Community involvement in the IAS Global Scientific Strategy: resources for advocates

19 May 2022

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Disclosure

No personal financial conflict of interest
Outline

• Community involvement in IAS strategy for a cure.
• Key community issues.
• Developing wider engagement and awareness.
The 2021 review covered 170 new papers in eight areas of cure research.

Writing group >40 experts globally.

Led by Prof Sharon Lewin and Dr Steven Deeks, this group included 1-3 community advocates in each sub-section.

Community input included 20 advocates from the US, Europe, SE Asia and Africa.
Three versions

• Main paper Nature Medicine: importantly published as open access.

• Summary for medical journalists (English, French, Portuguese, Spanish).


Explains cure research for people living with HIV. By community members (www.i-Base.info)
Key points

• Wider community awareness and involvement in cure-related research.
• Beyond advocates and CABs - to cover all demographics and populations.
• Broader inclusion: age, ethnicity, region.
• Current cures, barriers and advances.
• Ethics of cure-related research.
• Global access for research and final cure.
Wider community awareness

• Wider community awareness and involvement in cure research. This affects us all.
• *Current engagement is suboptimal.*
• Beyond advocates and CABs: capacity building all demographics and populations.
• Education and engagement to support shaping the research agenda including in trial design - and what community want from a cure.
Broader inclusion in studies

• Importance of equity and inclusion.
• By age - adults and children; race/ethnicity, geographical region. Not just white gay men in high income countries.
• To reflecting global need, diversity and subtype.
• Including social and behavioural research with biomedical studies.

Current cures and progress

- Loreen Willenberg, Esperanza patient.
- Visconti cohort (not cures but controlled without ART).

Pictures: Timothy Ray Brown, Adam Castillejo, Loreen Willenberg.
Ethics of cure-related research.

- Disconnect between researchers and participants: “no-one will be cured in this study” vs ”I might be lucky and be cured”.
- Community defined cures: stopping ART? Protecting partners? Testing negative?
- Importance of appropriate language.
- Safety - of interventions and stopping ART (ATIs)
Global access

• Concerns about future access need to be integrated into research.
• Not just an afterthought.
• Greatest need? - children and adults, where access to ART is most difficult etc
Cure awareness as treatment literacy

• People living with HIV know more about their health than many other conditions.
• Not just CD4 and viral load but also the viral reservoir, and difficulties of cure. It links to adherence and resistance.
• Optimism and hope have always been a community foundation – for treatment, a vaccine and a cure - even before ART.
Cure awareness as treatment literacy

Important to know a little about the viral reservoir - overlaps with adherence, resistance and hope.
Timeline and expectations…

- 10 years away - but closer than before!
- Likely to have several stages/parts.
- International networks are collaborating.
- (i) Eradication (cure) or (ii) Remission (no viral load without need for ART).
Thanks and questions

Community members of the writing group:

Richard Jefferys, Udom Likhitwonnawut, Alex Schneider, Siegfried Scwarze, Christina Antoniadi, Stephan Dressler, Magda Ferreira, Fatih Egelioglu, Arda Karapinar, Imelda Mahaka, Alain Volny-Anne, Magdalena Ankiersztejn-Bartczak, Ivana Benkovic, Buki Ayinde, Harriet Langanke, David Haerry, Jeff Taylor, Giorgio Barbareschi.