MARTIN DELANEY COLLABORATORIES
COMMUNITY
ADVISORY BOARD

# HIV CURE-RELATED RESEARCH
# COMMUNITY TRAINING NEEDS ASSESSMENT

A Project of the National Martin Delaney Collaboratory
Towards an HIV-1 Cure

MARCH 2021

CUREiculum

## ACRONYMS

| | |
|---|---|
| ACTG | AIDS Clinical Trials Group |
| ACTU | AIDS Clinical Trials Unit |
| AIDS | Acquired Immunodeficiency Syndrome |
| ART | Antiretroviral Therapy |
| ATAC | AIDS Treatment Activists Coalition |
| ATI | Analytical Treatment Interruption |
| AVAC | AIDS Vaccine Advocacy Coalition |
| BELIEVE | Bench to Bed Enhanced Lymphocyte Infusions to Engineer Viral Eradication |
| BIPOC | Black, Indigenous and People of Color |
| CAB | Community Advisory Board |
| CARE | Collaboratory of AIDS Researchers for Eradication |
| CBO | Community-Based Organization |
| CDC | U.S. Centers for Disease Control and Prevention |
| CEU | Continuing Education Unit |
| COVID | Coronavirus Disease |
| DARE | Delaney AIDS Research Enterprise |
| DNA | Deoxyribonucleic acid |
| ETE | End the Epidemic Initiative |
| HIV | Human Immunodeficiency Virus |
| HVTN | HIV Vaccine Trials Network |
| IMPAACT | International Maternal Pediatric Adolescent AIDS Clinical Trials |
| KP | Key Populations |
| LGTBQ | Lesbian, Gay, Bisexual, Transgender, Queer |
| MDC | Martin Delaney Collaboratory Towards an HIV-1 Cure |
| NMAC | National Minority AIDS Council |
| PLWH | People Living with HIV |
| TAG | Treatment Action Group |
| UCLA | University of California Los Angeles |
| UCSD | University of California San Diego |
| VISCONTI | Viro-Immunological Sustained CONtrol after Treatment Interruption |

## NEEDS ASSESSMENT COMMITTEE:

**Laney Henley** (UNC Chapel Hill); **Samuel Ndukwe** (UNC Chapel Hill); **Laurie Sylla** (defeatHIV CAB) **Jeff Taylor** (CARE & DARE CABs); **Marc Wagner** (I4C CAB) **Manuel Venegas** (defeatHIV CAB); **Michael Louella** (defeatHIV CAB); **William B. Carter** (BEAT-HIV CAB); **Lynda Dee** (DARE CAB); **Richard Jefferys** (Treatment Action Group); **Danielle Campbell** (DARE CAB); **Christopher Roebuck** (BEAT-HIV CAB); **Karine Dubé** (UNC Chapel Hill)

## Executive Summary

In Fall 2020, several members of the Martin Delaney Community Advisory Board conducted a needs assessment to better understand community training needs related to HIV cure-related research. By HIV cure research, we mean strategies that would eliminate HIV from the body or keep HIV durably suppressed without antiretroviral therapy (ART). This research can be very complex. It is important to make sure that research is informed by perspectives and insights from people living with HIV and other community stakeholders.

We are creating a curriculum to strengthen community capacity to understand and engage in discussions about HIV cure-related research. By providing basic information on a variety of topics in meaningful and accessible language, we hope that it will be understandable to a wide variety of audiences and learning styles.

We conducted a **needs assessment** to understand how to build more effective community education materials on HIV cure-related research. Most respondents (69%) agreed that there is a pressing need for better lay-audience information about HIV cure-related research. The information available is currently “too technical” for most people living with HIV (PLWH) to engage in meaningful conversations about HIV cure-related research.

**Nine key recommendations were generated based on findings from community needs assessment**:

1. Community participants in HIV cure-related research should be recognized as partners in the research process.
2. HIV cure-related educational and training materials should be communicated in language and formats that are accessible and meaningful both for PLWH and for communities disproportionately affected by HIV.
3. HIV cure-related educational and training efforts should address and seek to rectify the under-representation of women, Black, indigenous, and transgender individuals and other communities historically under-represented in HIV research and educational efforts.
4. HIV cure-related educational and training efforts should be explicit and clear about the risks and benefits of participating in HIV cure-directed clinical research, including possible physical, mental, and psychosocial effects.
5. Information about how to become involved with all aspects of the research process, ranging from study participation to serving on community advisory bodies to contributing to community engagement activities, should be provided.
6. Study protocol and informed consent documents should be presented in understandable language and audience-appropriate reading levels that explain realistic expectations of the study and current HIV cure-related science.
7. HIV cure-related education and training materials should be translated to languages that are appropriate for local audiences.
8. HIV cure-related education and training efforts should emphasize topics that are identified by respondents as being the most important, such as: ATIs, combination approaches, measuring the HIV reservoir, therapeutic vaccines, and broadly neutralizing antibodies, as well as ethical considerations.
9. Researchers and healthcare providers should continue to build trust with communities through hosting community forms, workshops, and trainings that are developed with significant input from community members.

## Background

In Fall 2020, several members of the national Martin Delaney Collaboratory Community Advisory Board (MDC CAB) conducted a needs assessment to better understand community training needs related to HIV cure-related research.

Research related to the cure or durable suppression of HIV has seen growing interest and funding among the scientific community. Reported cases of possible cures or sustained antiretroviral treatment (ART)-free HIV suppression have also sparked public interest in this field of research.

By HIV cure research, we mean strategies that would eliminate HIV from the body or keep HIV durably suppressed without antiretroviral therapy (ART). This research can be very complex. It is important to make sure that research is informed by perspectives and insights from people living with HIV (PLWH) and other community stakeholders. There is no question that the vast majority of people living with HIV want a cure, and surveys show long-term ART-free suppression is a worthy goal on the way towards an HIV cure. However, the science to get there is still in early stages and is more complex and ethically challenging than other types of HIV-related research. For community advocates to engage effectively with the scientific community, it is helpful for advocates, including those living with HIV, to understand the research processes, ethics, and HIV cure-related research strategies being pursued.  As such, the input of diverse groups of people living with HIV is needed now more than ever.

Several members of the national Martin Delaney National Community Advisory Board, which includes people living with HIV, community advocates, and community educators, have formed a working group to create a well-rounded HIV cure research education tool (called the CUREiculum) to increase HIV cure research literacy of among community members who do not have scientific or clinical training. This tool will be in the form of a modular curriculum, building on previously developed resources.

The goal of the curriculum is to strengthen community capacity to understand and engage in discussions about HIV cure-related research. By providing basic information on a variety of topics in meaningful and accessible language, it will be understandable to a wide variety of audiences and learning styles.

The needs assessment provides suggestions on how to build more effective community education materials on HIV cure-related research.

Below, we present results from this needs assessment, as well as key recommendations.

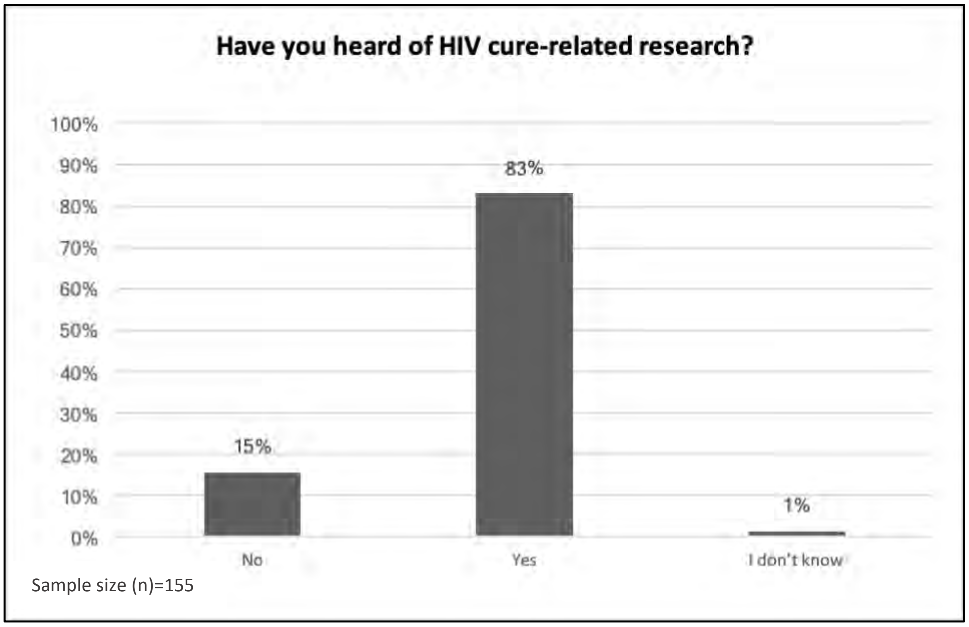
> “
>
> *Most people have no understanding of this area or of how much work is being done. Thus, the need for cure-related research information is immense.*

## Demographics of Respondents:

**Demographic Characteristics of Survey Respondents**

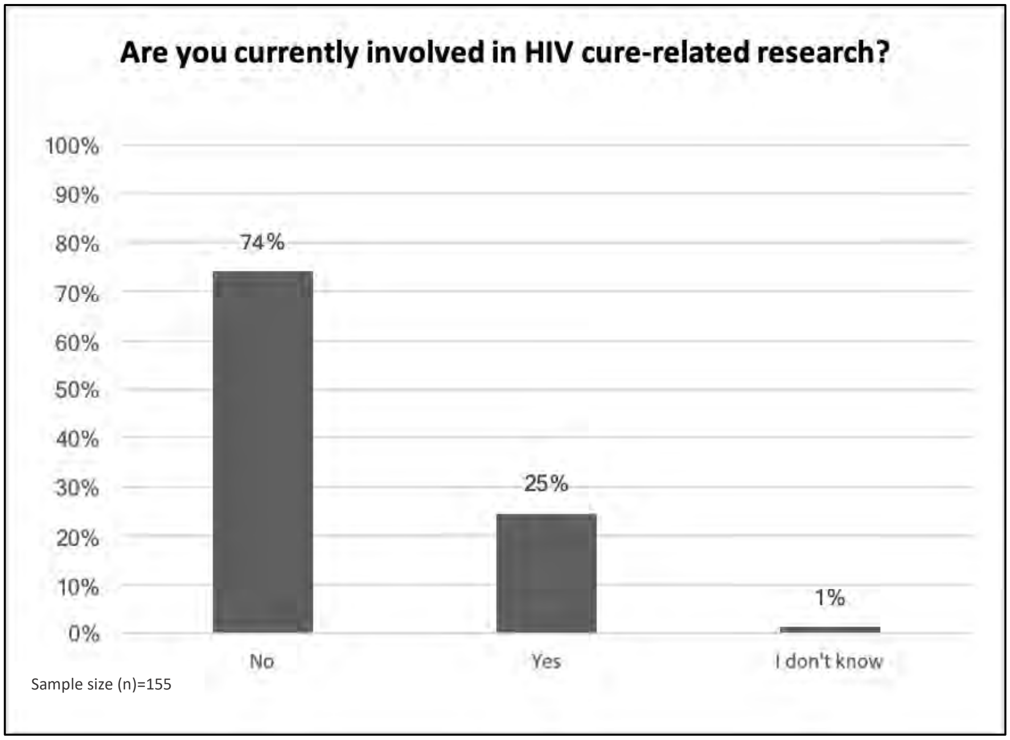
| | n | % | | n | % |
|---|---|---|---|---|---|
| **Gender** | **n=130** | | **Race** | **n=125** | |
| Woman | 47 | 36% | Native American/Alaska Native | 2 | 2% |
| Man | 75 | 58% | Asian | 8 | 6% |
| Transgender Woman | 1 | 1% | Native Hawaiian or Pacific Islander | 0 | 0% |
| Transgender Man | 0 | 0% | Black | 37 | 28% |
| Non-binary or gender queer | 4 | 3% | White or Caucasian | 70 | 53% |
| Something else | 1 | 1% | Other | 14 | 11% |
| Prefer not to answer | 2 | 2% | | | |
| | | | **Ethnicity** | **n=125** | |
| **Sex assigned at birth** | **n=129** | | Hispanic or Latino/Latina | 17 | 14% |
| Female | 47 | 36% | Not Hispanic or Latinx | 74 | 59% |
| Male | 80 | 62% | Not sure/Prefer not to answer | 16 | 13% |
| Intersex | 0 | 0% | Other | 18 | 14% |
| Prefer not to answer | 2 | 2% | | | |
| | | | **Highest level of formal education completed** | **n=126** | |
| **Age** | **n=121** | | Did not graduate high school | 1 | 1% |
| mean | 49 | | High school diploma or G.E.D. | 8 | 6% |
| median | 51 | | Some college, but no diploma | 21 | 17% |
| minimum | 15 | | 2-year college degree | 6 | 5% |
| maximum | 76 | | 4-year college degree | 37 | 29% |
| | | | Master's degree or Professional degree or equivalent | 39 | 31% |
| 15-29 | 15 | 12% | Doctorate degree or equivalent | 12 | 10% |
| 30-39 | 22 | 25% | Other | 2 | 2% |
| 40-49 | 20 | 17% | | | |
| 50-59 | 31 | 26% | Residency | n=125 | |
| 60-76 | 33 | 27% | In the United States, Puerto Rico, or US Territory | 95 | 76% |
| | | | Outside of the United States, Puerto Rico and US Territories | 30 | 24% |

## Familiarity with HIV Research:



Sample size (n)=155

## Current Involvement in HIV Cure-Related Research:



Sample size (n)=155

Out of the participants in the needs assessment, 74% were not involved in HIV cure-related research and 25% of the participants were.

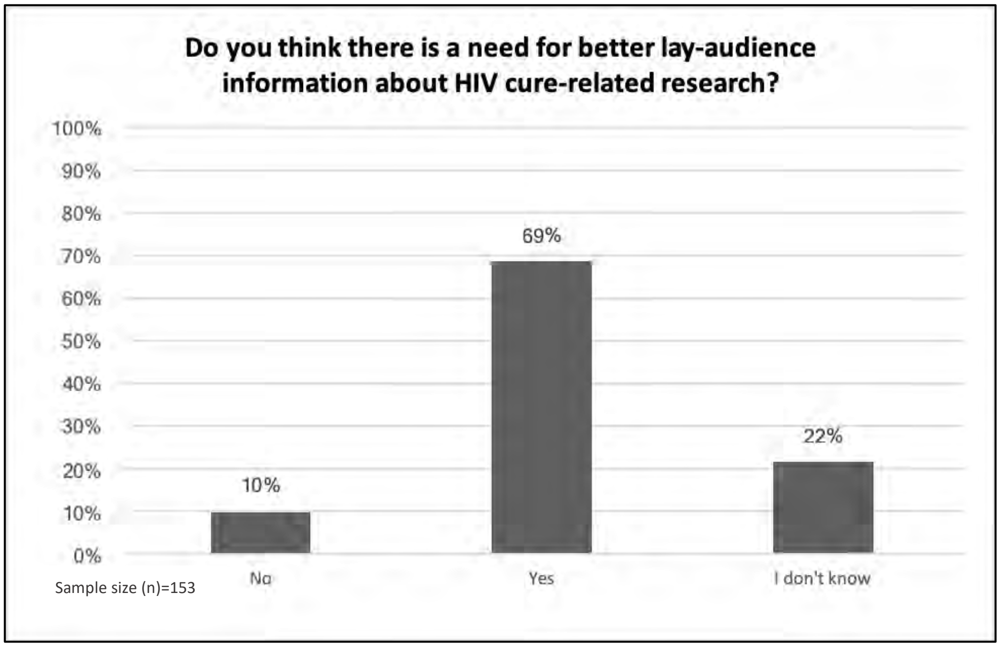
## Community Advisory Board (CAB) affiliations:

The majority of respondents indicated an affiliation with a community advisory board (CAB). Some respondents served on multiple CABs. CAB members included those from the Martin Delaney Collaboratories (e.g., defeatHIV, DARE, BELIEVE, I4C, CARE and BEAT-HIV). One respondent was affiliated with the amfAR Institute for HIV Cure Research CAB. Additional respondents reported affiliation with U.S.-based AIDS Clinical Trials Group (ACTG) Clinical Trial Unit CABs. Institutional CAB affiliations included those from the University of California San Diego (UCSD) AntiViral Research Center, UCLA Harbor and Care, University of North Carolina at Chapel Hill, University of Pennsylvania, Johns Hopkins University, and Case Western University. Other respondents reported being affiliated with The Well Project, the Pitt Men's Study, the ANCHOR study CAB, Bridge HIV, AIDS Treatment Activist Coalition (ATAC), HIV Vaccine Trials Network (HVTN), the International Maternal Pediatric Adolescent AIDS Clinical Trials (IMPAACT), and NMAC. International respondents were affiliated with the International AIDS Society (Research for Cure Academy), AVAC, and with the ACTG Global CAB.

## Current role of respondents:

Additional respondent roles included: person living with HIV (n = 7), long-term survivors (n = 3), HIV/health educator (n = 3), HIV medical case manager/peer navigator (n = 3), activists/advocates (n = 2), outreach coordinator (n = 1), research participant (n = 1), executive director of a community-based organization (CBO) (n = 1), research assistant (n = 1), healthcare provider (n = 1), biomedical student (n = 1), friend/family of persons living with HIV (n = 1), and a concerned citizen (n = 1).

## Perceived Need for Better Lay-Audience Information about HIV Cure-Related Research:



When asked the question "Do you think there is a need for better lay-audience information about HIV cure-related research?," the majority of participants, 69% said yes and only 10% said no.

## Perceived need for better lay-audience information about HIV cure-related research:

Respondents provided a range of reasons as to why there was a need for better community-friendly information about HIV cure-related research. One of the reasons given was that HIV cure-related research was very different from HIV prevention and treatment research (e.g., "*It's a huge, ever-changing topic that is very different from the HIV treatment or prevention research most people may have experience with*.").

Another reason was due to the limited understanding in the community about HIV cure-related research. For example, most community members still struggle to understand the purpose and the goals of HIV cure-related research. Other community members pointed to the need to debunk myths and misperceptions about HIV cure-related research. Having knowledge about HIV cure-related research could help bolster advocacy work to help refer and retain participants in clinical trials.

> *"At times people think that because there is treatment, it implies that there is a cure. This needs to be better understood by the general public and in turn learn more about prevention."*
>
> *"Most people have no understanding of this area or of how much work is being done. Thus, the need for cure-related research information is immense."*
>
> *"Health literacy/education about the issues of HIV cure research are a persistent need. It helps in awareness, better understanding of the challenges and discoveries being made."*

Several respondents mentioned wanting basic and simple materials about HIV cure-related research to facilitate understanding. The information available is currently "too technical" for most people living with HIV to understand and to help them engage in meaningful conversations about HIV cure-related research. The language used to present information needs to be modified to cater to audiences who may not have technical expertise regarding HIV cure-related research. Providing information in lay language will help reach a wider audience. Also, respondents indicated that not being able to understand HIV cure-related research dissuades many potential participants from engaging in research.

> *"Absolutely, and there is also a need for better lay-audience information about HIV in general. The general public is still confused, often using the terms HIV and AIDS interchangeably."*
>
> *"Clearly written, plain language with excellent use of graphics."*
>
> *"There is virtually nothing I can see that is on a basic level."*
>
> *"We need to be updated with accurate information on new breakthroughs for the cure. Use of simple nonmedical terms."*
>
> *"It is always important to include lay [language] in gathering and explaining research – especially because this is who the research will ultimately effect."*
>
> *"The average person doesn't understand the scientific terms, nor do most understand even how to read their labs."*
>
> *"People do not always understand the research that is available to them, as the wording used is often highly technojargon rich, and not understandable to the lay person."*
>
> *"I have not seen much info widely distributed in lay language (non-scientific)."*
>
> *"The average person might not understand all of the medical terminology."*
>
> *"It is always important to include lay in gathering and explaining research – especially because this is who the research will ultimately effect."*

A number of respondents mentioned that providing simple information about HIV cure-related research would help PLWH and affected communities more effectively engage in the research process:

> *"The vocabulary and proper knowledge of the science and protocols that deal with this field should be made common knowledge so that the community is able to voice an appropriate opinion to their community leaders."*
>
> *"Meaningful involvement of PLWH and other stakeholders is ethical and paramount to successful uptake should a cure become available."*
>
> *"PLWH need to stay informed about new research, and the importance of clinical trials. Without input, there will be no output."*
>
> *"Bottom up consultation processes. Community members should have their voice heard."*

Other respondents pointed out the need to clarify information about possible risks (and benefits) of HIV cure-related research (e.g., "*there is still confusion about what a cure could be and the risks/benefits of any studies*" and "*the risk of relapse needs to be more clear*.").

Other respondents described that we need to reach more diverse populations who are under-represented in research, particularly young people, Black/African Americans, and individuals who are transgender. This is particularly important given historical mistrust of biomedical research in certain populations who have been subjected to unethical research practices.

> *“More effective and large-scale outreach to youth.”*
>
> *“The need is greatest among people of color, notably African American PWA.”*
>
> *“For us, as transgender and intersex community, due to the hormone replacement, we need to have better understanding interactions. There’s a larger gap when it comes to cure.”*
>
> *“The mistrust that permeates medical research as it's related people of color has been eroded over the years. It is important educate the communities most affected by HIV about cure research. It empowers them to be accountable one to another.”*

Respondents noted that having basic information about HIV cure-related research would help them educate others about HIV cure-related research:

> *“Education, information is so important to me so I can pass it on to others; with knowledge comes power and we need to educate ourselves so we can educate others who have better self-esteem about ourselves.”*

Others described the importance of increasing transparency around the science of HIV cure to build trust among community members:

> *“We get bits-n-pieces, no follow-up what was originally announced for HIV cure, not transparent w/information sharing.”*
>
> *“The information is there but there is not enough effort being made to keep communities updated with follow up information about studies, etc. Not all countries or sites give communities enough time to learn about new studies before the studies commence, for them to be able to fully understand and provide the necessary community feedback.”*

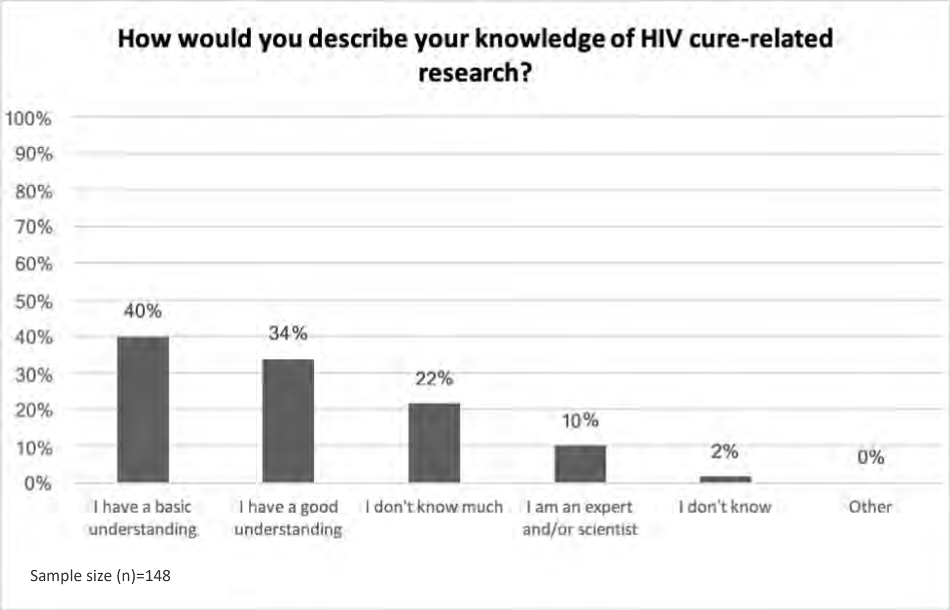
Respondents requested that information be organized on clear and centralized websites. They also recommended the use of social media platforms to share information:

> *"Would love to see a consumer-focused web site like the one created by CoVPN: clean, sophisticated, quality design.”*
>
> *“There is a lot out there already but very poor dissemination on social media. Educators not on social media will never be effective.”*
>
> *“Absolutely, central website, infographics, social media shareable video clips, etc.”*

Finally, one respondent explained that we also needed to provide education to researchers, particularly around the use of appropriate and non-stigmatizing terminology:

> *"Even researchers are confused. Researchers are still using stigmatizing and medically inaccurate terminology. The research literature is still publishing articles with the phrase ""full blown AIDS." There is no such thing and has no medical definition, yet scientists are still using it, peer-reviewers are not flagging it, and editors are still publishing it."*

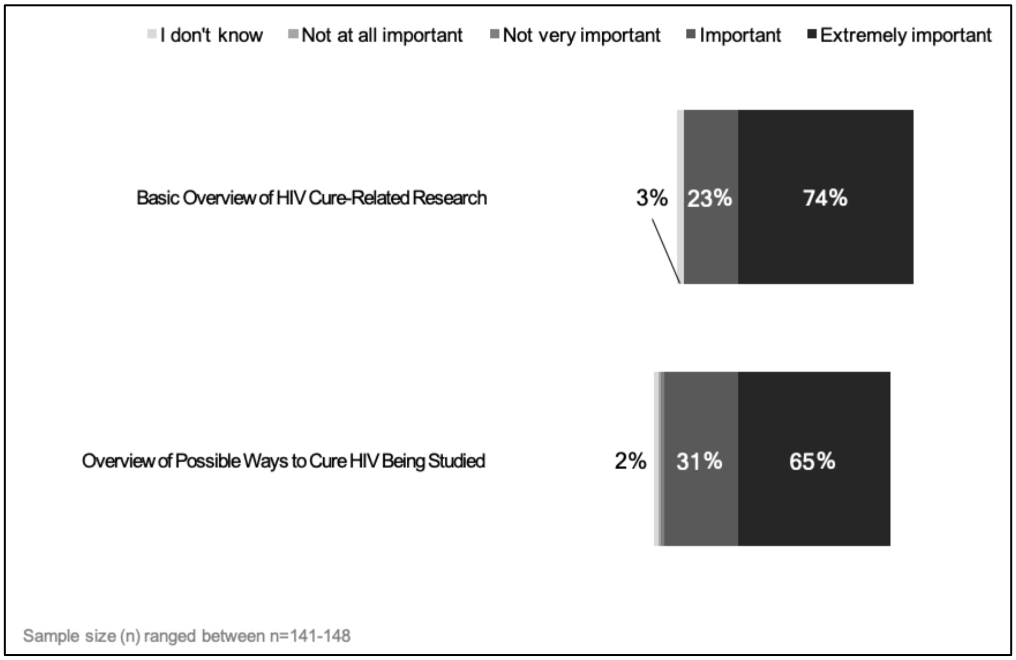
## Participants' Current Knowledge of HIV Cure-Related Research:



Sample size (n)=148

When asked to describe their current knowledge of HIV cure-related research, 40% of participants reported having a basic understanding of HIV cure-related research, 34% reported having a good understanding, 22% reported that they did not know much, and 10% reported that they were experts.

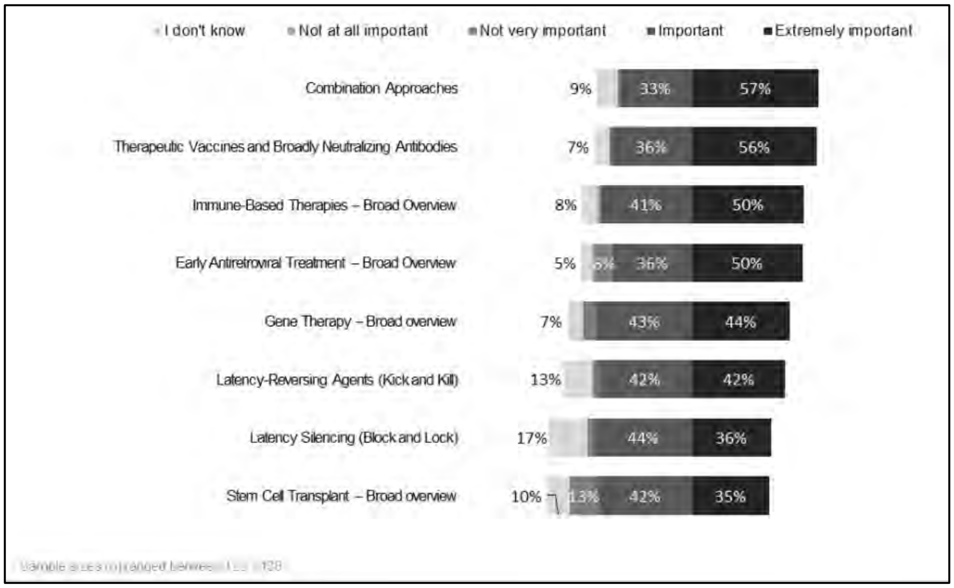
## Perceived Importance of Introduction/Basic Modules:



Sample size (n) ranged between n=141-148

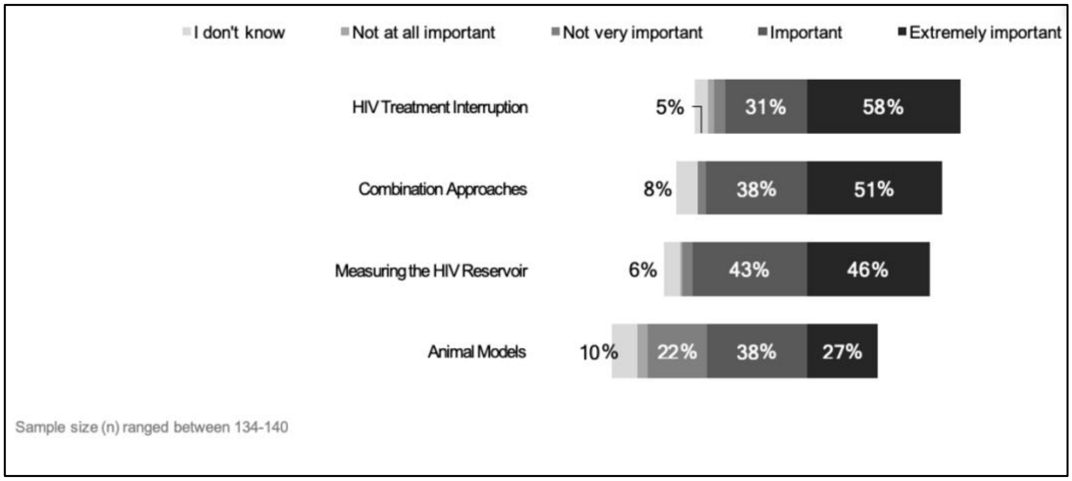
When participants were asked about what contents the introduction or basic modules should contain, approximately 3/4 of respondents considered a basic overview of HIV cure-related research extremely important, and 2/3 considered an overview of possible ways to cure HIV being studied extremely important.

## Perceived Importance of Modules on HIV Cure-Related Research Strategies:



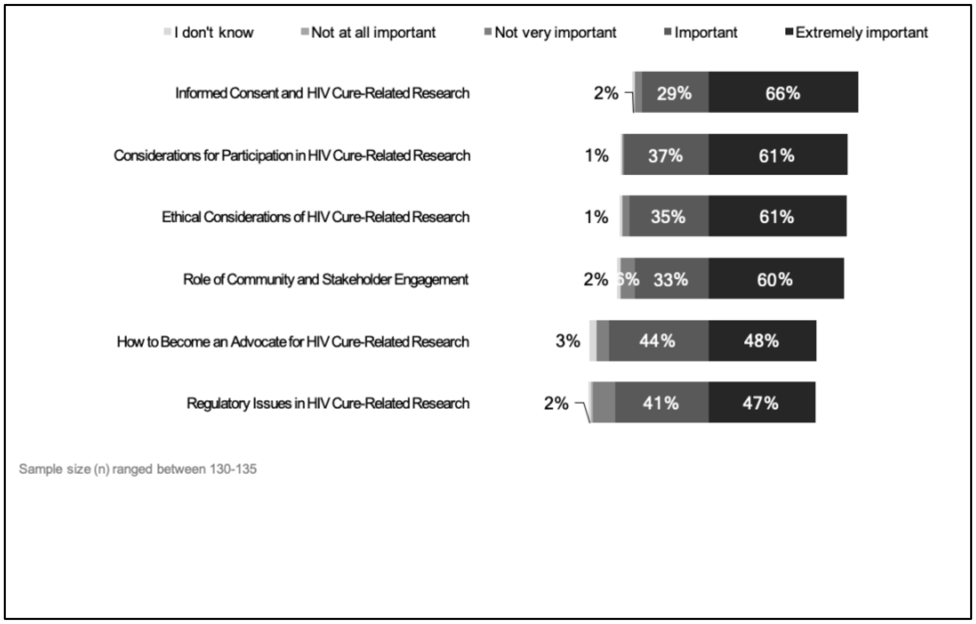
When respondents were asked about the perceived importance of modules on different HIV cure-related research strategies, over 50% of them considered 4 of these strategies to be extremely important to include in the training modules. Listed in the order of perceived importance, the 4 strategies were combination approaches (57%), therapeutic vaccines and broadly neutralizing antibodies (56%), immune based therapies (50%), and early antiretroviral treatment (50%).

## Perceived importance of Modules on Different Aspects of HIV Cure-Related Research:



Aspects of HIV cure-related research that respondents considered extremely important were analytical treatment interruptions (ATIs) (58%), combination approaches (51%), and measuring the HIV reservoir (46%). Meanwhile, respondents perceived modules on animal models (27%) as being less important.

## Perceived Importance of Module on Ethical, Regulatory and Community Considerations:



Sample size (n) ranged between 130-135

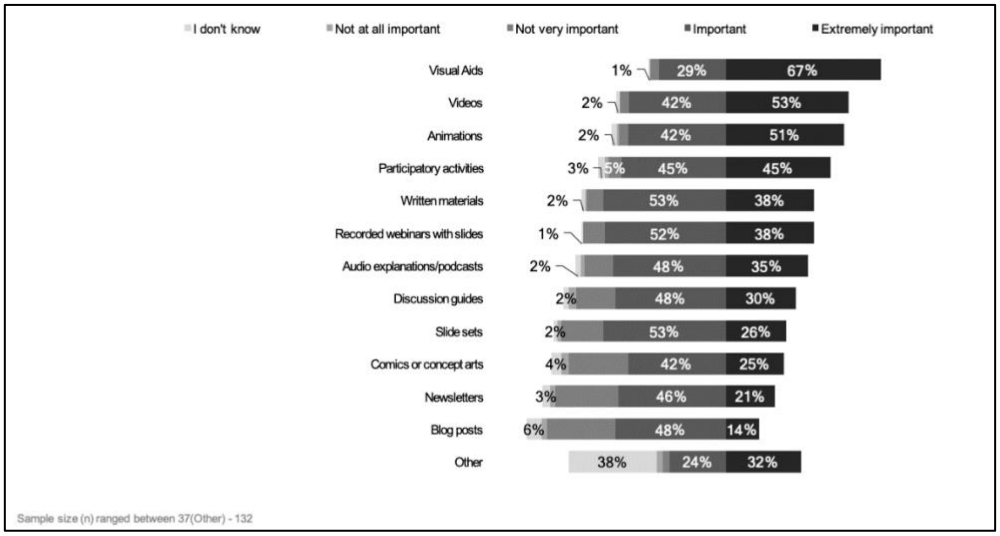
Over 3/5 of respondents considered modules on informed consent, participation in HIV cure research, ethical considerations, and the role(s) of community/stakeholders as being extremely important.

## Other suggested topics included the following:

| Themes | Exemplary Quotes: |
|---|---|
| HIV cure-related research approaches – including fact sheets | • *“Methods of cure”*<br>• *“Information about the various editing, splicing, protein blocking technologies would be interesting to know as well”*<br>• *“Carefully designed dissemination of facts and research strategies/processes/elements”* |
| HIV persistence | • *“Creating a comprehensive table of comparison between HIV and other virus, that accounts for all infection, replication and cellular destruction vectors would be interesting and a quick way to possibly learn and discern viral similarities and dissimilarities. Is it possible to create a tree of life to relate all viruses? That would be interesting.”* |
| Ethics of HIV cure-related research | • *“Ethics of the strategies like gene therapy”* |
| Perceptions of people living with HIV | • *“The concerns people living with HIV have that give them pause or make them react negatively”* |
| Population-specific considerations | • *“Population-specific considerations: BIPOC, cis women, transgender people”* |
| How to review an HIV cure-related clinical research protocol | • *“Would like to see more cure protocols coming through the ACTU advisory boards for their review and input”* |
| Hype vs. research – understanding stories about HIV cure-related research | • *“Hype vs. Research: The impact of news in the media”*<br>• *“People who have been in the media "representing" various approaches over time –i.e. Mississippi baby/child, Timothy Ray Brown, VISCONTI cohort, Boston patients, London patient, etc.”* |
| How to become an HIV cure-related research advocate | • *“How to become a cure advocate”*<br>• *“Advocacy to continue”*<br>• *“I am very interested in becoming an advocate”*<br>• *“As a CAB member how … to learn more, on the research side”* |
| Compensation issues | • *“Risk compensation in cure research”* |

| | |
|---|---|
| Comprehensive approach to education – e.g. COVID-19 (ACTIV-2 trial) | - *"Please see COVID-19 approach in all its aspects and apply to HIV: financial, scientific, disruptive, scope, optimism, timeline, hundreds of institutions private and public involved"* |

## Perceived Usefulness of Different Possible Formats:



Sample size (n) ranged between 37(Other) - 132

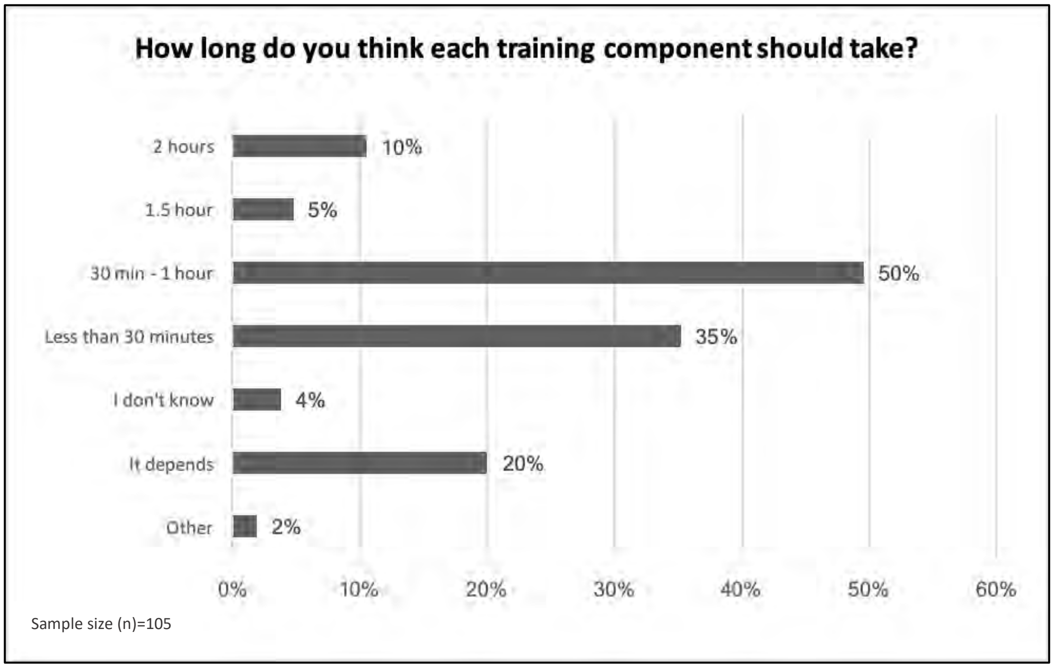
Visual aids, videos, and animations were the preferred formats for respondents.

## Additional suggested formats included:

- Activities that can spark discussion and questions
- Printed materials available for every presentation
- Open access database
- Two-minute read/video segments
- Online modules (tutorial style)
- Well-coordinated media campaign; outreach campaign
- Virtual sessions, so people can ask question
- Advocate classes
- Modules to be added to college and/or university curriculum (e.g., public health, nursing, pharmacy and medical students)

> “
>
> *As you pointed out, a website with HIV cure related research is vital to ongoing support and information dissemination. We often fragment the systems in which we live and work. Combining everyone in one location and providing links to other resources is the most efficient and effective way of disseminating information in our society*

## Lengths of Training Components:



Half of the respondents said that each training component should take between 30 minutes – 1 hour. A third of respondents indicated that components should be less than 30 minutes. However, two respondents indicated that the timeframe depended on the topic:

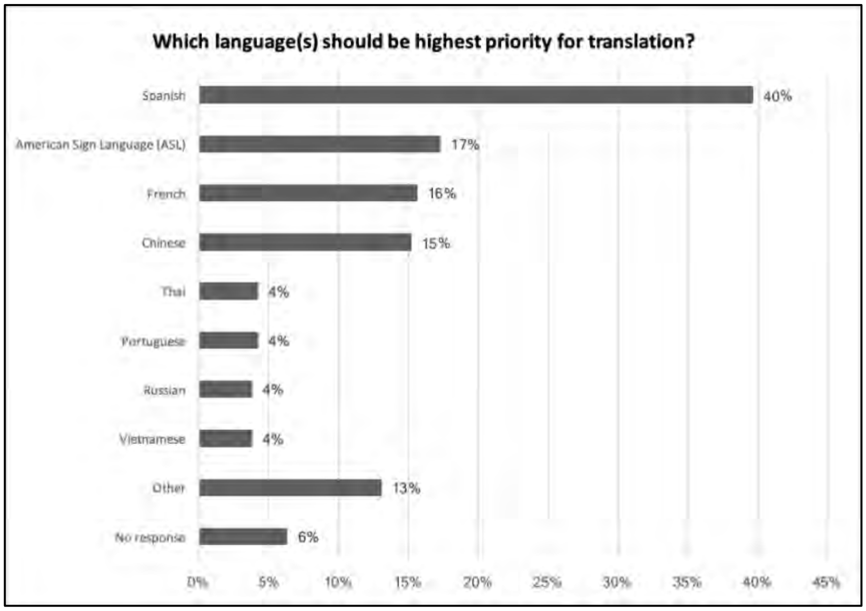
- *"Each one is going to warrant its own timeframe."*
- *"I would not necessarily put a timeframe to training. It would depend on the target population."*

Further, respondents indicated that the length of the training depended on a number of factors, such as learning objectives, complexity of topics and/or materials, level of understanding, topics or contents provided, audience, training modality, and a combination of factors.

| Themes | Exemplary Quotes: |
|---|---|
| Learning objectives | • *"The duration of training must depend on the learning objectives for the curriculum"* |
| Complexity of topics and/or materials | • *"Length may vary depending on the complexity of the topic"*<br>• *"Depend on the complexity of the material discussed on each topic"*<br>• *"Complexity of the subject matter relevant to the audience governs the amount of time for training"*<br>• *"Depends on the complexity and importance of the topic"* |
| Level of understanding | • *"On the understanding"* |
| Topics or contents provided | • *"On the content provided and the tools used, videos, images, etc."*<br>• *"On the information in the training. Some require longer times"*<br>• *"It will also depend on the topic and how to unpack all questions and suggestion that may come, in order for one to be clear about the section done on that day"*<br>• *"How much content would be discussed"* |
| Audience | • *"Depends on the audience"* |
| Training modality | • *"The method by which the material is being presented will probably affect the way that the material would be constructed and formatted within each* |

| | |
|---|---|
| | *type of component"*<br>- *"On what platform delivery format is used to present materials"*<br>- *"Online - Zoom, YouTube, etc."* |
| Multiple or combination of factors | - *"Depth of topic, audience level, and their attention span"*<br>- *"Less than 30 min but based on content/media: Segments can be broken up into 2 min reads or 5 min video"*<br>- *"On the content coverage and complexity of the research"*<br>- *"Depends of the purpose, audience, and context in which the training is offered.  If you are offering CEUs you would need to check with each governing body"* |

## Perceived Priority Languages:

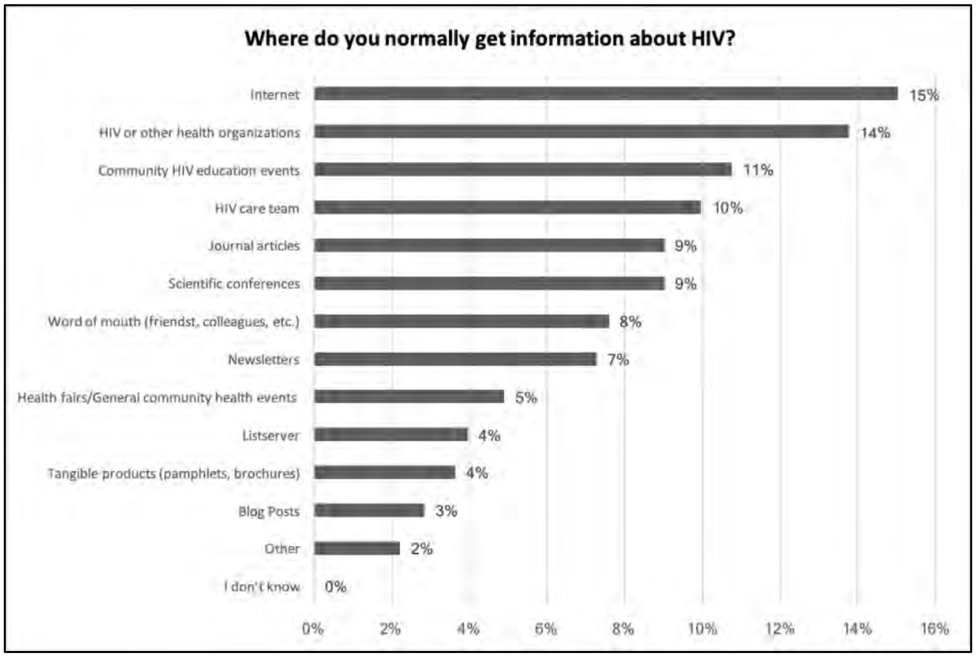


When asked about language translation priority, 40% of respondents perceived Spanish to be of the highest priority of translation. Other languages that respondents perceived to be of high priority for translation were American Sign Language (17%), French (16%), and Chinese (15%).

Other suggested languages included: English (n = 9), African languages (e.g. Zulu, Dholuo) (n = 5), Swahili (n = 3), Hindi (n = 3) and Arabic (n = 2). Other languages included: Korean, Malay, Nepalese, Amarhic, Somali, Russian, Ukrainian (n = 1 each). Other respondents indicated waiting materials translated in the languages of the local settings where information was being presented. It is important to remember that this is a heavily U.S.-based sample and may not be a reliable indicator of global translation priorities.

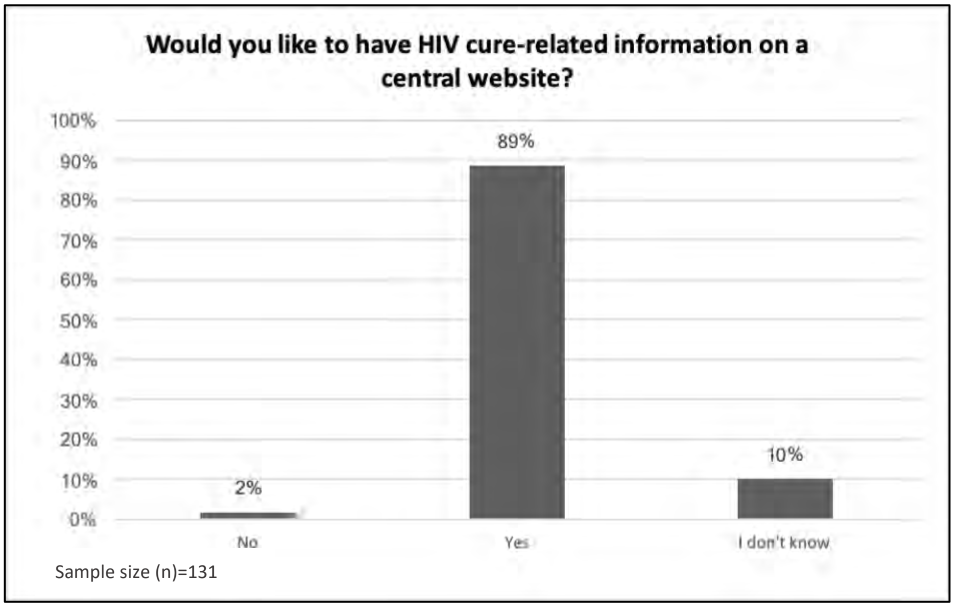
> "
>
> *To be able to have conversations with people who [know] their stuff. Dialoguing like that really helps....and listening to people have these conversations (like a podcast) also helps.*

## Where People Get Information From:



Respondents indicated that they usually get information about HIV from the internet. Those who selected the ‘Other' category indicated the following sources: PozHealth and other email listservs, HIV POZ magazines, HIV care provider, the internet, professional events and educational opportunities, social media (e.g., Facebook, Twitter, Google), department of health, U.S. Centers for Disease and Prevention (CDC), HIV cure-research academy, and community advisory board.

## Desire for Centralized Website:



89% of participants responded that they would like to have HIV cure-related information on a central website.

## What would be most helpful to you in understanding HIV cure-related research:

In terms of what would be most helpful to respondents in understanding HIV cure-related research, we received a diversity of responses such as: 1) centralized and trusted source of curated materials (e.g., website), 2) frequently used platforms (e.g., social media), 3) use of visuals and tables, 4) simplified materials created with community input, 5) combination of teaching modalities (e.g., videos,), 6) increased opportunities for meaningful dialogue, engagement and community-friendly trainings, and 7) consistent and timely updates about the science.

| Themes | Exemplary Quotes: |
|---|---|
| Centralized and trusted source of curated materials (e.g., website) | • *"A central place to go for info, i.e., a "library" or curated collection of quality material that can be trusted for accuracy/quality"*<br>• *"Where to get high-quality resource materials to educate participants and CAB members"*<br>• *"Information about different efforts to find the cure available in one single webpage"*<br>• *"A central website that is user friendly"*<br>• *"A site where this information would be presented, in clear terms"*<br>• *"As you pointed out, a website with HIV cure related research is vital to ongoing support and information dissemination. We often fragment the systems in which we live and work. Combining everyone in one location and providing links to other resources is the most efficient and effective way of disseminating information in our society"* |
| Frequently used platforms (e.g., social media) | • *"Utilize a platform that is frequently used. Social media, the news, etc."*<br>• *"Timely updates and news on Twitter"* |
| Use of visuals and tables | • *"Relatable imagery to medical scientific concepts"*<br>• *"Visual graphs and scientific explanations written in plain English easy for us to understand. That is how I learned about stem cell research, and DNA manipulation research. Both methods are promising. DNA manipulation is huge as the ramifications can be used in so much more than HIV alone"*<br>• *"Tables of detailed comparison between different things, like treatments, tech, etc."*<br>• *"Some kind of visual chart with the different approaches, where they are in process, what are the possible negatives"*<br>• *"Cartoons"*<br>• *"Infographics or animations"* |
| Simplified materials created with community input | • *"Content created by & curated for the HIV community"*<br>• *"Simplicity so that all learners are able to understand complex scientific information"*<br>• *"A lay-man's terminology of the various options being researched and how each is approaching the challenges of viral suppression"*<br>• *"The science behind how it works in layman terms"*<br>• *"Research descriptions written in non-scientific language"* |
| Combination of teaching modalities (e.g., videos, glossaries, etc.) | • *"Video[s]"*<br>• *"A written glossary of terms"*<br>• *"Not just one thing. Numerous educational tools are important to me"*<br>• *"Information in various mediums"*<br>• *"A comprehensive scope of cure-related research scheme to fit each strategy, approach, treatment, plan"* |
| Opportunities for meaningful dialogue, engagement and community-friendly trainings | • *"To be able to have conversations with people who [know] their stuff. Dialoguing like that really helps....and listening to people have these conversations (like a podcast) also helps"*<br>• *"Creation a conducive environment for discussion and community* |

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| | *engagement”*<br>- *“Do more trainings in HIV cure related research, have seminars whereby key focus is to ensure that people who are attending have more knowledge”*<br>- *“More engagement with all related stockholders”*<br>- *“Conference calls”* |
| Consistent and timely updates | - *“Regularly timed updates”*<br>- *“Conference recaps”* |

## Suggestions to help increase understanding of HIV cure-related research:

When asked about possible suggestions to help increase understanding of HIV cure-related research, respondents had several suggestions. These included creating a reliable resource hub, setting realistic expectations about the science, ensuring two-way communication and networking, outreach to communities of color and under-served communities, outreach to HIV care providers, engagement of previous trial participants, use of social media, and sustained, long-term initiatives.

| Themes | Exemplary Quotes: |
|---|---|
| Reliable resource hub | - *“Have a resource hub for sharing of resources”*<br>- *“I do think a web portal to various study alternatives would help anyone explore online. My experience has been that explanations get too scientific too quickly to understand and then I tune out. Levels of information need to be created that helps consumers at their level and along a continuum to those who are scientifically minded like TAG”* |
| Realistic expectations about the science | - *“A lot of people wrongly think a cure is around the next corner – think it is important to communicate that even if we're close to developing a cure that it will take years to bring to market and roll out”* |
| Two-way communication and networking | - *“Get teams of researchers & community people out into the community to educate each other (two-way communication, NOT top down)”*<br>- *“The central web site should have a place for open discussion and personal accounts so we can better network”* |
| Outreach to communities of color and under-served communities | - *“Outreach to communities of color”*<br>- *“More involvement with underserve communities!”*<br>- *“Target more LGBTQ population”*<br>- *“Involve more KP [key populations] advocates”*<br>- *“The researchers should reach the most vulnerable people and community”* |
| Outreach to HIV care providers | - *“National presentation to doctors/health professionals so that they might allow reference material to be available in their own community”*<br>- *“Providing training and webinars for healthcare staff; as well as other employers in the community”* |
| Engagement of previous HIV cure trial participants | - *“Engage spokespeople who have participated in trials or clinical research - I've found that very helpful. Also, carefully select for researchers who can speak to lay audiences effectively. Sometimes they get caught up in the jargon and high-level science and don't realize they have lost most of the audience”* |
| Use of social media | - *“Use social media to school youth”*<br>- *“Hire a social media expert”*<br>- *“Take use of different social platforms such as Facebook, Twitter, WhatsApp and Instagram, open up a networking site for all races on social media were people from various sites can interact and be educated”*<br>- *“Engage on social media more. Few of the other CAB members and community advocates I know are talking on social media about cure, they don't comment on cure posts, they don't participate in cure-related online groups. Their absence is felt, especially when trying to challenge* |

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|  | *misinformation. Sometimes it feels like there is no one else out there trying to discuss cure responsibly. Yet I know they have these conversations in person and via email.... let's bring them on to social media channels!!!"* |
| Sustained long-term initiatives | • *"Cure research is complex and gets little public attention/support from ASOs, HIV advocacy organizations, state and local health departments, etc. We need to create a broad, sustained, long-term initiative to generate and maintain public understanding and support for cure research. We also need to help determine where and how cure strategies fit into the federal plan to ETE"* |

## Additional thoughts about informing community members about HIV cure-related research:

When asked to provide additional thoughts about meaningful ways to inform community members about HIV cure-related research, respondents indicated the following: create videos, write blog posts, reach PLWH outside of traditional CAB networks, address community concerns around ATIs, reach out to minority-owned media, engage communities and scientists together in dialogue, reach out to HIV practitioners, educate journalists about proper reporting on HIV cure-related research, and find/mentor young advocates.

| Themes | Exemplary Quotes: |
|---|---|
| Create videos | • *"We need short n snappy videos that are cut/edited together like the creators on successful YouTube channels"* |
| Write blog posts | • *"I think having a blog or central site is great"* |
| Reach PLWH outside of CAB networks | • *"Informing PLWH outside of those involved in CABs"* |
| Address community concerns around ATIs | • *"I am currently involving communities in Kisumu about HIV cure, we need to understand the fears and anxieties to make a decision to participate in ATI studies; what government guidelines say about treatment interruption to ease the transition. Address the myths and misconceptions about research and the masking of COVID-19 that Africans are being used for the benefit of others and not them. Let's understand the communities we work with"* |
| Reach out to minority-owned media | • *"Solicit articles in minority-owned media"* |
| Engage communities and scientists together in dialogue | • *"Engage community and scientists together in discussions, planning, strategies, etc. as the community has the power to make sure cure research is acceptable in their communities"*<br>• *"Regular forums and town hall for constant feedback sessions"* |
| Reach out to HIV practitioners | • *"I think practitioners who are more of stakeholders on the cultural side as well as academia, are the ones that need to be listened to more intently, and given more opportunities to disseminate their own findings in their respective communities"* |
| Educate journalists about proper reporting on HIV cure-related research | • *"Many PLWH get their HIV information from the lay LGBT/HIV media such as POZ Magazine, PLUS, etc. Much of what these media publish about cure research is superficial, poorly written, and over-hyped. Why not co-opt the lay media to leverage their outreach capabilities by educating their journalists in cure research?"* |
| Find and mentor advocates | • *"Find younger advocates who can best utilize social media to reach all consumers"* |

## How community-friendly information about HIV cure-related research would be used:

Respondents indicated they would use the community-friendly information about HIV cure-related research in the following ways: to host educational workshops and/or discussions, present to clients and/or patients, involve community/peer educators, inform oneself, help destigmatize HIV, share with others and/or inform others.

| Themes | Exemplary Quotes: |
|---|---|
| Host educational workshops and/or discussions | • *“Build community literacy via our CAB's community education events and at CAB meetings”*<br>• *“To train potential cure trial participants, their family and/or partners (ex risks of ATI to uninfected partners and the importance of their taking PrEP & using barrier protection)”*<br>• *“I would host virtual and/or in-person workshops and discussion groups if the materials are well-written and effective for a general audience”*<br>• *“For educational purposes, and to share with my networks”*<br>• *“I would use the information to engage the general public at health fairs, and appropriate settings as Did You Know or Fun Facts”*<br>• *“For educational purposes and make available to all communities!”*<br>• *“Educate others on progress of cure research”*<br>• *“Group discussions”*<br>• *“Community forums”* |
| Present to clients and/or patients | • *“I would present it to our [REMOVED FOR ANONIMITY] clients”*<br>• *“I would give this information to my patients”*<br>• *“Provide to the patients in our clinic”*<br>• *“With patients and their friends and family”*<br>• *“If it can be promoted at the clinics, give the community members advocacy on their waiting time, about the importance of research, and to be part of clinical trials”* |
| Involve community organizations | • *“Involve as many community organizations and opinion leaders as possible”* |
| Inform self | • *“I would read it and consider my participation in either a trial or be better informed about the future”*<br>• *“For my own knowledge so I can inform others and reference them to the actual source of information”*<br>• *“For my own consumption and helping others. Giving hope to those affected”*<br>• *“Personal interest and to have enough knowledge to tell someone not involved in HIV basic information about the approaches. I've been to talks but have not come away with a chart that is a pathway through the main approaches”*<br>• *“Increase my understanding of HIV cure-related research”* |
| Help destigmatize HIV | • *“I would (use) this information to destigmatize the disease and encourage those who are carriers of HIV to consider participating in research to help find a cure”* |
| Share with others and/or inform others | • *“I would share it with my networks and use it to gain a better understanding for myself and others”*<br>• *“I share information and website info if it is requested”*<br>• *“I would communicate my knowledge with colleagues”*<br>• *“I would use the information to inform people with serious and well intended inquiries”*<br>• *“I would use it to educate others”*<br>• *“To share them on my own social media platforms with reflection and thoughts”* |

## Key Recommendations Following Community Needs Assessment

The committee makes the following recommendations for how to create more effective and relevant HIV cure-related research community training materials.

1. Community participants in HIV cure-related research should be recognized as partners in the research process. Educational materials should be created with robust community input. The best community education is based on two-way communication between researchers and community members.

2. HIV cure-related educational and training materials should be communicated in language and formats that are accessible and meaningful both for PLWH and for communities disproportionately affected by HIV. To maximize effectiveness and ease of understanding by diverse audiences in a variety of settings, we specifically recommend the following:
    a. Employ "lay person" language, rather than highly technical language.
    b. Use non-stigmatizing terms and "people first language."
        i. Examples and guidelines:
            1. HIV NIAID Language Guide (2020): Available at: https://impaactnetwork.org/DocFiles/News/NIAID%20HIV%20Language%20Guide%20-%20March%202020.pdf)
            2. Language, Identity, and HIV: Why do we keep talking about the responsible and responsive use of language? Language matters. *J Int AIDS Soc* 2012; 15 (Suppl 2): 17990. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3499898/

    c. Presentation formats should be varied and include visual images, tables, videos, animations, and combination formats. Our experience shows that "less is more." Training presentations of no more than thirty minutes, followed by time for community discussion, have been described as most effective. Opportunities for meaningful dialogue and mutual engagement should be provided.
    d. Disseminate information and engage community members via web platforms and social media.
    e. Provide community members with a central web-based research hub for access to reliable and timely information.

3. HIV cure-related educational and training efforts should address and seek to rectify the under-representation of women, Black, indigenous, and transgender individuals and other communities historically under-represented in HIV research and educational efforts. We recommend that educational materials and activities feature members of these communities as scientists and researchers, PLWH and research participants. It is important for people to see and hear from people like themselves. Listening to and learning from communities who have historically experienced unethical medical interventions and healthcare discrimination are essential to building trust and building systems that advance research justice.

4. HIV cure-related educational and training efforts should be explicit and clear about the risks and benefits of participating in HIV cure-directed clinical research, including possible physical, mental, and psychosocial effects. Although there may be few immediate personal benefits from participating in cure-related clinical research, the opportunity to contribute altruistically by participating in research should

be described and illustrated by personal testimonies of study participants.

5. Information about how to become involved with all aspects of the research process, ranging from study participation to serving on community advisory bodies to contributing to community engagement activities, should be provided. To build trust with communities, we recommend that information about HIV cure-related research process from the beginning to the end of a study is communicated openly with study participants and other community stakeholders. Research findings should be shared in a timely fashion in plain language with study participants and other community stakeholders. It is absolutely essential to share consistent and timely updates about HIV cure related research in order to build community literacy, trust, and engagement. Avenues for such communication include community meetings and presentations, community "townhalls" with researchers and stakeholders, and peer-based outreach to under-represented communities.

6. Study protocol and informed consent documents should be presented in understandable language and audience-appropriate reading levels that explain realistic expectations of the study and current HIV cure-related science. We underscore that informed consent should not be a one-time event, but an ongoing process.

7. HIV cure-related education and training materials should be translated to languages that are appropriate for local audiences. Our needs assessment demonstrated that Spanish and American Sign Language (ASL) are of the highest priority.

8. HIV cure-related education and training efforts should emphasize topics that are identified by respondents as being the most important, such as: ATIs, combination approaches, measuring the HIV reservoir, therapeutic vaccines, and broadly neutralizing antibodies, as well as ethical considerations.

9. Researchers and healthcare providers should continue to build trust with communities through hosting community forms, workshops, and trainings that are developed with significant input from community members. Proactive efforts to involve communities who have been historically under-represented in research, especially HIV cure-related research, are vital to develop educational and training materials that are meaningful, relevant, and advance equity and justice in the search for a HIV cure.