



## Why might some people with HIV feel concerned about using treatment as prevention?

By **Christy Newman, John de Wit, Asha Persson, Martin Holt, Limin Mao, Sean Slavin and Michael Kidd**

The more than thirty year history of HIV medicine has featured dramatic successes and controversies. While contemporary research continues to break new ground across many different areas, much of the policy and community debate regarding the science of HIV medicine has become focused on when and why to make use of antiretroviral therapy (ART). As outlined in a number of articles in this issue of *HIV Australia*, the details involved in translating clinical trial successes in this area into feasible and acceptable ‘real world’ practices remain confoundingly complex.

One of the major new features of the changing landscape of HIV medicine is HIV treatment as prevention (TasP). The implementation of TasP is being shaped by the still relatively new evidence from randomised controlled trials that the use of ART to reduce HIV viral load to

undetectable can dramatically reduce the risk of sexual transmission of HIV. Many clinicians, governments and advocacy organisations in Australia and elsewhere have now taken up strong and aligned positions by recommending all people with HIV use ART as early as possible, to prevent the risk of both individual illness and onward transmission posed by ‘untreated’ HIV infection.<sup>1</sup> Yet the personal and situated insights of those asked to take these medications daily, as prescribed, and for the rest of their lives, have been largely absent from these debates. In particular, little has been heard from the perspective of those who hold concerns regarding the increasingly central role of medications in managing both the individual and community impacts of HIV in Australia.

As part of a broader study on ART initiation, from 2012 to 2014 we

conducted semi-structured interviews with 27 people living with HIV around Australia who were not using treatment at the time of interview. Our research was particularly interested in understanding why some people with HIV may feel concerned about using treatment, including for HIV prevention. While the dissemination of results is ongoing, three initial publications reported a number of findings which we hope will contribute to broadening the debate regarding the acceptability of treatment – and of treatment as prevention – across the diversity of people living with HIV.<sup>2,3,4</sup> In this article we summarise some of the emerging lessons from this research.

As background, it is essential to recognise that while work continues on estimating the number of people with HIV who are not currently using ART<sup>5</sup>, this is a minority of people living with HIV in the

Australian context. Our interviews with members of that group also suggest very few are in conflict with medical providers on the issue of using ART.<sup>6</sup> Most people with HIV who are not currently using treatment have either been diagnosed only recently, are not able to use these medications for other health reasons, or have a prescribing doctor who is cautious about recommending initiation when not yet deemed essential.<sup>7</sup> This doesn't mean these individuals don't hold any concerns or fears about the use of ART, but it does mean they are open to the possibility of starting when the time is 'right' despite these doubts.

Along with recognising that most people with HIV are currently using ART, it is also important to appreciate that many feel greatly reassured that effective treatment has been shown to dramatically reduce the risk of inadvertently transmitting HIV to sexual partners<sup>8</sup>, in addition to providing benefits for their own health. However, in our research with non-ART users we observed very high levels of awareness of, yet little support for, the use of ART to prevent transmission to others<sup>9</sup>. Instead, participants expressed a number of recurring concerns about this strategy.

Concerns focused on perceived tensions regarding who would benefit from TasP – the person taking the medication, or the government responsible for reducing infections, for example – and questions about whether TasP would encourage an over-reliance on or over-valuing of treatment above other risk reduction strategies.<sup>10</sup> As a gay man who was ART naïve but open to commencing treatment put it:

*'From what I [understand], they want to, and quite rightly so, lower the infection rates throughout the country and ... the more people that can go on medication, the lower the viral loads will become to undetectable, the less infectious they will become and this in turn can lower the infection rates. But throughout talking with other people, some of us, not all of us, but some people have come to the conclusion that ... it's not a good enough reason for someone to go on medication and potentially risk their health ... People should be on medication ... for their own health, not for political reasons ... I would much rather go along the lines of either abstinence or protected*

*sex or no risk sex, rather than go on HIV medication ... No, for me [the decision to start treatment would be] for health reasons purely.'*

— Simon: gay man, 40s, born in English speaking overseas country.

As emphasised in this quote, many participants were concerned that TasP assumed that the only reliable or responsible way to mitigate the risk of transmitting HIV is to engage fully with biomedical approaches to prevention, which can (perhaps inadvertently) lead to some people with HIV feeling they are not trusted to modify their behaviour in other ways to reduce risk. Other concerns were expressed regarding a perceived shift in treatment norms as policy support increased for early initiation and treatment as prevention. In a troubling development, a number of participants believed that since TasP principles began to be emphasised in HIV policy, notably less support and encouragement was provided in clinical and community settings for open and honest conversations about the doubts and fears some people hold about medication use in general, and ART in particular.<sup>11</sup>

We know the concept of citizenship in liberal democracies such as Australia incorporates the expectation that individuals take personal responsibility for all key life decisions, particularly those involving health.<sup>12</sup> This expectation needs to be complemented by support for those who are engaged in practices of thinking carefully and critically about important health decisions, and to actively encourage conversations with those who feel unsure about how to resolve their fears about the

potential risks of taking medicines. Given that treatment as prevention is markedly extending the range of possible benefits of and complexities in making treatment decisions today, providing an appropriately expansive and supportive environment for community discussion is surely even more necessary at this point in the epidemic.

As we have also observed in our research, people with HIV may have very sound reasons for not placing their trust in medicine: they know there are potential harms, they know they risk developing resistance, they know that science cannot tell them what the effects will be of using ART over a very long period.<sup>13</sup> People with HIV also know that some of the greatest advances in the field also caused significant harm to those who were early adopters, and uncertainty lingers regarding the risks of jumping on to another pharmaceutical 'rollercoaster'.<sup>14</sup> Thus, while many would argue there is sufficient evidence available today regarding the safety and effectiveness of ART to counter any lingering doubts among potential consumers, reluctance to engage in a lifelong HIV treatment regimen is influenced by a far more complex and interrelated set of factors than simply awareness and appreciation of the potential benefits.

The process of making decisions about medication use is always shaped by individual history and circumstances. Since HIV treatment is a lifelong, daily practice, even if doubts are resolved, they may re-emerge over time, with ART involving, at a minimum, a once-a-day commitment to a lifelong therapeutic plan. Our participants defended their right to

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make treatment decisions carefully and based on their own unique circumstances and trajectories, without undue pressure or coercion from peers or prescribers, or the presumption that they needed to simply accept the evidence for commencing ART as clear and uncontroversial.

Opportunities for safe, supported dialogue and the exchange of peer accounts of the experience of treatment can reassure those with doubts, and comfort those who find the challenges and complexities of treatment significant. Thus, encouraging open conversations in clinical, community and policy contexts about these diverse perspectives will be essential in engendering public trust in a new era of treatment and prevention.

## References

- 1 For comment from Australian community HIV organisations regarding early treatment see: AFAO. (2015). *Groundbreaking evidence about early HIV treatment*. AFAO website news [online]. AFAO, Sydney. Retrieved from: <http://ow.ly/NxagF>
- 2 Newman, C., de Wit, J., Persson, A., Holt, M., Slavin, S., Kidd, M., et al. (2015). Understanding concerns about treatment-as-prevention among people with HIV who

- are not using antiretroviral therapy. *AIDS and Behavior*, 19(5), 821–831. doi: <http://dx.doi.org/10.1007/s10461-014-0959-9>
- 3 Newman, C., Mao, L., Persson, A., Holt, M., Slavin, S., Kidd, M. R., et al. (2015). 'Not Until I'm Absolutely Half-Dead and Have To:' accounting for non-use of antiretroviral therapy in semi-structured interviews with people living with HIV in Australia. *AIDS Patient Care and STDs*, 29(5), 267–278. 275 doi: <http://dx.doi.org/10.1089/apc.2014.0301>
- 4 Persson, A., Newman, C., Mao, L., de Wit, J. (forthcoming). On the margins of pharmaceutical citizenship: Not taking HIV medication in the 'treatment revolution' era. *Medical Anthropology Quarterly*.
- 5 Mao, L., de Wit, J., Adam, P., Post, J. J., Crooks, L., Kidd, M. R., et al. (2013). Australian prescribers' perspectives on ART initiation in the era of "treatment as prevention". *AIDS Care*, 25(11), 1375–1379. doi: <http://dx.doi.org/10.1080/09540121.2013.766304>
- 6 Newman, C., Mao, L., Persson, A., et al. (2015). op. cit
- 7 Mao, L., Adam, P., Kippax, S., Crooks, L., Post, J., Kidd, M., et al. (2015). The evolving views and practices of antiretroviral treatment (ART) prescribers in Australia. *Medical Journal of Australia*, 202(5), 258–261.
- 8 Persson, A. (forthcoming). 'The world has changed': Pharmaceutical citizenship and the reimagining of serodiscordance among couples with mixed HIV status. *Sociology of Health & Illness*.

- 9 Newman, C., de Wit, J., Persson, A., et al. (2015). op. cit
- 10 ibid.
- 11 Persson, A., Newman, C., Mao, L., et al. (forthcoming). op. cit.
- 12 Petersen, A., Davis, M., Fraser, S., Lindsay, J. (2010). Healthy living and citizenship: an overview. *Critical Public Health*, 20(4), 391–400. doi: <http://dx.doi.org/10.1080/09581596.2010.518379>
- 13 Newman, C., Mao, L., Persson, A., et al. (2015). op. cit.
- 14 Newman, C., Persson, A., Ellard, J. (2006). 'We just don't know': ambivalence about treatment strategies in the Australian community-based HIV media. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 10(2), 191–210.

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