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To cite this article: Tom Weeks, Edwin van Teijlingen & Pramod Regmi (2026) Stigma in UK health care: a key barrier to reaching zero HIV transmission by 2030, HIV Research & Clinical Practice, 27:1, 2653328, DOI: [10.1080/25787489.2026.2653328](https://doi.org/10.1080/25787489.2026.2653328)

To link to this article: <https://doi.org/10.1080/25787489.2026.2653328>



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Published online: 08 Apr 2026.



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Stigma in UK health care: a key barrier to reaching zero HIV transmission by 2030

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ABSTRACT

Background : With zero HIV transmission by 2030 firmly on the agenda of the UK Government, the UK Health Security Agency (UKHSA), the National Health Service (NHS), and the voluntary sector in the United Kingdom (UK), therefore, the objective of this review is to explore whether this ambitious goal is possible.

Methods: EBSCO, PubMed, and CHINAL databases were searched using relevant keywords around stigma/stigmatisation in the NHS/UK health care settings. In addition, hand-searching and reference mining were conducted. Data were extracted, synthesised, and presented through a narrative analysis.

Results: Initial searching yielded 68 papers, and six papers were eligible for this review. Thematic methods were used to analyse and synthesise the included studies. The results indicated that people living with HIV continue to express concerns about stigma and discrimination when accessing health care. These issues remain significant barriers to accessing health care services.

Conclusion: HIV-related stigma continues to undermine zero HIV transmission ambitions. Until this issue is effectively addressed, achieving the goal of zero HIV transmission by 2030 may remain challenging.

ARTICLE HISTORY

Received 3 February 2026
Accepted 26 March 2026

KEYWORDS

HIV; health care; stigma; stigmatisation; discrimination

Background

Across the globe, various levels of stigma are attached to human immunodeficiency virus (HIV). Over the decades trailblazing research and advances in HIV medicine and care have allowed people living with HIV to lead normal healthy lives, and for many people, their viral load is now undetectable.

Despite this advancement, the social stigma attached to the virus often persists. With the UK Government, organisations such as the British HIV Association (BHIVA) and voluntary sector services striving for zero transmission by 2030, there are still several barriers to overcome such as willingness to undertake HIV testing [1]. People living with HIV still face societal stigma as well as health care-based stigma and discrimination [2,3]. There are several barriers created by stigma and discrimination including: isolation, poor mental health, and disengagement [4]. Whilst the term ‘stigma’ is often poorly defined in research [5,6], Link and Phelan [7] made insightful comments regarding the term stigma in that ‘*we apply the term stigma when elements of labelling, stereotyping, separation, status loss, and discrimination occur in a power loss situation that allows the components of stigma to unfold.*’ This definition sets the precedence that individuals are excluded or seen different based on a range of factors which are not specified, predictably owing to the unquantifiable number of elements that one may face stigma in. Similarly, stigma can be summarised as ‘*stigma is dynamic, and that what is considered ‘acceptable’ toward certain groups in some contexts, would be ‘unacceptable’ in others,*’ [8]. However, in contrast to Barron and Hebl [8] defined discrimination to be ‘*societally unacceptable, and society has dictated some set procedures for enforcement and specified punishment for violators.*’ These definitions give ideation of the difference between stigma and discrimination from that of a personal position to a societal position.

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Despite health care workers having a general awareness of HIV as a blood borne virus (BBV) from an infection prevention and control (IPC) stance, there is still documented health-care-based stigma attached to the virus when people living with HIV access health services. The stigma and discrimination towards people living with HIV has the potential to perpetuate poor mental health and wellbeing [9,10] but also function as a barrier to accessing health care, thus representing an inequality to the patient group [11,12]. This review aims to assess: (a) to what extent there is a stigma attached to people living with HIV within the UK's health care system and (b) establish areas of research that could help change the attitudes, knowledge, and/or behaviours of health care service staff.

Methods

The PICO (population, intervention, comparison, and outcomes) method was used in the search for relevant literature [13]. Table 1 lists the search terms based on the PICO electronic databases (including EBSCO, PubMed, and CINAHL) that were searched, using Boolean operators, with details recorded in Figure 1, the PRISMA diagram [14]. After screening the title, abstract and full text, studies were selected based on the inclusion and exclusion criteria (Table 2). A review of the literature took place between March and April 2025. Following the search, the authors used thematic analysis was used to illicit key themes from the literature to draw discussion. The literature search

Table 1. Keywords.

HIV	Stigma	Health care	NHS
Human immunodeficient virus	Discrimination Prejudice	Health care Health	National Health Service UK Health Care

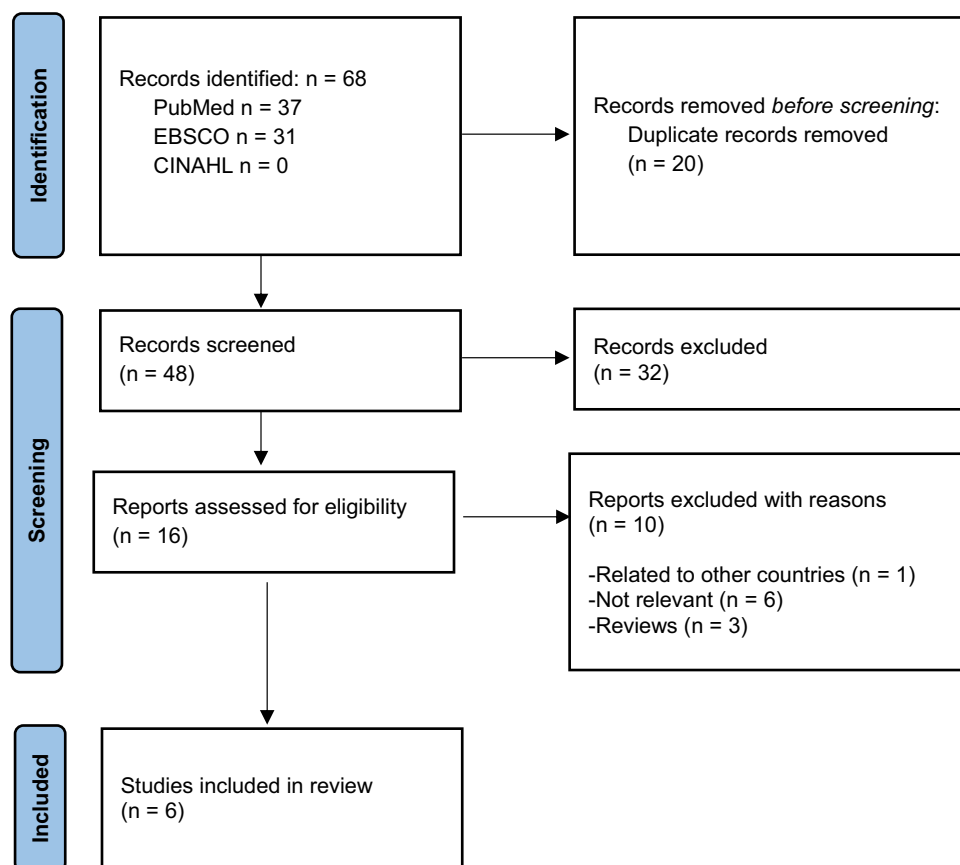


Figure 1. Flow diagram for the selection of articles for the review. N.B.—not relevant relates to literature that when screened has no relation to the review.

Table 2. Inclusion & exclusion criteria.

Inclusion	Exclusion
HIV	AIDS
Stigma	Societal
Health care	Non-UK countries
NHS/National Health Service	Child (children/paediatric)
UK health care	Maternity/obstetrics
Discrimination	Respiratory
	M-Pox
	Hepatitis (Hep)
	Dental
	PrEP
	Sexual abuse
	Mental health
	Nonbinary
	HBV

was narrowed to include publications between February 2020 and February 2025 (Table 3). Grey literature was excluded from the search to maintain a consistent level of methodological quality, ensure the feasibility and replicability of the search process, and focus the review on peer-reviewed sources with transparent and comparable reporting standards; however, grey literature will be used within the discussion to address emerging themes. Support from the Bournemouth University Library team was utilised in navigating the library search systems, and no ethical approval was required for this review.

Results

Figure 1 shows 68 papers were identified, and six were included in this review. The results show that people living with HIV continue to face discrimination and stigma when accessing health care services. Despite registered health professionals (Nurses, Doctors, Paramedics, etc.) having codes of conduct and the requirement for non-registrant staff to adhere to trust/organisational policy, it is concerning to see that, in recently published literature, stigma is a lived and experienced reality for people living with HIV when accessing health care services. Five out of the six papers make direct reference to such stigma, which would impact not only the ambition to reach zero new HIV transmission by 2030 but also has the potential to cause further complications for patients, such as isolation, disengagement, and poor mental health.

Noticeably most of the literature is qualitative and presented as either opinions sent to the editorial, subject matter expert reviews followed by literature offering analyses of themes from semi-structured interviews and/or group discussions.

Hedgeet al. [4] conducted 53 semi-structured interviews in the UK, including people living with HIV ($n = 21$), health and social care workers ($n = 24$) and charity/activists ($n = 13$), investigating stigma and discrimination before and after the advent of ART treatment. The collected data was then analysed using a thematic approach. Hedge et al. [4] found that media had a significant role within the portrayal of HIV and antiretroviral treatment as well as personal experiences impacting perceptions of care and stigma.

Lazarus et al. [18] undertook a two-phase study. Phase 1 consisted of 25 double-blind interviews with health professionals ($n = 12$), people living with HIV ($n = 7$), and HIV health insurers/payers ($n = 6$) in seven countries (Canada, France, Germany, Italy, Spain, UK, and USA). The aim was to identify areas where development is required to improve care for people living with HIV. Phase 2 was a literature search where themes related to the long-term success of people living with HIV were identified. Concluding that HIV is not widely recognised as a chronic condition, poor quality of life, health inequalities, poor mental health, high rates of comorbidities and associated stigma.

The study by Thornton et al. [19] included departments within UK hospitals (including outpatients and general practice). From each setting, a mix of Doctors, Nurses, Health Care Assistants, Administrators, and Virologists participated in group discussions as part of a training package upon the introduction of HIV point-of-care testing. These discussions were performed to understand the knowledge and the comfort of professionals undertaking HIV point-of-care testing. These discussions were then coded to highlight the common trends to formulate the overall findings.

Table 3. Literature summary of selected papers for review.

Citation	Description	Result
Anderson & Fenton [15] HIV-related stigma: A dangerous roadblock	Paper outlines UK Department for Health and Social Care's first anniversary of 'End HIV infections by 2030' plan. It discusses the current preventative methods of pre-exposure prophylaxis (PrEP), and the consensus of Undetectable equals Untransmissible (U = U). The authors refer heavily to the associated stigma of HIV and that of the stigma that people living with HIV face when accessing health care services	Societal stigma in 80%+ of cases following 2021 National AIDs Trust and Britain Thinks Study on HIV. Stigma and discrimination within health systems e.g. excessive infection control precautions, longer waiting times, disrespect, negligence, reduced confidentiality, delay or denial of treatment, poor support services. Paper refers to survey by Public Health England of 4400 people living with HIV: 1/5 experienced discrimination in health care; 1/10 avoided seeking care for fear of negative consequences; 1/3+ struggled to discuss HIV in primary care
Chenciner & Barber [16] noninfective complications for people living with HIV	Discusses societal stigma people living with HIV faces as well as opportunities and challenges that are emerging within HIV medicine with an emphasis on the need for clinicians to maintain a working knowledge of HIV and its potential complications	People living with HIV significantly more likely than the general population to be diagnosed with cancer and the discrepancies are not fully understood however barriers to care, bias amongst health care professionals and perceived stigma by people living with HIV may all be contributors
Fuster-Ruizde Apodaca et al. [17] Why we need to re-define long-term success for people living with HIV	Overview paper reflects upon work in HIV medicine over recent decades and the associated advancements, however, then discusses the long-term well-being of people living with HIV and the subsequent challenges of the continuum	Although attitudes are changing, stigma and discrimination still occur from e.g. ranging from health workers and employers to friends/family. The people living with HIV Stigma Index survey showed 1/8 people living with HIV were denied access to health services due to their HIV status
Hedge et al. [4] HIV-related stigma in the UK then and now: To what extent are we on track to eliminate stigma? A qualitative investigation	Qualitative study with 53 UK interviewees, incl. people living with HIV, health/social care staff, charity workers and activists investigating stigma and discrimination, focusing on both before and after the widespread use of effective antiretroviral treatment in 1990s	Found increased level of stigma within health care are associated with reluctance to get tested or to engage in HIV treatment. Some people living with HIV reported fear of discrimination from health workers and that stigmatising attitudes in health workers are frequently related to poor knowledge about HIV
Lazarus et al. [18] Long-term success for people living with HIV: A framework to guide practice	This paper is two-phase research programme to delineate the range of experiences of people living with HIV	Involving stigmatised individuals in Health Care Professional (HCP) training may help to break stereotypes and reduce stigma and that Interventions that have aimed to educate and train HCPs about HIV-related stigma and discrimination show promising results reducing stigmatising attitudes and behaviours and increasing knowledge among HCP's
Thornton et al. [19] Exploring staff attitudes to routine HIV testing in non-traditional settings: A qualitative study in four health-care facilities	Qualitative paper, part of HINTS (HIV testing in non-traditional settings) Study; All 16-65-year old patients were routinely offered an HIV test for 3 months in emergency dept, acute admissions unit, a dermatology outpatients and primary care practice in areas of high diagnosed HIV prevalence	Health workers felt HIV had been exceptionalised as a condition by medical profession. Initially study participants were apprehensive about concerns that testing could stigmatise/stereotype people living with HIV however there was support from staff to routinely offer HIV testing to normalise and destigmatise

Stigmatisation

The common trend from the explored literature confirms that people living with HIV consider stigmatisation or discrimination before or when accessing health care services in the UK, thus subsequently acting as a deterrence for people living with HIV accessing health care service. Whilst the UK Government has published its HIV Action Plan, with millions of pounds invested in testing and prevention, there is negligible mention of addressing education around HIV within this ambitious target [20,21]. Opt-out testing within health care settings has become a key contributor to identifying people living with HIV who may not be able to necessarily access sexual health services or know about the HIV transmission, therefore allowing for new cases to be identified and the individuals to be supported [21]. Whilst the NHS Action Plan invested in opt-out testing in the emergency department in London, Brighton, Manchester, Salford, and Blackpool, Thornton et al. [19] identified the stigma of HIV and the exceptionalisation of HIV testing as a condition. Initially, the staff in the respective departments were apprehensive about testing and that by

testing individuals, they may be seen as adding to the stigma and stereotyping of patients. However, there was training and support for staff to gain confidence in routinely offering HIV testing to normalise and destigmatise patients. Thornton et al. [19] concluded that there was a change in staff perceptions before and after training and further cited that HIV testing is feasible in general medical services. The implementation requires training and support best is provided by local sexual health services.

Hedge et al. [4], Anderson and Fenton [15], Chenciner and Barber [16], and Lazarus et al. [18] all concur that stigma is prevalent within health care settings concerning HIV and people living with HIV. With results showing one in five people living with HIV experiencing discrimination in a health care setting, one in ten had avoided seeking care for fear of negative consequences, and one-third reported that they struggled to discuss their HIV care/status within primary care. There is a consensus that the discrimination of people living with HIV faces within health care settings acts as a significant barrier to accessing health care services, thus increasing the health inequalities amongst the community. Anderson and Fenton [15] and Fuster-Ruiz de Apodaca et al. [17] both refer to the denial of access to services for people living with HIV based on a person's HIV status. This is not only evidence of discrimination under the Equality Act 2010, but also against their human rights [22,23]. It is widely known that people living with HIV are significantly more likely than the general population to be diagnosed with cancer [16], therefore such denial of health care could have a significant detrimental impact upon individuals' quality of life and health.

Awareness

A recurring theme is a lack of health care workers' awareness of HIV. Statutory and mandatory training within the NHS is set by the Core Skills Training Framework (CSTF). Current topics included in the CSTF are resuscitation, infection prevention and control, equality diversity and inclusion, safeguarding, manual handling, fire safety, information governance, health and safety, conflict resolution, and PREVENT. Whilst infection prevention and control and equality diversity and inclusion are mandated on the CSTF, the covered curricula of the respective areas do not include any form of HIV awareness. Whilst there are some online learning courses on e-learning for health, these are optional courses that NHS staff can do in their own time. The online HIV and sexual health programme was developed by the British Association for Sexual Health and HIV (BASHH), the Royal College of Physicians, the Royal College of Physicians and Surgeons of Glasgow, and the Royal College of Physicians of Edinburgh in partnership with Health Education England e-learning for health care. This collaboration has brought a range of subject matter experts together to draw on their knowledge and expertise to support with educating health workers interested in HIV and sexual health. Mandating such training or introducing in-house training could significantly benefit with the reduction of HIV stigma, as it would allow health care staff to be more aware of stigma and how to function as an advocate for people living with HIV. However, in the absence of mandated training in most NHS Trusts, it would prove difficult to develop a culture within health care where HIV is normalised, and stigma is challenged. With that said, Manchester University NHS Foundation Trust, has introduced a mandatory training package for their staff online via e-learning for health to raise awareness of HIV within the trusts. McQuillan [24] at the British HIV Association (BHIVA) Spring Conference presented their findings from the introduction of the mandatory package. Since the inception of the package, the trust has seen staff's awareness of HIV raise significantly with 25% of staff reporting they understand the ways people living with HIV experience stigma, 34% of staff feeling more confident in providing care for people living with HIV and 36% feeling more confident about the language being used when talking to someone living with HIV.

A limitation of the review was that there was little literature published over the last five years specifically relating to HIV stigma within the health care setting, and as such, the discussion is limited, with the found themes being complementary to each other in the literature.

Discussion

Stigma remains one of the most pervasive and detrimental barriers to accessing health care services for people living with HIV. Extensive medical literature highlights that people living with HIV face an

elevated risk of comorbidities, including cardiovascular disease, various cancers, and cognitive impairments. These health challenges underscore the urgent need for equitable, stigma-free health-care environments.

Interestingly, Barts Health NHS Trust in 2019 conducted an internal survey within the trust to explore staff's knowledge of HIV and staff's attitudes towards people with HIV. Through the distribution of a paper-based questionnaire, the research team received 411 responses, which highlight some results of concerns. The presented results include:

- 80% of respondents having not heard about U = U (undetectable = untransmissible).
- 76% did not feel confident discussing HIV with patients.
- 52% thought people living with HIV should be at the end of operating lists.
- 47% thought they may get HIV from a needle stick injury.
- 38% felt at risk of acquiring HIV when treating patients.
- 25% would consider isolating patients in a side-room due to their HIV status alone.

However, the benefit of this internal study was that 82% of respondents requested further information and training on HIV [25]. Similarly, the Royal Free London NHS Foundation Trust conducted a similar study within the trust to explore knowledge and attitudes toward people with HIV, and the results are like that of Barts Health. Whilst it can be appreciated that the development and implementation of staff training within health care can be difficult, there are the current packages available on e-learning for health, as referred to as well as training packages available from organisations such as HIV Hearts and Minds [26], HIV Confident [27], and other charitable organisations including Terrance Higgins Trust and National AIDS Trust.

With that, the newly published HIV Action plan for 2025–2030 refers to the stigma 77 times detailing *‘Stigma still affects too many people living with HIV. Despite significant advances in HIV treatment and awareness, too many people living with HIV continue to face stigma, racism, homophobia, discrimination, and other challenges that affect their wellbeing and access to care’* [28]. Priority 4 is ‘Thrive’ this priority address stigma and improvement to quality of life, which includes detailed education plans on HIV for staff.

This review advocates for a review of health worker training on HIV in light of the 2025 HIV Action plan as well as a systematic wide eradication of stigma championing awareness and inclusivity is promoted. It is essential not only to dismantle barriers to care but also to address broader health inequalities and promote HIV awareness. Crucially, it reinforces the principle that individuals are not defined by their HIV status. Thus, the hypothesis would be that as stigma diminishes, patients may be more likely to attend appointments, adhere to treatment plans, and maintain consistent contact with health workers. This would lead to a reduction in missed appointments and staff time, yielding both clinical and operational benefits.

Conclusion

This review highlights ongoing issues surrounding the stigmatisation of HIV and people living with HIV when accessing health services. Stigma continues to act as a significant barrier, limiting access to services or deterring people living with HIV from seeking care. A key emerging theme is the urgent need for health care staff to undertake education and training on HIV, including prophylaxis, treatment options, and strategies for advocacy and activism. Unless a clear training programme is devised and disseminated addressing these themes following on from the 2025 HIV Action plan, stigma and inequality will remain major obstacles to achieving the goal of zero HIV transmission by 2030. Further research is needed to better understand HIV-related stigma within health care.

Acknowledgements

We acknowledge the Bournemouth University Library Services for their support.

Author contributions

CRedit: **Tom Weeks:** Methodology, Project administration, Writing – original draft, Writing – review & editing; **Edwin van Teijlingen:** Supervision, Writing – review & editing; **Pramod Regmi:** Supervision, Writing – review & editing.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Ethics

Not required.

Funding

This article is funded by the Bournemouth University.

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