The lack of fair financial rewards, as mentioned earlier, is indeed an obstacle for meaningful, ethical, and respectful community inclusion. However, beyond material rewards, community members are much more likely to be motivated to collaborate and feel

intrinsically rewarded if leaders of a community can communicate the practical benefits of participating in any given research project.

Communication is crucial not only within the community but also between community and researchers. Some experts have expressed concerns about the way that some researchers tend to approach communities without using appropriate structures and communication channels, and without respecting local cultural customs. It is essential that researchers are mindful and respectful about these dynamics at play. One of the important elements of respectful and open communication is that the community members receive feedback on what researchers found in due time.

ACCESSIBILITY AND ADJUSTMENT OF THE RESEARCH PROCESS

Besides material and non-material incentives, it is essential to define the objectives, timelines, and processes of a research project in a way that is accessible and clear for community members. Everyone involved wants to understand the what's and the why's. Researchers who intend to practice meaningful community inclusion must make efforts to cooperate with the community in outlining the objectives of their work. They also need to communicate the background and objectives of

their research to all stakeholders and, if necessary, discuss with their collaborators why it is in their interest to be involved in a study.

Researchers must do this with careful attention and considerations for the cultural, sociodemographic, and linguistic context, i.e., adapt the language, the communication platforms, and formats to accommodate the needs of the community.

RESEARCH DISSEMINATION

Scholars have a strong motivational drive to publish their work in high-quality scientific journals. The dissemination of findings is a conventional indicator of academic success and prolific output. In other words, the number and quality of studies a researcher publishes determines their job prospects, the reputation of their institution(s), grants, tenure, etc. However, to someone that is not accustomed to the world of academia (that is most community members), the timelines, fees and review processes of scientific publishing can be daunting. In consequence, there is often little motivation among community members to engage with the process.

The peer-review process is one of the major parts of the academic publishing process highlighted

by the experts as outstandingly challenging. It is the anonymous (blind or double-blind) evaluation system used to assess the quality of a manuscript before it is published. Peer review is a labor-intensive procedure that, albeit essential, does not normally involve remuneration of reviewers.

From the point of view of the community, it seems that academic peer reviewers often come across as less than competent in the niche of drug-related research, often seem to hold significant ideological bias, or simply lack compassion. Indeed, in mainstream, non-drugs-related journals it is difficult to find reviewers with an appropriate understanding of and experience in working with people who use drugs, or reviewers who are contributing to the field based on lived or living experiences. Anecdotal evidence also shows that sometimes language used by reviewers their feedback diminishes the authors' confidence and motivation. This, in turn, seems to be a contributing factor to increase the perceived difficulty of improving the manuscript.

Moreover, while academics are motivated, and even pressured, to publish in high-quality scientific journals as the ultimate goal of a research exercise, community members are normally more interested in utilizing the output of a project for their goals (e.g., advocacy), and in a vastly different format. In order for the research to have tangible practical impact, community members and the general public need the results to be translated into non-scientific language, and in ways that are relevant to them and their specific living contexts.

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MAKING MEANINGFUL INVOLVEMENT HAPPEN

The previous section focused on challenges in meaningful community involvement in research. This chapter, in turn, discusses several areas essential for successful engagement of people who use drugs.

Specific considerations are often necessary to ensure that people who use drugs are able to make the most of the involvement opportunities available. These considerations differ across levels of engagement (i.e., from being merely an interviewee to fully-fledged collaboration). For example, taking part in an online survey may require knowledge of the subject-matter, but serving as a board member on an advisory council to a research project is a far more skill-demanding activity. Successful and meaningful community involvement in research requires time and training, especially at higher levels of involvement. All stakeholders who commit to meaningful involvement, therefore, need to identify what skills are needed for their initiative, and dedicate resources to the necessary training.

There are well-known (although not very widespread in mainstream academic research) mechanisms for establishing partnerships between researchers and community members. These mechanisms provide an alternative to traditional research approaches and involve community members in the entirety of the process of the study, therefore from the design to the evaluation process and dissemination.

COMMUNITY-BASED PARTICIPATORY ACTION RESEARCH: PRINCIPLES

Participatory (collaborative) research involves developing a relationship between a research unit within an academic institution and a community-based organization, representing underserved communities (Washington, 2004). Action research is a philosophy and methodology of research seeking transformative change through the simultaneous process of taking action and doing research, which are linked together by critical reflection (Reason and Bradbury, 2008). Community-based participatory action research (CBPAR) is a quasi-combined approach to action research, emphasizing participation of and action by members of communities affected by that research (Reason and Bradbury, 2008). CPBAR is an effective combination of mechanisms that can have profound effects on individuals, communities, and organizations by empowering community members to contribute expertise and develop their own solutions to problems.

Therefore, a key recommendation for any researcher is to follow the principles of community-based action research, including a key aspect of CBPAR, the collective inquiry. Collective (i.e., collaborative) inquiry is grounded in the experience and social history of non-academic

collaborators and emphasizes the full involvement in research decisions of all active participants as co-researchers. This understanding of the collaboration model allows researchers to consider the geography and culture of the community in their research, identify structural and systemic issues underlying their subject, and build trust between researchers and community members. In addition, it allows researchers to establish shared interest(s) and focus point(s) with the community and thus further facilitate two-way communication and the establishment of reciprocal relationships. This, however, requires academic researchers to have a strong commitment to inclusivity, and to invest in cultivating networks outside the timeframe of their data collection.

THE ROLE OF PEER-LED ORGANIZATIONS AND ADVOCATES

While some might go as far as to advocate that researchers and people who use drugs should not be considered as two mutually exclusive roles (Salazar et al., 2021), institutional barriers might still keep people who use drugs away from conventional mechanisms of education, and consequently, employment in academia. It is essential for stakeholders in academia to seek out, engage, empower, and invest in the sustainability of local communities and peer-led organizations as these organizations already center around people

who use drugs and their expertise.

Informed by their lived experiences, and having access to positions of power within organizations, people who use drugs have the autonomy to set organizational objectives. Peer-led organizations have proved themselves to be operating with respect and openness, centering the needs and skills of community members, in addition to working towards improvement of health and wellbeing of people who use drugs. Therefore, when communities and peer-led organizations establish a collaborative framework, they provide researchers and their members with a unique opportunity to cooperate without committing any one individual to be entrenched in time-consuming institutional demands.

Consequently, the most important recommendation for communities is to organize into structured groups, put efforts into empowering group members, enhance their expertise, and network on their behalf with research institutions. To this end, peer-led organizations might find it useful to set up directories of subject-matter experts for multiple reasons: to recognize and empower community members and their knowledge; to have an overview of areas of expertise the organization can rely on; to have a list of contacts for easy access; and to be able to instantly identify possible collaborators, should an academic project request participation. Community-based organizations have a low participation threshold, are led by community members, and dedicate resources to networking as well as maintain and support networks. Moreover, they can be best positioned to reach, select, train and incentivize community members to participate in research projects and are also better positioned,

than any single individual, to handle the publishing hurdles experienced by grassroots projects.

There are many ways in which other stakeholders can also play a significant and constructive role in enhancing and fostering community involvement in research. Advocates, for example, can play a key role in this process by helping to facilitate communication between the research team, the community, and the decision makers. This will in no small part contribute to bridge the gap between seats of power and the affected populations. Promoting action research can be a powerful tool for advocates to serve the communities' needs since, as mentioned before, the purpose of action research is to trigger change by taking action and conducting research simultaneously.

ETHICAL CONSIDERATIONS AND ETHICS COMMITTEES

Traditionally, ethics committees review research proposals involving human participants and their planned data collection procedures to ensure compliance with local and international guidelines. They are also responsible for protecting the research subjects, as well as taking into account the impact on the community and the environment. The ideal committees' composition should reflect both gender balance and social diversity. Research ethics committees often include both researchers

and non-researchers. It is because non-scientific members may be better equipped to identify certain risks, particularly those related to social, legal, or cultural considerations. Meanwhile scholarly experts must determine the study design's validity and procedures. However, they tend to still be very distant and disconnected from the practice.

Traditionally, emphasis on community engagement raises ethical considerations that go beyond individual-level protection and researchers conducting community-based participatory research often complain about the way in which ethics committees oversee their research (see Guta and Voronka, 2020 and Tamariz et al., 2015). This poses an obstacle for meaningful inclusion for researchers and for communities in taking a leadership role in or initiating research.

Setting up an independent ethics committee able to advise and approve community-led projects could specifically support studies that involve people who use drugs. Such initiative could fill the gap in the existing system, whereby academic ethics committees' members have often no connection whatsoever to the field and realities on the streets, and consequently no understanding of certain processes or challenges.

Moreover, the traditional process of applying for ethical approval for a study seems to be highly challenging for non-academic authors, particularly when involving a submission of an extensive application package. Having an independent ethics board or committee made of adequately skilled practitioners and community representatives could address some of the aggravating procedures

that are characteristic for the mainstream ethical approval procedures.

TRAINING OF THE COMMUNITY PEER-REVIEWERS

As mentioned earlier, meaningful community involvement in research requires individuals to possess certain skills required for studying social and health phenomena. Peer-led organizations might therefore plan to dedicate resources to training their members to become researchers. Moreover, it is worth considering to train people who use drugs to also serve as reviewers, since working with academic peer reviewers has been identified by the experts as one of the more challenging parts of the publishing process. Community members are not used to the academic review process and may not possess necessary tools and mechanisms that protect them from experiencing criticism. They are also often deeply affected by the research topic, so receiving harsh and critical feedback can feel personal and intensely discouraging.

This is one of the main frustrations in the community in relation with research and publishing that can be addressed by investing in the training and compensating of the community peer-reviewers. Consequently, it is in the best interest of community-led organizations to identify and empower experts and train them to be able to

participate in the peer-review process. This way, members of affected populations can support the enhanced involvement of their community in research by providing constructive feedback, taking into consideration not only purely academic aspects of research, but also the validity of lived and living experiences.

DEMOCRATIZATION OF SCIENCE: OPEN ACCESS AND LANGUAGE

Overall, organizations are better positioned to establish networks and relationships with editors and publishers than any single individual. Organizations in good standing with various academic/scientific stakeholders are also in an ideal position to negotiate with publishers about open access fees and partnership deals. By doing so, they can help facilitate mutually beneficial long-term partnerships. On one hand academics have a perpetual need to publish their research projects, whilst on the other hand advocates require up-to-date, and relevant data from the field.

Community organizations are also likely to have the necessary know-how to translate academic language to accessible, digestible pieces of information to various community members, professionals in the field, and the society as a

whole. Community organizations are also able to train researchers so that they are able to meaningfully engage with the communities, and present their results in a way that is more understandable for non-academics.

One may propose that in the context of meaningful community involvement and the democratization of science, the most important tool is the allocation of budget and resources towards increasing community involvement in research. This needs to be a strategic decision brought forward by peer-led organizations and communities. It should also be fostered by advocacy efforts to set up international funds that contribute to the realization of such projects. Once sufficient funds have been secured to cover the expenses of meaningful community involvement in research, organizations should also be aware of the potential benefits of open access publishing and consider this when budgeting. By making their research more easily accessible, organizations can increase their impact and reach.

Finally, another important aspect to consider is monitoring. Despite the increasing emphasis on the establishment of community-academic partnerships (CAP) across multiple disciplines, there are no tools for monitoring such collaborations. It would be worth considering to create a standardized, international CAP toolbox with indicators and (self-)assessment tools. Such a toolbox would help to ensure that certain quality standards and codes of conduct are in place.

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GOOD PRACTICE EXAMPLES

HARM REDUCTION JOURNAL X FILTER: YOUNG PEOPLE, DRUGS AND HARM REDUCTION SPECIAL ISSUE

Academic research published with the collaboration of and for young people who use drugs, including research focused on harm reduction, are very scarce. This is despite the fact that the majority of the global population of people who use illicit drugs is composed of adolescents and young people (UNODC, 2022). Furthermore, young people are also disproportionately impacted by a range of drug- and drug policy-related harms. Suboptimal services for young people exacerbate this problem. Therefore, youth-specific harm reduction programs, general service providers, policymakers and peers would all benefit from more perspectives and data from youth who use drugs.

To help to address this shortfall, the Harm Reduction Journal (a peer-reviewed journal established in 2004 and affiliated with Harm Reduction International), the National Harm Reduction Coalition and the Eurasian Harm Reduction Association — have partnered with Youth RISE and Filter to create a special series Young People, Drugs and Harm Reduction in 2021. The initiative, partially funded by the Robert Carr Fund, was meant to center the voices of young people who use drugs and include them in the

scientific process. It also sought to identify barriers that prevent and hinder the publication of youth-led research.

Coordinators of the project established an Advisory Council, with an extraordinary level of representation of young people and advocates for the rights of young people who use drugs. Several interest groups have been also established, based on a survey circulated among community organizations and youth advocacy groups.

Once topics of interest and collaborators were identified, the coordinators assigned an experienced senior researcher to advise each working group, who periodically reviewed the manuscript-in-making and, when necessary, recommended improvements. The series was guided by a commitment to open science and where open access fees might obstruct participation, means of support have been made possible by the participating academics' institutions.

The project has made significant contribution to primarily connect senior academic staff to emerging researchers. It has also contributed to promote youth expertise and dedicated funds to cover various expenses along the publishing journey. The project contributed also to train involved senior staff to use a respectful and inspiring language, and to balance their leadership role with that of a collaborator. Ultimately, the project facilitated a two-way exchange of expertise. The output of this project can be viewed on the Harm Reduction Journal's website.

PEERS ON WHEELS

One of the major challenges for improving the access to hepatitis C testing and treatment in Australia is that several visits to a healthcare provider are required with multiple different tests to confirm active infection. To address this obstacle, The New South Wales Users and AIDS Association (**NUAA**) has partnered with The **Kirby Institute**, **NSW Health**, and selected Local Health Districts to co-lead, co-develop, and co-implement a peer-led mobile hepatitis C testing model in New South Wales, Australia.

In preparing the most effective intervention possible, the **Peers on Wheels (PoW)** staff have undertaken multiple research projects with the involvement of both researchers and future service users. They identified key points that led to their success, particularly: (1) partnering with organizations where people who use drugs are in power, and (2) supporting the sustainability of partner organizations, so they can set their own directions and governance – this is called a practice of “funding for authority”.

The PoW staff provided a low-threshold structure for individual community members to engage in the research process. Moreover, community members received appropriate training, which they have identified as essential, as “[one] can’t expect peers to know everything even if something seems like a self-evident in our spaces” (MJ Stowe, interview 12.08.2022).

The project concluded with the implementation

of peer-supported services, point-of-care HCV testing, and linkage to care to enhance treatment uptake among people who inject drugs. Being able to access the testing and enrollment for treatment in one visit turned out to be a real game-changer for people who would normally have to navigate several visits across many service providers in a complex health care system.

NCHALO COMMUNITY CAFÉ

In October 2017, a community-based workshop called the **Nchalo Community Café** was conducted in rural Chikwawa, Southern Malawi. The workshop aimed to improve good practices in community-based health-related research and involved stimulating participatory dialogue with target audiences to gain a deeper understanding of barriers to trust. The overarching aim of the workshop was to further develop the understanding of ‘good’ practice. The workshop used a world café format, and included a range of community members, community leaders, government extension workers and researchers. Participants were divided into groups of up to five people, facilitated by a table host, and group members rotated every 20 minutes. This format allowed for effective dialogue, rapid collation of information and exchange between participants. It also allowed members to express their thoughts through verbal conversations, written notes, illustrations or video blogs. This ensured

participants of all levels of literacy could feel comfortable in sharing their experiences and ideas.

On the one hand the project managed to explore issues around building trust and identifying barriers and concerns among communities and stakeholders in Chikwawa district, and on the other hand the researchers encouraged the creation of ideas around strengthening relations and developing mutual understanding between community members and stakeholders when engaging with research programs. Finally, the project identified and documented good practices and recommendations for better collaboration between communities and researchers.

THE NORTH CAROLINA SURVIVORS UNION

The North Carolina Survivors Union (NCSU) is a “drug-user union in central North Carolina” in the United States. NCSU maintains strong professional relationships with researchers and academic institutions and has served as a subcontractor on numerous research projects with the National Institutes of Health (NIH) and the U.S. Food and Drug Administration (FDA). Among the union’s esteemed research outputs are **The Methadone Manifesto, lessons from local syringe services, a study on take-home methadone during COVID.**

Successful collaboration between NCSU and external research organizations has been driven by attainment of genuine, meaningful

collaboration. NCSU has developed processes to avoid tokenistic inclusion, such as delegating people with experiences and their expertise to an advisory board, where they are locked out of actual decision-making processes. Research collaborations begin with an informal meeting between NCSU and researchers to discuss research objectives, methods, findings dissemination, party responsibilities, and other relevant issues. This way, project ideas are born through collaboration, rather than the usual route of researchers approaching the organization with a fully developed project they intend to undertake.

The framework encourages community-initiated research questions, centering the needs of those engaging in the behaviors in question. The very first meeting lays down the cornerstones for a mutually beneficial and respectful collaboration, thus ensuring research aims to directly benefit the community. As projects materialize, NCSU creates an infrastructure where expressions of community needs, requests for modifications and adjustments of expectations are welcome. Such projects have facilitated the conduction of on-site needs assessment surveys, in-person interviews, development of health education materials, and more. Once the implementation phase has come to an end, the results’ dissemination strategy prioritizes community-based utilization. Research projects undertaken by NCSU and its research partners are designed to benefit both academics and the community.



**Community based research
is a way of survival**

- Urban Survivors Union

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CONCLUSIONS

This paper asserts that people who use drugs are uniquely positioned to provide accurate and valuable insights on a wide range of topics (from drug use behaviors, to understanding of novel synthetic drugs and the nuances of the drug market) due to their living and lived experiences. This situates communities of people who use drugs perfectly to collaborate with researchers on studies related to drug use and drug policy, including harm reduction interventions and services.

Although there seems to be a renewed interest in drugs-related topics from academia (and at least a handful of academia-affiliated individuals with personal commitment to the topic in the current landscape of community organizations and NGOs in Europe), there are still major obstacles in producing more scientific output with community leadership. These obstacles involve primarily (1) lack of systematically inclusive collaboration (2), complex publishing processes, and (3) scarce funding.

While there is no universal formula for successful initiatives or models for community involvement in research, this paper explored mechanisms that can be applied to different contexts to promote more meaningful engagement. The most important factors contributing to overcome involvement barriers are financial support, (more specifically, dedicating a budget to scientific staff within community-led organizations), covering publishing fees and organizing appropriate, needs-tailored trainings.

While engaging people who use drugs might come with a unique set of challenges, it is imperative that institutions prioritize it and create capacity for

meaningful inclusion and engagement of people who use drugs and community-led organizations to leverage their position in the academic field. To do so, it is advised to implement the following recommendations.

FOR SKATEHOLDERS IN ACADEMIA

The difference between participation and collaboration must be genuinely reflected on. In framing a research project and setting its objectives, the involvement of people who use drugs-led organizations is of key importance. This approach not only supports the community and helps to avoid tokenistic involvement, but also facilitates relationship-building with the community and understanding of specific cultural variables. Furthermore, by adapting communication, setting relevant goals, aligning timelines and funding mechanisms, the academic would be in a better position to study society. Recognizing structural barriers and influences at both macro and micro level is important also for researchers, including reflection on one's own privilege and addressing power imbalances between involved actors.

Community-based participatory action research has been identified as a model for best practices. To ensure sustainability and maximize impact, academic stakeholders must embrace meaningful engagement as a norm, not an exception.

FOR COMMUNITIES OF PEOPLE WHO USE DRUGS



Strategic attention to scientific work is an important first step in accelerating community inclusion in academic projects, conducting research and publishing. This means the need of establishing formal commitments, as well as budgeting and decisions about human resources. Organizations will benefit from setting up databases of subject-matter experts and train members to step in to fill in gaps, i.e., train competent reviewers on niche topics.

AS FOR POLICY RECOMMENDATIONS

Some consider it helpful to establish procedures where researchers should attain approval from district committees, community leaders and other key groups before starting their research. Meanwhile, others find it restricting and fear even less motivation from the academic community for meaningful inclusion. However, there seems to be an overwhelming agreement that certain

requirements need to be in place to propel the issue forward. For example, researchers should clearly explain the inclusion and exclusion criteria of a study; how they plan to collect data; and what this data will be used for. To monitor the fair conduction of community-academic partnerships, it would be worth advocating for an international CAP toolbox and monitoring or (self-)assessment tools, thus ensuring that certain quality standards and codes of conduct are in place.

Furthermore, the following points have been identified during the project as actionable items to ensure meaningful community-involvement:

-  Align research goals, methods and timelines with community needs and understandings, as academic timelines and funding cycles often don't match up with the interests of communities. It is advised to set up strategic partnerships well before the implementation phase of a study. Strategic partnerships, by default, build on trust and are able to adapt to shifting realities seamlessly. Researchers must ensure access to decision-making for participants throughout the process and secure their agency and autonomy. It is necessary to be clear about preconceived ideas of what collaboration looks like from the start - equitable dynamics need negotiations and flexibility.
-  Being honest about power dynamics and structural barriers for involvement goes hand in hand with recognizing collaborators' strengths and aligning on when and who needs to step in or step up. All involved (both academic and community) researchers must

agree on who is best suited to address what issue, and recognize the advantages of stepping back or stepping aside.

and highlight the following key aspects: be upfront about payment, provide options, pay in cash and cover other costs.

- Researchers must give time and space for people to develop ideas and express them.
- Researchers must consider what aspects of one's identity are at the forefront at various stages of the process. It is advisable to understand which community members are interested in participating in which parts of a study, and clarify who is motivated to provide valuable input in different areas.
- Working with bottom-up values, such as patience, just dynamics, humility, clarity on ways to contribute (without assuming agreement) is crucial. Therefore, academics must reflect on how they conceptualize knowledge and expertise, what exactly they expect from collaborators and what they are willing to offer them.
- Researchers also need to consider their training(s) to be tailored to the needs and accessible to communities. This involves, when necessary, adjusting the medium/ methods and the content.
- Researchers must provide equitable pay to community members. **The Peer Payment Guide**, developed by the BC Centre for Disease Control, is an extensive and itemized guide for compensating collaborators with lived or living experiences. It should be considered a golden standard regarding the financial aspects of the engagement process

7

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