

Summary

The meeting centered on the critical role of community engagement in HIV research and quality improvement, highlighting the necessity of including the voices of people living with HIV in decision-making processes. Dr. Carla Torres introduced her background and the Binational Family Agency's work. The group discussed the Denver Principles, the importance of community advisory boards, and actionable steps to ensure ongoing communication and representation in research. The meeting also addressed strategies to improve the quality of HIV care, emphasizing patient engagement, education, and advocacy. Discussions included the separation of prevention and care, the impact of healthcare policies, social determinants of health, Ryan White service eligibility, and the introduction of a patient advocacy checklist.

Outline

1. Introduction of Dr. Carla Torres • 0:00:08

- Dr. Carla Torres is a Vee Healthcare American Academy HIV specialist and medical director of the Binational Family Agency in Tijuana, providing free HIV services for 20 years.
- She is present to discuss research and quality improvement for people living with HIV.

2. Importance of Community Engagement • 0:03:27

- The Denver Principles, established in 1983, emphasize self-empowerment and activism for people living with HIV.
- Community engagement in research is crucial, ensuring that people living with HIV are not just participants but active partners in the research process.

3. Call for Participation in Advisory Boards • 0:08:05

- Participation in community advisory boards (CABs) is essential for lending a voice to the community's needs and experiences.
- Members are encouraged to share their experiences and insights to influence research and policy effectively.

4. Action Items for Community Engagement • 0:16:04

- Regular meetings should include reviews of upcoming advisory board activities and research developments.
- Assign someone to follow up on research outcomes and ensure the community's voice is represented in discussions.

5. Focus on Research Goals • 0:18:01

- The group should decide on a primary focus for their advocacy efforts, such as striving for a cure for HIV.
- Inviting external experts to share insights on research can enhance the group's understanding and impact.

6. Improving Quality of Care • 0:18:47

- The group aims to enhance the quality of care for individuals living with HIV, addressing the challenge of maintaining consistent care.
- Peer support is vital for keeping individuals engaged in their care, especially during difficult times.

7. Separation of Prevention and Care • 0:20:25

- It is crucial to distinguish between prevention and care, as prevention can eliminate the need for lifelong treatment.

- Participants discussed the importance of informing others about the implications of living with HIV and related health issues.

8. Health Education and Patient Support • 0:23:03

- Continuous education about health conditions and their management is essential for patients, especially as they age with HIV.
- Support groups play a significant role in providing peer support and sharing valuable health information.

9. Impact of Policies on HIV Care • 0:25:20

- Recent healthcare policies have affected access to medications and services for individuals living with HIV.
- Participants were encouraged to share personal experiences related to policy changes that impacted their care.

10. Social Determinants of Health • 0:28:05

- Factors such as geographic location, housing, and access to nutritious food significantly influence health outcomes and access to care.
- The discussion highlighted the need for awareness of how these determinants affect individuals living with HIV.

11. Ryan White Services and Eligibility • 0:31:20

- Ryan White services are still available but are subject to changes based on federal poverty levels and funding.
- Participants discussed the importance of understanding eligibility criteria and the potential impact of changes in income on access to these services.

12. Patient Advocacy and Checklist Introduction • 0:34:10

- A checklist was introduced to help patients advocate for their health by ensuring they receive necessary tests and screenings.
- Participants expressed interest in using the checklist during medical appointments to enhance communication with healthcare providers.