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Beyond community engagement: perspectives on the meaningful involvement of people with HIV and affected communities (MIPA) in HIV cure research in The Netherlands

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ABSTRACT

Background: Meaningful involvement of people with HIV and affected communities in HIV cure research is essential to ensuring that cure research efforts are conducted transparently, socially justly, and ethically. This study set out to investigate how people with HIV and affected communities are involved in cure research in the Netherlands and explore what can be done to optimize involvement and engagement.

Methods: Eighty-five semi-structured online, telephone, and face-to-face interviews were conducted with people with HIV ($N = 30$), key populations ($N = 35$), and key informants (KI; $N = 20$) in the field of HIV. The interviews were analyzed using reflexive thematic analysis.

Results: Awareness of the meaningful involvement of people with HIV (MIPA) efforts was low among people with HIV and key populations, which contrasted with KI, who exhibited greater awareness. People with HIV and KI emphasized the importance of MIPA in ensuring the representation of lived experiences in HIV cure research and fostering trust between communities and researchers. Practical implementations of MIPA were unclear, ultimately resulting in difficulties defining MIPA beyond clinical trial participation. People with HIV and key populations also doubted their skills and self-efficacy to make meaningful contributions when confronted with involvement beyond participating in research and clinical trials.

Conclusions: MIPA is crucial for improving the quality, transparency, and ethical conduct of HIV cure research. It emphasizes the need for increased awareness and funding, standardized guidelines to ensure meaningful involvement, and combat tokenism and misconceptions.

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Introduction

HIV is universally incurable, making the search for an HIV cure a top priority in global HIV research [1]. With the unprecedented rapid advancements made in the COVID-19 vaccination, researchers are optimistic about achieving a clearance cure or sustained ART-free durable control [1]. While biomedical research is crucial in developing potential cures, it is equally important to involve people with HIV and affected communities meaningfully in the research process [2,3].

Collaborating with those connected through location, common interest, or similar situations in addressing the issues affecting their well-being is known as community engagement (CE) [2]. CE coincides with improved health outcomes [3,4], increased feelings of empowerment [5], improved health behavior, and self-efficacy [4]. However, power imbalances between communities and researchers often impede effective CE [5–7]. Similarly, a lack of trust and positive relationships, akin to the early days of the AIDS epidemic, can challenge CE [8,9]. Conversely, CE

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improves trust between researchers and communities [10,11]. Furthermore, CE is challenged by limited resources, including time, staffing, and funding [5,7,8].

The importance of CE in the HIV field becomes apparent when looking at the challenges encountered during pre-exposure prophylaxis (PrEP) research and implementation [12,13]. These challenges in PrEP dissemination could have been avoided had the community been engaged during the research process [12,13]. CE further enhances research quality [11], ethics, and relevance, protects communities from exploitation, and ensures beneficial outcomes [14]. According to Pratt [15], CE is crucial in research as it promotes social justice.

In the field of HIV, there is the Meaningful Involvement of People with HIV and affected communities (MIPA), which goes beyond CE by ensuring decision-making capacities for the community [16]. In the 1980s, the first stream of people with HIV took to the streets to demand a say in HIV politics, treatment, and research [17]. The then-developed Denver Principles were the basis of the Greater Involvement of People with HIV (GIPA), which has evolved into MIPA [18,19]. MIPA includes actively engaging people with HIV and affected communities, from developing the research questions and study designs to data collection, analysis, interpretation, and dissemination [20]. MIPA entails two core principles: (1) to ensure the recognition of the contribution of people with HIV and affected communities in response to the epidemic, and (2) to establish an environment where people with HIV and affected communities can contribute to this response. It is imperative that involvement goes beyond people with HIV being participants in the research and aims to empower those most affected by the addressed issues [21]. MIPA is highly supported, as reflected by the UNAIDS Global AIDS Strategy 2021–2026 [22] and by its inclusion in the UNAIDS/AVAC Good Participatory Practice (GPP) Guidelines for Biomedical HIV Prevention Trials [23]. However, as there are no standard criteria of what it entails to *meaningfully* involve people with HIV and affected communities [24,25], ensuring MIPA in HIV research can be challenging.

In recent years, a call has been made to increasingly involve people with HIV, their partners, and other family members in HIV cure research. MIPA is crucial to ensure that cure research and communication align with the needs of people with HIV and that the promised potential benefits outweigh the costs [16,26]. While great efforts have been made, current

involvement of people with HIV in cure research is often limited to occur in the early stages of clinical research (such as trial design and participant recruitment) [27,28], limiting the scope of MIPA throughout the entire research process. Furthermore, these efforts often adopt a utilitarian approach [28] that asks the affected community for feedback on readily established ideas rather than empowering the community to contribute their original thoughts and ideas [29]. Additionally, in recent cure research, people with HIV and affected communities rarely received adequate financial compensation for their time and efforts and have had limited influence regarding research processes [16].

Current knowledge on how people with HIV and affected communities are and can be involved in HIV cure research is increasing but remains limited. A 2023 systematic review by Noorman and colleagues [28] underscores that additional research to uncover diverse approaches to social engagement throughout all research phases is needed.

HIV cure research coincides with several ethical challenges, such as experimental trials in otherwise healthy participants [30] and with uncertain or no benefits [31]. Thus, MIPA is crucial in (ethically) advancing cure research. However, challenges remain broad and persistent. In the Netherlands, the Dutch activist HIV organization and funder, Aidsfonds, initiated and coordinated the NL4Cure initiative. NL4Cure is a collaborative effort by a diverse group of stakeholders, with CE among its main focuses. In light of the NL4Cure initiative and current suboptimal engagement levels [32], this study set out to investigate how people with HIV and affected communities are involved in cure research in the Netherlands. Furthermore, it aimed to explore what can be done to increase the involvement of people with HIV and affected communities, such as partners without HIV and, in the context of the Netherlands, MSM without HIV [33] and how they prefer to be involved in HIV cure research. Uncovering these insights can facilitate and enhance the community's involvement in future HIV cure research, ensuring more inclusive, transparent, ethical, socially just, and impactful cure research efforts [4–7].

Methods

Study context and design

The Netherlands provides an exciting context for research perspectives on HIV cure research. Within the healthcare system in the Netherlands,

antiretroviral treatment (ART) is widely available. In 2022, among those diagnosed with HIV in the Netherlands, 96% are on ART, out of which 96% are virally suppressed [33]. Although ART dramatically improves health outcomes and quality of life, people with HIV still face challenges related to side effects, stigma, and disclosure [34]. These persistent challenges highlight a continued need to understand the lived realities of people with HIV.

Qualitative research enables participants to freely share their lived experiences and perspectives, which, in turn, aids in a deeper understanding of the complex dynamics of this research [35]. Through interviews and a bricolage approach [36] of combining grounded theory [37] and reflexive thematic analysis [38,39], we captured the lived experiences, perceptions of, and perspectives on HIV cure (research) of people with HIV, key populations, and occupational key informants in the field of HIV (KI). Bricolage underscores using different methodological approaches as needed for the research, rather than being limited by a predetermined methodological perspective [40].

In this research, key populations are understood to be men who have sex with men without HIV (MSM) and romantic partners of people with HIV who do not have HIV themselves. As most new HIV diagnoses in the Netherlands occur among MSM [41], their insights and perspectives are essential to incorporate in HIV-related research in the Netherlands. Furthermore, occupational KI is here defined as individuals with paid positions in the field of HIV, such as HIV specialist nurses, professors, and patient/community organization leaders, who possess specialized expertise and insights crucial for understanding and addressing HIV-related topics and issues. Meaningful involvement is integral to our research; hence, we adopted a participatory qualitative approach [6] in this study. The Dutch HIV Association contributed to the grant proposal, and community and professional advisory boards (CAB & PAB) were involved in establishing the research questions, designing this study, recruiting participants, and interpreting the findings. The community advisory board consisted of three cis gay males with HIV, one cis female with HIV, one gay non-binary person with HIV, and one cis male without HIV who identifies as part of the MSM community. None of the members had a migration background, and their ages ranged between 30 and 60. The professional advisory board consisted of six people employed in the field of HIV, namely two HIV clinicians, two HIV consultants, one social scientist, and a board member of the Dutch HIV

Association. One-third of the PAB members were cis females, and two-thirds were cis males.

To ensure transparency and clarity, the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were followed (Supplementary Appendix I) in both the design and the reporting of this study. This study was approved by the ethics boards of the first and third authors' affiliated organizations.

Participants

People with HIV ($N=30$, 35.3%), key populations (MSM($N=19$, 22.4%); partners ($N=16$, 18.8%)), and KI ($N=20$, 23.5%) were recruited purposively between July 2020 and January 2023 and through snowball sampling [42]. We acknowledge potential overlap between participant groups. However, individuals were characterized as part of a specific group depending on the purpose for which they were recruited. Potential participants eligible for inclusion in the study were individuals aged 18 years or older who spoke the Dutch or English language and could be grouped into any of the participant categories (persons with HIV, KP, or KI). A total of 86 participants were recruited, diverse in gender, age, and migration background (see Table 1 for participants' sociodemographic characteristics), while 85 participants were included in the data analyses (one person withdrew consent). KI were recruited using the researchers' networks, while people with HIV and KP were recruited through the Dutch HIV Association and HIV specialist nurses. For KP, additional recruitment occurred through other HIV organizations. Recruitment was stopped when no new insights or perspectives emerged during the analyses.

Data collection

Semi-structured, in-depth, one-on-one, telephone or online interviews were conducted *via* a university-approved platform. After COVID-19 restrictions were lifted, interviews also took place face-to-face, depending on the participant's preferences. Interviews with people with HIV ranged from 47 to 103 min ($M=72$ min), with key populations from 38 to 95 min ($M=61$ min) and with KI from 16 to 59 min ($M=38$ min). TAM and MAJN conducted the interviews. TAM is a cis female, biracial, heterosexual PhD candidate without HIV, and MAJN is a cis female, Caucasian, heterosexual PhD candidate without HIV. Participants were asked to provide informed consent online and completed a small demographic

Table 1. Descriptive statistics for sociodemographic variables.

	<i>M (SD); min–max</i>	<i>N (%)</i>
People with HIV		30 (35.5%)
Age	49 (14.531); 27–78	
Gender identity		
Cisgender man		19 (63.3%)
Cisgender woman		10 (33.3%)
Transgender woman		1 (3.3%)
Sexual Identity ^a		
Gay		17 (56.7%)
Bi		3 (10.0%)
Straight		10 (33.3%)
Migration background ^a		7 (23.3%)
Years living with HIV	21 (13.279); 2–42	
Diagnosed before 1997 ^b		13 (43.6%)
Diagnosed between 1997 and 2018		14 (46.7%)
Diagnosed after 2018		3 (10.0%)
ART use		
Yes		30 (100%)
Years without ART	3.5 (5.865); 0–24	
MSM		19 (22.4%)
Age	35 (10.268); 24–55	
Gender Identity		
Cisgender man		19 (100%)
Sexual Identity ^a		
Gay		16 (84.2%)
Bi		2 (10.5%)
Other		1 (5.3%)
PrEP and PEP use		
Has used PrEP		12 (63.2%)
Has used PrEP and PEP		1 (5.3%)
Has not used PrEP or PEP		6 (31.6%)
Migration background ^a		6 (31.6%)
Partners of persons with HIV		16 (18.8%)
Age	49 (13.032); 26–66	
Gender Identity		
Cisgender man		12 (75.0%)
Cisgender woman		4 (25.0%)
Sexual Identity		
Gay		10 (62.5%)
Straight		6 (37.5%)
PrEP and PEP use		
Has used PrEP		8 (50.0%)
Has not used PrEP or PEP		8 (50.0%)
Migration background		2 (12.5%)
Key informants in healthcare		20 (23.5%)
Age	51 (9.017); 36–65	
Gender Identity		
Cisgender man		13 (65.0%)
Cisgender woman		7 (35.0%)
Years active in the HIV field	18 (9.943); 5–39	

^aKey informants in healthcare were not asked about their sexual identity or migration background.

^bDiagnosis cutoff is based on the introduction of highly active antiretroviral therapy (HAART) in 1996.

questionnaire prior to the interview. Participants were asked for their age, gender and sexual identities, and when relevant ART, PrEP and PEP use, and year of diagnosis.

Interviews were conducted using interview guides developed collaboratively by the researchers and the PAB & CAB based on their lived experiences, expertise, and existing literature. Interview guides were developed for people with HIV, key populations, and KI (respectively [Supplementary Appendix II–V](#)). However, the people with HIV and key populations interviews focused on the six research questions

aligning with the project's overarching research objectives, namely, (1) the awareness of HIV cure (research), (2) interest in HIV cure (research), (3) the meaning of HIV cure (research), (4) the meaningful involvement of people with HIV and key populations in HIV cure research, (5) stigma surrounding an HIV cure, and (6) nomenclature and communication regarding HIV cure (research). The interviews with KI focused on the final three research questions. This paper reports on the data exploring the meaningful involvement of people with HIV and key populations in cure research only (objective 4).

Data processing and analysis

Interviews were digitally recorded and professionally transcribed verbatim. Although COREQ guidelines recommend returning transcripts to respondents, we decided to present the findings to the PAB and CAB to ensure the findings were congruent with their experiences and realities, rather than returning transcripts to participants to limit respondent burden. Recordings were deleted after transcription. ATLAS.ti 9.0 was used for analysis. A combination of elements of reflexive thematic analysis, as described by Braun and Clarke [38,39], and grounded theory [37] was used to identify and report prevailing and recurring themes. Reflexive thematic analysis acknowledges the subjectivity of researchers as a valuable resource for in-depth, nuanced and contextually sensitive qualitative research analyses [39]. Furthermore, through line-by-line analysis, grounded theory allows a close engagement with and promotes a deep understanding of the data [37]. This bricolage approach offered a flexibility and richness to our analysis process [36,40].

TAM conducted the initial line-by-line analysis of all transcripts, generating a preliminary codebook. To improve the quality and interpretative depth [39] of the analysis, MAJN separately coded one-third of the interviews ($N=28$) using this codebook. Discrepancies within the codes were discussed between TAM and MAJN and, where necessary, adjusted. TAM then revisited all transcripts again with the finalized codebook. The coded text segments were then reviewed to identify potential themes, which, in turn, were further refined, defined, and named.

Following the initial analysis, the co-authors, PAB and CAB were consulted to aid in interpreting the preliminary results. Upon their insights, interpretations were adjusted or expanded where necessary.

Results

Four main themes were identified during the analysis: (1) awareness of MIPA, (2) importance of MIPA, (3) MIPA in cure research, and (4) barriers to MIPA in HIV cure research. Corresponding quotes to the themes and subthemes can be found in [Table 2](#).

Awareness of MIPA

Overall, most people with HIV and key populations were unaware of *current efforts* to MIPA in HIV cure research, with many indicating the interviews in this study to be their first encounter with the concept (quotes 1,2,6–8). Consequently, people with HIV indicated they were of the impression that MIPA entailed being kept ‘up to date’ with research, or participation in clinical trials, interviews or other types of research. These responses indicate a *misconception* (quotes 9–12). While participation in research is valuable, it only partially encompasses what MIPA entails, which includes involvement through all phases of research. In contrast to people with HIV and KP, the awareness and understanding of MIPA among KI was high. Almost all KI mentioned some form of current efforts to involve people with HIV in cure research (e.g. The NL4Cure agenda) (quotes 3–5).

Further, MIPA initiatives were reported to have become more common in recent years, indicating an *increase in MIPA efforts* (quotes 12–15). However, similarly to people with HIV, a significant amount of KI suggested participation in interviews or updating the community as valid MIPA efforts. Additionally, retrospective consultation or ‘checks’ were conveyed as credible initiatives. Some people with HIV and key populations indicated that while they were not personally aware of current efforts, they expected that *community and patient organizations* would be aware and thus represent the interests of people with HIV by being involved in all MIPA efforts in cure research (quotes 16–18).

The positive trend towards increased MIPA, as perceived by KI, is promising. However, the low overall awareness of MIPA and current efforts to improve MIPA in cure research of people with HIV and key populations emphasizes the necessity to upscale efforts to enhance MIPA in cure research.

Importance of MIPA

The main reason for involving people with HIV in cure research conveyed by participants was to have the *lived experiences* of people with HIV represented

in HIV cure efforts (quotes 19–21). People with HIV and KI further mentioned the importance of MIPA by emphasizing how those most and directly affected by HIV should have a say when decisions are being made about HIV, as it would have fundamental *consequences* for the overall quality of HIV-related services and research (quotes 22–23). Understanding the experiences of and collaborating with people with HIV was expected to improve the quality of HIV research and care, not only because the research is about them but also because it could lead to innovative ideas and recognition of their needs. Increased trust in the research and an eventual cure was also voiced as a possible result of involving people with HIV in cure research. Trust was not only found as a result of involving people with HIV in cure research but also as an essential prerequisite to ensuring MIPA principles in cure research. The KI in particular, discussed other *prerequisites* to foster efficient MIPA in cure research and discussed circumstances such as transparency and ensuring diversity in community representatives (quotes 24–26). These responses shared by the participants highlight the imperativeness of MIPA in cure research. It is worth noting that these perspectives did not emerge as prominent themes within the key population responses.

MIPA in cure research

While most participants found MIPA important, they were also uncertain what this would look like practically across all participant groups. When asked to reflect further on what engagement and meaningful involvement could look like, all participant groups found it challenging to provide practical examples. Following the initial difficulties, participants reported diverse ‘*roles*’ one could have in cure research (quotes 27–31). People with HIV mentioned being a representative and the bridge between researchers and the HIV community. People with HIV were also found to be involved in cure research through their role as experts by experience (quotes 27–28).

In discussing these roles, participants often discussed the *role of community and patient organizations* in MIPA in cure research. Organizations were posited to be an important bridge between the HIV community and researchers, and a channel by which people with HIV can be provided with information (quote 29–31).

Community and patient organizations, as well as HIV care professionals and community representatives, were also considered to have a role (expedition

Table 2. Quotes regarding meaningful involvement of people with HIV and affected communities in HIV cure research.

Theme	Sub-theme	Participant type	Gender identity	Age	Additional information	Quote number	Quote
Awareness of MIPA	Current efforts	Person with HIV	Cis man	31	Diagnosed with HIV in 2020	1.	<i>I don't dare to say because this [interview] is the first research that I have come across.</i>
Awareness of MIPA	Current efforts	Person with HIV	Cis man	27	Diagnosed with HIV in 2018	2.	<i>I actually have no idea [about current MIPA efforts], to be honest. I don't know. [...] I'm participating in this interview</i>
Awareness of MIPA	Current efforts	Key Informant	Cis man	51		3.	<i>Since recently we have a panel of people with HIV who make a statement about various submitted proposals when it comes to 'what is the importance, what are tips to improve it, what might the researcher not have thought of, how could it be expanded?'</i>
Awareness of MIPA	Current efforts	Key Informant	Cis man	59		4.	<i>There are of course a number of initiatives in which the Dutch HIV Association is involved in the development or the design of the research, but also people who are not part of an association but who contribute ideas as patients or clients [...] I think NL4Cure is also such an initiative in which I think people with HIV are involved.</i>
Awareness of MIPA	Current efforts	Key Informant	Cis man	43		5.	<i>I think the most important example is NL4Cure in the Netherlands where the Dutch HIV Association is also involved, where involvement is one of the four goals, even the first. We ask about the importance of a cure for people with HIV and we keep them informed. People need to be informed. You will eventually achieve your goals.</i>
Awareness of MIPA	Current efforts	Key Populations [Non-Partner]	Cis man	27		6.	<i>I think very little is done [to involve MSM in HIV cure research], at least from what I gather [...] if it happens, then I think I am not exposed to it.</i>
Awareness of MIPA	Current efforts	Key Populations [Non-Partner]	Cis man	37		7.	<i>Actually, I know very little about that [efforts to involve MSM in HIV cure research]. I must say. Apart from the channels that I receive as an activist, you know, I don't get much of it. And then I think to myself: if I already get little information, how little awareness must others have?</i>
Awareness of MIPA	Current efforts	Key Populations [Partner]	Cis man	40		8.	<i>I have never heard about it [involving partners in HIV cure research]. My partner also has never told me about it.</i>
Awareness of MIPA	Misconceptions	Person with HIV	Cis man	39	Diagnosed with HIV in 2008	9.	<i>You should really take people along the journey, from 'okay this is where we are now, this is what we know about the virus, to this is where we are in the trials, we're researching if, for example, we can elicit it and what that elicitation looks like, and this is what we've found so far, which helps us understand, but we need to conduct further research in this area, which could be a next step.'</i>
Awareness of MIPA	Misconceptions	Person with HIV	Cis woman	51	Diagnosed with HIV in 1992	10.	<i>Well, what we're doing now, these interviews, that's very nice. And further trials on test subjects at the AMC [hospital] are being conducted, but these are usually men who are interviewed there, and they also receive a comprehensive examination of blood values, health, condition, and they will then be followed for a few years to see what can be done to contribute more to someone with HIV. Not much [is being done], yes trials, guinea pigs, involving us in research about what come in the future</i>
Awareness of MIPA	Misconceptions	Key informants	Cis woman	51		11.	<i>Through interviews, I think [get people involved in cure research]. [...] The research takes place with HIV patients, so if you want to motivate them to participate in research, you will also need to know in advance how to motivate them. By interviewing them [...] You can approach and ask them about this subject in all kinds of ways and ask them about their knowledge in this area, but also their expectations, their vision, and any fears. The best way to do that is by interviewing them extensively. That seems to me to be an appropriate method to clarify that.</i>
Awareness of MIPA	Misconceptions	Key Populations [Partner]	Cis woman	63		12.	<i>I find it quite hard to say to be honest. Yeah, I actually just don't know what it precisely entails</i>
Awareness of MIPA	Increase in MIPA efforts	Key Informant	Cis man	56		13.	<i>It has been getting better and better. In all kinds of research, you see people with HIV being involved from the get-go. People with HIV are even involved when writing a [research] proposal and that just makes the research much better.</i>
Awareness of MIPA	Increase in MIPA efforts	Key Informant	Cis man	36		14.	<i>I think more and more is being done about it. [...] in our cure research [...] we have had a connection with the Dutch HIV Association for some time.</i>

(continued)

Table 2. Continued.

Theme	Sub-theme	Participant type	Gender identity	Age	Additional information	Quote number	Quote
Awareness of MIPA	Increase in MIPA efforts	Key Informant	Cis man	51		15.	An example from my own work - we've recently introduced a patient panel at every research evaluation. [...] essentially, it's a panel of individuals living with HIV who provide feedback on the various proposals. They consider factors such as the significance of the research, suggestions for improvement, potential oversights by the researcher, and ideas for expansion.
Awareness of MIPA	Involvement of community and patient organizations	Person with HIV	Cis woman	64	Diagnosed with HIV in 2000	16.	[...] perhaps through the Dutch HIV Association [Dutch HIV Advocacy Organization] where many people are also HIV positive. Perhaps they will be involved or through Aidsfonds [Dutch HIV funder] they also have people who have HIV. They may also be involved. Further, in my personal contacts with others, I have not heard of them being involved. But that might come, I don't know. One wouldn't be able to put money on it. I can imagine that the Dutch HIV Association is involved, or at least lobbies to stay and be involved, so to say. But other than that, I really don't know.
Awareness of MIPA	Involvement of community and patient organizations	Person with HIV	Cis woman	55	Diagnosed with HIV in 1983, has a migration background	17.	
Awareness of MIPA	Involvement of community and patient organizations	Key Populations [Non-Partner]	Cis man	27		18.	I can imagine it [attempts to involve people with HIV and affected communities] happens, perhaps at the municipal health services [...]. There is also the COC [Dutch LGBT organization] and other organizations that deal with this. So perhaps it [attempts to involve people with HIV and affected communities] happens there.
Importance of MIPA	Lived experiences	Person with HIV	Cis woman	48	Diagnosed with HIV in 1996, has a migration background	19.	I think people with HIV should be involved. That you have the opinion, the experience, the experience with the virus itself, with what you do, with medication and you can compare that [...] with the results that come from research. In that sense. And also taking medication and side effects, yes, I think that is very important.
Importance of MIPA	Lived experiences	Person with HIV	Cis woman	55	Diagnosed with HIV in 1983, has a migration background	20.	A researcher or, you also notice it with a physician, they just can't think of everything. He doesn't know what it's like to have something make you so nauseous or ... So, in theory things may seem very nice, but in practice it turns out that something is very demanding, you can take that into account for next time.
Importance of MIPA	Lived experiences	Key Informant	Cis man	56		21.	'Nothing about us without us.' That's so obvious to me. If you want to have very good HIV care, good HIV prevention, and improve the quality of life for people with HIV, then you need people with HIV, because they know what it is all about, they are also the experts in living with HIV.
Importance of MIPA	Consequences	Person with HIV	Cis woman	62	Diagnosed with HIV in 2014	22.	[...] involving everyone everywhere, discussing and providing feedback, and moving forward from there. It does mean taking an extra step each time [...]. But I believe that, ultimately, this will reach more people and find more individuals willing to engage with research. It also involves exploring potential cures and thereby building more trust in the ultimate outcome. If a cure is found, it should involve people with HIV right from the start, in every aspect. [...]. I believe it will greatly benefit the scientists in their efforts.
Importance of MIPA	Consequences	Key Informant	Cis man	50		23.	Especially in cure research, it is important to know whether people are interested in the outcome of the research at all. [...] then the researchers also know 'we can go in this direction, but ultimately this research will not lead to people taking part in it [a cure for HIV].'
Importance of MIPA	Prerequisites	Person with HIV	Cis man	39	Diagnosed with HIV in 2008	24.	[...] most important to involve them [people with HIV]. [...] trust in research, without trust in life you have nothing. Even if you have a great remedy. So, it's about trust, clarity, transparency.
Importance of MIPA	Prerequisites	Key Informant	Cis man	56		25.	You have to ensure if there is trust and if people understand each other [...] then you just get better research

(continued)

Table 2. Continued.

Theme	Sub-theme	Participant type	Gender identity	Age	Additional information	Quote number	Quote
Importance of MIPA	Prerequisites	Key Informant	Cis man	39		26.	<i>It is especially important that you really involve [people], that you are sincere. For me that entails clarifying your intentions [...]. And that you respect the people you are asking [feedback] from.</i>
MIPA in cure research	Roles of people with HIV	Person with HIV	Cis man	44	Diagnosed with HIV in 2021	27.	<i>I do think that people should listen carefully to what the needs are, so the research that you conduct is definitely good and in my opinion that also helps the researchers to conduct research in a direction that is also desirable.</i>
MIPA in cure research	Roles of people with HIV	Person with HIV	Cis man	66	Diagnosed with HIV in 1995	28.	<i>[...] y can also use these people [people with HIV]. [...] they are kind of ambassadors or conduits of information to others [...] then you are like an expert by experience so to say, then you're involved.</i>
MIPA in cure research	Roles of community and patient organizations	Person with HIV	Cis man	30	Diagnosed in 2015	29.	<i>I just wonder you can't involve all people with HIV in that [cure research], but I think it's important to involve patient associations and maybe other focus groups.</i>
MIPA in cure research	Roles of community and patient organizations	Key Informant	Cis man	56		30.	<i>People need to be informed about everything that is happening. The Dutch HIV Association also has an important task in ensuring that good up-to-date information is available for people with HIV.</i>
MIPA in cure research	Roles of community and patient organizations	Key Informant	Cis man	36		31.	<i>I think that throughout the entire scientific process, it is important to reach out to people. This can be through representatives of the community, or organizations.</i>
MIPA in cure research	Early involvement	Key Informant	Cis man	65		32.	<i>I think it's really important to have the people [with HIV] involved from the start, so even with the questions of 'how should we set it up? How should we communicate that? What would be acceptable.</i>
MIPA in cure research	Early involvement	Key Informant	Cis woman	62		33.	<i>[...] my appeal to every researcher who is working on a cure, on HIV, is to seek contact, and establish maintain contact with people with HIV at a very early stage.</i>
MIPA in cure research	Involvement of key populations	Key Populations [Partner]	Cis man	64		34.	<i>Yes, it [involving partners] depends on how they interact with each other. We are interested in each other, but there are also partners who say: well, that's your thing, I don't have it; so todeloo.</i>
MIPA in cure research	Involvement of key populations	Key Populations [Non-partner]	Cis man	26		35.	<i>People with HIV are a part of the community I am a part of, and if I can do something to help someone else in the community, in any way, I feel that I should do so.</i>
MIPA in cure research	Involvement of key populations	Key Populations [Partner]	Cis man	52		36.	<i>Well, I think it's [involving partners in cure research] nice. I believe it's beneficial. There is often a lot of focus on the patient themselves. But the patient is often broader, and the partner is a very significant person in the whole process.</i>
Challenges to MIPA in cure research	Uncertain contributions	Person with HIV	Cis woman	48	Diagnosed with HIV in 1996, has a migration background	37.	<i>What could I contribute? The only contribution I can make is to just participate in the research, I can't think of anything else than participation or maybe assisting people who participate</i>
Challenges to MIPA in cure research	Uncertain contributions	Key Populations [Non-Partner]	Cis man	25		38.	<i>Yeah, I think that's [cure research] more a role for a researcher [...]. Of course, I almost say yes to anything, I'll always think along but that's also my nature. But if I'm looking at it critically, then I think, what can I add to this, what can I say that someone else can't add?</i>
Challenges to MIPA in cure research	Lack (research) of skills	Person with HIV	Cis man	36	Diagnosed with HIV in 2020	39.	<i>I personally think that those who have no knowledge should not be included in the decision-making processes and the analyses of research data [...]. You must entrust that to the people who are trained for that. But it would be good to involve those who are interested in the results or conclusions that are drawn from that.</i>
			Cis man	57		40.	

(continued)

Table 2. Continued.

Theme	Sub-theme	Participant type	Gender identity	Age	Additional information	Quote number	Quote
Challenges to MIPA in cure research	Lack of (research) skills	Key Populations [Partner]			Has a migration background		I respect that, that people want to be involved. [...] But [...] you must respect scientists and assume they have the best intentions. [...] It should not be that they [people with HIV] should have influence on policy based on some kind of pseudo-expertise. It should be based on actual knowledge, concrete scientific evidence, because experience is nice and all, but it is not the same as things that can be proven scientifically
Challenges to MIPA in cure research	Lack of (research) skills	Key Informant	Cis man	36		41.	When you examine a cell in a laboratory, you end up doing it simply to help a patient, but the patient will not be able to say much about that cell. We [researchers] really must have to figure that out ourselves. That's what we studied for. But if you're talking about social issues, seeing the urgent need - and that is cure - but also the social issues that are at play with HIV and things that we just think a lot less about, then you really need the input from people who also have it [HIV] and who just experience it [HIV].
Challenges to MIPA in cure research	Skepticism	Key Informant	Cis man	65		42.	Very often, it's the case that patient involvement only really happens after the fact and then is kind of used as an excuse [to claim meaningful involvement]. And they [researchers] ask stuff [input] but then it turns out everything is already decided.
Challenges to MIPA in cure research	Skepticism	Key Informant	Cis man	50		43.	It [MIPA in cure research] varies. We sometimes notice that they [the Dutch HIV association] are involved because the subsidy provider demands that the patients' interests be included in the research

of contact between researchers and community, facilitation of meaningful involvement) in reaching, informing, and recruiting people with HIV to become meaningfully involved in all forms of cure research.

KI in healthcare also discussed the importance of *early involvement of people with HIV in cure research* (quotes 32–33). This beginning was considered to start as early as applying for funding, and the involvement should be significant in every facet along the way.

Among the key populations, there was a great variety in their opinions on *involving key populations in cure research* (quotes 34–36). Those key populations who were also partners mentioned that the dynamic in the relationship influenced their perceptions regarding the importance of involving partners in cure research. Some considered it a collective responsibility, others viewed it as something their partners with HIV should partake in independently, and yet others expressed a desire for involvement separate from their partners with HIV. Furthermore, almost all non-partner key populations indicated their community's involvement to be important to cure research as they considered HIV to be prominent in the MSM community.

Participants suggested how people with HIV and their representing organizations could be involved in HIV cure research. The interview responses implied an understanding of the relevance of involving people with HIV in all aspects of HIV cure research, specifically in earlier stages, and KI mostly put this forth.

Challenges to MIPA in cure research

The most significant obstacle to MIPA encountered in this research was the *uncertainty* that people with HIV and key populations felt towards their contribution to cure research (quotes 37–38), their limited understanding of MIPA, and their perceived *lack of (research) skills* (quotes 39–41). Assuming MIPA meant participation in research, the participants expressed a great willingness to be involved in non-clinical research. However, when confronted with the broader concept of MIPA, approximately half of the participants altered their perspective. They indicated a need for more self-efficacy and appropriate skills to contribute meaningfully.

Key informants partially agreed but considered the input of people with HIV highly relevant and valuable depending on the type of research conducted (e.g. clinical versus non-clinical). As an indicator of mistrust between the community and researchers, there

was some *skepticism* among the key informants with more activist occupational roles regarding the involvement of people with HIV in research (quotes 42–43). They indicated that people with HIV and their respective community organizations should be brought on board right at the outset of research projects but that this often does not happen. People with HIV did not mention this concern.

These results indicate that efforts to meaningfully involve people with HIV and affected communities leave much to be desired. While, overall, the opinion towards MIPA seems positive, and participants indicated a willingness to be involved in cure research other than as participants, it remains unclear what this could look like in practice.

Discussion

This research aimed to explore how people with HIV and affected communities are involved in cure research in the Netherlands and how this can be improved. The interviews with people with HIV, KI, and key populations provided meaningful insights into the importance of MIPA in HIV cure research in the Netherlands.

This research uncovered that despite the perceived high importance of MIPA, many people with HIV were not aware of exactly how they can be meaningfully involved in cure research and whether their involvement can substantially contribute to cure research efforts. Key populations additionally expressed uncertainty about the importance of their involvement. In addition to the significance of partner dynamics and ethical considerations in HIV cure research, it is imperative that partner key populations especially, understand the importance of their involvement in HIV cure research given the implications analytical treatment interruptions may have [43,44]. These results suggest a need for more awareness, guidance, information dissemination, and support to promote and facilitate MIPA in cure research.

Unfortunately, participants' initial understandings of MIPA appeared to position people with HIV in a more tokenistic or assisting rather than a decision-making capacity. This aligns with how current efforts to engage people with HIV often take a utilitarian approach [28]. We argue that MIPA efforts should transcend CE and empower people with HIV and affected communities to make decisions regarding HIV cure research [16]. Practically, as reflected in our research methodology, this could take the form of collaborative, egalitarian partnerships between

researchers and communities, in which communities and researchers prioritize research avenues together. Reza-Paul and colleagues [45] provide several examples of community engagement strategies in PrEP research and roll-out. Furthermore, Spieldenner and colleagues [46] discuss community engagement approaches in relation to molecular HIV surveillance. Early and consistent involvement throughout all research facets would increase the likelihood that research is relevant and decision-making ethical [47], in addition to ensuring research is conducted ethically, socially just, and transparently [12,35,48,49]. Future research endeavors efforts should, therefore, focus on methods to increase awareness and promote and increase MIPA in cure research.

The participants' responses reinforce the significance of incorporating the expertise and experiences of those most affected by HIV. In line with previous research, participants indicated that the involvement of people with HIV and affected communities not only enhances the quality of cure research [11] but additionally leads to improved alignments between the desires of the community and research efforts [50], fosters trust and transparency between the community and researchers [10,11], and, creates more inclusive, patient-centered and effective cure research that positively impacts those with and affected by HIV [21,51]. Furthermore, when MIPA is embedded from the onset of research and continued frequently and consistently, it improves the dissemination of research results and actions taken upon those results. Additionally, involvement of people with HIV and affected communities can positively improve the acceptance and distribution of a future cure [52].

The encountered misconception of MIPA's scope among people with HIV and key populations elicits further concerns. When confronted with the broader scope of MIPA, the misconceptions resulted in a decline in willingness to be involved in cure research and a lack of understanding of its importance. This decline coincides with expressions of self-doubt, further indicating the necessity for dialogue, specifically regarding the importance of lived experiences and perspectives of people with HIV and those affected by it. Thus, it is imperative for the research and scientific community to continue emphasizing that MIPA plays a vital role in clinical outcomes [53].

The expressed self-doubt among people with HIV, furthermore, poses a challenge to patient empowerment. Bravo and colleagues [54] conceptualized patient empowerment as a spectrum where people vary in their 'state' of empowerment. Some key

indicators of a person's 'state' were their self-efficacy, health literacy, and perceived control, with high levels representing an empowered patient [54]. The results presented in this study suggest that we need more patient empowerment interventions. In a systematic review on the efficacy of empowerment interventions, Stepanian and colleagues [55] reported on the beneficial effects of group format and community settings in empowering patients. This aligns with the roles of patient and community organizations in MIPA improvements assigned by our participants.

Furthermore, as participants often cited a lack of appropriate knowledge and skills as a challenge to being meaningfully involved in HIV cure research, it should be noted that people with HIV can be considered experts without having disease-specific knowledge [53] and can, therefore, meaningfully contribute to the research process. In addition, given the perceived lack of knowledge and skills, building and enhancing research literacy is crucial for empowering individuals to fully engage in MIPA [52].

Misconceptions regarding MIPA's scope and the difficulty in generating practical examples of how to include people with HIV and affected communities in all aspects of research among KI suggest a potential lack of skills in this regard. This coincides with the need for more standard criteria for MIPA and how it can be ensured [24,25]. We, therefore, recommend the development of consolidated criteria for MIPA in cure research that goes beyond clinical research and includes concrete examples of how communities can be meaningfully involved in the search for an HIV cure. Frameworks for community engagement in research, upon which can be drawn, are available. For example, Bain and colleagues [56] developed the Framework for Effective Engagement of Communities

for the sub-Saharan African context. Furthermore, having consolidated criteria could also aid in alleviating some of the skepticism about tokenism surrounding MIPA [57]. Lau and colleagues [16] provided some strategies for enhancing MIPA, such as building long-term relationships between the community and researchers and ensuring the community has decision-making power. In addition, in Table 3, we have summarized key recommendations related to MIPA in cure research based on the current study's findings. However, they noted that consolidated criteria solely, will not be effective in increasing MIPA. Consolidated criteria should be developed alongside a robust change in the research landscape, tackling research that undermines the importance of community involvement.

Strengths and limitations

This study has strengths and limitations that should be considered when interpreting the results. One strength was that the qualitative nature of this research ensured an in-depth understanding of the topics addressed by exploring participants' perspectives and experiences. Another strength was that this research was conducted in accordance with the MIPA principles with the insightful contributions of our PAB and CAB, which increases community relevance and transparency. A third strength was the triangulation embedded in our study design. We triangulated across data sources and actively sought diverse perspectives in our samples. A final strength was the robust qualitative sample included in this study including its diversity and representation of the HIV epidemic in the Netherlands. In the Netherlands, approximately 80% of the people with HIV are men,

Table 3. Key recommendations for MIPA in cure research.

Recommendation	Rationale
Increase awareness, guidance, and support for MIPA in cure research. This can, for example, be achieved by designing accessible information campaigns and developing skill training for both researchers and community members on how to effectively engage in MIPA practices.	Many people with HIV are not aware of how they can be meaningfully involved in cure research, indicating a need for more awareness and support.
Fund and incentivize collaborative approaches where decision-making power is equally shared between the community and researchers.	Ensuring decision-making power enhances the authenticity of the role of the community within research. It further promotes ethical decision-making and social justice in research and combats tokenism.
Integrate MIPA principles into standard research protocols and ensure MIPA is a core aspect of funding acquisition.	Adding MIPA as a requirement for funding acquisition transforms MIPA from being optional to a fundamental part of the research process.
Implement patient empowerment interventions to improve research self-efficacy among people with HIV.	Empowerment interventions can improve self-efficacy, health literacy, perceived control, and self-advocacy skills, all essential for effective meaningful involvement.
Implement community health and research literacy initiatives to improve the health and research literacy of the community	Enhancing literacies among the community fosters greater collaboration between communities and researchers, which ensures equal decision-making power, and makes the research process more inclusive.
Develop consolidated criteria for MIPA in cure research beyond clinical aspects.	Standard criteria for MIPA will clarify how communities can be involved in HIV cure research and combat tokenism, improve transparency, and offer guidance on best practices for involving people with HIV in HIV cure research.

19% are women and 1% are transindividuals. Over half of the people with HIV in the Netherlands are 50 years of age or older and 44% have a migration background [33].

In terms of limitations, it is essential to highlight that participants initially encountered challenges understanding MIPA which may have impacted their initial responses regarding its importance. Another limitation was that most of the interviews were conducted online. Online interviews can impede the development of a comfortable and trusting environment, which can result in a lack of depth and quality of participants' answers [58]. Whilst the primary purpose of our chosen method, and qualitative research as a whole, is to seek deep understanding within a particular context rather than produce (statistical) generalizable findings [35,39], it is worth noting the context in which this current study has taken place. Given the privileged context regarding access to (health)care and medication, the representativeness may be limited to other high-income countries with similar circumstances.

Conclusion

MIPA is highly relevant and important, and a positive trend toward including people with HIV and affected communities in HIV cure research can be observed. MIPA improves the quality of cure research and ensures research is transparent, socially and ethically just. Furthermore, we argue for adequate funding and consolidated criteria on what MIPA entails and how this can be achieved in all aspects of cure research. This is beneficial for strengthening MIPA and, additionally, helps tackle tokenism and misconceptions. Therefore, we suggest integrating MIPA into the research default, paving the way for more ethical, socially just, and impactful future research.

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