youme&hiv
the serodiscordant couples study

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## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>iv</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>1</td>
</tr>
<tr>
<td>Recommendations</td>
<td>2</td>
</tr>
<tr>
<td><strong>1. Introduction</strong></td>
<td>3</td>
</tr>
<tr>
<td><strong>2. The Study</strong></td>
<td>5</td>
</tr>
<tr>
<td>2.1 Recruitment</td>
<td>5</td>
</tr>
<tr>
<td>2.2 Interviews</td>
<td>5</td>
</tr>
<tr>
<td>2.3 Analysis</td>
<td>6</td>
</tr>
<tr>
<td>2.4 Scope of this report</td>
<td>6</td>
</tr>
<tr>
<td><strong>3. Participant Profiles</strong></td>
<td>7</td>
</tr>
<tr>
<td><strong>4. Sexual Practices</strong></td>
<td>9</td>
</tr>
<tr>
<td>4.1 Condom/less sex</td>
<td>9</td>
</tr>
<tr>
<td>4.2 Non/monogamy</td>
<td>10</td>
</tr>
<tr>
<td>4.3 Positioning</td>
<td>11</td>
</tr>
<tr>
<td><strong>5. HIV Treatment</strong></td>
<td>12</td>
</tr>
<tr>
<td>5.1 Treatment uptake</td>
<td>12</td>
</tr>
<tr>
<td>5.2 Attitudes towards ART</td>
<td>12</td>
</tr>
<tr>
<td><strong>6. Treatment as Prevention</strong></td>
<td>14</td>
</tr>
<tr>
<td>6.1 Knowledge and views of TasP</td>
<td>14</td>
</tr>
<tr>
<td>6.2 Impact of TasP on sexual practice</td>
<td>14</td>
</tr>
<tr>
<td>6.3 TasP and risk perceptions</td>
<td>16</td>
</tr>
<tr>
<td>6.4 Knowledge and views of PrEP</td>
<td>17</td>
</tr>
<tr>
<td><strong>7. Clinical Engagement</strong></td>
<td>21</td>
</tr>
<tr>
<td>7.1 Viral load testing</td>
<td>21</td>
</tr>
<tr>
<td>7.2 HIV testing</td>
<td>22</td>
</tr>
<tr>
<td>7.3 STI testing</td>
<td>22</td>
</tr>
<tr>
<td><strong>8. Advice and Reflections</strong></td>
<td>24</td>
</tr>
<tr>
<td>8.1 Advice to other couples</td>
<td>24</td>
</tr>
<tr>
<td>8.2 Advice to policymakers and service providers</td>
<td>25</td>
</tr>
<tr>
<td>8.3 Interactive workshop with stakeholders</td>
<td>25</td>
</tr>
<tr>
<td><strong>References</strong></td>
<td>27</td>
</tr>
<tr>
<td><strong>Appendix A: Interview Schedule</strong></td>
<td>35</td>
</tr>
<tr>
<td><strong>Appendix B: Publications and Outputs</strong></td>
<td>38</td>
</tr>
</tbody>
</table>
### List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1</td>
<td>Sexuality, gender and serostatus</td>
<td>20</td>
</tr>
<tr>
<td>Table 2</td>
<td>Type of serodiscordance</td>
<td>21</td>
</tr>
<tr>
<td>Table 3</td>
<td>Sexual practices</td>
<td>22</td>
</tr>
<tr>
<td>Table 4</td>
<td>Sexual practice and type of serodiscordance</td>
<td>23</td>
</tr>
<tr>
<td>Table 5</td>
<td>Sexual positioning</td>
<td>24</td>
</tr>
<tr>
<td>Table 6</td>
<td>Testing</td>
<td>24</td>
</tr>
</tbody>
</table>
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACON</td>
<td>AIDS Council of New South Wales</td>
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<tr>
<td>AFAO</td>
<td>Australian Federation of AIDS Organisations</td>
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<tr>
<td>AIDS</td>
<td>acquired immune deficiency syndrome</td>
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<tr>
<td>ARCSHS</td>
<td>Australian Research Centre in Sex, Health &amp; Society</td>
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<tr>
<td>ART</td>
<td>antiretroviral treatment</td>
</tr>
<tr>
<td>ASHM</td>
<td>Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine</td>
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<tr>
<td>CSRH</td>
<td>Centre for Social Research in Health</td>
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<tr>
<td>HIV</td>
<td>human immunodeficiency virus</td>
</tr>
<tr>
<td>HPTN</td>
<td>HIV Prevention Trials Network</td>
</tr>
<tr>
<td>NAPWHA</td>
<td>National Association of People with HIV Australia</td>
</tr>
<tr>
<td>PrEP</td>
<td>pre-exposure prophylaxis</td>
</tr>
<tr>
<td>STI</td>
<td>sexually transmitted infection</td>
</tr>
<tr>
<td>TasP</td>
<td>treatment as prevention</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<td>UNSW</td>
<td>University of New South Wales</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
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**Interviewer** Asha Persson.

**Editor’s note on interview quotes**

Words in square brackets are editorial interpolations, made either to provide explanations or to preserve the anonymity of the interviewee. Ellipses […] indicate an editorial cut, usually made because the interviewee repeated themselves or said something irrelevant to the point for which the quotation is being cited.
Executive Summary

Sexual practice
A spectrum of sexual practices was described by participants: nine couples (all gay) consistently used condoms with penetrative sex, 11 couples had consensual condomless sex, two did not have penetrative sex, and three alternated between condoms and condomless sex (in two heterosexual couples to facilitate or prevent conception). Couples who had met after the positive partner’s diagnosis were more likely to practice condomless sex than those who had met before diagnosis, especially among gay couples. Heterosexual couples were more likely to practice condomless sex regardless of when they met. Very few of the gay couples used strategic positioning, and most negative partners were the receptive partner. A majority of couples described themselves as monogamous.

HIV treatment
In 20 of the 25 couples represented in the study, the positive partners were on antiretroviral treatment (ART), with a further three planning to start. There was strong support for HIV treatment expressed by both HIV-positive and HIV-negative partners. Treatment was a central theme across almost all interviews and commonly framed as fundamental in serodiscordant relationships because of its capacity to protect the health of both partners and thereby enable a sense of sexual safety, normality, and future.

Treatment as prevention
There was broad awareness of treatment as prevention (TasP), or at least of the effects of treatment on viral load and infectiousness. All but one HIV-positive partner had an undetectable viral load. Both HIV-positive and HIV-negative partners were strongly in favour of TasP, particularly in the context of serodiscordant partnerships. Yet TasP had diverse impacts on perceptions of risk and thus on couples’ sexual practice. Regardless of sexual practice, a large majority reported not being particularly worried about transmission, citing their risk as very low. Several HIV-negative partners felt it was much safer having sex with a positive partner on ART than with casual partner of unknown status. Two thirds of participants had heard about pre-exposure prophylaxis (PrEP), but many couples did not see it as relevant because they felt their current sexual practices were already safe enough.

Clinical engagement
There was a very strong commitment among HIV-positive partners to regularly monitor their viral load. Being in a serodiscordant relationship was a major motivator for positive partners to remain actively engaged with clinical care. About two thirds of the HIV-negative partners regularly tested for HIV, primarily for reassurance or as part of routine health check-ups, rather than based on concern about transmission. Most of the negative partners who did not test regularly were heterosexual. Less than half of the participants tested regularly for other sexually transmissible infections (STIs).
Recommendations

Clinical services, HIV policy, community health promotion programs and serodiscordant couples are operating in a time of evolving social and scientific understandings of TasP and PrEP. It is therefore recommended that:

- Health promotion strategies targeting serodiscordant couples be flexible and nuanced, to ensure that individual serodiscordant couples see TasP and PrEP as options with the capacity to reduce anxiety about HIV transmission and enable new forms of intimacy. Without nuance, such promotion may be seen as irrelevant, increase rather than decrease anxiety about transmission, or potentially increase expressions of stigma concerning those with or without undetectable viral load.

- The HIV sector responds to PrEP literacy gaps between heterosexual and gay people living with HIV. This is to ensure that clinics and support organisations are resourced to provide relevant information about PrEP to serodiscordant heterosexual couples, including how to access PrEP and the circumstances in which PrEP might be beneficial, for example in relation to conception or when the HIV-positive partner is not able to achieve an undetectable viral load.

- The promotion of TasP is considered in the context of its relationship to testing services for HIV and viral load. Increasing the availability and convenience of testing services for serodiscordant couples will be important if the benefits of TasP and PrEP are to be maximised. This may include a mix of home-based and rapid testing services. Specifically, we recommend that:
  - The HIV sector explores easily accessible testing options for HIV-negative partners in heterosexual serodiscordant couples.
  - Further research and analysis of existing data be undertaken to better understand the HIV testing needs of serodiscordant couples, including barriers to testing, access to HIV rapid testing and the suitability of home-based testing technology for these couples.
  - The HIV sector collaborates to ensure the application of testing guidelines assists couples and clinicians to identify how frequently HIV-negative partners should test with reference to different risk-reduction strategies, including TasP, and whether the couple has a monogamous or non-monogamous relationship.

- The HIV sector investigates ways to more effectively address HIV-negative partners in serodiscordant couples as a specific group with unique clinical and health promotion needs that are distinct from those of their HIV-positive partners, other at-risk groups and the general HIV-negative population.

- Health services actively refer newly diagnosed patients in serodiscordant partnerships to peer support programs run by community organisations, particularly heterosexual men and women who might have less ready access to sources of information and support.

- Messages from health promotion and clinical services be accurate and consistent, as well as compatible with the specific risk reduction strategies adopted by individual couples. For example, promoting PrEP and condoms to serodiscordant couples who have already incorporated the extremely low chance of transmission with undetectable viral load into their lives may be seen by couples as incongruent and therefore reduce the credibility of the services.
This report describes a set of key findings from *YouMe&HIV*, a qualitative study of serodiscordant gay and heterosexual couples in New South Wales (NSW), the Australian state with the largest population of people with HIV. As the first study of its kind in Australia, it aimed to examine how couples experience and manage their mixed HIV status in a changing HIV epidemic. The study directly responded to the call to “improve understanding of the experiences and HIV prevention needs of people in serodiscordant relationships”, which had been outlined as a social research priority by the NSW Ministry of Health (2006). The study was funded by the NSW Ministry of Health and commenced shortly after the Ministry released its HIV strategy, *A New Era* (2012), which set ambitious HIV treatment and prevention targets in response to the United Nations’ (2011) political Declaration on HIV and AIDS, which called on the world to intensify its efforts to eliminate new HIV transmissions.

Couples with mixed HIV status exist wherever the epidemic exists. In Australia, the *HIV Futures* surveys have found that, across time, between a quarter and a third of people with HIV have an HIV-negative primary partner (Ezzy et al., 1998, Grierson et al., 2013). There are no global statistics on the prevalence of serodiscordant relationships, but the World Health Organization (WHO 2012a) estimates that as many as half of all HIV-positive people in long-term primary relationships have an HIV-negative partner. HIV research from around the world similarly suggests that these relationships are common (Chemaitelly & Abu-Raddad, 2014, Eyawo et al. 2011, Dunkle et al. 2008, UNAIDS 2009, Saggurti and Malviya 2009, Guzman et al. 2006, Beyeza-Kashesya et al., 2009, WHO 2012b).

Even though serodiscordant relationships are relatively common, they remain largely invisible because of HIV-related stigma, particularly in the context of sex. Indeed, sexually intimate serodiscordant relationships have long been considered a primary driver of the global HIV epidemic (UNAIDS/WHO 2009, NIMH 2010, King, et al. 2012, Chemaitelly & Abu-Raddad, 2012). Research over time and in diverse global settings has consistently found that condom use is far from the norm in these couples, even when they are aware of their mixed HIV status (Skurnick et al., 1998, van der Straten et al., 1998, Buchacz et al., 2001, Milam et al., 2006, Aidala et al., 2006, Stevens and Galvao 2007, Bradley et al., 2008, Reis and Gir 2009, Orengo-Aguayo and Pérez-Jiménez 2009, Hernando et al., 2009, Beyeza-Kashesya et al., 2010, Lau et al., 2013). The same has been found among serodiscordant couples in Australian research (Grierson et al., 2012, Persson, 2015a, Persson et al., 2009).

However, the notion of serodiscordant partnerships as a key context for HIV transmission is now being challenged by the rapidly moving field of HIV medical science, which has radically changed how the virus and its transmission are understood. Serodiscordant couples have played a crucial role in these recent “game-changing” (Sidibé 2011) breakthroughs in HIV medicine, most notably TasP or “treatment-as-prevention” (Muessig & Cohen 2014). Several clinical trials with heterosexual and gay serodiscordant couples have demonstrated that people with HIV who are on effective antiretroviral treatment are sexually non-infectious under certain conditions, thereby reducing the...
chance of transmission to a sexual partner to near negligible (Cohen et al. 2011; Rodger et al. 2014, Grulich et al., 2015). Serodiscordant couples have also been instrumental in trials showing that pre-exposure prophylaxis (PrEP) is another potentially effective biomedical HIV prevention technology (Grant et al., 2010, Baeten et al., 2012).

Changes in HIV treatment guidelines in several resource-rich countries, including Australia, reflect a rapidly growing global agenda for early and universal treatment of HIV infection in response to the mounting evidence of its capacity as a public health strategy, as well as its long-term individual health benefits (ASHM 2014, WHO 2012a, UNAIDS, 2012, INSIGHT START Study Group 2015). In Australia, as elsewhere, there is little disagreement among HIV advocates, clinicians, medical and social scientists that TasP is clinically effective, but there has been much debate about how biomedical prevention technologies will “work” outside the controlled milieus of clinical trials, especially their population-level effectiveness, their “real-world” implementation, and the political and ethical implications for people with HIV and for their clinicians (e.g. Kippax, 2015, Cameron and Godwin 2014, Mao et al., 2013, Wilson 2012, Persson, 2015b). Social scientists in particular have argued that biomedical HIV prevention will be ineffective if it disregards the myriad of social factors that shape sexual practices, risk perceptions and treatment uptake (Dowsett, 2013, Nguyyen et al., 2011, Adam, 2011; Kippax & Stephenson, 2012; Kippax et al., 2011; Persson, 2013a).

As TasP and PrEP are recent developments, the research literature on the acceptability and uptake of these prevention technologies among affected populations is understandably still relatively small (Young and McDaid, 2014, Holt et al., 2014, Carter, et al., 2015, Auerbach, et al., 2015, Young, Flowers and McDaid, 2015, Kubicek, et al., 2015). Notably, despite the key role of serodiscordant couples in biomedical prevention trials, and despite being identified as a primary target group for TasP (WHO, 2012b), studies that focus specifically on mixed-status couples are particularly scant (Ware et al., 2012, Brooks, et al., 2012, Curran et al., 2014).

Knowledge about serodiscordant couples outside the confines of controlled clinical studies remains limited more broadly. Given that the advances in biomedical HIV prevention are still being debated and investigated, it is perhaps not surprising that much of the research related to serodiscordance continues to be preoccupied with “risk” (Persson 2013b, Persson, Ellard and Newman 2015). The literature is largely dominated by public health and behavioural research, which is focused on sexual risk behaviour and HIV transmission in serodiscordant couples (e.g. LaCroix et al. 2013; Starks et al. 2014; Baggaley et al. 2013, Lasry et al., 2014, Loutfy et al., 2013). What we find less often in the literature is qualitative research that explores how serodiscordant partners themselves perceive “risk” and manage their mixed HIV status; this is still an under-developed, albeit growing field (e.g. David and Flowers, 2011, Beougher et al., 2013, Kelly and Lohan, 2011).

As advances in medical science have repositioned HIV as a manageable chronic condition and created new opportunities for intimate and reproductive relationships in the context of HIV, it is timely to examine not only how couples negotiate new prevention technologies, but also how these technologies and the science behind them affect how serodiscordance itself is perceived. Such information is equally valuable in terms of informing prevention policies and health interventions by providing a nuanced understanding of the ways intimate serodiscordant partnerships can not only shape but also prevent pathways to HIV risk.
2. The Study

As the first qualitative study of gay and heterosexual serodiscordant couples in Australia, YouMe&HIV aimed to build a picture of the social, medical, and sexual worlds of these couples and to understand how they experience and manage their mixed HIV status in a changing epidemic. The study was conducted between 2013 and 2016 by the Centre for Social Research in Health at UNSW Australia in collaboration with the Kirby Institute (UNSW), the Australian Research Centre in Sex, Health and Society (La Trobe University), and several community HIV organisations, including the Heterosexual HIV Service (Pozhet); the Multicultural HIV and Hepatitis Service NSW; Positive Life NSW; ACON; Family Planning NSW; and the Albion Centre. The study was funded by the NSW Ministry of Health and the Australian Government Department of Health. Ethics approval was granted by the UNSW Human Research Ethics Committee (approval reference no: HC12627) and ACON’s Research Ethics Committee (approval reference no: 2013/2).

2.1 Recruitment

Participants were recruited through flyers, word-of-mouth, and the websites and print media of HIV community organisations. Recruitment materials specified the purpose of the study: to better understand the experiences of mixed-status couples in the biomedical age and for this knowledge to inform policy and health promotion. Study participants had to be 18 years or older, be in a committed and sexually active serodiscordant relationship of at least 2 months, and live in Greater Sydney, the Northern Rivers region, the Hunter and Newcastle region (at a later stage in the recruitment process, people from any regional area in NSW were eligible to participate). HIV status was based on self-report and “committed” relationship was self-defined. The study was open to both couples and individual partners so as to not disadvantage individuals whose partner did not want to participate, as well as to optimise recruitment and maximise the diversity of stories and relationships represented in the study.

2.2 Interviews

Interviews with “key informants” were conducted as part of the initial phase of the study, with the purpose to canvass key issues for serodiscordant couples from the perspectives of HIV service providers who work closely with this population. Twenty HIV service providers participated in semi-structured interviews between February and June 2013. They worked in various professional capacities in state-based public health settings, including hospital HIV clinics, sexual health clinics and government-funded state-wide HIV organisations. They included three HIV/sexual health doctors, three infectious diseases specialists, five clinical and community nurses, four HIV educators and health promotion officers, three social workers, and two psychologists/counsellors. Nine were located in regional centres, while 11 were located in metropolitan Sydney and outer Sydney suburbs. These interviews focused on what the service providers saw as significant issues
for serodiscordant couples generally, as well as specifically in relation to the implementation of TasP. Key issues identified in these interviews informed the development of the interview schedules for serodiscordant couples and have been discussed in detail elsewhere (Persson, 2015b).

Interviews with people in serodiscordant relationships were conducted between mid-2013 and late-2014, either face-to-face or by phone, depending on participants’ preference and location. The majority of face-to-face interviews were conducted in the participants’ homes or in a private room at an HIV community organisation. Except for three couples who opted to be interviewed together, partners were interviewed separately to ensure they were able to speak freely and confidentially. Interviews lasted 1.5 hours on average, though some were considerably longer, and covered a range of social, medical, relational, and sexual issues relevant to serodiscordance (Appendix 1: Interview schedule). The semi-structured, in-depth interview format allowed study participants to thoroughly explore these issues and tell their story in their own way. All interviews were conducted by Asha Persson.

2.3 Analysis

The interviews were digitally recorded, transcribed verbatim and de-identified to protect confidentiality. All participants were allocated a pseudonym. Interview transcripts were coded by hand, generating “open” codes to organise the material into thematic categories based on the interview questions. Using thematic analysis, the foundational method for qualitative analysis (Guest 2012), these broad categories were organised into sub-categories, focusing on identification of recurrent and divergent themes within and across interviews. The resulting thematic codes were then analysed in detail to build a rich and contextualised understanding of the key issues that arose across the interviews.

2.4 Scope of this report

This report focuses on the data collected through the study which reveals new information about HIV treatment and prevention among serodiscordant couples in the biomedical era. However, the interviews explored a wider array of additional issues related to living serodiscordantly, which yielded rich stories and interesting and important themes. Aspects of that broader span of material are explored in other publications and presentations, including stories of how participants met their partner, telling and being told about HIV, everyday impacts of mixed HIV status, reproduction and family life, stigma and normality, serostatus identities, and trust in relation to partners, HIV medicine, and HIV care providers (see Appendix 2: Publications and outputs). Further publications of some of these themes are also forthcoming. We also wish to acknowledge that some of the findings and interview quotes in this report have previously been published in peer-reviewed journal articles (Persson 2015a, Persson, Newman and Ellard 2015). A comprehensive bibliography of serodiscordant literature is compiled at the end of this report, providing a resource for couples, researchers, and other stakeholders.
3. Participant Profiles

In all, 38 people took part in an interview, including 30 men, six women, one transwoman and one transman. Of these participants, 18 were HIV-positive and 20 HIV-negative. Thirteen couples (n=26) and 12 individual partners participated, representing 25 couples in total, including one “throuple” (involving three partners). This included 16 gay couples, seven heterosexual couples, one gay man/transman couple, and one transwoman/heterosexual man couple. The high proportion of gay men reflects the pattern of HIV infection in Australia, which has a concentrated epidemic among gay men. There are an estimated 27,150 people living with HIV in Australia (Kirby Institute 2015).

Table 1: Sexuality, gender and serostatus

| Gay men        | 24 | HIV-positive: 10  |
|               |    | HIV-negative: 14 |
| Heterosexuals | 11 | HIV-positive women: 4 |
|               |    | HIV-negative men: 2 |
|               |    | HIV-positive men: 2 |
|               |    | HIV-negative men: 3 |
| Bisexual      | 1  | HIV-positive |
| Transgender   | 2  | HIV-positive transwoman: 1 |
|               |    | HIV-negative transman: 1 |
| HIV-positive  | 18 | Couples represented in the study = 25 |
| HIV-negative  | 20 | (including one “throuple”) |
| Couples       | 13 (n=26) | Gay couples: 16 |
| Individual partners | 12 | Heterosexual couples: 7 |
|               |    | Transman/gay man: 1 |
|               |    | Transwoman/heterosexual man: 1 |

Fourteen participants resided in Sydney; 12 resided in the Northern Rivers region, while another 12 resided in other regional areas in NSW. Most couples co-habited. There was considerable diversity among participants in terms of age, cultural background, employment status, and relationship length. Information about educational status was not collected. Ages ranged from 25 to 70 years old, with the majority in their 30s and 40s. Just under a third of the participants were born overseas, and two had immigrant parents. Cultural backgrounds included South America, East and West Africa, Southern Europe, the Middle East, Asia, the USA, the UK, and New Zealand Pakeha and
Maori. A slight majority (n=20) were in full-time employment, three of whom were self-employed, four were recently unemployed, nine received income support, including the disability support pension, veterans’ pension, old age pension and Newstart, and five were studying or looking after children, or both. Relationship length ranged from 2 months to 20 years, with an average of 3-5 years. One man was recently single, but was included due to having been in a 20-year long serodiscordant relationship.

Twelve participants had a total of 23 biological children. Six of these children were born in the context of a serodiscordant relationship; two were conceived through IVF, while in one case the mother had not been aware that she was HIV-positive at the time of conception. At the time of the study, two couples were attempting to conceive (one through condomless sex and one through IVF), and another child was about to be born (to an HIV-positive gay donor father). Three participants had adopted or step-children. In all, there were 29 children associated with the participants.

Twelve couples had met already serodiscordant (i.e. they had formed their relationship after the positive partner’s HIV diagnosis), while 13 couples had met prior to one partner being diagnosed with HIV. In four of these couples, the diagnosis was received shortly after the relationship had started, and in three couples, infection was attributed to sex outside the relationship. All HIV-positive partners had disclosed their HIV status to their HIV-negative partner, except for one participant who was in a new relationship of only five months and who was not having penetrative sex. This participant had been in a previous and mutually known serodiscordant relationship for many years, and was planning to disclose also to the new partner.

Table 2: Type of serodiscordance

<table>
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<td>Met before HIV diagnosis</td>
<td>13</td>
</tr>
<tr>
<td>- Diagnosis occurred shortly after start of relationship</td>
<td>4</td>
</tr>
<tr>
<td>- Infection due to sex outside the relationship</td>
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4. Sexual Practices

4.1 Condom/less sex

A variety of sexual practices were described by the study participants. Nine couples (all gay) consistently used condoms with penetrative sex, 11 couples had consensual condomless sex, two did not have penetrative sex, and three couples alternated between condoms and condomless sex, which in two heterosexual couples was based on trying to either facilitate or prevent conception.

We are now using condom a lot, because we don’t [want to] have more kids for sure ... But all those years we never use condom. Yeah. Never. We never use condom. We are using condoms now just preventing pregnancy. He is not using condom because he’s preventing anything to be infected from HIV, no (Jasmine, 28 years old, HIV-positive, born overseas).

Table 3: Sexual practices

<table>
<thead>
<tr>
<th>Sexual practice</th>
<th>Couples</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condoms (consistently)</td>
<td>9</td>
<td>all gay</td>
</tr>
<tr>
<td>Condomless</td>
<td>11</td>
<td>• gay couples: 5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• heterosexual couples: 5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• transman/gay man: 1</td>
</tr>
<tr>
<td>Mixed condoms/condomless</td>
<td>3</td>
<td>• gay couples: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• heterosexual couples: 2</td>
</tr>
<tr>
<td>Non-penetrative sex</td>
<td>2</td>
<td>• gay couples: 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• transwoman/heterosexual man: 1</td>
</tr>
</tbody>
</table>

Some gay couples were well-established in their condom use and did not present it as an issue. However, several gay couples found condom use frustrating, but described it as non-negotiable in the perceived absence of any reliable alternative. To quote 41-year old HIV-positive partner Leo:

I mean obviously ... I’d like to be more intimate with him without condoms, but I mean that’s not possible. And I understand that. But that’s what happens. I mean, you don’t choose who you fall in love with ... [so] we just take care of each other in that respect.

It was particularly challenging for some couples who had practiced condomless sex prior to one partner being diagnosed, when they suddenly had to introduce condoms into their sexual dynamics, as 28-year old HIV-negative partner Damien explained:

Like it’s annoying, but what can I do? ... We were both agreeing straight away [to use condoms]. I think he’d probably prefer it, if it wasn’t for the closeness thing. But, actually, he did say to me, like with a little bit of anger, like, “We’re never gonna be able to not use them again,” and I just [said], “Well what can we do? I mean we can get upset and stamp our
Couple who had met already serodiscordant were more likely to practice condomless sex than those who had met before diagnosis, especially among the gay couples. Heterosexual couples were more likely to practice condomless sex regardless of when they met. There might be several explanations for this, including less exposure to prevention messages and safe sex cultures compared to gay men, heterosexual gender dynamics and the cultural construction of heterosexual sex as “natural” (Persson and Richard, 2008, Persson, Barton and Richards, 2006). However, most heterosexual couples also made references to TasP, undetectability, and epidemiological science that suggests the risk of transmission is low in the context of heterosexual vaginal sex (Boily et al., 2009).

| Met before diagnosis/ condoms | 7 | gay couples: 7 |
| Met before diagnosis/condomless sex | 5 | heterosexual couples: 4, gay throuple: 1 |
| Met after diagnosis/condoms | 2 | gay couples: 2 |
| Met after diagnosis/condomless sex | 9 | gay couples: 5, heterosexual couples: 3, transman-gay man couple: 1 |

These sexual patterns are fairly consistent with research from across the world, which shows that condom use is far from the norm among couples in known serodiscordant relationships (see Persson 2013b). We explore these sexual practices in more detail in the section on treatment as prevention.

4.2 Non/monogamy

A majority of couples (n=14) described themselves as monogamous, including seven gay couples, the transwoman/heterosexual man, and all heterosexual couples (except for one couple who had recently divorced due to infidelity). Seven gay couples had an open relationship, while two gay couples and the transman/gay man couple only had sex with others together. Those who had an agreement to only have sex with others together tended to also describe their relationship as “monogamous”. In some couples, the open relationship was more “in theory than practice” as they did not act on their agreed permission to have external sex. Conversely, some monogamous gay couples struggled with trust, worrying that their partner was secretly having sex outside the relationship.

> The trust between us has certainly caused us problems at times ... I don’t know about him, but I haven’t had, you know, I haven’t played with anyone else since we’ve been together. He doesn’t, he doesn’t believe that.

Monogamy or open relationships were primarily based on preference rather than related to HIV. Some couples had become more sexually introspective after the diagnosis, turning to each other for sexual solace and solidarity. However, two couples had decided to open their relationship in direct response to the HIV-positive partner’s diagnosis as concerns about potential transmission within the relationship had affected their sex life:

> He was being cautious and I was feeling that I had to be cautious as well. And, in a way, I guess that’s why he also accepted to open the relationship early because, yeah, I guess he
felt that we couldn’t be as passionate as we used to be (Ramón, 38 years old, HIV-negative, born overseas).

Only one couple, a gay couple who had condomless sex, described HIV as a contributing factor in their decision to be monogamous:

Just the fact that I could have picked up an STI has stopped me actually playing around anyway, because I thought, “Well I don’t actually wanna risk getting an STI because of what I’m doing with [partner]. I don’t wanna risk him.” So I ended up becoming monogamous just because I actually wanted to keep myself well and keep [partner] well ... So, yeah, I guess HIV did play a role in that because of all the STI stuff getting mixed up with that and just try and minimise risk again (Blake, 42 years old, HIV-positive).

Those with an open relationship, or who played with others together, generally had agreed rules around how to safely manage outside sexual interactions. While this was seen as fairly straightforward in terms of prevention strategies, it was sometimes challenging emotionally. A few of the HIV-negative partners said they felt uncomfortable or threatened by their partner’s ability to have bareback sex with other positive men, while they felt restricted to using condoms both within and outside the relationship. In some cases, it was the positive partners who felt that their negative partner had more sexual opportunities than they did because of their HIV status.

### 4.3 Positioning

None of the couples practiced strategic positioning\(^1\) as a deliberate risk reduction strategy, although most were aware of it. Sexual positioning was exclusively based on preference or heterosexual gender.

Well [partner]’s always been the top for us … I suppose it’d be probably less safe I guess, when I think about it … No, that was just the natural way that we reacted (Elliott, 62 years old, HIV-negative).

Anal sex was not practiced by any of the heterosexual couples or by the transman/gay man couple. Four gay couples described themselves as versatile, while one gay couple and the transwoman/straight man couple did not have penetrative sex. In 13 couples, the HIV-negative partner was the sexually receptive partner; this included two heterosexual women and the transman. In six couples, the HIV-negative partner was the insertive partner; this included four heterosexual men. Hence, in the majority of gay couples, the receptive partner was HIV-negative. Most couples knew that this positioning was considered less safe, but there was a general sense that treatment-as-prevention had made sexual positioning redundant or less important as a risk reduction strategy.

#### Table 4: Sexual positioning

<table>
<thead>
<tr>
<th>Sexual Positioning</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receptive HIV-negative partners</td>
<td>13</td>
</tr>
<tr>
<td>- women: 2</td>
<td></td>
</tr>
<tr>
<td>- transman: 1</td>
<td></td>
</tr>
<tr>
<td>- gay men: 10</td>
<td></td>
</tr>
<tr>
<td>Insertive HIV-negative partners</td>
<td>6</td>
</tr>
<tr>
<td>- heterosexual men: 4</td>
<td></td>
</tr>
<tr>
<td>- gay men: 2</td>
<td></td>
</tr>
<tr>
<td>Versatile couples</td>
<td>4</td>
</tr>
<tr>
<td>Non-penetrative sex</td>
<td>2</td>
</tr>
</tbody>
</table>

\(^1\) Strategic positioning is the practice of choosing a different sexual position depending on the serostatus of one’s partner. In terms of risk reduction, it is considered safer if a person with HIV takes the receptive position during condomless anal sex with an (known or assumed) HIV-negative partner, based on the belief that it is less likely for HIV to be transmitted from a receptive partner to an insertive partner in this context (Van den Ven, 2002).
5. HIV Treatment

5.1 Treatment uptake

In Australia, antiretroviral treatment (ART) for HIV infection is readily available through both public and private health clinics and is subsidised by the federal government through the Pharmaceutical Benefit Scheme. HIV treatment coverage in Australia is relatively high by international standards. According to surveillance data, up to 73 percent of people with diagnosed HIV were on antiretroviral therapy at the end of 2014, with an estimated 92 percent having an undetectable viral load, suggesting high medication adherence and regular monitoring of blood (Kirby Institute, 2015).

Treatment uptake was high in this study. All participants were residents and Medicare eligible and thus access to treatment was well-supported. Of the 25 HIV-positive partners in these couples, 20 were taking antiretroviral treatment (80%) and had an undetectable viral load, except for one man who had only recently started treatment. Another three were planning to start treatment in the near future. Almost all found their treatment regimen easy to manage, and issues around side effects or adherence were rarely raised. However, side effects were cited as the reason two HIV-positive partners had stopped treatment and were also mentioned as a concern by two participants who were about to start for the first time.

5.2 Attitudes towards ART

There was strong support for HIV treatment among both HIV-positive and HIV-negative partners. Treatment was a central theme across almost all interviews and was commonly framed as essential because of its capacity to protect the health of both partners. Many spoke in favour of the new strategy of early treatment. In the words of 31-year old and overseas-born Luke, who was recently diagnosed and keen to start treatment:

I’ve seen ads and I’ve read a few articles in magazines about how they used to say you didn’t have to go on it straight away. They used to leave [treatment] as long as they could, but now they think the longer-term health benefit and a way of reducing transmission is to go on it sooner, like straight away … Initially, I thought it was lots of different tablets, lots of side effects. Now I’ve learnt that it’s just one tablet a day ... So it’s different to what I first thought, yeah. I’m all for like medication, really.

There was a consistent pattern among HIV-positive partners to describe treatment as a “given” when in a mixed-status relationship, as “doing the right thing”, and as being worth any potential downsides. Many described it as their responsibility to protect their partner by taking treatment, as 38-year old Merlin explained:

I just think it’s my responsibility to not be the person that makes him positive ... If there was any question of me going off my medication because it suited me health-wise, I wouldn’t because it would, like that protection for [my partner] wouldn’t exist anymore ... To be
honest, from my perspective as the positive person, I actually think everybody just needs to man-up a little bit and not try to pass the buck onto other people, and actually just do something themselves. Like, if all you have to do is take medication, I mean it's kind of not that hard … Just take the fucking pills!

HIV-negative partners welcomed the protection that treatment provided, but tended to place more emphasis on their partners’ health. They often expressed a certain ambivalence about treatment, being concerned about its potentially toxic effects on their partner’s body, while seeing it as critical to their partner’s long-term health and therefore to the viability of the relationship.

I said to [partner], “If you weren’t taking your medication every single day”, which he does and he has major panics if he doesn’t … “if you were just going at it half-half … that would be a totally different situation”. There would be no relationship because he’s not taking responsibility for his health (Daniel, 37 years old).

I think a lot of my concern for him is just his health, in general. And I know that, generally, once you’re on medication, like whilst the side effects may or may not, you know, have a major impact upon your life, the earlier you start, generally, the better long-term outcomes you have the less damage the virus can do to your body. And, in spite of me saying that for the last 10 months, he’s only just starting it now. [That’s] bad (Damien, 28 years old).

Like Damien, nearly all HIV-negative partners preferred their partner to be on treatment and non-treatment had the potential to be a source of conflict and worry, as 38-year old Ramón, whose partner refused treatment, explained:

I just can’t agree with that, although I understand that he may be feeling sick of the medication … I have to respect his decision … [But] I would prefer him to, to be on the medication … If my partner was [on] treatment, it would be, yeah, it would give me a lot of peace of mind, ‘cause, yeah, you don’t know how his viral load is going … with the treatment, you know that he won’t get sick as easily.

For a few participants, both HIV-negative and HIV-positive, treatment had made an intimate relationship with a serodiscordant partner possible where it had not been in the past, as 36-year old Imran observed:

I think that’s probably why I’m in a relationship where I’m not really affected by my partner being HIV … because he’s on medication. It’s keeping him undetectable, you know, so. I think that’s it, because 10 years ago I don’t, can’t see myself being with someone who’s HIV … Because the medication drops the viral load … [so] they’re not really passing on the HIV to a negative person if they’re on medication.

Similarly, 42-year old Blake explained how the recent so called “treatment revolution” had overturned his previous rule to never have sexual relationships with HIV-negative men:

I just decided many, many years ago that … it’s just a no-go zone, which kind of narrowed my field down a little bit to just positive men … I guess I’ve been living in a fairly limited view of how all this had to work for me and now I just feel freer … I can actually love who I love, rather than be limited to: “Are you positive or not?” Yeah, that’s big … The landscape has changed … There’s treatments. There’s pathways. There’s ways forward. And it gives space for, you know, relationships to happen, to evolve that I guess we once thought weren’t possible.

While treatment was not generally presented as a deal-breaker by either HIV-negative or HIV-positive partners, it was certainly seen as a hugely helpful tool and a significant enabler of serodiscordant relationships, providing safety and health for both partners and, as such, a sense of normality and future.
6. T reatment as Prevention

6.1 Knowledge and view of TasP

Early treatment of HIV infection for the dual purpose of health and prevention has become a central component of the domestic HIV strategy (Australian Government Department of Health 2014), a strategy supported by community and clinical HIV organisations (ACON 2013; NAPWHA 2013; ASHM 2013). In New South Wales, where this study took place, early treatment and treatment-as-prevention (TasP) have been heavily promoted by the state government (NSW Ministry of Health 2012, 2015) and by a lengthy and highly visible campaign called Ending HIV, which many study participants were aware of.

With the exception of four, the participants were familiar with the term “treatment-as-prevention”, and all were certainly aware of the concept that treatment reduces viral load and thereby infectiousness. Regardless of socioeconomic background, most couples had some knowledge of current research on TasP, with many being highly attuned to developments in HIV prevention by virtue of being in a serodiscordant relationship, through their own research, or through media coverage, health promotion campaigns or discussions with their doctor.

Both positive and negative partners were overwhelmingly positive towards TasP and the emerging global support for antiretroviral therapy as an HIV prevention strategy, and three recently diagnosed men explained that the Ending HIV campaign had encouraged them to consider early treatment. However, several participants raised some concerns about the message of TasP and its potential implications as a general prevention strategy, including that it might place undue pressure on people to start treatment and that it might cause people to “throw away the condom” and have “riskier” sex, particularly in the gay community. There was nevertheless broad consensus around the significance of TasP in their own mixed-status relationship. Echoing the general sentiment among the study participants, this is how 44-year old Georgia put it:

Oh, I think it’s a positive thing. Especially with the research that shows that, you know, the risk of transmission is lowered ... matching, you know, what [the risk factor] would be with condom use ... I can speak as a positive person; the fear of infecting someone else is just overwhelming, especially somebody you love. And so, you know, [TasP] would help you to be able to relax and enjoy your sex life, enjoy your relationship with your partner. It’s one less thing to worry about.

6.2 Impact of TasP on sexual practice

It was clear that most couples embraced TasP, but they did so differently. Couples provided divergent views on HIV transmission risk in the context of TasP and hence its implications for sexual practice, as revealed by three distinct themes (this discussion has previously been published in

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2 http://www.endinghiv.org.au
Persson 2015a). In the most common theme, particularly among gay couples, TasP was framed as “an extra layer of protection” alongside continued condom use. Even though these participants believed that treatment drastically reduced transmission risk, TasP was not considered sufficient or safe enough on its own, which is largely in line with what is still the dominant public health message in the TasP era (albeit increasingly less categorically). Despite condoms not being 100 percent effective, they were not prepared to rely on TasP alone unless proven to provide 100 percent protection. Referring to the HPTN052 study (Cohen et al., 2011), Cory, a positive partner in his mid-30s, explained:

We'll still have protected sex ... 'Cause [TasP]'s not 100 per cent perfect ... I don't want that risk. I don't want him to get it ... For me, that 96 per cent report, that's not good enough ... I need a lot more ... At the moment; I’m anti unprotected sex under all circumstances.

Not even the PARTNER Study (Rodger et al., 2014), which shows that TasP renders transmission risk negligible, could convince some that it was safe, including 51-year old overseas-born Cameron who had lived through the trauma of the early epidemic and his partner’s HIV diagnosis six years prior:

Whether it’s four per cent or .5 per cent, there’s still a risk ... [and] if there's any risk, it doesn’t make sense because the implications of that are so great ... the emotional impact of [partner] knowing that he had given me HIV would be just too awful to bear ... the upside of not having to think about putting a condom on is just, it is kind of minute in its significance compared to the downside of getting it wrong or being unlucky.

For these couples, TasP provided a greater sense of safety, but had no impact on their sexual practice. This was also the case for another group of couples, but in quite a different way. In the second theme, TasP provided “welcome relief, reassurance or validation” for those who had already practised condomless sex for some time. Overseas-born Flynn, a negative gay partner in his late 30s, said: “The thing is that, this new information ... sort of confirmed what we did, why I'm still negative”. Jasper, a negative heterosexual man in his early 30s, explained his reaction to hearing news about the PARTNER study:

The other day there was something on the news where they were pretty, I can't remember what it was, but they were like 99 per cent sure that, that there is virtually no transmission ... So hearing that the other day, we were like, not that that would have changed anything, honestly, but even hearing that has just like made me, has just enforced what I thought more ... it’s obviously that small, that tiny of a risk.

This is how Georgia, a positive woman in her mid-40s, described the impact of TasP on her existing sexual practice:

[Condomless sex] was very scary at first but, you know, it’s something that has to be negotiated as a couple ... But now having seen the release of the [Australian HIV strategy, which endorses TasP] and understanding that this is a common consensus ... it’s taken that uncomfortableness away, that fear away ... To me it’s even safer now, if you know your status and if you have an undetectable viral load.

Therefore, like some of the other couples, Georgia and her partner continued with their existing sexual practice, but felt that TasP provided them with more support to do so. However, for a handful of couples, TasP did contribute to a change in their sexual practice. In the third theme, TasP provided “permission to commence condomless sex”, especially among those who disliked condoms or who experienced erectile problems or latex-sensitivity. Simon, a negative gay man in his early 30s, explained:

It’s just natural to wanna have sex without condoms because of erectile dysfunction and because it just feels, feels nicer ... I sort of discussed with my doctor about, you know, the viral loads and new studies have come out showing that, if the viral load is down as
undetectable, the probability of getting HIV is extremely, extremely low.

Merlin, in his late thirties, described how he and his negative partner Daniel were “very strict” about using condoms when they first met. However, their initial intentions were soon challenged by Daniel, a transman, repeatedly getting latex-induced thrush and by “falling in love”. “When you’re kind of barrelling head-long into that, we did start to have slip-ups”, Merlin explained, resulting in “terrible fits of guilt”. This led him to pull “away from sex a little bit” to keep Daniel safe. Hearing about the concept of TasP changed all that. The fact that they only had vaginal sex and that Merlin had been undetectable for years meant, in his view, that “we’re really perfect candidates to use that method”. Daniel, also in his 30s, recalled the moment:

And then that study [HPTN052] came out ... So then we were like relieved, really, and able to kind of go ahead [and have condomless sex] ... I could sit there and go, “These are the facts. If he has his medication every day ... I’m willing to take the risk because I know he’s doing everything he possibly can to keep me safe”.

6.3 TasP and risk perceptions

One theme that cut across most couples, regardless of their sexual practice, was that TasP “lessened anxieties about transmission” (the discussion in this section has been previously reported in Persson 2015a). Only four participants expressed significant concerns about risk, while another handful said they were somewhat worried, but knew the risk was small realistically, typified by comments such as: “I know the risk is almost zero, but I still worry a little bit”. The majority (80%) claimed to not be worried about HIV transmission, describing the risk as “minimal”, “non-existent”, “very” or “extremely” low. Those who had condomless sex were generally less concerned about transmission than couples who stayed committed to condoms.

Overall, positive partners were more likely to express anxieties around sexual safety and potential transmission, which is consistent with previous research. Their narratives were often ambivalent, as if unable or apprehensive to decisively leave behind the paradigm of infectiousness that has long defined the epidemic and embodied experiences of HIV-positivity. As 36-year old Oliver remarked:

I’m slightly paranoid about it ... [But] Simon’s going, “Oh the PARTNER Study says that, if you have an undetectable viral load, it’s practically impossible to give HIV to your partner ... You won’t give it to me”, you know, “trust me” … Even my doctor tells me there’s no risk in it. But I am a little bit insecure about that ... I take my treatment regularly, because even though [that fear] is deep down in the back of your brain, you know that treatment is one of the best preventative measures. The last thing I ever want is Simon getting HIV … [But] he is the one who keeps reminding me about all the studies.

Although concerns about transmission were not absent among HIV-negative partners, they were generally highly invested in framing their partner as safe and keen to de-dramatise HIV, challenging the notion that they were “at-risk”. As 48-year old, overseas-born Charlie put it: “I’m sort of like doing things right for myself [prevention-wise]. And I’ve [also] gotta really take into consideration that I’m dealing with someone else’s feelings here; it’s not just about me”. Many described the possibility of transmission as simply part of the relationship, on par with any manner of issues that couples live and deal with, and remote enough to not let it define the relationship or be an ongoing concern. Adam, in his mid-30s, had had condomless sex for many years with his partner:

I think that we have a fair bit of confidence around, you know, [her] health and, you know, and a very sort of miniscule risk of transmission ... I don’t actually feel that intimate contact with my partner is sort of significantly sort of risky for me to be concerned ... I sort of take that as part of the relationship. I can’t see how I can have a loving relationship with [my wife] and be preoccupied with fear about becoming HIV-positive ... it just seems
incompatible.

Keeping things in perspective was a common theme among the negative partners, as were references to TasP research. Simon, who practised condomless anal sex, was fully immersed in this new territory:

I'm not scared of [HIV] at all ... I know the probability of getting it is not zero, but I know it's extremely low, extremely low. And my doctor's an HIV doctor and I've spoken to him about that too ... New studies have come out showing that, if the viral load is down as undetectable, the probability of getting HIV is extremely, extremely low ... I know there's still that slight risk there, but there's a slight risk with anything in life ... The probability of that happening, if we play our cards right, I feel is extremely, extremely low... We do look at the science.

As Simon's quote illustrates, undetectability was central in the narratives of serodiscordant sex recounted by participants. Nearly all volunteered that their or their partner's viral load was undetectable, as if this clinical information was privileged with implicit significance over any specific sexual information. That is, “undetectable” was often deployed as shorthand for the safety of serodiscordant sex, no matter a couple's sexual activities. Miles, in his late 60s, described how learning about the science around viral load eliminated HIV as a potential relationship issue when he fell in love:

Lucinda and I met, and hugged, and it was just perfect ... I had no great medical knowledge of [HIV] ... One thing [Lucinda's doctor] helped me with is to talk about the [research] and the implications of it ... And he said that, as Lucinda had said, that there's something like a 0.00024 chance of cross-contamination if the viral load is undetectable ... So I just settled into being with Lucinda and the HIV wasn't really an issue to me.

Several negative partners emphasised that they were much safer having sex with their undetectable positive partner than they would be in other sexual situations. As Jack said, "I know what I'm dealing with". Forty-eight-year old Charlie explained:

I'm safer with [my positive partner] because I know it and I can face it head on, and do something about it rather than thinking that someone is negative and being at total risk.

Similarly, 39-year old Flynn said of his partner:

I know this person, I can trust this person. This person is not going to lie to me. So, if he say he's undetectable, he's on treatment, he has no STIs, that's all the tick.

The notion that it is safer to have sex with a positive person on treatment than with a casual partner of unknown status echoes an emerging narrative in US gay communities (see Sobo 2014, LeBlanc, 2014, Grindley, 2014), which hints at a potentially radical inversion of what constitutes safe and risky sex in the context of HIV. There was considerable hope among the couples in this study that greater knowledge about TasP could help to shift community attitudes and lessen the stigma of both HIV and serodiscordant relationships.

6.4 Knowledge and views of PrEP

Two thirds of the participants had heard about pre-exposure prophylaxis or PrEP. Not all of those were familiar with the actual term “PrEP”, but were aware of the concept and had a reasonably good understanding of how this biomedical prevention technology works. This is a small sample, but there was no obvious difference between gay and heterosexual couples, or between urban and regional participants, or HIV-positive and HIV-negative partners in terms of knowledge of PrEP. Only one negative partner was taking PrEP.
PrEP was explained to those interviewees who had not previously heard of it. The interviews revealed a range of views. Many couples were decidedly uninterested in using PrEP as a prevention strategy, for a number of reasons. Regardless of sexual practice, a perceived low risk of transmission was commonly cited. For example, PrEP was described as “overkill” in the context of TasP and undetectability. PrEP was also seen as unnecessary by some gay couples who were well-established in their condom use. As Aldo, a negative partner in his early 30s, said: “Why take pills when you can use condoms?” As with TasP, a lack of solid scientific evidence of 100 percent efficacy was also a concern, as were the unknown effects of the drug:

I think where there’s any kind of, you know, margin for transmission, however small that is, you know, it still doesn’t outweigh the mild inconvenience of having to take precautions (Cameron, early 50s, gay, negative).

[The idea that] he should take the risk of going on long-term medication so that we can just have unprotected sex and not know what that’s gonna do to his body I think is a stupid thing for me to ask (Cody, mid-30s, gay, positive)

Other reasons for disinterest in PrEP included not being highly sexually active anymore, not having penetrative sex, and the potentially high cost of the medication. A few HIV-negative partners also had difficulties reconciling the idea of taking HIV medication when they did not have HIV:

What’s the point in taking those tablets every day? Because then, if you had [HIV], you’d be taking the tablets every day. So it’s just the same as almost living with it (Aldo, early 30s, gay, negative).

You’re taking anti-HIV medications that you would be taking if you were infected … If I can use condoms … why would I wanna go on this medication that I would be taking to prevent taking further medication in the future—like it just kind of didn’t add up in my mind (Damien, late 20s, gay, negative)

A number of couples expressed some interest in PrEP and had discussed it, but ultimately decided against it, for reasons to do with concerns about side effects and drug resistance, or other medical conditions that could be compromised by PrEP. However, some said they would definitely consider PrEP if their positive partner’s HIV treatment failed. Misinformation or misunderstanding seemed to play a role in one couple’s decision. At the time of their interview, they were trying to conceive using condomless sex and timed ovulation. They had considered PrEP as an added precaution in conjunction with TasP, but 27-year old Emma, who was the negative partner, had been told by their HIV provider that PrEP could only be taken a few times when trying to conceive:

At the time I thought to myself … “what’s the point in me taking it for only a couple of times, if that’s all I’m able to?” … Like if it was probably something that would, that I could take for as long as, you know, we wanted to try [to conceive], we’d probably do it. ‘Cause, so maybe it’s a good question we should, we could actually ask [doctor]; how come I can’t continue to take that?

Among those who expressed a clear interest in PrEP, the reason differed slightly depending on whether couples had condomless sex or not. For example, Jasper, Simon and Charlie, who did not use condoms with their positive partners, explained that PrEP would make them feel even safer having sex. Jasper, a heterosexual man in his 30s, had never heard of PrEP before, but was enthusiastic:

If I knew about something like that, I’d take it … If it was to actually work and to save the possibility if something happened then, yeah, definitely. Why not, you know? Like it’s only a tablet at the end of the day, compared to the other flip of the coin (Jasper, 30s, heterosexual, negative).
Simon, also in his 30s, saw PrEP as a safeguard against potential viral fluctuations:

I’m prepared to go on the PrEP program, but the PrEP program hasn't been released … I do believe PrEP should be available because, see, what if Oliver’s viral load spikes over 300? What if he has a really, bout of an illness that anybody can get, like, I don’t know, glandular fever or something where your immune, where anybody’s immune system can be down? Well the viral load could just pop up all of a sudden, you know. So there should be that safeguard there.

For Charlie, a sense of shared responsibility around sexual safety was the driver behind his decision to take daily PrEP, the only HIV-negative partner in the study to do so. He and his partner, who was on , had condomless anal sex and Charlie was often the receptive partner:

I had to sit back and evaluate how I was thinking about whose role it was to do the protecting. And it was like, well, yeah, I was putting a lot of the onus on him to protect me from him and that, and that’s not really how it should be. I mean the onus is on me to protect me, the same as it would be, you know, if I was having random sex with other people; it would be on me to protect myself.

Another HIV-negative partner who did not use condoms with his partner also emphasised greater safety as the reason he was interested in taking PrEP, although not in relation to his serodiscordant relationship; rather he wanted to take PrEP occasionally for the purpose of having condomless casual sex with other gay men.

Participants who used condoms either regularly or inconsistently with their partner and who expressed an interest in PrEP, reasoned that it might make them feel safe enough to start having condomless sex, or feel less conflicted when “slipping up”. This, they speculated, could facilitate more intimacy or remove certain psychological barriers and so enhance their relationships:

The benefits for our relationship would probably be better than now … because I think [partner] still has the impression that he’s somehow dirty because we always need to have protected sex … He doesn’t like the idea that I would have to take medication every day just to be with him. But I think somehow that’s better than having a perceived barrier between us (Connor, 20s, gay, negative).

I think it’s a fantastic idea … we may even have sex more often, which is kind of — well we need to have this discussion, you know. For, not just his health reasons, but it may help us in other ways as well. Like strengthen our relationship (Bruno, 40s, gay, positive).

Beyond their own personal interest or disinterest in PrEP, about half of the participants saw a role for PrEP in serodiscordant partnerships, based on its perceived capacity to enable several important relationship dynamics, including safety, condomless sex, greater intimacy, safe conception, and shared responsibility. Two participants strongly advocated that PrEP should be available to all serodiscordant couples:

I have very strong views about PrEP. I think PrEP should be given to everyone in a serodiscordant relationship (Oliver, 30s, gay, positive).

They’ve got the stuff out there to be able to, to bring the risk right down to just about zero and, you know, we’re consenting adults. We know the risk factors. We know that something can be done about it. Let’s do it! … I’ll be challenging the government on this and I will be advocating for it (Charlie, 40s, gay, negative).

The other half of the participants saw PrEP as less relevant to serodiscordant couples, on the basis that serodiscordant relationships already tend to be relatively safe because of factors such as condoms, TasP, monogamy, mutual awareness of serostatus, regular HIV and viral load testing. These participants saw PrEP as more relevant to those in the gay community who have condomless
casual sex. However, they were quite divided on whether the availability of PrEP would be sound policy or not, with some speculating that it would encourage “unsafe” sex and increase STIs, and others arguing that it is a good and realistic idea and would help to keep people safe.

In summary, serodiscordant couples are typically considered a key target group for PrEP and these findings suggest that PrEP has some appeal for this group. However, they also suggest that not all mixed-status couples are necessarily interested in PrEP, or see PrEP as more relevant to them compared to other potential users that could also benefit from its availability.
7. Clinical Engagement

These couples were highly engaged with the field of HIV medicine and care through the use of treatment and associated services for monitoring and testing.

Table 6: Testing

<table>
<thead>
<tr>
<th>Testing</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Viral load testing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(every 2-6 months)</td>
<td>24</td>
<td>1</td>
</tr>
<tr>
<td><strong>HIV testing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(every 3-6 months)</td>
<td>17</td>
<td>8</td>
</tr>
<tr>
<td><strong>STI testing - positive partners</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(every 6-12 months)</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td><strong>STI testing - negative partners</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(every 6-12 months)</td>
<td>13</td>
<td>12</td>
</tr>
</tbody>
</table>

7.1 Viral load testing

There was a very strong commitment among HIV-positive partners to regularly monitor their viral load, and most did so every three months on average and no less than every six months. Being in a serodiscordant relationship was a major motivator for positive partners to remain actively engaged with clinical care and vigilant around viral load.

I get tested every sort of two months, not every three months, ’cause I’m paranoid, you know. But that’s just for me because I am in the position of a serodiscordant relationship. I don’t wanna wait three months and find out my viral load’s skyrocketed (Cody, 30s, gay, positive).

I make sure that, when I get my viral load, when I go to my doctor’s appointments and, and get my results for my CD4 and viral load, I always share that information because it’s, he doesn’t ask it but it’s my way of saying, “Hey, look, I’m doing well.” And plus I have an undetectable viral load so that’s information for him, for him to feel safe, you know (Georgia, 40s, heterosexual, positive).

As Georgia’s quote suggests, HIV-negative partners were generally kept informed about viral load test results and felt reassured by this:

I know how much it reduces the risk ... I know he’s compliant. I know he takes his pills and,
you know, whenever he gets tested, you know, he reassures me “undetectable” and all that sort of stuff (Jack, 40s, gay, negative)

7.2 HIV testing

About two thirds of the HIV-negative partners tested for HIV every 3-6 months, while a third tested less frequently. Those who tested regularly explained that the testing was more for reassurance or was part of regular health check-ups, rather than based on any specific concern about transmission. Most of the negative partners who did not test regularly were heterosexual. However, none of the negative partners never tested for HIV; once every two or three years was the minimum. It was difficult to tell whether some negative partners were less pro-active around testing because they did not actually see themselves as being at any risk, or because they did not want to give their positive partners that impression, or make them feel “really diseased” as 25-year old Connor put it. However, some clearly saw frequent testing as unnecessary:

It’s a bit erratic but I will continue to have HIV testing along the way ... Oh, once a year, once every two years probably. See I feel less at risk now because of my heightened awareness and my total, you know, given [partner]’s experience, my total commitment to safe sex. It’s just, it’s, it’s actually less; my, my risk factor is much lower than it used to be (Cameron, early 50s, gay, negative).

Although some positive partners felt comforted by infrequent partner testing, especially when it was sanctioned by their HIV doctor, positive partners were generally keen for their negative partner to test on a regular basis, as 42-year old Justin explained:

My partner has regular check-ups ... he has tests and things like such. So he’s always been good sort of thing ... His last [test] was negative ... That’s always a relief for me. It’s a relief for him, I’m sure, but I’m the one that seems to sort of be “Oh all good”, you know. “Doing the right thing. Happy with that!”

Positive partners sometimes had to remind or push their negative partners to get tested, as Georgia described: “He hasn’t [tested] in the last 12 months and I chase him up and chastise him about it”. Similarly, Cody said:

[He] probably gets tested less regularly than I would like him to ... So I tell him to go get bloody tested, because I worry about it ... He goes “Oh no, it doesn’t matter”. He’ll wait six months. He doesn’t care ... I have to push him to get tested more often than he would probably do ... That’s how much he doesn’t worry about it. He doesn’t think we’re taking a risk, obviously (Cody, 30s, gay, positive).

HIV testing seemed to work best in relationships when it was framed as part of routine health checks, which decoupled it from serodiscordance. This tended to be more easily accomplished among gay men who, unlike heterosexuals, were already accustomed to a culture of testing: “It’s just general housekeeping”, as 30-year old Aldo said. Or as Marcus, in his early 50s, noted: “I’m self-motivated in doing that. It’s like part of my health check program”.

7.3 STI testing

Regular testing for sexually transmissible infections (STIs) was less common than viral load and HIV testing. Testing for STIs by both partners every 6-12 months was reported in 10 couples, while nine couples never or rarely tested for STIs. In the remaining six couples, only one partner tested for STIs regularly, or they did not know if their partner got tested. Among the heterosexual couples, regular STI testing was reported by only one couple in which both partners were accustomed to regular blood tests due to a history of injecting drug use. Monogamy was cited as the main reason for not
testing for STIs among both heterosexual and gay couples: “There’s no need to ... we don’t stray outside our relationship ... So we don’t test for other STIs” (Hugo, 60s, gay, positive).

Like HIV testing, STI testing seemed to work best for the gay couples when it was framed as simply part of regular health-checks, or when framed as a matter of HIV health, because it decoupled the test from trust, which was an issue in some monogamous couples.

    Syphilis, gonorrhoea, Chlamydia ... I still get tested every three months ... because our immune systems are severely compromised ... It’s part of my treatment plan, you know. And even though I’m in a monogamous relationship, it just gives me additional security (Oliver, 30s, positive).

    If you’re in a supposedly monogamous relationship, there isn’t the need to test every three or six months, you would expect, for STIs. But, you know, there’s always that “Well, are they being completely 100 per cent honest?” That’s always in the back of your head too, you know. They may have been out there, you know, gallivanting around with God knows who. I’ve heard those stories over and over and over, over the years (Bruno, 40s, positive).

One heterosexual negative partner, who did not himself test, strongly advocated for STI testing to be incorporated into HIV testing for negative partners as a matter of course for the sake of the positive partner’s health. This would mean that couples would not have to rely on trust, nor have to negotiate whether testing is needed, but it would simply be routine in the context of serodiscordant couples.
8. Advice and Reflections

It was clear that these serodiscordant couples had embraced TasP in the way hoped and encouraged by local and global health agencies. Across the interviews, HIV treatment was clearly seen as important in serodiscordant relationships because of its capacity to protect the health of both partners and thereby enable a sense of safety and normality. There were obvious signs that TasP is shifting perceptions of what constitutes “safe sex” in the context of HIV, detaching the virus from its history of being seen and managed as highly infectious. Although serodiscordance was managed in diverse and sometimes complex ways in these couples, their relationships were not necessarily defined by “risk” and “difference” as often assumed. Despite some sexual and social challenges, most couples managed HIV well and felt safe with each other.

8.1 Advice to other couples

When asked to give advice to hypothetical others who face the prospect of a mixed-status relationship, nearly all participants emphasised honesty and trust as necessary keystones of a successful serodiscordant relationship. As positive partner Merlin described it, “You have to not be lying to your partner about what you’re doing sexually with other people ... So, yeah, [serodiscordance] kind of adds an opportunity to be honest”. While honesty and trust are valued relationship qualities generally, they take on particular meanings in mixed-status partnerships, not only in relation to sex outside the relationship, as well as within, but also in relation to viral load test results and taking medication because of the potential risks to both partners’ health posed by dishonesty or lack of communication. “If there’s no trust, it’s just not gonna work”, negative partner Troy said.

Knowledge was seen as helpful, even critical to honest dialogue. Participants urged other serodiscordant couples to educate themselves by asking questions, doing research and speaking to health care professionals, “so you don’t have to be ignorant and you don’t have to be paranoid”, as positive partner Dennis said. A related message was to not let outdated misconceptions or fears of HIV impact on potential love, because it is altogether possible to work out how to live with serodiscordance and overcome any challenges it may pose, not least when couples realise that medical advances have radically transformed HIV. As Jack, a negative partner, summed it up:

[It’s] really important information to get out there in terms of, you know, trying to debunk the myth that you [can’t] have a good serodiscordant relationship ... Don’t let serodiscordance get in the way of having a loving, fulfilling relationship. Because I’m proof that it doesn’t need to.

Implicit in much of their advice was the idea that HIV is a joint concern, which might explain the endurance of some of these couples. “It’s as much your issue as it is their issue”, negative partner Charlie insisted: “If you just treat [HIV] as their issue, you’re gonna fail. It’s a shared thing. It’s not
just about someone having a disease and you not having a disease” (Persson, Ellard and Newman, 2015).

8.2 Advice to policymakers and service providers

Easier access to testing for serodiscordant partners was raised by several participants. This included rapid or home-based HIV testing for negative partners and the development of home-based viral load testing for positive partners. Heterosexuals tended to express more concerns about lack of easy access to HIV testing. Eliza, for example, questioned why rapid testing was being rolled out for gay men in NSW, rather than for everyone, especially for all negative partners regardless of sexual orientation. Positive partner Georgia explained why home-based viral load testing would be helpful:

If there was some way to be able to do your viral load at home, you know, once a fortnight or something like that, if they came up with something like that, you know, like they do with the diabetes test, that would probably make me, as the positive person, more comfortable. Because I thought, “How could I ever go home and tell my partner, ‘Hey, my viral load went up and I’m having, developed a resistance to a medication,’ for example, and I didn’t know for four months”? And we’ve been having unprotected sex. So it’s still fearful.

As this quote suggests, couples were keen to do the right thing and stay safe, but recognised that viral load can be affected by different factors. Hence, more regular testing might be required and desirable by some couples for periods of time, at least until they have concrete evidence that TasP works and is reliable over time.

Another issue that came up in some interviews was a perceived lack of attention to HIV-negative partners, both by clinicians and in the HIV sector more broadly. Some argued that negative partners needed to be engaged by service providers much more firmly in terms of both testing and support, and that this would benefit not only the negative partner but the positive partner as well (Mahoney, et al., 2015). This is how 34-year old Adam put it:

It’s just a funny, one-sided thing that goes on. I mean, you know, I’d be quite amenable to sort of more attention than what I get. If it’s not even for my own sake; if it was for [my partner]’s sake, you know … it’s obviously a factor for her health, even if they’re not sort of so worried about me … I suppose, you know, like “we really want, you know, the assumed negative partner to get tested once every six months, for the sake of the positive partner” or something like that … In serodiscordant couples they aren’t actually paying a great deal of attention to the negative partner. I don’t know, maybe the rates of transmission aren’t that high. Either that or it’s, you know, it is a real hole in services at the moment.

8.3 Interactive workshop with stakeholders

A research workshop was hosted at UNSW Australia in May 2015 to present and discuss some of the emerging results from the study. Given the rapidly evolving landscape of HIV medicine and biomedical prevention technologies, the workshop was conducted to provide an opportunity for service providers and stakeholders to be involved in the early stages of research findings rather than at the post-report end, so that sector input could inform the focus of the research report. The workshop was a joint event by the Centre for Social Research in Health and the Kirby Institute (UNSW Australia) and the Australian Research Centre in Sex, Health and Society (ARCSHS) and was facilitated by Graham Brown (ARCSHS).

In addition to findings from the YouMe&HIV study (CSRH), findings from the Opposites Attract study (the Kirby Institute) were also presented, as well as an overview of the HIV Futures data (ARCSHS)
on serodiscordance across time. These presentations provided the basis for lively discussions among the workshop participants, who held policy, practice or research expertise relating to serodiscordant couples. Questions were raised about how services can more effectively engage both partners in serodiscordant couples when most service activities are necessarily focused on (and funded to support) the positive partner. Differences in the needs and experiences of couples identifying as gay or heterosexual were also examined, as was the complex influence of cultural background and geographic location.

A valuable conclusion that emerged from the workshop discussions was that TasP can be incredibly empowering and liberating for serodiscordant couples, enabling a welcome sense of social and sexual belonging and “legitimacy”. However, a number of important issues were also raised. Implications of TasP for changing understandings of and approaches to HIV disclosure was a concern for a number of workshop participants, as was the recognition that those positive partners who are not able to successfully achieve viral suppression, for varied reasons, are not likely to benefit in the same way. Workshop participants cautioned that we need to stay vigilant that TasP does not become a one-size-fits-all solution, or a blanket norm that can place coercive obligation on couples and people with HIV more broadly, creating new forms of exclusion and stigma, as well as overshadowing issues such as mental health, immigration, and other social complexities around HIV (Newman, Persson, Brown, Ellard and Bavinton, 2015).


Curran, K., Ngure, K., Shell-Duncan, B., Vusha, S., Mugo, N.R., Heffron, R., et al. (2014) ‘If I am given antiretrovirals I will think I am nearing the grave’: Kenyan HIV serodiscordant couples’
attitudes regarding early initiation of antiretroviral therapy. AIDS, 28, 227–233.


Holt, M. (2013) HIV pre-exposure prophylaxis...


and meta-analysis. PLoS ONE, 9(11), e111175
review of HIV transmission between heterosexual
serodiscordant couples where the HIV-positive
partner is fully suppressed on antiretroviral
therapy. PLoS ONE, 8(2): 1-12
Mahoney, M., Weber, S., Bien, M. & Saba, G.
(2015) "I have it just like you do": Voices of HIV-
negative partners in serodifferent relationships
receiving primary care at a public clinic in San
Francisco. AIDS Care, 27(3), 401-408.
Maksud, I. (2012) Secrets and silences:
Unspoken aspects of conjugal life for HIV/AIDS
serodiscordant couples. Caderno de Saúde
Pública, 28, 1196-1204.
Mao, L., de Wit, J., Adam, P., Post, J., Crooks,
prescribers’ perspectives on ART initiation in
the era of ‘treatment as prevention’. AIDS Care,
25(11), 1375-1379. doi:10.108%9540121.2013.76
6304.
McGrath, J.W., Celentano, D.D., Chard, S.E.,
(2007) A group-based intervention to increase
condom use among HIV serodiscordant couples
in India, Thailand, and Uganda. AIDS Care, 19,
418-424.
McMahon, J., Myers, J., Kurth, A., Cohen,
S., Mannheimer, S., Simmons, J., et al. (2014)
AIDS Patient Care and STDs, 28(9): 462-474.
Mendelsohn, J., Calzavara, L., Dafty, A., Mitra,
S. et al. (2015) A scoping review and thematic
analysis of social and behavioural research
among HIV-serodiscordant couples in high-
Correlates of unprotected sex among adult
heterosexual men living with HIV. Journal of
Urban Health, 83, 669–681. doi:10.1007/s11524-
006-9068-z
Miranda, D.B., Matão, M.E.L., Campos, P.H.,
for HIV: From the social context to the
serodiscordant conjugality. Journal of Nursing
UFPE Online, 7, 589-597.
Moore, J., Saul, J., VanDevanter, N. & Kennedy,
of HIV-serodiscordant heterosexual couples. In:
Barbee, A. and Derlega, V. (Eds). HIV and Social
Interaction (pp.165-192). Thousand Oaks, CA:
Sage.
HIV prevention for serodiscordant couples.
Current HIV/AIDS Reports, 11(4), 434-446.
Mujugira, A., Baeten, J.M., Donnell, D.,
Characteristics of HIV-1 serodiscordant couples
enrolled in a clinical trial of antiretroviral pre-
exposure prophylaxis for HIV-1 prevention. PLoS
ONE, 6, e25828
Muldoon, K.A., Duff, P.K., Birungi, J., Ngolobe,
M.H., Eun Min, J., King, R., et al. (2014)
Decisions, decisions: The importance of condom
use decision making among HIV sero-discordant
couples in a prospective cohort study in
Uganda. Sexually Transmitted Infections, 90,
408-412.
NAPWHA (2014) Poz Action: The Vital Role of
PLHIV in HIV Prevention. National Association of
about-us/poz-action/poz-action-vital-role-plhiv-
hiv-prevention
Bavinton, B. (2015) Understanding the promise
of biomedical prevention for couples of mixed
HIV status: Workshop report. HIV Australia,
13(2), 43-44.
Nguyen, V-K., Bajos, N., Dubois-Arber, F.,
epidemic: from HIV treatment as prevention to
HIV treatment is prevention, AIDS, 25(3), 291–3,
doi:10.1097/QAD.0b013e3283402c3e
NIMH Multisite HIV/STD Prevention Trial for
African American Couples Group (2010)
Risky sexual behavior and correlates of STD
prevalence among African American HIV
serodiscordant couples. AIDS and Behavior,
springerlink.com/content/1090-7165/14/5/
NSW Ministry of Health (2012) NSW HIV
Strategy 2012-2015: A New Era. NSW Ministry


YouMe&HIV: The serodiscordant couples study

Matters, 19(37), 184–193. doi:10.1016/S0968-8080(11)37552-0


Appendix A

Interview Schedule

Demographics

- Age
- Cultural background
- Employment/education
- Children/family
- Year of diagnosis/meeting their partner

Serodiscordance

- **Before you tested positive/met your positive partner, were you aware of HIV? Was it something that you thought about?** (Explore awareness and knowledge of HIV prior to diagnosis/relationship; whether they saw HIV and HIV risk as being personally relevant. Explore main avenues of information: HIV prevention campaigns, friends, media (newspapers, TV), education, etc.)

- **Tell me a bit about how you met your partner?** (Explore whether the HIV diagnosis occurred prior to the relationship, or during, e.g. due to late diagnosis or sexual contact outside the relationship. Explore events, feelings and how they negotiated the situation at the time)

- **How does HIV figure in your relationship?** (Explore communication, silence, to what extent HIV is foregrounded/backgrounded in the relationship, whether HIV is seen as a shared issue/experience, whether decisions around HIV are made jointly or not)

- **What do you see as the main issues for you as a couple?**
- **What do you think are the main issues for your partner?**
- **What is the most challenging and the best thing about the relationship?**
- **Do you find it easy or difficult to talk about HIV with your partner?**

HIV treatment

- **Are you/your partner currently on any HIV treatment?**
- **When making decision around treatments, is this something that you and your partner discuss and decide together?**
• How do you feel about HIV treatments? (Explore belief systems around medicine and how these affect how they negotiate their own or their partner's treatment situation and their relationship. Explore concerns/hopes for the future)

• How do you feel about (your partner) being on/not being on treatment? (Explore reasons why, and how they think things would change if they or their partner stopped/started. What would happen to health, the relationship, sexual practice, transmission risk, etc.?)

• Would you consider yourself well-informed about HIV treatments? (Where do they get their information from? Is the available information useful? Do they actively seek out new information about treatments? Is it important to stay informed? Why? Why not? Is their partner informed about treatments or not?)

• Have you/has your partner ever taken PrEP? Can you tell me a bit about that? (Explore reasons for taking PrEP, or reasons for not taking PrEP in situations where others might have. Gauge interviewee’s knowledge of, and attitude to, PrEP)

• Are you aware of the current push for treatment-as-prevention and plans to drastically reduce HIV infections in Australia and globally? (If yes, how did they hear about it? If no, provide information. Explore knowledge, understanding and views about TasP and the treatment-revolution, and whether they see it as relevant personally, etc.)

**Sexual practice and prevention**

• How important is sex in your relationship / your life?

• What effect does HIV have on your sexual life, if any? (Explore impact of HIV on sexuality, sexual practice, sexual wellbeing, and attitude to sex)

• Tell me about your understanding of ‘safe’ and ‘unsafe’ sex before you tested positive/met your partner? (Explore extent of prior awareness around ‘safe sex’ messages and whether they saw such messages/practices as being personally relevant or not)

• Tell me a bit about your understanding of ‘safe’ and ‘unsafe’ sex now, has it changed? (Explore perceptions around viral load and infectivity, in particular, and what impact that has hasn’t on sexual practice and notions of ‘safety’; explore any tensions or discrepancies between their perception of safety/risk and actual sexual practice)

• Do you and your partner have any particular risk-reduction strategy when it comes to sex? (Strategy inside/outside relationship? explore rationale and consistency of strategy, to what extent the strategy has been mutually negotiated, whether they and their partner are comfortable with this strategy, and whether it has changed over time, if so why?)

• Would you consider yourself well-informed about HIV prevention? (Where do they get their information from? Is the available information useful? Does interviewee actively seek out new information about prevention? Is it important to stay informed? Why? Why not? Is their partner informed about prevention or not?)

• Do you/your partner get tested for HIV? (Explore frequency, barriers, reasons why, why not, etc., pre- and post-counselling, how the interviewee feels about this and how their partner feels about it)
• What does it mean to you to be negative / What does it mean to you that your partner is negative?

• Do you worry about the possibility of infecting your partner/becoming infected? (Explore feelings around this, how they negotiate those feelings or discuss with their partner, and how such feelings relate to sexual strategies used by the couple)

• Do you/your partner get tested for other STIs? (Explore reasons, frequency, etc.)

Contraception and reproduction

(Warning: questions on contraception will only be asked of heterosexuals, but questions about reproduction will be asked of all participants)

• Are you and your partner currently using contraception (what kind?)

• What influenced your decisions in relation to contraception? (Explore the role of HIV; explore discussion and decision-making in the couple; explore discussions with health care providers; who introduced the topic? were they offered a range of options? do they feel they were given enough information and support?)

• Do you currently have children or plan to have children? (Explore whether the children were born during the relationship, whether prior to their/partner’s HIV diagnosis? if post-diagnosis, how did/or will they approach trying to have children?)

• Has HIV influenced your decisions around parenting and/or reproduction? (Explore discussion and decision-making in the couple, explore discussions with health care providers; who introduced the topic? were they offered a range of options? do they feel they were given enough information and support?)

• Have you used fertility services in the past or are you planning to use them in the future? (Explore whether they have used or are planning to use IVF, sperm washing, what has been their experience of these services?)

HIV-related services and resources

• Where do you get information about HIV and sex from? (Explore whether such information is actively sought out, what they think about that information (useful, confusing, relevant, etc.), and whether their partner actively participates in seeking out, understanding and discussing such information)


• Do you see any health service in relation to HIV? (Explore what kind of service? reasons for accessing that service? frequency, barriers? how they feel they are treated as a positive/negative partner? satisfaction with the service, are their needs being met?)

Concluding the interview

• What advice would you give another positive/negative person who is entering a serodiscordant relationship?

• Is there anything you would like to add or elaborate on? Is there any issue that you feel we haven't covered in this interview that is important to you that you would like to talk about?
Appendix B

Publications and Outputs

Peer-reviewed publications


In Australia, ‘treatment-as-prevention’ (TasP) is currently being rolled out across New South Wales (NSW) as part of the state government’s new HIV strategy. Following the promising results of recent clinical trials, antiretroviral treatments have been reframed as a global HIV prevention tool and imbued with great hopes of radically reducing sexual transmissions and even ending the pandemic. Alongside broad acknowledgement of its efficacy, TasP has generated much international debate among medical and social scientists about its ‘real-world’ implementation and its clinical, sexual and ethical implications for people with HIV. The success and effectiveness of this biomedical intervention hinge on its acceptance and uptake by target populations, but also by those tasked with implementing it. However, little published research currently exists on attitudes to TasP among of HIV service providers. This article draws on interviews with 20 clinical and non-clinical HIV service providers working in public health settings in NSW. These interviews were conducted as part of a qualitative study on couples with mixed HIV status, considered prime candidates for TasP. A series of tensions unfolded in the interviews, revealing significant ambivalence in relation to TasP as a general public health strategy for couples. Understanding this ambivalence is significant to the ongoing debate and effective practice of this promising biomedical prevention technology as TasP becomes a key policy response to the global epidemic in coming years.


In this article, I revisit the question of whether HIV can ever be reimagined and re-embodied as a potentially non-infectious condition, drawing on a current qualitative study of couples with mixed HIV status (serodiscordance) in Australia. Recent clinical trials have consolidated a shift in scientific understandings of HIV infectiousness by showing that antiretroviral treatment effectively prevents the sexual transmission of HIV. Contrary to common critiques, I explore how the increasing biomedicalisation of public health and the allied discourse of ‘normalisation’ can in fact de-marginalise stigmatised relationships and sexualities. Invoking Ecks’s concept of ‘pharmaceutical citizenship’, I consider whether the emerging global strategy of HIV ‘treatment-as-prevention’ (TasP) can open up new trajectories that release serodiscordant sexuality from its historical moorings in discourses of risk and stigma, and whether these processes might re-inscribe serodiscordant
sexuality as ‘normal’ and safe, potentially shifting the emphasis in HIV prevention discourses away from sexual practice toward treatment uptake and adherence.


At a time when advances in biomedicine have rendered people with HIV non-infectious under certain conditions, much public discourse on HIV remains stuck in a paradigm of ‘risk’, which does little to lessen the divide between people with and without HIV in society or challenge the way intimate relationships across this divide are typically stigmatised as undesirable and problematic. We rarely hear the stories of couples who live with mixed HIV statuses and how they themselves perceive and manage their so-called ‘serodiscordance’. In this article, we examine such stories by mixed-status couples in Australia. In stark contrast to the dominant discourse, these couples invoked narratives of love, the everyday unimportance and manageability of HIV, and recent developments in HIV medicine, thereby challenging the way serodiscordant sexuality has been cast in public health research. Drawing on Ken Plummer’s work on hidden sexual stories, we consider not only the content of their stories, but the broader significance of stories to the world in which they are enacted, of storytelling as a rally for social and political recognition and legitimacy. Reflecting on our own role in the co-production of research stories, we argue that by moving marginalised sexual stories out of silence, stigmatised communities and researchers can conjointly and incrementally shape a new public discourse and new forms of ‘intimate citizenship’.


This chapter draws on interviews with a diverse range of couples with mixed HIV status who took part in the qualitative YouMe&HIV study in Australia. A theme of ‘trust in medicine’ stood out across the twenty-five gay and straight relationships represented in the study. This concept has particular meanings in high income settings where there is an increasing attention being paid to preventing HIV transmission in serodiscordant couples through the use of new biomedical technologies. Our analysis found that trust in medicine revolved around trust in HIV pills, providers and partners. Running counter to the oft-cited phenomenon of a ‘decline in public trust’ in late modernity, trust emerged as a crucial element, because so much is at stake in these relationships, and because recent advances in HIV medicine open up new possibilities for these couples. We argue that it is important to take account of the lived experiences of serodiscordant couples in understanding the social dynamics of trust in advanced liberal democracies, and in developing new ways to strengthen and support trust relations among couples with mixed HIV status.

**Conference presentations**


Persson, A. (2016) Biomedical prevention and serodiscordant sexuality: Researching intersections and upshots. Margins and Belonging: the 14th Social Research Conference on HIV, Viral Hepatitis and Related Diseases, CSRH, UNSW (March)


Community media


Workshops and community presentations


Persson, A. (2015) YouMe&HIV: Overview of participants and key findings. Serodiscordant Studies Workshop, UNSW Australia (May)


Persson, A. (2014) YouMe&HIV: preliminary findings on TasP and sex in serodiscordant couples. Short Street Sexual Health Clinic, St George’s Hospital (March)

**Media coverage**


