

# Social engagement and the quest for an HIV cure: A systematic review on the views of stakeholders of HIV cure.

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## Background

As research into the development of an HIV cure advances, assessing the views of the main stakeholders becomes crucial to ensure alignment between clinical progress and the needs of intended beneficiaries.

By collecting and summarising existing research, this systematic review aims to provide an overview of the perspectives of HIV cure research stakeholders and identify areas for future research.

## Methodology

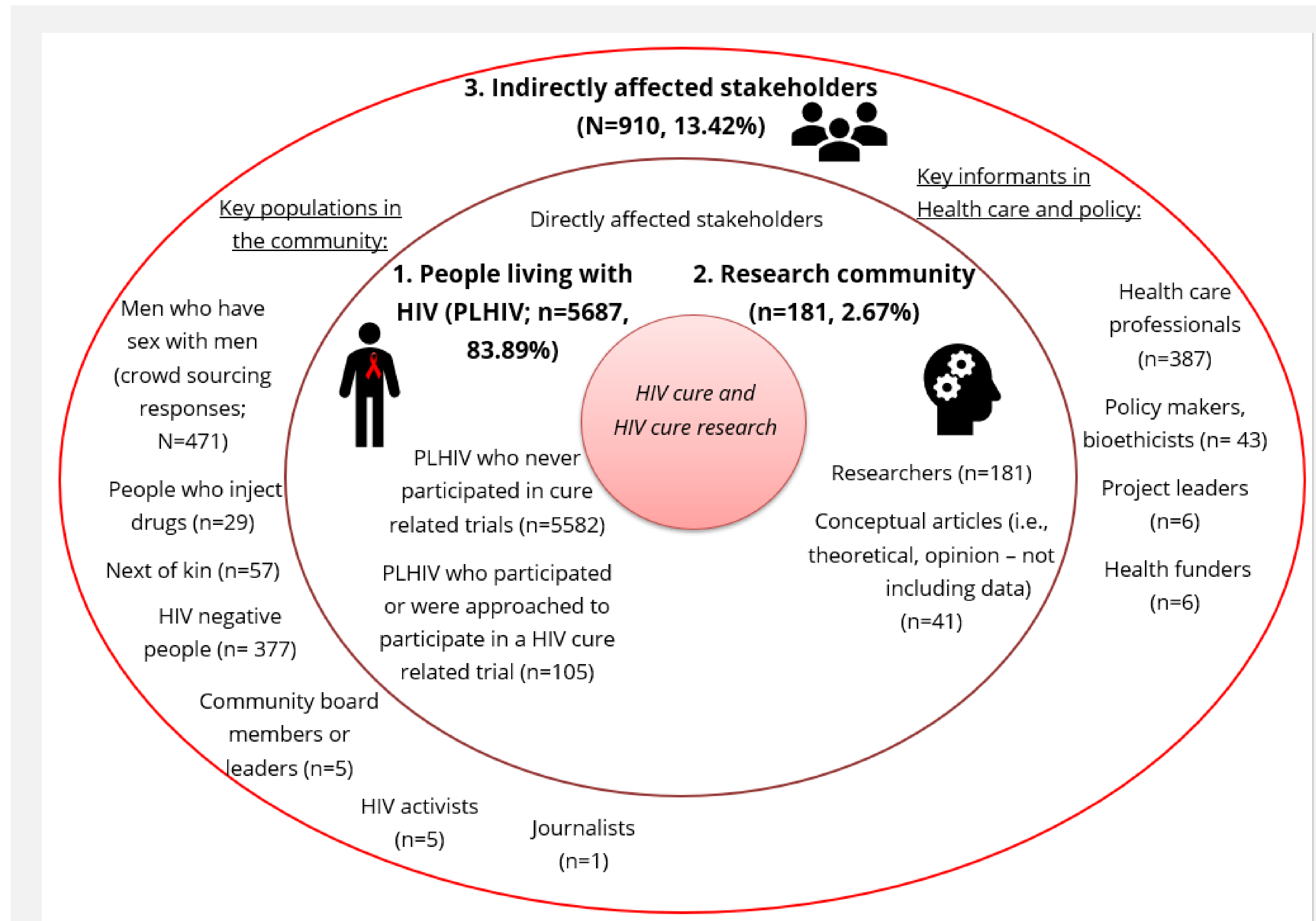
- The databases PubMed, Embase, Web of Science and Scopus were searched.
- Inclusion criteria: papers published in or before July 2020 that reported perspectives of stakeholders, directly or indirectly affected by HIV cure.
- The protocol is registered in the PROSPERO International Prospective Register of Systematic Reviews (registration number CRD42020190942).

## Results

79 papers were included

- 38 conceptual papers (i.e., theoretical, opinion – not including data)
- 41 empirical papers which collected data amongst a total of 6779 stakeholders

Figure 1 displays the stakeholders identified across the included papers. The textbox below displays the main findings amongst the three identified groups of stakeholders.



**Figure 1** Identification of the different stakeholders in HIV cure and HIV cure research

### 1. People living with HIV



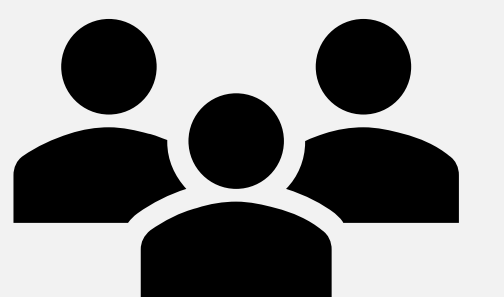
- **View HIV cure** as something **positive**, but still **unattainable**.
- PLHIV prefer a **sterilizing cure over a functional cure**.
- **Majority research is on willingness to participate** in HIV cure research.
  - **Willingness to participate** in HIV cure research **relatively high** among PLHIV.
  - **Related to** gender, ethnicity, age, duration of infection, viral suppression status, perceived health, financial status and HIV activism.
  - Health and psychological benefits, altruism and social benefits, scientific advancement, financial compensation and having access to information and education **motivate PLHIV** to participate in cure research.
  - **Deterrents** include health risks and social risks, including transmitting HIV.

### 2. Research community



- **Collaborative partnership** amongst international scientists from different disciplines is important.
- Agreement that **stakeholders should be engaged at an early stage**.
- There is **no single best population** for HIV cure research. However, **participant selection should ensure diversity**, demographics seem to play a role in willingness to participate in HIV cure research and could affect results.
- The importance of **communicating correct information** to potential participants is stressed to ensure validity of informed consent and prevent misconceptions.
- **The word cure** should be avoided in informed consent.
- There is **no clear way to measure risks and benefits** of HIV cure research; these are largely unknown.
- During analytical treatment interruption, researchers should take responsibility for the prevention of **HIV transmission to non-participants and implement** practical solutions.

### 3. Indirectly affected stakeholders



- This is a **heterogenous** group.
- **Views on HIV cure** ranged from **uncertain to hopeful**.
- It is important to **engage and inform broader communities** to gain support for HIV cure.

## Conclusion

Research with PLHIV typically focused on cure acceptability, with a utilitarian focus on willingness to participate in HIV cure research. The themes of concern to the research community highlight ethical and practical considerations of HIV cure research. The relatively limited available research amongst the heterogenous group of indirectly affected stakeholders addressed HIV cure communication and engagement.

To ensure alignment between the clinical progress of the scientific community and the needs and views of PLHIV and other stakeholders, further socio-behavioural research into the perspectives of PLHIV and other stakeholders is needed. More specifically, research with PLHIV needs to go beyond a focus on willingness to participate and provide a more in-depth understanding of PLHIV's awareness, importance and meaning of HIV cure and HIV cure research. Additionally, more research among other indirectly affected stakeholders is necessary as currently research is limited.