

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



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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.

# Third IAS 5-year review

The 2021 review covered 170 new papers in eight areas of cure research.

Writing group >40 experts globally.

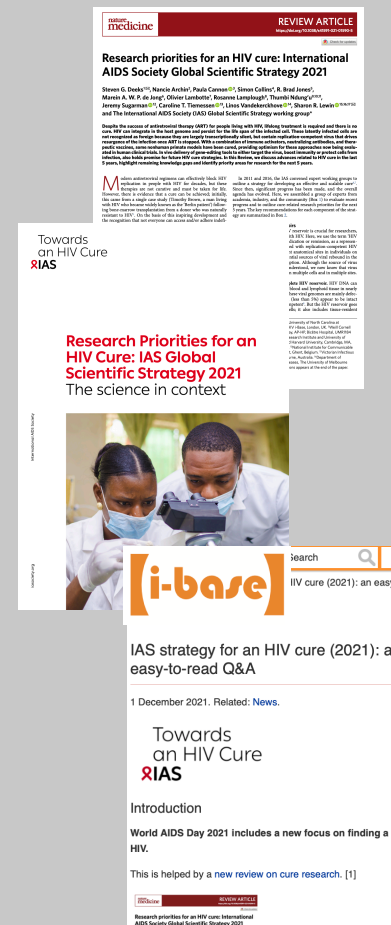
Led by Prof Sharon Lewin and Dr Steven Deeks, this group included 1-3 community advocates in each sub-section.

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).
- Non-technical Q&A: everyday language. Reading age 11-12. Easy for translations. Explains cure research for people living with HIV. By community members ([www.i-Base.info](http://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

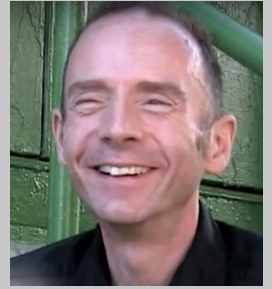
- Importance of equity and inclusion.
- By age - adults and children; race/ethnicity, geographical region. Not just white gay men in high income countries.
- To reflecting global need, diversity and subtype.
- Including social and behavioural research with biomedical studies.

Refs: Barr L, Jefferys R: A landscape analysis of HIV cure-related clinical research in 2019. J Virus Erad, 2018 and 2019.



# Current cures and progress

- Four stem cell cures in patients from Berlin (Timothy Ray Brown) in 2008, London (Adam Castillejo) in 2019, Düsseldorf in 2019, and the US in 2022.
- 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

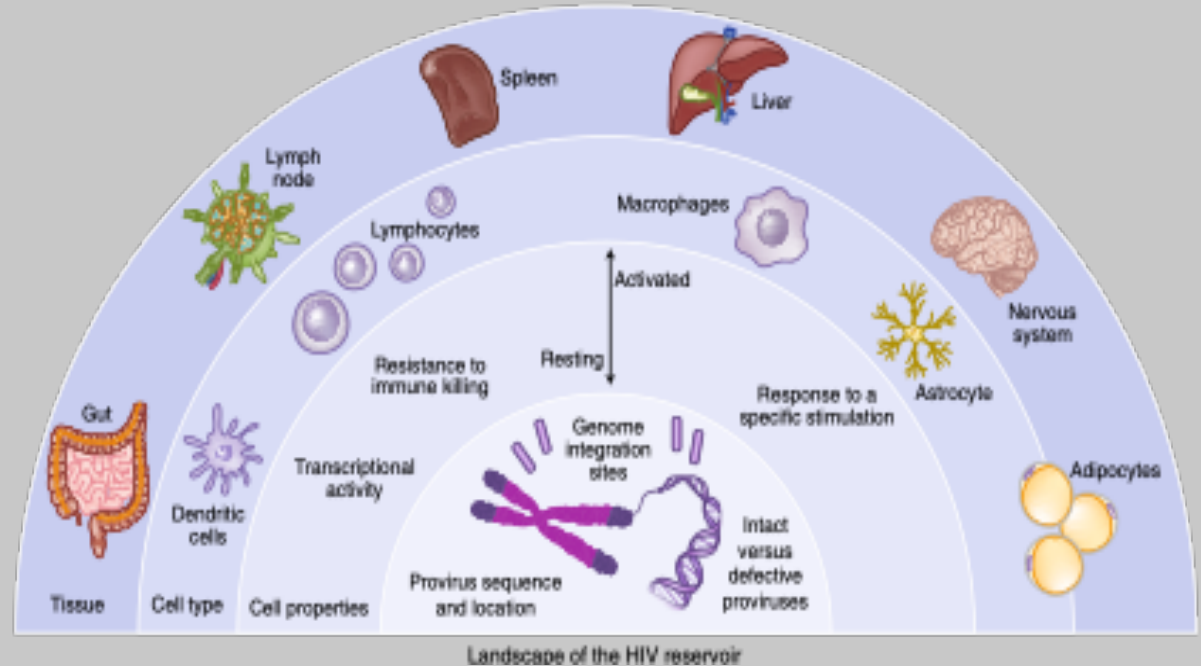
- Concerns about future access need to be integrated into research.
- Not just an afterthought.
- Greatest need? - children and adults, where access to ART is most difficult etc

# 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.

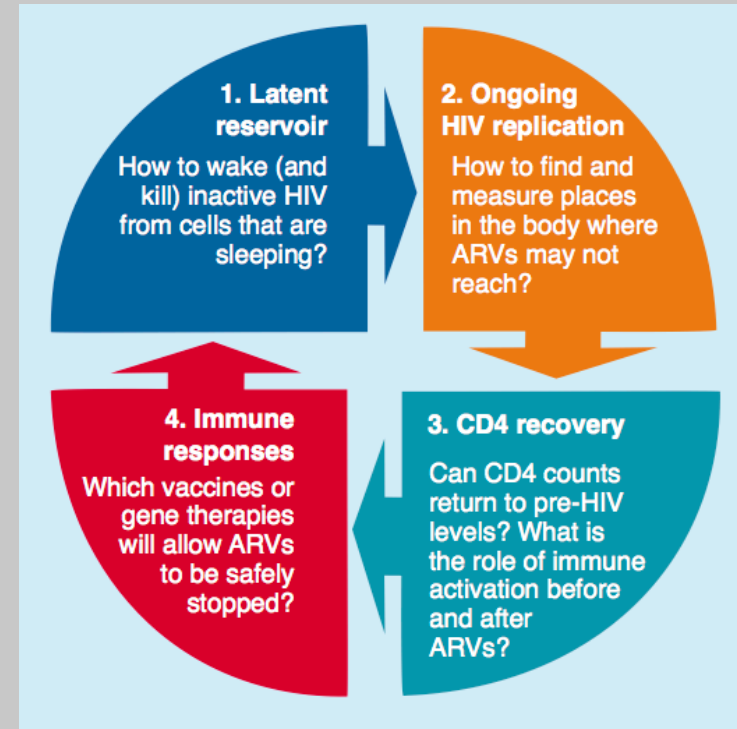
# Cure awareness as treatment literacy

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:

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