Participation In
HIV Cure Clinical Trials
from the
Participants Perspective

Building community capacity to engage with cure media & confidently start a discussion on considering trial participation

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September 2018

AUSTRALIAN HIV
Cure Community Partnership
BRIDGING HIV CURE SCIENCE AND THE HIV COMMUNITY

napwha national association of people with HIV australia

I acknowledge we are on the land of the Gadigal people from the Eora nation and give my respect to their elders, past present and emerging.

I want to begin my presentation by
thanking people living with HIV
past present
who have generously shared their time, talent,
experiences, and bodies for the purposes of
research.

I acknowledge, appreciate, honor and respect
your acts of love
to & for us

Our HIV journey is a love story

Pic source – Ken Crosswell, The lives of Stars

**The Love
Cascade
or
The Love
Care
Continuum**

Choosing to love

**builds bridges
breaks down barriers
collaborates and gives
joyfully co-creates**

HIV, Ebola, ...?....?

How does love choose to respond in that moment?

With loving health care

consumption of health commodities for profit $ is health care less

We are scientists with you!

- Since the beginning we have engaged in finding a cure
- Many of us live with and can handle uncertainty e.g. starting ARV, oral sex
- We trusted you with our lives thankyou we trust you, we trust, we trust,
- Well actually we love you ☺

Loving to know & trials

Risks & Benefits	Global North Context?	Global South Context?	Each Participants Context?
What I know is ..	Consent Monitor Response	Consent Monitor Response	Consent Monitor Response
What I know I don't know is..	v	v	v
How will the Unknowns be managed	Optimise collaboration	Optimise collaboration	Optimise collaboration

Do good – when we know better we do better
Do no harm – contain minimise
Autonomy – informed consent
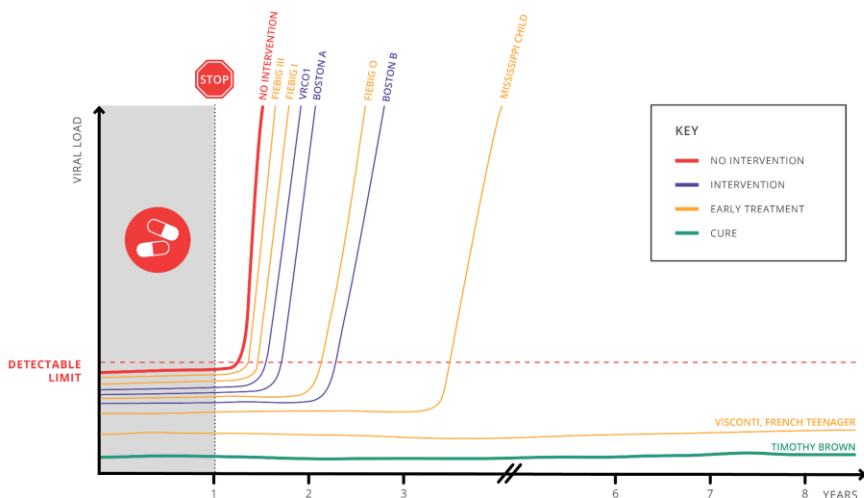Equity, Fairness – Inclusion

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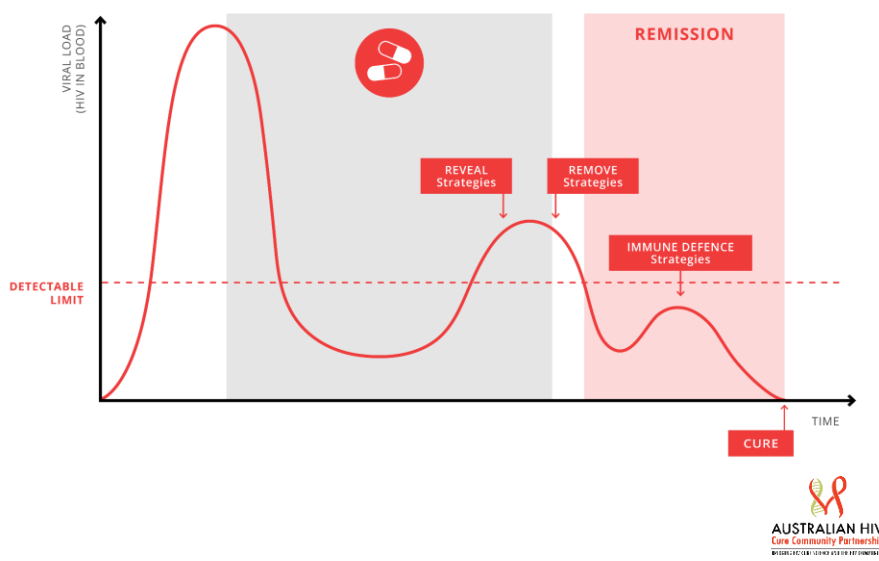Cure Community Partnership

Research phases and time

Pre-clinical	Phase 0/pilot	Phase 1	Phase 2	Phase 3	Phase 4
In vitro or animal models	Healthy or people with condition	Healthy or people with condition	People with condition	People with condition	People with condition
Novel strategy	Principle	Safety	Efficacy	Efficacy	Monitoring and evaluation
	<15	20-80	100's	100's to 1000's	1000's
No standard design.	Short duration, proof-of-concept trial, first in humans	Evaluate safety, establish dosage and identify side effects	Determine if treatment works as intended, more safety	More efficacy, usually in comparison to other standard interventions. Monitor adverse events	After market monitoring to understand adverse events. May assess use in combination with other therapies or for different condition.
<1 year	<1 year	months	months-years	years	ongoing

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Possibilities for HIV remission

HIV overview

Loving consideration – next steps

- Protect our partners e.g. context matters, PrEP, a Rapid Home HIV Viral Test (trials TI, remission, u=u, nature of relationships, vaccine, min resistance)
- Oz/global, ready to go, opt in, participant ready research/trial data set, that also maps individual values, beliefs, context and willingness and postcodes for politics.
- Honour role of participants with bios & personal story
- Be at the table with you to design research/trials and protocols, GIPA & MIPA
- Be your champion when you fail, HIV humbles everyone.
- Be with you to share our success

Every year we have the chance to lovingly save a million lives, a million points of loving light.

Yes its worth it!
Yes love is worth it!
Yes I will participate in a cure trial
yes I choose to give love

Thank you everyone for being a part of loving health care

HIVCure.com.au

Polling question 1

Imagine you are a wealthy philanthropist with 100million or more to invest, which HIV cure strategy would you choose?

A- Broadly neutralising antibodies

B- Gene therapy

C- Kick and Kill

D- Block and lock

E- All of the above

Polling question 2

Imagine you are living with HIV, which HIV cure strategy would you be willing to participate in?

A- Broadly neutralising antibodies

B- Gene therapy

C- Kick and kill

D- Block and lock

E- All of the above