

# Mr Simon Collins

HIV i-Base

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COMPETING INTEREST OF FINANCIAL VALUE $\geq$ £1,000:	
Speaker Name	Statement
Mr Simon Collins	None
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# Primary infection: to treat or not to treat? A community perspective



Simon Collins  
[www.i-Base.info](http://www.i-Base.info)

# Background

- Acute (<1 mo after infection/SC) vs
- Early (within 6 months of infection/PHI) – only an option for this minority of people.
- 14% of people are diagnosed early (19% MSM) <sup>[1]</sup> – likely to increase – HIV incidence largely linked to people unaware of HIV status: 2015 = YEAR TO TEST?
- It is a serious advocacy concern that treatment is not offered equally in all clinics.

1. PHE, HIV in the UK, 2013 - based on RITA, Appendix 5.

# i-Base Q&A

Advocacy service to support people with information.

Phone, email & web information service to informed choices.

Information needs to be accurate, up-to-date, balanced and easy to understand.

Never “what would you do”.



# Newly diagnosed

- Generally, a positive test is unexpected
- Generally, still traumatic (“think 80s”)  
“looked down walking over the bridge” [1]
- Wide age: 20% <35 – 25% >50 years [2]
- Different reactions and responses
- Individualising calls is essential



1. Young People's Discussion on HIV, September 2014, 56 Dean St. 2. HPE, 2013. Appendix 6.

# Patient choice: novel idea

- BHIVA guidelines include that patient choice should be central to HIV management.
- That treatment should be individualised.
- All patients have the chance to be involved in making decisions about their treatment.
- This can be unusual for someone to hear.
- It means people need to be asked.

BHIVA guidelines, HIV Medicine (2014), 15 (Suppl. 1), 1–88.

# Context for discussion

- Early ART (within 6 mo) is an interesting issue
- Guidelines based on same evidence disagree
  - UK = absence of proof of benefit vs risk
  - US = stronger for PHI (BII) than chronic >500 (BIII)
- There is no right answer – this depends on individual interpretation and choice
- UK access supports choice
- Also research options, inc. seroconverters register



# Potential benefits: ART in PHI

- Limit viral evolution, diversity, latent reservoir, preserve CD4, CD4:8 ratio, viral set point [1-6]
- Retain HIV-specific profile similar to LTNP [7]
- May be easier to cure with future research? [8]
- Reduce transmission risk, +/- condoms [9]
- 'Normalise' HIV – in coming to terms with HIV [9]
- Minimal impact in terms of lifetime ART [10]
- Replicate VISCONTI criteria [11]

1, Ananworanich (CROI 2013); 2. Primo-SHM (PLoS Med 2012); 3. SPARTAC (NEJM, 2013); 4 Strain MC (JID 2005); 5. Buzon (J Virol 2014); 6. Lécuroux (AIDS 2009); 7. Rosenberg ES (Nature 2000); 8. IAS Roadmap (2012); 9. PARTNER study (CROI 2014). 10. UK Seroconverters Register (BHIVA 2014); 11. VISCONTI (PLoS Path, 2013).

# Potential risks: ART in PHI

- Unknown aspects of treatment (vs HIV)
- Side effects: short-term, long-term
- Inconvenience, clinic visits, monitoring
- Daily reminder of HIV (1 minute a day?)
- Adherence, change in lifestyle
- Resistance (if not adherent)
- Medicalise life
- “lifelong treatment”

# Cautions: ART in PHI

- **Might make no difference – a chance...**
- **Life expectancy already normalised based on deferring ART until CD4 is ~350**
- **May never be a cure: rebound after 10 yrs <sup>[1]</sup>**
- **Better and easier drugs may come later**
- **Transmission may not be an issue (lifestyle related, choice, partner status etc)**

1, Chun T-W (AIDS 2010)

# UK access (if not offered)

- Rational for treating in PHI includes reduction in onward transmission.
- The evidence that ART lowers the risk of transmission should be discussed with all patients and a decision to start should be respected and ART started at any CD4 count.
- Option to change doctor or clinic.

BHIVA guidelines, HIV Medicine (2014), 15 (Suppl. 1), 1–88.

# Four practical issues

- 1) Likely time without ART
- 2) Issue of lifelong treatment
- 3) Research – now and in the future
- 4) Choice – discussion when relevant

# Likely time without ART?

- Assumption of five years without treatment
- Prospective data from UK Seroconverters Register is exactly matched for this group
- Median time to ART: 1.4 yrs (IQR 1.3 – 1.7)
- At CD4 <350 for 50% and >500 for 25%
- Excluded starting due to symptomatic acute

1. Parsons V. UK Seroconverters, BHIVA 2014. n=347 people diagnosed in 2009/10 within 6 months of infection.

# Lifelong treatment?

- Emphasis on life-long treatment is unhelpful: creates an unnecessary psychological hurdle - commitment to treatment is better.
- Switching/modification is common and easy.
- Stopping not recommended in guidelines but absolute risk from stopping once is very low.
- “you are the person taking the meds, so you can decide when to do this”.
- Stopping is an option.

# Research

- UK Seroconverters Register
- START results – clinical issues – CD4 >500
- CHERUB group – looking at future interventions in the UK for cure research
- HEATHER study – UK database for long term non- or slow progressors
- Global focus on cure and vaccine is optimistic



# Choice

- After the 6 months window there appears little urgency for when to start. Within this window there is an ethical issue to discuss US guidelines, cure studies and Visconti results.
- Early treatment can be effective way to manage an HIV diagnosis but will not be for everyone. Need to be asked – whatever the final outcome.
- I would not want to find out later that my doctor thought these were not important issues.

# Feedback

“I am happy that I started treatment early. I have complete belief in the treatment. I have had no real side effects. And the main factor that the treatment is destroying nearly all the HIV in me, makes me very happy to have started as early as I did.”

“I am still disappointed with my first doctor for not carefully considering my wishes in wanting to go on treatment. It was such an important decision and at a very fragile time.”

# Thank you

Thanks to following people for help with discussion and comment:

Callers to i-Base phonenumber

Polly Clayden

Lenny Estrada

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Richard Jefferys

Memory Sachikonye

# What is most important?

“Patients with recently diagnosed PHI may be in a particularly vulnerable psychological state and thus...

A) Want to do everything they can to feel more in control of a difficult situation.

B) Want to understand options if any decisions is unique to the 6 month window.

C) Are ill-prepared to commit to starting long-term treatment.

D) May want to return to as near normal life as possible with partners.

# US DHHS (2014)

- “...rationale ... based on theoretical benefits and the extrapolation of data from strategy trials”.
- Little new data on clinical benefit: only 6/26 references after 2011 (most on testing, transmission or resistance) – rated BII (compared to BIII for chronic with CD4 >500)
- Many plausible reasons refer to “acute” rather than early and recognises “early” is still too late.
- Conclusion: this is NOT an evidence-based decision for clinical benefit.

# Case study

- MSM ~ 50yo
- Diagnosed at central London NHS clinic
- One exposure risk within previous 50 days, supported by symptom and behaviour history
- Keen to start ART to reduce risk to any future partner, but also to “get back to normal”
- First CD4 = 520 cells/mm<sup>3</sup>; VL ~ 300 copies/mL

# Case study

- Dr: “you are a long term non-progressor”
- No option of treatment
- No discussion of TasP
- Told to come back in three months for monitoring.
- Via advocacy, contacted different clinic for second option and started ART within 6 month window

# Practical balance

- **Individualise:** +/- symptoms +/- risk history
- **Theoretical:** limits HIV-related risk
- **Optimism:** cure research or stopping treatment
- **Practical:** median time to start is 1.4 years
- **Normalise life:** reducing risk to partners, take control over HIV
- **Flexibility and safety:** few pills, can switch
- **Stopping is an option.**