A national evaluation of HIV nurses’ knowledge, attitudes and practices towards Treatment as Prevention (TasP)

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Report on a 2013 study carried out by the National HIV Nurses Association (NHIVNA)

Published by: Mediscript
December 2013
EXECUTIVE SUMMARY

Introduction
There is now conclusive evidence supporting the use of antiretroviral therapy (ART) as a strategy for reducing the risk of HIV transmission. Treatment as Prevention (TasP) describes the public health or community benefits derived from this strategy. Findings from the HTPN052 study [1], published in 2012, showed a significant reduction in HIV transmission in serodiscordant heterosexual couples attributed to the use of ART. As a result, international guidelines are starting to support initiating antiretroviral therapy early, with a prevention rationale [2]. The British HIV Association (BHIVA) now advises that healthcare professionals should proactively talk to their patients about the impact of ART on viral transmission and the possibility of starting treatment early for prevention purposes [3].

Within the UK, nurses are taking leading roles in all aspects of routine HIV testing and HIV care. Successful integration of TasP, as a new initiative into standard care, will, therefore, require a well-informed and highly skilled nursing workforce. There is currently little known about nurses’ attitudes, practices or experiences in relation to TasP. This is a gap that the study sought to fill.

Research aims and objectives
The study aimed to explore nurses’ knowledge, attitudes and beliefs in relation to TasP in order to:

i) identify training and support needs

ii) explore the ways in which TasP may impact upon nursing care delivery

Methodology and methods
A mixed-methods research design was adopted comprising two phases: an online survey followed by in-depth telephone interviews.

The online survey was disseminated to the NHIVNA membership (n=244) via email. The response rate was 33% (n=81). A filter question was included which invited respondents to volunteer to be interviewed by telephone. Ten interviewees were then purposively selected to represent the diversity of the NHIVNA membership. The interview schedule was designed to follow up on key findings emerging from the survey and to enable complex topics to be explored in more depth. The survey was analysed using descriptive statistics. The interview data were analysed thematically.

Findings
The study revealed considerable diversity and lack of clarity in nurses’ understanding of the scope of the term ‘TasP’. Overall, nurses saw it as their role to facilitate discussion with patients around TasP as part of a multidisciplinary and partnership approach to care provision. Many potential benefits of TasP were identified, particularly if it is delivered as part of an individualised prevention-and-care package. Nurses also saw TasP as a possible empowering and motivational element of care for people living with HIV, potentially encouraging patients to adhere to treatment, disclose their status or seek testing. Study findings suggested that nurses feel skilled and competent in terms of general communication around sexual health and risk behaviour, but feel less confident to discuss TasP in the context of more complex patient scenarios. They also expressed concern around possible negative consequences of TasP, for example: an increase in sexual risk behaviours, challenges with long-term treatment adherence and the potential for drug resistance.

Nurses felt that their practice vis-à-vis TasP was currently hindered by a lack of in-depth clinical guidance, and unclear local policies and care pathways in this area. Likewise, respondents also highlighted a lack of availability and opportunity to attend further education on the topic, and noted a need for the development of information resources for patients around TasP.
Discussion and recommendations
This study has identified the nursing role in relation to TasP as including health promotion, advocacy, clinical assessment and care. Deficits in nurses’ knowledge and confidence regarding TasP were identified in this study, and need to be addressed proactively at national level, with opportunities for continuing professional development made readily and locally accessible.

The study suggests that nurses need support to address TasP with their patients through the development of a range of tools, training and resources. Such resources should be aimed at both nurses and people living with HIV, and should include interactive workshops, online learning and opportunities for sharing experience and advice.

Nurses also require clearer clinical guidance. In particular, locally relevant pathways, policies and support are needed in order to enable nurses to confidently facilitate discussions with patients around TasP.

Conclusion
For TasP to be widely and successfully rolled out as a strategy, innovations for improving engagement and retention in care will be essential, alongside efforts to improve uptake of HIV testing and STI prevention and treatment. A re-focus on supporting treatment adherence is important and ongoing, vigorous efforts to ensure effective partnership working with PLHIV will be vital. NHIVNA should look for opportunities to work in collaboration with other organisations, such as ANAC, EHN, IAPAC and the HIV Community. Sharing expertise and innovation will help nurses make a valuable contribution to the success of this challenging intervention.
## CONTENTS

1. **INTRODUCTION**  
2. **THE UK CONTEXT**  
3. **NURSING ROLES IN HIV CARE**  
4. **STUDY OBJECTIVES**  
5. **STUDY DESIGN AND METHODOLOGY**  
6. **PHASE 1 RESULTS: SURVEY**  
   - Participant characteristics  
   - Defining ‘TasP’  
   - Reported knowledge and confidence about TasP  
   - Education and training  
7. **CONCLUSION**  
8. **PHASE 2 RESULTS: QUALITATIVE INTERVIEW DATA**  
   - Characteristics of participants  
9. **KEY THEMES IDENTIFIED**  
   - 9a) Understanding TasP  
   - 9b) Perceived benefits of TasP  
   - 9c) Nursing advocacy  
   - 9d) Concerns about TasP  
   - 9e) Complexity  
   - 9f) Supporting the nurse’s role  
10. **DISCUSSION**  
   - Understanding TasP  
   - Benefits  
   - Concerns and supporting the nursing role  
   - Limitations  
11. **RECOMMENDATIONS**  
   - Acknowledgements  
   - References  

*Evaluation: Treatment as Prevention in HIV – Appendix*
1. INTRODUCTION

Treatment as prevention (TasP) describes the public health or community benefits derived from the use of antiretroviral therapy (ART) to decrease the transmission of HIV. In 2008 the Swiss Federal Commission for HIV/AIDS made the first definitive statement on the impact of treatment on transmission for serodiscordant couples, albeit with a series of caveats [4]. This year the World Health Organization (WHO) concluded that ART has contributed to the global decrease of 20% in the estimated number new HIV infections between 2001 and 2011 [5].

Evidence for TasP to date has primarily been provided through the HPTN052 study [1], a randomised controlled trial that examined the ability of ART to prevent HIV transmission in heterosexual serodiscordant couples through vaginal intercourse. Findings from the study showed a 96% reduction in HIV transmission in these couples attributed to the use of ART. However, significant additional conditions were required to achieve this reduced level of risk, as follows: no concurrent sexually transmitted infections (STIs) present in either partner; viral load tests every 3–4 months recorded as undetectable (below 50 copies/mL), with this level sustained for more than 6 months. For this benefit to be realised, a continued and high level of ART adherence is clearly critical, as is openness and honesty within these sexual relationships, reliable clinic attendance and regular, negative STIs screens.

The San Francisco Men’s Health Study reported that the introduction of ART in 1996 [6] was potentially linked to decreased incidence of new HIV infections within gay serodiscordant couples. However, outside of that study, evidence remains limited as to whether TasP provides the same prevention benefit to MSM, or for different sexual acts, as it did to the monogamous serodiscordant heterosexual couples enrolled in HPTN052.

While more studies are clearly needed, on a global front, guidelines for HIV treatment are starting to support initiating antiretroviral therapy early, with a prevention rationale. The World Health Organization advocated in 2013 that partners with HIV within serodiscordant couples should routinely be offered ART to reduce transmission to HIV-negative partners, as a result of ‘high-quality evidence’ [2].

2. THE UK CONTEXT

The British HIV Association (BHIVA) and Expert Advisory Group on AIDS (EAGA) issued a joint position statement in 2013 recommending that healthcare professionals should ‘discuss the evidence for the effectiveness of ART with all people living with HIV’ [3], as one option for preventing onward transmission to sexual partners. The statement recommends that ART should be ‘offered to all HIV-positive people who want to protect their partners from the risk of HIV infection’, even if they have no immediate clinical need for treatment themselves.

The BASHH/BHIVA 2012 guidance on safer sex advice [7] recommends advising patients that taking ART and having an undetectable viral load reduces the risk of transmission, but notes that such discussions should also include advice that a residual risk may remain; however, as yet there are no in-depth guidelines which specifically cover the use of treatment as prevention in practice. Furthermore, from April 2013, significant changes in the way that HIV treatment, care and prevention services are commissioned within the NHS have generated uncertainty for many, particularly around funding and potential fragmentation of some aspects of these services [8]. The potential public health benefits of a new HIV prevention strategy such as TasP, in reality, will be contingent upon a wide range of health system and service delivery factors.
3. NURSING ROLES IN HIV CARE

Nurses are on the front line of care and represent the largest group of healthcare workers. Working with PEPFAR-funded organisations internationally, nurses Vitiello and Willard state that ‘nurses are proven leaders ... who continue to adapt standards and practices to meet the needs of their [HIV] patients’ [9]. Furthermore, these authors suggest that recognising and understanding the training and support needs of those nurses who interact with people affected by HIV is ‘vital to ensuring the successful implementation of guidelines, and an integral part of a comprehensive approach to the prevention of onwards transmission’.

In the UK, nurses working in the field are taking the lead on service delivery in all aspects of routine HIV testing and HIV care. In addition, ‘non specialist nurses should be working with colleagues from sexual health/HIV services to keep up to date with advances in HIV prevention’ [10], so that they can direct patients in their care appropriately and play a part in normalising and rolling out HIV testing.

A well informed and highly skilled nursing workforce will clearly be an essential component influencing the success of integrating TasP, as a new initiative, into standard of care. Nurses working in the field will be required to have the knowledge and confidence to address the potentially complex issues that TasP may raise for people in their care. A comprehensive literature search, however, identified a lack of understanding in relation to HIV nurses’ involvement and views on TasP and on their related training and support needs. The current study was therefore designed to investigate nurses’ views on, and experiences of TasP in a UK context, and to elicit information that could inform future education and support initiatives.

4. STUDY OBJECTIVES

- To explore nurses’ knowledge, attitudes and beliefs in relation to TasP
- To identify any knowledge gaps around TasP
- To identify any skills deficits that nurses describe in relation to communicating about sensitive issues with patients
- To identify and explore barriers that nurses may face within clinical practice in relation to TasP
- To establish if there is a need for an e-learning module to support and complement nurses’ existing knowledge in this subject area
- To establish the most acceptable format for additional learning materials or skills development in relation to this topic

5. STUDY DESIGN AND METHODOLOGY

The study was led by a small steering committee (SC), chaired by an executive member of the National HIV Nurses Association (NHIVNA). The steering committee included NHIVNA members, a community/patient representative, a BHIVA representative and a doctor working in public health. Funding was obtained through an educational grant from Gilead Sciences Ltd. Ethical approval was obtained from the University of Nottingham, Faculty of Medicine and Health Sciences Ethics Committee. Data were collected by a project research assistant.

Mixed-method research design allows for the exploration of both quantitative and qualitative data, obtained in an area of interest which is contextual, potentially complex and where diverse perspectives and experiences are anticipated [11]. With this in mind a sequential mixed-method design was used, comprising: an online survey (Phase 1), followed by ten semi-structured telephone interviews (Phase 2). The findings from Phase 1 helped inform and guide Phase 2 of the study.
In March 2013 the survey was piloted and amendments made according to feedback received from the SC. In April, the online survey was disseminated to the NHIVNA membership (n=244) via email. Information about the study also appeared on the Association’s website and in the members’ E-round-up. Two reminder emails were sent over a 3-week period to increase the response rate, and a prize-draw incentive was also offered. Return of the questionnaire was taken to imply informed consent. At the end of the 3-week timeframe, the online questionnaire was closed and the data were then analysed using descriptive statistics. (The questionnaire can be viewed in the Appendix.)

A filter question within the online questionnaire invited participants to leave contact details if they would like to participate in the telephone interviews. Fourteen respondents indicated an agreement to be interviewed. Of these, ten participants were then purposively selected to represent the diversity of NHIVNA’s membership in terms of regional location and workplace setting. The interview schedule was designed to follow up on key findings emerging from the survey and to explore complex topics in more depth. Respondents were contacted by telephone to agree a convenient time for interviews and were then emailed a project information sheet and consent form, to be returned to the research assistant before the interview. Interviews were conducted by telephone, digitally recorded, anonymised and then transcribed by an external agency. The data were then analysed thematically.

6. PHASE 1 RESULTS: SURVEY

The overall response rate for the online survey was 33% (81/244), which included three NHIVNA members working overseas. However, as the study objectives concerned the UK context only, these three responses were excluded from the analysis – hence the results show 78 as the total denominator.

**Participant characteristics**

The geographical areas where respondents worked reflected the regional spread of the NHIVNA membership during that year (2012) (Table 1).

<table>
<thead>
<tr>
<th>Geographical areas</th>
<th>Respondents: % / n</th>
</tr>
</thead>
<tbody>
<tr>
<td>North</td>
<td>18 / 14</td>
</tr>
<tr>
<td>Midlands and East</td>
<td>13 / 10</td>
</tr>
<tr>
<td>London</td>
<td>34 / 27</td>
</tr>
<tr>
<td>South</td>
<td>27 / 21</td>
</tr>
<tr>
<td>Scotland</td>
<td>8 / 6</td>
</tr>
<tr>
<td>Wales</td>
<td>0 / 0</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>0 / 0</td>
</tr>
<tr>
<td>Other</td>
<td>0 / 0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100 / 78</strong></td>
</tr>
</tbody>
</table>

The variety of settings in which these members worked also reflected the NHIVNA membership (Table 2). Some nurses worked in more than one setting, which applied particularly to those working outside London and those with smaller cohorts. Of those who worked in the community, approximately half also saw patients in outpatient and inpatient settings. In Scotland the majority of HIV nurses were affiliated to infectious diseases units (IDUs).
The size of patient cohorts registered in different settings varied (Table 3). One-third of respondents were working in larger units, where more than 1000 patients were accessing care.

<table>
<thead>
<tr>
<th>Work settings</th>
<th>Respondents: % / n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
<td>28 / 22</td>
</tr>
<tr>
<td>Specialist HIV outpatients care</td>
<td>52.5 / 41</td>
</tr>
<tr>
<td>Genitourinary medicine</td>
<td>23 / 18</td>
</tr>
<tr>
<td>Midwifery/obstetrics</td>
<td>4 / 3</td>
</tr>
<tr>
<td>Infectious diseases unit</td>
<td>14 / 11</td>
</tr>
<tr>
<td>Paediatrics</td>
<td>3 / 2</td>
</tr>
<tr>
<td>Specialist HIV inpatient care</td>
<td>13 / 10</td>
</tr>
<tr>
<td>Palliative/hospice care</td>
<td>0 / 0</td>
</tr>
<tr>
<td>Voluntary sector</td>
<td>1 / 1</td>
</tr>
<tr>
<td>Other (e.g. non-clinical/advisory/research and managerial roles)</td>
<td>13 / 10</td>
</tr>
<tr>
<td>Total*</td>
<td>n/a / 118</td>
</tr>
</tbody>
</table>

*NB: Some respondents working in multiple settings

The majority of respondents were experienced and senior nurses, with 64% working at band 7 or 8, and more than half having worked in the field for over 10 years. Of those identifying themselves as ‘other’, two were self-employed, one nurse worked for a voluntary sector organisation and another nurse identified as NHS management (Tables 4 and 5).

<table>
<thead>
<tr>
<th>Number of patients in cohort</th>
<th>Respondents: % / n</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤100</td>
<td>13 / 10</td>
</tr>
<tr>
<td>101–200</td>
<td>10 / 8</td>
</tr>
<tr>
<td>201–500</td>
<td>18 / 14</td>
</tr>
<tr>
<td>501–1000</td>
<td>19 / 15</td>
</tr>
<tr>
<td>≥1000</td>
<td>34 / 26</td>
</tr>
<tr>
<td>Not sure</td>
<td>0 / 0</td>
</tr>
<tr>
<td>Not applicable</td>
<td>6 / 5</td>
</tr>
<tr>
<td>Total</td>
<td>100 / 78</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NHS job bands</th>
<th>Respondents: % / n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Band 5</td>
<td>5 / 4</td>
</tr>
<tr>
<td>Band 6</td>
<td>24 / 18</td>
</tr>
<tr>
<td>Band 7</td>
<td>51 / 39</td>
</tr>
<tr>
<td>Band 8</td>
<td>13 / 10</td>
</tr>
<tr>
<td>Other / non-NHS</td>
<td>7 / 5</td>
</tr>
<tr>
<td>Total (There were 2 non-responders)</td>
<td>100 / 76</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Length of time working in HIV</th>
<th>Respondents: % / n</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 year</td>
<td>0 / 0</td>
</tr>
<tr>
<td>1–2 years</td>
<td>5 / 4</td>
</tr>
<tr>
<td>2–5 years</td>
<td>18 / 14</td>
</tr>
<tr>
<td>5–10 years</td>
<td>17 / 13</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>54 / 42</td>
</tr>
<tr>
<td>Non-HIV specialist with working knowledge</td>
<td>6 / 5</td>
</tr>
<tr>
<td>Total</td>
<td>100/ 78</td>
</tr>
</tbody>
</table>
Defining ‘TasP’

There was considerable diversity of understanding with regard to the concept of TasP (Table 6). The majority (67%) felt that TasP included prevention of mother-to-child transmission (MTCT). Forty percent of respondents felt that TasP included post-HIV exposure prophylaxis and approximately half also perceived TasP to incorporate pre-HIV exposure prophylaxis. The majority (88%) agreed that TasP referred to the practice of prescribing ART to an individual, regardless of clinical disease status, with the aim of minimising risk of onward transmission. For several questions there were significant numbers of non-responders. It is unclear why.

<table>
<thead>
<tr>
<th>Please select which of the following statements describes TasP:</th>
<th>‘Yes’ responses:</th>
<th>‘No’ responses:</th>
<th>‘Unsure’ responses:</th>
<th>Total responses:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention of mother-to-child transmission using ARVs during pregnancy</td>
<td>67 / 44</td>
<td>26 / 17</td>
<td>7 / 5</td>
<td>66</td>
</tr>
<tr>
<td>Provision of ARVs to infants born to HIV-positive mothers</td>
<td>43 / 26</td>
<td>44 / 27</td>
<td>13 / 8</td>
<td>61</td>
</tr>
<tr>
<td>Provision of ARVs to an HIV-negative individual immediately following likely exposure to HIV</td>
<td>39 / 24</td>
<td>50 / 31</td>
<td>11 / 7</td>
<td>62</td>
</tr>
<tr>
<td>Prescribing ARVs to someone with HIV, earlier than clinical guidelines currently recommend, in order to reduce the chance of onward HIV transmission</td>
<td>88 / 66</td>
<td>7 / 5</td>
<td>5 / 4</td>
<td>75</td>
</tr>
<tr>
<td>Strict adherence to ARVs in HIV-positive individuals so that an undetectable viral load is reached, thereby reducing the risk of transmission to others</td>
<td>63 / 42</td>
<td>28 / 19</td>
<td>9 / 6</td>
<td>67</td>
</tr>
<tr>
<td>Provision of ARVs to HIV-negative individuals in order to prevent HIV infection should exposure occur</td>
<td>51 / 34</td>
<td>34 / 23</td>
<td>15 / 10</td>
<td>67</td>
</tr>
</tbody>
</table>

Reported knowledge and confidence about TasP

The vast majority (92%) of respondents agreed that discussing TasP with patients should be a role for ‘any competent and trained healthcare professional’, with only 3% (2/77) seeing it as a role for another member of the multidisciplinary team. Over half (48/78) had already had a discussion about TasP with patients, the topic having been broached by both nurses and patients (51% vs 45%, respectively).

The questionnaire asked nurses if they were familiar with the 2013 BHIVA/EAGA position statement on TasP: 66% of respondents (n=50) were and 34% (n=26) were not. All those who were aware believed it to have had an impact on care, with one-third perceiving the statement to be of considerable influence in terms of future clinical practice. Interestingly, the majority (79%) of nurses reported not yet having seen any TasP-related changes made to practice or policy in their own locality or workplace. In relation to funding, only 8% (6/78) of respondents stated that they felt well informed about funding arrangements for access to TasP within their clinical area.

In terms of knowledge, 35% ‘agreed’ that they possessed up-to-date knowledge, although 42% responded negatively to the question and 23% declined to answer. Reported confidence was aligned with perceptions of feeling up to date, and with feeling sufficiently skilled to explore the concept of TasP with patients. Nurses were almost evenly split in terms of those who felt sufficiently skilled and those who did not.
### Education and training

Twenty-two per cent of respondents said they had already received some training on the topic of TasP (Table 8), but the majority (78%) had not.

<table>
<thead>
<tr>
<th>Table 7: Self-perception statements – knowledge, confidence, ability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statement</td>
</tr>
<tr>
<td>-----------</td>
</tr>
<tr>
<td>I have enough time in my consultations to discuss TasP with my patients</td>
</tr>
<tr>
<td>I feel sufficiently skilled to discuss the issue of TasP in depth</td>
</tr>
<tr>
<td>I possess up-to-date knowledge in relation to TasP</td>
</tr>
<tr>
<td>I feel confident discussing TasP with my patients</td>
</tr>
<tr>
<td>I feel that discussing TasP is the role for another member of the MDT</td>
</tr>
<tr>
<td>I feel concerned about how patients might react if I initiate discussion about TasP</td>
</tr>
<tr>
<td>I am well informed about the funding of TasP in my area</td>
</tr>
</tbody>
</table>

### Table 8: TasP training received

<table>
<thead>
<tr>
<th>Respondents: % / n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes 22 / 17</td>
</tr>
<tr>
<td>No 78 / 61</td>
</tr>
<tr>
<td>Unsure 0 / 0</td>
</tr>
<tr>
<td>Total 100 / 78</td>
</tr>
</tbody>
</table>

A variety of resources had been accessed by nurses on the topic (Table 9), with half the respondents reporting looking at information from more than one source. The word ‘training’ might not have been interpreted as ‘education’ by some of the respondents, as several who answered ‘no’ to the ‘training’ question, subsequently indicated that they had accessed workshops and seminars.

<table>
<thead>
<tr>
<th>Table 9: Types of resource accessed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responses: % (n/78)</td>
</tr>
<tr>
<td>Information booklets</td>
</tr>
<tr>
<td>Attended in-house teaching</td>
</tr>
<tr>
<td>Attended conference seminar</td>
</tr>
<tr>
<td>Attended workshop/study day</td>
</tr>
<tr>
<td>Accessed online resource</td>
</tr>
<tr>
<td>Medical/nursing journal</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Total responses given*</td>
</tr>
</tbody>
</table>

*Multiple categories selected
In relation to skills development and support, nurses identified a range of resources/actions as potentially useful developments that would enable them to advocate on behalf of patients for access to TasP (Table 10). There was a strong desire for clear, locally relevant clinical pathways and educational resources for patients, and for further clinical research evidence.

Respondents were also asked for their views on the usefulness of a range of possible educational resources (Table 11). All suggested formats were considered useful, with the most popular being study days and workshops, especially if held locally.

**Table 10: Resource desired**

<table>
<thead>
<tr>
<th>Resource desired</th>
<th>Responses: % (n/78)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better background knowledge</td>
<td>72 (56)</td>
</tr>
<tr>
<td>More clinical evidence</td>
<td>60 (47)</td>
</tr>
<tr>
<td>Communication skills training</td>
<td>24 (19)</td>
</tr>
<tr>
<td>Educational resources for patients</td>
<td>69 (54)</td>
</tr>
<tr>
<td>More support from other HCPs (healthcare providers)</td>
<td>27 (21)</td>
</tr>
<tr>
<td>More support from voluntary sector</td>
<td>6 (5)</td>
</tr>
<tr>
<td>Clearer local clinical framework/pathways</td>
<td>67 (52)</td>
</tr>
<tr>
<td>Additional resources not required</td>
<td>5 (4)</td>
</tr>
<tr>
<td>More time in consultations</td>
<td>38 (30)</td>
</tr>
<tr>
<td><strong>Total responses given</strong>*</td>
<td>n/a / (288)</td>
</tr>
</tbody>
</table>

*Multiple categories selected*

Respondents indicated that they see facilitating discussion around and access to TasP as a role for nurses. NHIVNA members are already experiencing a demand for skills and knowledge in this respect, within their consultations with patients. While they report having the general skills needed (such as feeling able to have discussions with patients about sexual risk behaviours), they feel less well equipped and guided on the specific issue of TasP, especially in more complex patient scenarios. The need for more clarity on the definition and concept of TasP and a demand for further education around the subject was identified, including how this prevention strategy will be funded and how it will work in practice. These findings warranted further exploration and informed the interview schedule for Phase 2.

**Table 11: Beneficial educational resources**

<table>
<thead>
<tr>
<th>Type of resource</th>
<th>Selected ‘very useful’: % / n</th>
<th>Selected ‘somewhat useful’: % / n</th>
<th>Selected ‘not useful’: % / n</th>
<th>Total responses: n / 78</th>
</tr>
</thead>
<tbody>
<tr>
<td>E-learning</td>
<td>62 / 46</td>
<td>34 / 25</td>
<td>4 / 3</td>
<td>74</td>
</tr>
<tr>
<td>Reading materials online</td>
<td>58 / 43</td>
<td>38 / 28</td>
<td>4 / 3</td>
<td>74</td>
</tr>
<tr>
<td>Hard copy reading materials</td>
<td>50 / 35</td>
<td>44 / 30</td>
<td>6 / 4</td>
<td>69</td>
</tr>
<tr>
<td>Study days</td>
<td>80 / 59</td>
<td>17 / 12</td>
<td>3 / 2</td>
<td>73</td>
</tr>
<tr>
<td>Conference lectures</td>
<td>70 / 51</td>
<td>29 / 21</td>
<td>1 / 1</td>
<td>73</td>
</tr>
<tr>
<td>Interactive workshops</td>
<td>76 / 55</td>
<td>21 / 15</td>
<td>3 / 2</td>
<td>72</td>
</tr>
<tr>
<td>Short education sessions</td>
<td>82 / 60</td>
<td>12 / 9</td>
<td>6 / 4</td>
<td>73</td>
</tr>
</tbody>
</table>

**7. CONCLUSION**

Respondents indicated that they see facilitating discussion around and access to TasP as a role for nurses. NHIVNA members are already experiencing a demand for skills and knowledge in this respect, within their consultations with patients. While they report having the general skills needed (such as feeling able to have discussions with patients about sexual risk behaviours), they feel less well equipped and guided on the specific issue of TasP, especially in more complex patient scenarios. The need for more clarity on the definition and concept of TasP and a demand for further education around the subject was identified, including how this prevention strategy will be funded and how it will work in practice. These findings warranted further exploration and informed the interview schedule for Phase 2.
8. PHASE 2 RESULTS: QUALITATIVE INTERVIEW DATA

Characters of participants
The interview participants (n=10) were purposively selected and represented a diverse range of settings, felt to be representative of NHIVNA’s membership. Participants worked in a range of settings and came from varied regions of the UK. Seven out of ten participants worked across more than one setting and all except one had more than 5 years’ HIV experience. All participants were considered to be senior, based on their working grades, which were band 6 and above. Cohort size and demographics varied considerably. All but one of the interviewees had experience of engaging in three or more discussions with their patients around TasP. Table 12 represents the characteristics of interviewees and their cohorts as described by themselves.

Table 12: Participant characteristics

<table>
<thead>
<tr>
<th>RESP</th>
<th>Experience in HIV (approx)</th>
<th>Setting</th>
<th>Cohort size (approx)</th>
<th>Cohort characteristics</th>
<th>Region</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>&gt;10 years</td>
<td>Community</td>
<td>200</td>
<td>MSM. BAHet. Few IVDU</td>
<td>South</td>
</tr>
<tr>
<td>B</td>
<td>5 years</td>
<td>Community, Op, Ip</td>
<td>N/S</td>
<td>N/S</td>
<td>Midlands</td>
</tr>
<tr>
<td>C</td>
<td>4 years</td>
<td>Community</td>
<td>N/S</td>
<td>MSM/mixed</td>
<td>Midlands</td>
</tr>
<tr>
<td>D</td>
<td>&gt;5 years</td>
<td>Specialist midwifery</td>
<td>N/S</td>
<td>Females, majority BAHet</td>
<td>London</td>
</tr>
<tr>
<td>E</td>
<td>&gt;10 years</td>
<td>Voluntary sector</td>
<td>N/S</td>
<td>Mixed</td>
<td>London</td>
</tr>
<tr>
<td>F</td>
<td>&lt;5 years</td>
<td>Specialist Op</td>
<td>&gt;2000</td>
<td>MSM/mixed</td>
<td>London</td>
</tr>
<tr>
<td>G</td>
<td>7–8 years</td>
<td>Op, Ip</td>
<td>700</td>
<td>Mixed</td>
<td>Scotland</td>
</tr>
<tr>
<td>H</td>
<td>N/S</td>
<td>GUM OPD</td>
<td>N/S</td>
<td>Mixed</td>
<td>North</td>
</tr>
<tr>
<td>I</td>
<td>N/S</td>
<td>Mental health, HIV</td>
<td>N/S</td>
<td>BAHet majority. Some IVDU and MSM</td>
<td>London</td>
</tr>
<tr>
<td>J</td>
<td>&gt;20 years</td>
<td>Community</td>
<td>400</td>
<td>Mixed</td>
<td>North</td>
</tr>
</tbody>
</table>

**RESP** = Respondent; **BAHet** = Black African heterosexuals; **IVDU** = Intravenous drug users; **MSM** = Men who have sex with men; **Op** = Outpatient care; **Ip** = Inpatient care; **N/S** = Not specified; **GUM** = Genitourinary medicine; **OPD** = Outpatients Department

9. KEY THEMES IDENTIFIED

The majority of interviewees (8/10) reported caseloads where the vast majority of patients were already taking ART (principally to minimise disease progression), and so opportunities for new discussions on the topic of TasP were not commonplace at the time of interviews. Of the nine nurses who reported having had discussions with patients about TasP, seven had personally initiated at least one of those discussions.

As in the survey, a lack of clarity in respect of the term ‘TasP’ was revealed, as was diversity in nurses’ perceptions of their skills and confidence to discuss the topic with patients. Several significant concerns about the impact of TasP on individuals were highlighted, as well as issues associated with proposals for the wider roll-out of this intervention. Nurses also identified many positive factors arising from both the process and outcome of this prevention strategy. The following table summarises the key themes arising from the ten recorded interviews. Findings are also illustrated in more depth using verbatim quotes taken from interview transcripts.
### Table 13: Key themes identified

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
</tr>
</thead>
</table>
| a) Understanding TasP         | • diversity and uncertainty in defining the term and in understanding of the concept  
                                | • lack of guidelines and clinical pathways                                  
                                | • limited access to training and education                                  |
| b) Perceived benefits of TasP | • as a motivator for starting treatment and for adherence                  
                                | • as one of a package of prevention initiatives                            
                                | • as a reassuring element in the support of newly diagnosed and serodiscordant couples  
                                | • as an opportunity to enhance the likelihood of retention in care          
                                | • empowerment and potential impact on fear and stigma                      |
| c) Nursing advocacy           | • responding to patient questions and demands                              
                                | • instilling a philosophy of shared care and partnership working           
                                | • working with and through the MDT                                         |
| d) Concerns about TasP        | • potential for increase in sexual risk behaviours and complacency         
                                | • a challenge for long-term adherence                                     
                                | • a risk in terms of side effects and drug resistance management           
                                | • impact on relationships, both sexual and clinician–patient               |
| e) Complexity                 | • diversity and complexity of patients’ clinical, social and psychological situations  
                                | • need for individualised advice and care                                   
                                | • effective communication around risk                                       |
| f) Supporting the nurse’s role| • additional support requirements                                          
                                | • clinical guidelines and local initiatives, e.g. pathways                 
                                | • education: resources and format                                          
                                | • patient education resources                                              |

### 9a) Understanding TasP

All but one respondent was clear that TasP meant offering ART to individuals to prevent onward HIV transmission, regardless of the individual patient’s own clinical need:

**RESPONDENT J:**

“I would define treatment as prevention as talking to patients about the opportunity to take HIV medicines ... before we would necessarily be looking at that clinically for them, so where their CD4 count’s over the 350.”

However, the respondents also demonstrated a degree of uncertainty over defining TasP. Six respondents felt that it was an ‘umbrella’ or ‘catch-all’ term which included preventing MTCT through prescribing ART and pre-exposure prophylaxis:

**RESPONDENT C:**

“Yes, and we do a lot of post-exposure prophylaxis, so yeah, that is inclusive of that too, and pre-exposure ARVs, I guess that also counts.”

**RESPONDENT J:**

“... and if for any reason they feel like it would be beneficial to prevent transmission to partners, or I guess, or children, then it’s that too.”

National HIV Nurses Association
Other respondents saw TasP as a more narrowly defined concept, more closely reflecting WHO guidelines and the BHIVA/EAGA position statement:

**RESPONDENT A:**
“We would include treatment in pregnancy ... but we wouldn’t include PrEP as treatment as prevention.”

**RESPONDENT J:**
“I don’t really deal with anyone negative generally so I don’t think I would include PrEP. I suppose it is treatment as a way of prevention in a way, but it’s not my understanding [of TasP].”

Interviewees were asked about the source/s of their current knowledge base on TasP. Three expressed confidence in the benefits of TasP as demonstrated in the latest research findings, namely the HPTN052 study:

**RESPONDENT A:**
“I’m a believer really ... it just shows us that controlling viral load and getting it down, and keeping it down for long enough, is such an effective way of reducing transmission that I don’t need much conversion really.”

**RESPONDENT B:**
“That study ... the findings are very significant ... and have got really good potential.”

9b) **Perceived benefits of TasP**

All the participants who had initiated discussions reported viewing TasP as a motivating factor when facilitating patient readiness to start ART, and also when exploring strategies for supporting treatment adherence.

TasP was also seen as having a positive and rewarding impact on self-acceptance and therefore on relationships, and this was promoted as a further benefit to starting and remaining on treatment, illustrated here:

**RESPONDENT E:**
“... if they are in relationships or are wanting to start new ... I say that they can feel more confident in terms of having sex.”

**RESPONDENT D:**
“It [an HIV diagnosis] can break the family ... and then the other side will say, ‘Okay, how do we work around this? Because I love my wife or husband ... how can you help us to keep our ... family together?’ Well, this [TasP] provides us with an option ... like a saving grace.”

The possibility that people could feel empowered by actively taking steps to reduce their infectivity – and that some individuals may be more willing to take the risk of allowing such new relationships to develop as a result – is illustrated by the following excerpts:

**RESPONDENT E:**
“... some people have told me that they want to be treated sooner because they just don’t want to be going around with an active virus, they want to control it ... and not pass it on.”

**RESPONDENT C:**
“... before [TasP] they were not following through [in new relationships] because they get to that point where they feel the secrecy is too much.”
Four participants talked about working specifically with people who were newly diagnosed and, again, they saw TasP as a strategy to encourage and reassure patients:

**RESPONDENT D:**
“Right from the point of diagnosis … we make them aware of it [TasP] and we work with them … obviously, the negative partner gets a lot of anxieties, and this helps to address them … to like, keep the family unit happy.”

Also expressed, and linked to the sub-theme of empowerment, was the possibility that the impact of TasP could be even more widespread, by reducing fear surrounding the disease and its infectivity:

**RESPONDENT C:**
“ … in my mind I think of it as taking the fear out of HIV and once you take the fear out of HIV … the stigma and the discrimination will naturally die.”

A further benefit highlighted by several interviewees was a perception that TasP may have the potential to enhance retention in care, particularly in those patients receiving a new HIV diagnosis and who, in the participants’ experience, were seen as particularly vulnerable to not returning for clinical follow-up. However, in the one example given – whereby a patient was offered TasP in such a scenario – the individual was lost to follow-up despite the intervention.

Another sub-theme that arose was the individualised nature of TasP-related discussions. TasP is clearly seen as only one aspect of a range of prevention strategies, to be tailored within an individualised package of transmission risk-reduction options, as acknowledged in the following quotations:

**RESPONDENT B:**
“*I think the important thing always is to know that everybody is different and that people have choices, that they have an informed choice and … that they are presented with all the facts, on all the options.*”

**RESPONDENT F:**
“*It can be looking at, like, clean needles, it can be looking at using condoms and things like that. Always thinking about what else can we offer alongside treatment as a prevention.*”

**9c) Nursing advocacy**

Seven of the ten participants interviewed expressed confidence in their role as patient advocates in relation to TasP. The three participants who did not feel confident in advocating for patients cited as a reason the belief that their knowledge on TasP was insufficient. All participants felt that they possessed pre-existing skills which allowed them to facilitate discussion around sexual risk effectively: this was something they had already been doing, as part of their health promotion role within clinical practice.

One of the participants who voiced reservations about initiating TasP discussions, due to perceived lack of knowledge, indicated her unease around this – seeing lack of foresight as a weakness in terms of providing proactive care:

**RESPONDENT F:**
“* … what is slightly sad here, and just making me think talking to you … I probably wouldn’t have suggested it to him, and I should have, but then he suggested it to me … and I had to go away and look into it.*”
The nurses interviewed reported that in general, and to date, most patients with whom these discussions had taken place had been well informed and confident in voicing their own ‘case’ for TasP. Overall, however, the respondents felt their patients’ knowledge varied considerably. The nurses reported that their more informed patients tended to use the internet as a source of information and were also likely to be accessing voluntary sector groups where information-sharing took place. Four participants identified MSM as a cohort who appeared, in general, better informed about TasP. Four respondents had experienced MSM attending consultations with the specific purpose of raising and discussing the subject of TasP. This is reflected in the following transcript extracts:

**RESPONDENT F:**
“... our large MSM cohort ... are a knowledgeable group of patients in general. I think there are some people who are extremely knowledgeable and read up precisely on these things.”

**RESPONDENT G:**
“... his partner was quite well informed and they were planning, so they wanted to be absolutely certain not to transmit.”

**RESPONDENT C:**
“... people have been coming in for a while, asking about PrEP, and we have a few discordant gay couples, their partners are negative, who are now saying ‘we’ve heard about this [TasP], what is happening?’ So I think people in our cohort are just starting to hear, and will be interested in going on it [treatment] for prevention reasons.”

The other six respondents had so far found that very few of their patients had raised the question of TasP and believed that they had little awareness, if any, of recent research evidence. Some suggested this was due to a lack of patient-orientated information in circulation and that the new research findings had not yet filtered through to service users. Other patient priorities were also suggested as a reason for this. For example, within a mental health setting, clinical issues such as TasP were reported as low on the agenda for HIV-positive people experiencing mental illness, as in this excerpt:

**RESPONDENT I**
“It [TasP] would just not be a priority for them to be honest. HIV is the least of their concerns, getting them to keep taking their antipsychotics is my biggest challenge, otherwise they will stop taking all their meds anyway.”

A sub-theme also emerged around multidisciplinary working. All participants believed that they worked within multidisciplinary teams where case discussion and communication was effective. This effective team approach was seen as an important element for TasP to be successfully integrated into local practice. All reported that, so far, the use of TasP had been a shared responsibility – seen as something for team discussion on a case-by-case basis, rather than as a standard of care, as this respondent explains:

**RESPONDENT B:**
“We all discuss things like this [TasP] in our weekly meeting ... bring the case up, then make decisions, so it’s not me on my own and I know what the consultants’ viewpoints are.”

Where participants reflected on the experience of interactions with patients, TasP discussions were commonly viewed as examples of effective partnership working. One interviewee went away to read up on the topic after a patient of hers initiated a discussion that she had felt ill-equipped to engage in.
RESPONDENT F:  
“... but then that is good because you know that’s partnership isn’t it, and I could then suggest
this [TasP] to somebody else.”

It was also highlighted that this partnership approach to working can be used to inform others:

RESPONDENT H:  
“... he was very intelligent and he’s made a very informed decision to do this. He had done his
homework and, you know, was able to present a really clear case, which then I was able to share
with other team members.”

9d) Concerns about TasP
Whilst there was an overall sense of confidence amongst respondents towards the recently
published evidence, a few expressed concerns about the limitations of research findings to date.
In particular there were concerns about lack of evidence to support TasP in MSM, and for different
sexual acts. A desire for further research on this was expressed:

RESPONDENT A:  
“... Well, I don’t think we know ... what the difference is really between becoming undetectable, if
you can call that day zero, and six months later ... and maybe we will never get concrete evidence.”

RESPONDENT D:  
“There are some statistics of it [TasP] from the Ugandan cohorts ... but referring to that would be
iffy. Something which is locally relevant ... would be much more useful, because, obviously, those ...
were different situations.”

The possibility of TasP resulting in behaviour change, specifically disinhibition around sexual
risk-taking, was voiced in five of the ten interviews, and the following comments indicate that the
participating nurses were concerned about complacency developing in their cohorts:

RESPONDENT A:  
“I suspect that in real life there will be people who throw the condoms away the instant that they
are undetectable.”

RESPONDENT J:  
“The guidelines will inevitably be cautious, it will say, you know, six months of undetectable viral
load and regular STI screening or monogamy, but I suspect patients will know that and then kind of
stretch them.”

Further to this, some participants voiced concerns around what TasP might mean as regards long-
term adherence, and ultimately the risk of drug resistance developing, especially when patients were
faced with side effects, as described below:

RESPONDENT J:  
“You know, when they are not feeling bad themselves beforehand, and then they take them
[antiretroviral drugs] and feel awful, and are expected to carry on for years ... and then split with
their partner anyway ... I think it might become difficult to motivate them on it in the long term.”

RESPONDENT H:  
“... one of the things I have trouble with is ... with people starting early is they have side effects,
that might have a negative effect on adherence ... and that puts their sex partners at risk.”
In relation to the dynamics within serodiscordant couples’ relationships, there was concern regarding the risks of a lack of transparency and/or honesty within such relationships; and even the possibility of coercion, where TasP is favoured by only one partner:

**RESPONDENT F:**
“A classic example that I always think of was that I had a patient who was newly HIV positive, good CD4 count ... about 700, but saying he was very keen to start ARVs very early. This was a gay gentleman who had lots of sex with other men, but also lived with a long-term partner, and wanted to do it because he wanted to minimise risk to him ... but he wasn't being upfront.”

**RESPONDENT B:**
“... there's so many other things always around a relationship ... and the possibility of the whole idea of a partner putting them, or you, under pressure.”

The potential impact of TasP on the nurse–patient relationship also came under question. Four respondents acknowledged that they felt uncomfortable discussing sexual practices and risk in relation to TasP, especially in complex scenarios, such as outside of heterosexual monogamous relationships or where they sensed coercion within the relationship. These four nurses talked of feeling under pressure to commit to certainties when discussing risk with some patients, and the sense of a burden of responsibility that this engendered was clearly expressed:

**RESPONDENT C:**
“... the difficulty is when someone says ... ‘Okay, give me the figures. When you say “Low risk” ... what do you mean?’ I’m trying to help them make an informed choice, but that is based only on the information they are willing to give me, and even then ... low-risk isn’t a no-risk.”

**RESPONDENT H:**
“... and they say ‘So, what are you saying I should do?’ When someone puts you on the spot like that ... it's difficult.”

**RESPONDENT H:**
“... they put the ball back in your court and ... it's not like I don't have to have them on my conscience.”

Communicating effectively and in depth with patients around transmission-risk behaviours and the use of TasP was identified as challenging. A concern that warrants particular exploration is the theme of complexity within the real lives of the patients that nurses work with.

9e) **Complexity**
The complexity of sexual relationships and social scenarios encountered by respondents, and the difficulties in reaching any consensus or producing guidelines which could encompass this individuality, was a key concern. This diversity is well illustrated by the following account of one patient’s comments within a nurse–patient conversation:

**RESPONDENT D:**
“He [the patient] said, ‘So I told this guy I was positive and he didn’t mind. He just took some of mine [ART], and then they came in another day to clinic for more [PEP]. Well, it’s what America is doing, so he used my own medication ... lots of others do, too.’”

During the course of the data-gathering, a notable disparity emerged: many who acknowledged the complexity of patient relationships, beliefs and circumstances later on in the interviews, had earlier reported that broad guidelines and criteria for TasP would be helpful to them in clinical practice. Several respondents expressed discomfort in encountering some of these complex scenarios:
RESPONDENT G:
“In reality I think that that is complicated and difficult, because in some ways it’s quite easy to just say yeah, go for it, we don’t want you passing it [HIV] on ... but I don’t think it’s at all as simple as that … there are loads of complex social circumstances.”

The participants’ views on what currently exists by way of support and information, and what they require to further assist them in this aspect of their work, was explored, as outlined below.

9f) Supporting the nurse’s role
From a practical standpoint, addressing TasP in nurse consultations was seen as something that can currently be managed within existing clinic time. Most interviewees felt privileged because they have sufficient clinic time to discuss such issues. However, it was felt that clinic-based resources such as consultation times, clinic space and pharmacy services, would need to be reviewed should TasP be widely rolled out.

As previously discussed, the multidisciplinary team was identified as a valued source of support, guidance and information for all respondents. Despite MDT working being widely recognised as an environment for the effective sharing of knowledge, nine out of ten nurses were not aware of the development or existence of any local, TasP-related initiatives. Even if, for example, in-house clinical pathways or Trust/Directorate policies in relation to TasP had been, or are currently being developed in these workplaces, it is clear that these nurses have not been engaged in the process to date.

There was acknowledgement that the many variables and complexities of patients’ circumstances would be challenging to accommodate within a set of generic TasP guidelines. This sentiment was neatly summed up:

RESPONDENT A:
“... all that diversity ... well, it’s going to be hard for a guideline to capture.”

Whilst nine of the ten respondents said that they knew of the BHIVA/EAGA position statement, there was no evidence in the interviews that the details given in this document were being referred to, as a resource to support nurses’ discussions with patients. Guidance in the form of user-friendly algorithms for different at-risk groups was suggested as a potential way forward, alongside a desire for hard facts to support such discussions, as indicated here:

RESPONDENT J:
“I mean, the simple numbers about the transmission and risks ... those would be pretty handy as well.”

RESPONDENT B:
“If you could get one resource that would make it clear at a glance ... because you just always struggle with risk and how they can lower it ... So, yeah, if there was something concrete ... like a flow chart with criteria, on paper to make it clear, that would be great.”

The need for further nurse education was identified by all participants, including those who currently felt up to date and confident on the subject of TasP. Education delivered in the form of workshops was viewed as particularly desirable, as these provide opportunities for sharing experience and discussion. Several participants had attended a NHIVNA workshop on TasP and expressed a desire for a repeat of this in different locations. Several participants also requested that, ideally, these workshops should be run locally to increase accessibility, with regional sessions also being of value. The inclusion of case studies to explore various concepts was highlighted as especially useful, where the case studies were identified in advance by attendees and brought forward for group
discussion with an expert panel. This format was felt to be more meaningful as it is reflective of the front-line experience of nurses and the lived experience of their patients.

**RESPONDENT I:**

“If it could be made real, by us bringing our own case studies to the workshop ... to the table for discussion ... that would be so useful.”

In addition, web-learning resources had also been used previously and liked by the majority of participants. The accessible nature and the option to ‘dip in and out’ within working time restrictions were considered highly beneficial. The existing NHIVNA e-learning resource was mentioned by four interviewees and well regarded as an educational resource both for themselves and for other nurses in their teams, especially students.

A dearth of patient education materials to support discussion was identified by all participants. Hard copy materials for this purpose are seen as valuable to aid discussions, and currently lacking. Three participants indicated that they would use an online patient resource during consultation time; however, most indicated that they would point patients in the direction of website resources, to access away from clinic. Most participants currently rely on National Aids Manual (NAM) for patient-friendly resources. None of the participants, when asked, were aware of any specific patient information leaflets available currently, which explore TasP specifically.

10. DISCUSSION

**Understanding TasP**

Consistent across both parts of this study was a consensus that discussing TasP with patients is an appropriate role for nurses to undertake, alongside other suitably knowledgeable and skilled members of the multidisciplinary team. Another consistent theme was the considerable diversity in the understanding of the term ‘TasP’. Approximately 20% (15/78) of questionnaire respondents abstained from answering one or more of the questions designed to determine how the term TasP was understood, and there was considerable variation in views about the scope of the term – for example, whether ‘TasP’ does or does not include the use of ART in pregnancy to prevent mother-to-child transmission or the use of post-exposure prophylaxis. It could be that, as patients are not yet widely presenting to nurses asking about TasP, it has not been seen as a priority; thus information on the subject may not have been actively sought, and the research findings have not filtered through to some.

In addition to this lack of clarity in the definition, there was a widespread lack of awareness regarding how TasP was to be funded in local areas. If nurses are unsure that local policy supports the prescribing of TasP, then this could be a significant deterrent to their raising the topic for discussion with patients. Clearly, defining a new treatment strategy is important as it facilitates mutual understanding for all stakeholders.

This in turn is relevant to the development of appropriate policies, guidelines and educational initiatives and in the allocation of resources including skills and clinical time for effective implementation.

**Benefits**

Nurses see TasP as an additional element and choice for patients to add to the armoury of transmission prevention strategies. Facilitating preparedness to start ART and ongoing adherence support has been a major element of the role of the HIV nurse since Highly Active Anti-Retroviral Therapy (HAART) first became available – and nurses see TasP as an opportunity to motivate and encourage their patients to start and continue to take treatment reliably. TasP could be readily integrated into an approach to care, such as through motivational interviewing (MI), which seeks to work in partnership with patients towards increasing self-acceptance and instilling self-confidence.
Nurses interviewed take the view that TasP provides an opportunity for people living with HIV (PLHIV) to proactively reduce their infectivity, whilst still investing in sexual relationships. In turn this could go some way to reducing the guilt and isolation experienced by many PLHIV – and the stigma which arises, to some extent, from fear and ignorance around transmission.

**Concerns and supporting the nursing role**

While nurses clearly see antiretroviral treatment as having an important role to play as a prevention strategy, they are concerned about the ‘human’ impact, rather than the logistics, of rolling out TasP nationally and locally. Some of the concerns highlighted by interviewees reflect those raised in the explanatory notes accompanying the BHIVA/EAGA position statement [3]. For example, there is a degree of uncertainty regarding the impact of TasP on complex social factors such as HIV-related stigma, the possibility of coercion into treatment and potential for disinhibition of sexual behaviour.

Despite a view that HPTN052 findings are credible and relevant, our findings suggest that nurses may be hesitant to recommend TasP across their diverse patient cohorts until more evidence is available to clarify several significant questions. These include the transmission risks in MSM and for different sexual practices, and the challenges for long-term treatment adherence that TasP may entail. The interviews revealed that nurses can feel uncomfortable with the onus of responsibility when discussing sexual behaviours and transmission risk in relation to TasP. Nurses did not identify their communication skills as lacking, and it is not the discussion of sexual practice that causes discomfort, but rather the perceived (and actual in some cases) pressure to give exact figures in terms of risk calculations. It may also be that patients themselves are uncomfortable with the inexact nature of these discussions, and this could be a valuable issue to explore through further research.

The World Health Organization states, ‘TasP requires a shift in perspective from both clinicians and patients, who now need to consider not only the clinical benefits, but also the prevention benefits of accepting and adhering to treatment’ [12]. Furthermore, the WHO stresses, ‘retention in care and long-term adherence are of serious concern for all ART programmes and introducing TasP may improve or decrease performance in these areas’ [12]. Maximising the potential benefit of TasP requires those working on the ‘front line’ to think about the role they can play in these aspects of care, while ensuring that individual patient rights are respected. Nurses in both parts of this study appear to be aware of these factors and are starting to consider what this means for their practice. If TasP is to be widely rolled out, then nurses will need to feel supported and confident in the strategy’s benefits versus its risks – which means that more work is needed in researching the outcomes of implementing TasP for individuals; and in developing nationally and locally agreed practice guidelines.

**Limitations**

The study’s limitations must be acknowledged:

- While Part 1 was reflective of the geographical distribution and grading seniority of NHIVNA membership, there are many nurses working in the field who are not current NHIVNA members.
- Although a good response rate was obtained (33%), the relatively small study size means that some views and experiences have not been captured.
- This was a UK-specific study which does not reflect the experiences of nurses working elsewhere.
- As volunteers, the interview participants were a self-selecting group – which was then purposively sampled to reflect the geographical distribution and workplace setting diversity of the Association’s membership. This may mean that a disproportionate number of nurses appear at least aware of the topic of TasP and considered its implications prior to interview. However, this level of awareness and engagement may not be present in all nurses working in HIV.
- Sporadic drops in sound quality when recording the telephone interviews unfortunately resulted in loss of some pertinent parts of dialogue.

National HIV Nurses Association
11. RECOMMENDATIONS

Analysis of both phases of the study has revealed considerable gaps in the knowledge and confidence of many nurses working in the specialty, in relation to TasP. There is a lack of clarity around the subject from a clinical perspective and also in relation to the logistics of how the initiative could be rolled out and funded. BHIVA states that the positive partner of sero-different couples can have early treatment, and therefore individual clinics should be having this discussion at Trust/Department level, with good communication across the team. These deficits in knowledge and communication need to be addressed proactively by providing opportunities for the sharing of experience and discussion, and by devising a dynamic programme of education and clinical support. In response to the study’s findings, the development of an educational resources package, including interactive workshops held in accessible locations, an online learning resource and the promotion of opportunities for ongoing sharing of experience and advice, should be prioritised.

In a meta-analysis [13] reviewing results of 25 studies of the impact on sexual risk behaviour of ART and beliefs regarding transmissibility, beliefs about HIV transmission and reduced concerns about unsafe sex were associated with a greater likelihood of risky behaviour, so nurses are right to be aware of the potential impact of TasP on sexual risk behaviour. Further research is certainly warranted; meanwhile, nurses should accommodate this knowledge into their nursing needs assessments and care planning.

Patient-friendly information resources were identified as lacking but desirable. Nurses continue to use printed materials to reiterate the information they give in consultation time. Nurses also indicated that they direct patients to certain websites to reinforce patient education. There is a clear demand for such materials, and NHIVNA should consider opportunities for co-working with treatment advocates nationally, to produce these resources.

If TasP is to be widely used as a strategy for the prevention of onward transmission, then innovative strategies for improving engagement in care and a refocus on supporting treatment adherence will be required, alongside efforts to improve STI prevention and treatment. Updating and continuing to develop a range of tools to support informed decision-making, treatment readiness and partnership working will also contribute to the success of TasP. NHIVNA should look for opportunities to work in partnership with other organisations, such as ANAC, EHNN and IAPAC, sharing expertise and innovation to help nurses make a valuable contribution to the success of this exciting but challenging intervention.
ACKNOWLEDGEMENTS

The authors would like to thank Dr Murad Ruf, Dr Sarah Fidler, Mr Robert Fieldhouse, Dr Hilary Curtis, Ms Jane Bruton and Mr Nathan Ault for advising on the project. We also thank Mediscript, NHIVNA’s Secretariat, for providing administrative support. We are grateful to the NHIVNA members who gave up their time to be interviewed. Finally, we acknowledge Gilead Sciences Ltd for providing a grant to NHIVNA to fund this study.

REFERENCES


Dear NHIVNA member

Treatment as Prevention (TasP) is an emerging topic in HIV at the moment and NHIVNA wish to gain insight into your views and experience of this issue. We would also like to establish if there is a need for further education and support in this respect.

In order to gather accurate and representative information we would be very grateful if you could complete this questionnaire which should take up to 15 minutes to complete.

The findings will be analysed, published and used to develop resources to support your educational and clinical requirements. The questionnaires are anonymised unless you choose to give your name and contact details at the end.

Please note that your answers are NOT SAVED until completion on page 2.

1. Please indicate the setting in which you currently work (tick all that apply)
   - Community
   - Specialist HIV Outpatients Department
   - Genitourinary Medicine
   - Midwifery/Obstetrics
   - Infectious Diseases Unit
   - Paediatrics
   - Specialist HIV Inpatient Care
   - Palliative/Hospice care
   - Voluntary sector
   - Other: ____________________________

2. Which of the following geographical areas do you work in? (please tick one)
   - North
   - Midlands and East
   - London
   - South
   - Scotland
   - Wales
   - Northern Ireland
   - Other
   - Please indicate: ____________________________

3. What is the approximate size of your department’s HIV patient cohort?
   - 100 or fewer
   - 101–200
   - 201–500
   - 501–1000
   - 1001 or more
   - Not sure
   - Not applicable

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4. Please indicate at which level you are currently employed?
- Band 5
- Band 6
- Band 7
- Band 8
- Other or non-NHS

Please provide details: ________________________________________

5. How long have you been working specifically in HIV?
- Not specialising in this field
- Less than 1 year
- 1 to 2 years
- 2 to 5 years
- 5 to 10 years
- More than 10 years
- I am not a specialist but need to have a working knowledge of HIV

6. Are you familiar with the BHIVA/EAGA position statement 2013, in relation to TasP?
- Yes
- No
- Not sure

7. If ‘Yes’, what impact do you think the BHIVA/EAGA statements will have on your future clinical practice?
- No impact
- A little impact
- Moderate impact
- Considerable impact

8. Do you have any additional comments?
Add comment here ________________________________________
________________________________________
________________________________________
________________________________________

9. Please select which of the following statements describes TasP? (tick as many as apply)

<table>
<thead>
<tr>
<th>Prevention of mother to child transmission using Anti Retroviral medication (ARVs) during pregnancy</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provision of ARVs to infants born to HIV-positive mothers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provision of ARVs to an HIV-negative individual immediately following likely exposure to HIV</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Prescribing ARVs to someone with HIV, earlier than clinical guidelines currently recommend, in order to reduce the chance of onward HIV transmission</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
10. Have you ever received any training on TasP?
Yes ☐
No ☐
Not sure ☐

11. Which, if any, resources have you accessed to date, in order to enhance your knowledge of TasP? (please tick any that apply)
- Attended in-house teaching ☐
- Attended a seminar at a conference ☐
- Accessed an online educational resource ☐
- Attended a workshop/study day ☐
- Medical/Nursing journal articles ☐
- Information booklets ☐
- Other ☐
Please state: ________________________________________

12. Has your workplace changed or instigated any practices or protocols as a result of the recent research findings or EAGA/BHIVA statement 2013, in relation to TasP?
Yes ☐
No ☐
Don’t know ☐
Please comment: ________________________________________

13. In your view, whose role should it be to facilitate discussions with patients about TasP? (tick one)
- This is a doctor’s role ☐
- This is a nursing role ☐
- This is a pharmacist’s role ☐
- This is a health advisor’s role ☐
- This is a role for any health professional who has the relevant training and competence ☐
- This is a role for voluntary sector/patient advocacy workers ☐
- Other ☐
Please comment: ________________________________________

14. Have you ever had a discussion about TasP with a patient?
Yes ☐
No ☐
Not sure ☐
15. If 'Yes' who initiated this discussion?

- Myself
- The patient
- Other HCP
- Other

Please indicate: ________________________________

16. From the list of statements given below, please tick the box to indicate which best reflects your views:

<table>
<thead>
<tr>
<th>I have enough time in my consultations to discuss TasP with my patients</th>
<th>I strongly disagree</th>
<th>I disagree</th>
<th>I neither agree nor disagree</th>
<th>I agree</th>
<th>I strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel sufficiently skilled to discuss the issue of TasP in depth</td>
<td></td>
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<tr>
<td>I possess up to date background knowledge in relation to TasP</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I feel confident discussing TasP with my patients</td>
<td></td>
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<td></td>
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<tr>
<td>I feel that discussing TasP is the role for another member of the MDT</td>
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<tr>
<td>I feel concerned about how patients might react if I initiate discussion about TasP</td>
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<tr>
<td>I am well informed about the funding of TasP in my area</td>
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</tbody>
</table>

17. How comfortable do you feel in discussing levels of risk in relation to different sexual practices with your patients?

Please select your answer on a star rating from 1 to 5, where 5 is 'very comfortable' and 1 is 'very uncomfortable'.

1  
2  
3  
4  
5  
18. How confident would you currently feel in advocating for your patients to access TasP in the following scenarios:

Please select an answer on a star rating from 1 to 5, where 5 is ‘very confident’ and 1 is ‘not at all confident’ for each scenario.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>An HIV-positive pregnant woman who is worried about the risk of transmitting HIV to her baby</td>
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</tr>
<tr>
<td>A serodiscordant monogamous heterosexual couple who are trying to have a baby, where the male partner is HIV positive</td>
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<tr>
<td>A serodiscordant monogamous gay male couple who want to stop using condoms</td>
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<tr>
<td>An HIV-negative gay male who is encouraging his HIV-positive partner to take ART for prevention purposes</td>
<td></td>
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<tr>
<td>A gay male couple who have both tested HIV-positive and who have other sexual partners</td>
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<td></td>
</tr>
<tr>
<td>An HIV-positive gay male who informs you that he has unprotected anal sex with multiple partners</td>
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<tr>
<td>A lesbian couple, one partner of whom has HIV and who use sex toys together</td>
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<tr>
<td>An HIV-positive heterosexual single female who currently uses recreational drugs regularly and has had difficulties with medicines adherence in the recent past</td>
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</tbody>
</table>

19. From the list below, are there any resources which you feel would help you to better advocate on behalf of your patients for access to TasP (please tick any that apply)?

Better background knowledge  
More clinical evidence to support the use of TasP  
More training in communication skills  
More educational resources for patients  
More time with patients in consultations  
More support from other professionals  
More support from the voluntary sector  
A clearer local clinical framework or pathway  
I don’t need additional support, I feel confident with my current knowledge and skills  
None of the above  
Other  
Please describe: _________________________________________
20. If further training and education is made available on the subject of TasP, how useful would you find the following?

<table>
<thead>
<tr>
<th>Training Method</th>
<th>Very useful</th>
<th>Somewhat useful</th>
<th>Not useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>E-learning</td>
<td></td>
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<tr>
<td>Reading materials online</td>
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<tr>
<td>Hard copy reading materials</td>
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<tr>
<td>Study days</td>
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<tr>
<td>Conference lectures</td>
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<tr>
<td>Interactive workshops at conferences</td>
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<tr>
<td>Short education sessions run in my workplace</td>
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</tr>
</tbody>
</table>

21. Please suggest any other forms of training or education that would be useful:
Enter suggestion___________________________________________

22. Now you are almost finished …

The next stage of this project is to conduct some short interviews with NHIVNA members, for those willing to participate, to explore your views, experiences and support needs around TasP in more depth. The interviews will be undertaken via telephone, so they can be done at any time and in any place – at your convenience. The interviews will be conducted by the TasP project research assistant and will be entirely confidential.

Please indicate here whether or not you would be willing to be contacted for an interview:
NO thanks  □
YES, I am happy to be contacted to undertake an interview □

Please click on "Next page". Your answers have not yet been saved.
If you wish to check your previous answers, please use the "Previous page" button.
Do not use your browser "Back" button as doing so will clear all your answers.

23. Please leave your details here:
Name ____________________________________________
Email address _____________________________________
Contact number ____________________________________

24. Would you prefer to be contacted via email or telephone?
Email  □
Telephone □

25. When is a good time to call?
Please suggest which days and times of the week are best for you:
___________________________________________

Please click on "Submit form". Your answers are not saved until you do so.
National HIV Nurse Association

NHNA aims to provide an academic and educational forum for the dissemination of original nursing research in the field of HIV/AIDS.

We also aim to address the communication and support needs of nurses working in this area.

We hope that these activities will assist in the promotion of good practice in the care of people with HIV.