

# HIV testing in primary care: a small-scale qualitative study to gain understanding

Rebecca Kelly<sup>1</sup> and Joanne Garside<sup>2</sup>

<sup>1</sup>Registered Nurse Adult; <sup>2</sup>Principal Lecturer, University of Huddersfield

## Abstract

**Background:** Approximately 10,400 people are living with HIV but are unaware of their condition. Late diagnosis can impact on quality of life and prognosis is, therefore, a significant health issue.

**Method:** A qualitative research study was used with primary care clinicians to ascertain knowledge, understanding and current practices of clinicians to promote HIV testing of high-risk individuals in primary care. Using semi-structured interviews ( $n=7$ ) the questioning focused on HIV testing guidelines, prevalence, late diagnosis and perceptions of where best to test. Interview data were thematically analysed.

**Results:** *Avoidance, paternalism, resources and knowledge* were the emergent final themes. In brief, none of the clinicians could name or reference any guidance on HIV testing. One had heard of self-testing and the majority were unsure about its efficacy, reliability and its impact on resources. Most were concerned about the psychological impact.

**Conclusion:** Participants in this study had a lack of knowledge of guidance; however, they demonstrated a readiness to improve their practice. Recommendations focus on education, awareness and a promotion of lowering the threshold for testing in areas with a higher than national average late diagnosis.

## Introduction

In 2016, 89,400 people were living with HIV in the UK. Included in that figure are the estimated 12% of individuals unaware of their status [1]. It is estimated that approximately 10,400 people are unaware of their HIV status, which in turn adds to the risk of unknowingly transmitting the virus [1]. In 2017, it was revealed that people diagnosed with HIV since 2008 have a life expectancy of 78 years with effective treatment [2]. Individuals can live a long and good quality life with HIV, now a long-term condition and not an immediate death sentence. This, however, is not possible without promoting testing and raising awareness.

In 2008, the British HIV Association, British Association of Sexual Health and HIV and the British Infection Society jointly produced guidelines on the diagnosis of HIV [3]. This publication highlights how important early diagnosis is and recognises that late diagnosis increases risk of morbidity, mortality and reduces the potential benefit to treatment. It also asserts that consent procedures should now be the same as for any routine blood test.

Late diagnosis in reference to HIV is a term used to describe a person with a CD4 cell count  $<350$  cells/mm<sup>3</sup> [4]. Mocroft *et al.* highlight the importance of avoiding late diagnosis, which can reduce the efficacy of treatment and increase the risk of premature death [5, 6]. In their UK study, Iwuji *et al.* found that late diagnosis was most common in those over the age of 50 [7]. Previously banned self-testing kits are now promoted for personal use by the World Health Organization [8], and The Terence Higgins Trust offers free HIV self-testing kits to individuals deemed at higher risk of contracting HIV and also test for HIV [9]. The Department of Health press release, 'Modernisation of HIV rules to better protect public', also overrides this ban on the purchasing of self-testing kits [10].

Anecdotal evidence suggests that clinicians in general practice were not aware of this change in policy, or that self-testing is available for all [11]. Guidelines recommend HIV testing be performed in GP surgeries [10, 12]. This study is set in a locality not classed as having a high prevalence of HIV yet 57% of those diagnosed with HIV are diagnosed late in comparison to the national figure of 42% [1]. With this in mind, the questions of interest are where and how should testing be undertaken, who is responsible for offering the test and is timing essential to attempt to rectify the issue?

## Method

This study was a qualitative research project exploring local clinicians' knowledge of HIV testing in detail and to understand current practices. The aim being to explore clinicians' awareness of the current HIV guidelines and to understand decision-making processes when requesting HIV tests.

Prior to data collection ethical approval was gained from both the Local Community Partnerships and the University of Huddersfield, UK, which supervised the research. The study was set in a local primary care surgery in the north of England. To gain as much information from different perspectives, all clinicians in the surgery with requesting rights for blood tests were invited to be interviewed. Eight clinicians were approached and seven agreed. All clinicians provided informed consent before being interviewed.

## Data collection and analysis

The seven participants included GPs, advanced nurse practitioners, practice nurses and one healthcare assistant; all of whom see potential high-risk patients autonomously and all have the authority to request blood tests. To maintain anonymity of participants no job titles will be presented against the findings. The

participants were made up of five females and two males and from a variety of healthcare backgrounds.

Semi-structured interviews were the chosen method of collecting data. The interviews served as an opportunity to understand a primary care clinician's thoughts on HIV testing and were all recorded and transcribed verbatim upon completion of the final interview. Field notes were taken to record other non-verbal observations.

Thematic analysis was used to describe, analyse and interpret data gained and the process by which themes were founded [13]. NVivo was used to organise the data. All themes were discussed and negotiated prior to final agreement between authors.

## Results

Four key themes were highlighted from the data: *Avoidance, resources, knowledge and paternalism.*

### Avoidance

Avoiding the issue was a recurrent practice with three participants actually using the phrase 'Bury your head in the sand' whether it was about their personal view or the perceived view of why the patient may not seek medical attention and request testing. The suggestion being that it was the patients' responsibility to request testing and not up to the clinician to offer. Concern was raised about patients potentially using a self-testing kit and not acting on the result.

### Resources

Costs, both financial and time, were issues raised as potential barriers to HIV testing. Participant 3 highlighted that there:

*... is a cost factor for anything we do in primary care, which is why we justify it would not be appropriate for testing all the patients ... er ... as a routine test, but if we suspect or a certain group of patients who fall into 'that' criteria then we could arrange testing.*

Participant 1 commented about offering HIV tests to lower-risk patients:

*We've got to try and watch the budget.*

Another, participant 4, argued:

*... it helps in identifying them earlier because its prevalence would go up ... but keeping in mind the cost-effectiveness of testing.*

Finally, participant 5 justified as follows:

*I think there are competing time factors when patients do come in ... time is of the essence in general practice.*

### Knowledge

On exploring participants' understanding of HIV guidance and how to support early diagnosis only one of the seven participants was aware of self-testing kits for HIV but did not know where they were available from and none of the participants were aware of HIV guidelines regarding either HIV testing in a clinical setting or self-testing.

Two participants, 1 and 4, were unclear about the practicalities for patient information for example:

*I'm not quite clear on the implications for insurance and things like that.*

One recognised how practices and patient experience may vary in specialist and general areas:

*... then STD clinics ... it's all very anonymised over there [in primary care] ... this is going to go on your record and just make sure they're OK with that.*

### Paternalism

Paternalism was the final theme discovered in this research, a term used to represent people coupling authority with care and often suggestive of a person believing they knew what is best for another [14]. Participant 3 defended:

*... if that person does that test in isolation and thinks oh my God I've got HIV and my life's ruined? I wouldn't want them just making that decision.*

Out of the all the participants, five believed stigma was an important factor for them. Four of these five suggested that they avoided offering patients tests as they did not want to offend because of the manner HIV can be transmitted in their opinion, naming promiscuity, drug use and men who have sex with men as factors. Participant 6 argued their decision-making:

*It would worry me if they thought I was being in some way discriminating, discriminatory you know? Am I picking up on this person because they're from Zimbabwe or because ... they're gay and you know they've been fairly promiscuous?*

- not recognising it would only take one encounter to transmit the virus and to suggest testing would indicate promiscuity.

## Discussion

While the findings of this study are based on a limited number of participants, it clearly highlights that there is a lack of knowledge and understanding of guidance about early diagnosis of patients at high risk of HIV, which, due to the national issue with late diagnosis, may resonate with other primary care practices.

Avoidance owing to varying defences seems to be the issue at hand; from time and resources to making assumptions about a patient's reaction in a hypothetical situation. In the main, the participants were driven by concern for the patient in these situations and one could argue that the clinicians had good intentions to protect the patient, for example, not wishing them to take an HIV self-test in isolation [15]. However, unless the clinician knows the patient and their whole belief system they are unable to truly advocate for them in this way [16]. In short, patients should be fully involved in decision-making with treatments but if a clinician does not offer all the options for fear of offending then the patient's autonomy is reduced [17].

Recommendations include:

- Promoting patient involvement without making prior assumptions on their belief systems;
- Considering the late diagnosis figures separately from prevalence of HIV when reviewing local requirements for offering tests;

- Improving education and awareness of local issues and national policy drivers to deliver safe and effective health care; and
- Further research to ascertain if these issues and findings are indicative of the national picture.

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## Conflict of interest

The authors have declared no conflicts of interests.

## References

1. Public Health England. *Towards elimination of HIV transmission, AIDS and HIV-related deaths in the UK*. 2017. Available at: [assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/675809/Towards\\_elimination\\_of\\_HIV\\_transmission\\_AIDS\\_and\\_HIV\\_related\\_deaths\\_in\\_the\\_UK.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/675809/Towards_elimination_of_HIV_transmission_AIDS_and_HIV_related_deaths_in_the_UK.pdf) (accessed April 2018).
2. Teeraananchai S, Kerr SJ, Amin J *et al*. Life expectancy of HIV-positive people after starting combination antiretroviral therapy: a meta-analysis. *HIV Med* 2017; **18**: 256–266.
3. British HIV Association, British Association of Sexual Health and HIV, British Infection Society. *UK National Guidelines: HIV Testing 2008*. BHIVA. Available at: [www.bhiva.org/guidelines.aspx](http://www.bhiva.org/guidelines.aspx) (accessed March 2018).
4. Kirwan PD, Chau C, Brwon AE *et al*. *HIV in the UK: 2016 report*. PHE. Available at: [www.gov.uk/government/publications/hiv-in-the-united-kingdom](http://www.gov.uk/government/publications/hiv-in-the-united-kingdom) (accessed March 2018).
5. Dai SY, Liu JJ, Fan YG *et al*. Prevalence and factors associated with late HIV diagnosis. *J Med Virol* 2015; **87**: 970–977.
6. Mocroft A, Lundgren JD, Sabin ML *et al*. Risk factors and outcomes for late presentation for HIV-positive persons in Europe: results from the Collaboration of Observational HIV Epidemiological Research Europe Study (COHERE). *PLoS Med* 2013; **10**: e1001510.
7. Iwuji CC, Churchill D, Gilleece Y *et al*. Older HIV-infected individuals present late and have a higher mortality: Brighton, UK cohort study. *BMC Public Health* 2013; **13**: 397.
8. WHO. *Global health sector strategy on HIV, 2016–2021*. Available at: [www.who.int/hiv/en/](http://www.who.int/hiv/en/) (accessed March 2018).
9. Terrence Higgins Trust. Terrence Higgins Trust: What we do. Available at: [www.tht.org.uk/our-charity/Our-work/What-we-do](http://www.tht.org.uk/our-charity/Our-work/What-we-do) (accessed March 2018).
10. Department of Health. *Modernisation of HIV rules to better protect public*. 2013. Available at: [www.gov.uk/government/news/modernisation-of-hiv-rules-to-better-protect-public](http://www.gov.uk/government/news/modernisation-of-hiv-rules-to-better-protect-public) (accessed April 2018).
11. Flowers P, Riddell J, Park C *et al*. Preparedness for use of the rapid result HIV self-test by gay men and other men who have sex with men (MSM): a mixed methods exploratory study among MSM and those involved in HIV prevention and care. *HIV Med* 2017; **18**: 245–255.
12. NICE. NICE HIV testing guideline. Available at: [www.guidelines.co.uk/infection/nice-hiv-testing-guideline/252881.article](http://www.guidelines.co.uk/infection/nice-hiv-testing-guideline/252881.article) (accessed April 2018).
13. Clark V, Braun V. Thematic analysis. *J Posit Psychol* 2017; **12**: 297–298.
14. Robb M. The end of paternalism? *Nurs Manag* 2004; **10**: 32–35.
15. Groll D. Medical paternalism: part 1. *Philos Compass* 2014; **9**: 186–193.
16. Zomorodi M, Foley BJ. The nature of advocacy vs. paternalism in nursing: clarifying the ‘thin line’. *J Adv Nurs* 2009; **65**: 1746–1752.
17. Griffith R, Tegnah C. Shared decision-making: nurses must respect autonomy over paternalism. *Br J Community Nurs* 2013; **18**: 303–306.