

APPG Inquiry HIV and COVID-19

Joint Response from the British HIV Association (BHIVA) and British Association for Sexual Health and HIV (BASHH)

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Contact: Laura Waters (lwaters@nhs.net) & BHIVA (bhiva@bhiva.org) / John McSorley (john.mcsorley@nhs.net) & BASHH (bashh@mandfhealth.com)

The British HIV Association (BHIVA) is the leading UK association representing professionals in HIV care. Since 1995, it has been committed to providing excellent care for people living with and affected by HIV. BHIVA is a national advisory body on all aspects of HIV care and provides a national platform for HIV care issues. Its representatives contribute to international, national and local committees dealing with HIV care. In addition, it promotes undergraduate, postgraduate and continuing medical education within HIV care.

The British Association for Sexual Health and HIV (BASHH) is the lead professional representative body for those managing sexually transmitted infections (STIs) and HIV in the UK. It has a prime role in education and training, in determining, monitoring and maintaining standards of governance in sexual health and HIV care. BASHH also works to further the advancement of public health in relation to STIs, HIV and other sexual health problems and acts as a champion in promoting good sexual health and providing education to the public.

1. EXECUTIVE SUMMARY

- 1.1. The experience of BHIVA and BASHH as organisations, and of their members, as collected through recent UK-wide surveys, confirms that HIV testing, prevention and treatment services have been impacted markedly by the outbreak of COVID-19, through significant changes in how care is delivered, routine monitoring, medication supply, staffing and major confusion generated by the Government miscommunication about HIV and COVID-19 risk.
- 1.2. People living with HIV (PLWH) are already disproportionately affected by:
 - Issues exacerbated by the pandemic, such as anxiety, depression, social isolation and financial insecurity;
 - Factors associated with COVID-19 risk and severity: social deprivation, crowded accommodation, key worker status, BAME status.
- 1.3. Despite excellent outcomes in terms of retention in HIV care and effective treatment, there were major pre-existing gaps in mental health care and social support. In addition, despite a reduction in the number and proportion of people living with undiagnosed HIV, national guidelines dating back as far as 2006 had not been implemented routinely, such as HIV testing in Emergency Departments (EDs) primarily due to lack of funding.
- 1.4. Finally, the lack of equitable access to HIV pre-exposure prophylaxis (PrEP) across and within the four nations, with the protracted saga in England yet to yield routine PrEP provision, was a major issue prior to the advent of COVID-19. PrEP remains a crucial tool in eliminating new HIV transmission by 2030 and the already delayed commissioning in England must be a priority as we enter the service recovery phase following major reduction in access to sexual health services during COVID-19.

- 1.5.** HIV and sexual health services have seen major, rapid change secondary to COVID-19 contingency planning with many staff redeployed, marked reductions in sexual health activity and almost exclusive shifts to non-face-to-face consultation and deferred health monitoring for HIV services. Most services have avoided medication HIV switches, including for medication-related side effects, and non-urgent referrals to other specialities have effectively halted. Careful assessment of the impact, both negative and positive, of ‘hands off’ care is crucial in order to best plan services for a post-COVID future.
- 1.6.** We must ensure that any service redesign is safe (has reduced access to services yielded mental or physical harm?) effective (has less frequent monitoring increased the rate HIV treatment failure and drug resistance?) patient-centred (while urgency negated our abilities to consult PLWH about contingency plans, they must be central to redesign during the recovery phase) and standards-based (we must ensure any efficiencies achieved through lessons learned, and new technologies implemented thanks to COVID-19 are utilised to ensure all services meet national standards in terms of co-morbidity screening, support services and patient engagement).
- 1.7.** A major source of anxiety and confusion for patients, their clinics and their employers, was the woefully inaccurate and disorganised Government communication about Shielding. At the very start, the incorrect assertion that “all people eligible for flu vaccination” and “people with HIV/AIDs” were at increased risk generated much anxiety. BHIVA, through collaboration with third sector organisations such as the Terrence Higgins Trust, and other professional bodies, such as the European AIDS Clinical Society, was quick to generate accurate guidance for PLWH and their health care providers around COVID-19 risk.
- 1.8.** We worked closely with the UK Community Advisory Board (UK-CAB, a network for community HIV treatment advocates) to ensure accurate information was conveyed to PLWH. Despite this, and despite HIV never appearing on the Chief Medical Officer’s list of people who should shield, many people with well-controlled HIV received advice to shield. This generated a huge amount of anxiety, and required significant time from clinical and third sector services to reassure people and reiterate our existing advice.
- 1.9.** DHSC has since admitted this was an error but many comments received from our members reflect the ongoing harm and uncertainty created by these mixed messages. Had the DHSC better engaged HIV services we could have avoided, or at least limited, the harm caused by this erroneous advice. Advice provided by the HIV Clinical Reference Group (CRG) to NHSE very early in the COVID-19 response was completely ignored (seemingly thanks to lack of communication between DHSC and PHE) meaning the small number of people who we did advise to shield (ie those with a very impaired immune system) were initially unable to access the Government Shielding Support to which they should have been entitled.
- 1.10.** Another source of anxiety for HIV services and service users was reliability of medication supply. A lack of clear, central communication from NHSE, compounded by major (and ongoing) delays to the publication of an HIV contingency plan from the HIV CRG, created significant drug supply shortages and urgent mitigation by pharmacy services to ensure uninterrupted supplies. The inability of existing medication delivery to include new users, again solved by individual HIV pharmacies through use of alternative postal and local delivery services, highlighted the lack of capacity and resilience in our existing structures. While HIV services have generated major cost savings through the widespread use of generic HIV medication, it is generic supplies that are most fragile, as demonstrated throughout COVID-19 and illustrated by a requirement to switch to more costly branded products to ensure continued supply. Needless to say, unplanned changes to medication and shorter than usual supplies have compounded the existing anxieties of many PLWH and necessitated increased contact with HIV services.

- 1.11.** Assuming later analysis reveals no harm, the rapid reconfiguration of HIV services has demonstrated the resilience of our care models, and the flexibility of our services - but what is acceptable during a national emergency may be far less so as the pandemic ceases. The importance of sustaining innovation (both in terms of HIV testing and delivery of HIV care,) monitoring patient experience and ensuring people without access to the tools for 'virtual care' are not left behind cannot be overstated.
- 1.12.** Finally, as an organisation, BHIVA has cancelled two major educational events with a consequent loss of income from sponsors and subscriptions and major impact on the provision of education to members. Although online platforms can be utilised to deliver educational content they do not replace the face-to-face and informal interactions with peers that drives facilitates knowledge-sharing and idea generation. In addition, research into non-COVID topics has all but ceased and future of the previously world-leading HIV research undertaken in the UK, which has undoubtedly contributed to our outstanding HIV outcomes, is precarious. Potentially major risks to research include funding (from research organisations and the pharmaceutical industry), limited face-to-face contact and reduced access to laboratory testing and imaging which will reduce opportunities for innovation and new approaches to prevention, diagnosis and management.
- 1.13.** Our unprecedented online traffic and social media hits have highlighted just how important our guidance has been throughout COVID-19 and our collaborations with the afore-mentioned organisations, but also those outside our usual sphere, such as the Intensive Care Society, have affirmed the importance of BHIVA in guiding and supporting best care for PLWH.

2. SUMMARY OF RESPONSES TO BHIVA MEMBER SURVEY (47 RESPONDENTS)

2.1. Question 1: Has access to HIV prevention, treatment and care services been affected by COVID-19? If so, can you tell us how?

87% responded yes

Themes

1. Almost all face-to-face consultations were switched to telephone, driven both by NHS requirements to stop non-essential face-to-face activity but also by reluctance of patients to attend services. Concerns included: the people at most risk (eg those who are Shielding) being the most likely to need face-to-face assessment; patients assuming services were closed; severe disruption to routine vaccination, cervical screening and cardiovascular risk assessment; and the switch to a less holistic service.
2. Prescribing was maintained, with some supply issues (there were shortages of some HIV medications, particularly in the early COVID-19 period) requiring shorter prescriptions.
3. Routine monitoring was deferred for most and blood tests undertaken only where deemed urgent; medication switches were deferred to avoid the need for face-to-face visits and monitoring.
4. Significant reduction in HIV testing (one service reported zero HIV testing due to lack of premises and laboratory capacity) resulting in concerns about late HIV diagnosis, which may be further exacerbated through possible misdiagnosis (eg HIV related pneumonia being misdiagnosed as COVID.)
5. Reduced access to PrEP with some services reporting pauses in recruitment to the IMPACT Trial and, in Belfast, the abrupt closure of its PrEP clinic.

2.2. Question 2: Is there evidence to suggest that COVID-19 is affecting adherence to HIV medication or treatment for co-morbidities?

26% responded yes

Themes

1. Some reported improved engagement and adherence in some patients due to COVID-related fears.
2. Several described significant efforts required to prevent interruption to HIV medication
3. Major medication supply challenges for people stranded abroad.
4. Whilst negative outcomes were considered to be a definite possibility, it was recognised that any long-term impact of these may not be apparent at this point in time. However, over the short-term no clear evidence of harm has yet emerged.
5. Since our main marker of adherence is based on blood viral load testing and we are limiting testing we don't yet know.

2.3. Question 3: Are there any concerns that undiagnosed HIV could become an issue during the pandemic because of reduced health service availability? What is being done?

66% responded yes

Themes

1. Many respondents expressed concern that limited access to, or even closure of, sexual health services will have a negative impact on health seeking and HIV testing. Others flagged reduced blood testing (in general, and for HIV specifically) in primary care as a concern.
2. Social distancing advice poses a barrier to people disclosing risk.
3. Online testing was mentioned by several respondents, including the rapid launch in Scotland (established by HIV Scotland and Waverley Care with some NHS funding) and a 6-month extension of existing online testing in Northern Ireland (though concern that funding beyond this period has not been secured,) but many expressed concern that rollout has been slow and the promised national rollout has not materialised (“the picture in London as led by 56 Dean street is unfortunately not mirrored across the country” and “when there is hope for something like this, which then doesn't appear, it delays the overall response”), that some online screens limit HIV testing to ‘high risk’ groups (though one respondent flagged that the Local Authority has agreed to not restrict HIV testing for a month after lockdown measures are eased.)
4. Suspension of ED testing for some, although at least two London services (Croydon and UCH) have managed to get long-awaited ED HIV testing plans off the ground thanks to COVID-19, though with concerns that funding may not be sustained.

2.4. Question 4: What are the main concerns being voiced by people living with HIV during this pandemic?

Themes:

1. General health, concern about increased COVID-19 risk and whether they should shield (the confusion generated by DHSC was particularly anxiety provoking for PLWH who received incorrect Shielding advice which was discordant to the advice from HIV organisations: “mixed messages are difficult for patients.”)
2. Access to HIV care, contacting HIV clinics and medication supply.
3. Missing routine tests and when we can return to normal.
4. Fears around attending services.

5. Mental health, impact of social isolation.

2.5. Question 5: Mental health is being impacted for many people during this crisis, are people living with HIV disproportionately impacted and if so, what mental health support are they able to access?

55% responded yes

Themes

1. A mixture of responses regarding increased mental health issues vs no evidence of an increase; “patients are expressing issues with mental health but so are other patient groups.”
2. With reduced face-to-face contact it is hard to ascertain any impact on mental health and it is far too early to draw conclusions. Assessment of the impact of COVID-19 on mental health is highly complex (some subgroups who will be affected more than others, and some may actually see an improvement in mental health) – a detailed commissioned study on this topic (rather than reliance on quick surveys) is crucial to generate data of sufficient quality and breadth.
3. Isolation a big challenge but reduced access to support groups.
4. Telephone support, virtual support groups, food parcels.
5. Increased access to HIV information.
6. Some described increased access to mental health support, others reported reduced HIV psychiatry and psychology service access due to redeployment and some flagged that access is poor at the best of times.
7. Increased signposting to generic IAPT services.

2.6. Question 6: What employment issues are people living with HIV having in relation to COVID-19?

Themes:

1. General concerns regarding job security and finances, particularly for self-employed; many PLWH work in highly affected sectors such as hospitality and the airline industry; many PLWH, particularly BAME people, work in the health and care sectors. Several respondents felt concerns were not unique to PLWH though others were clear that confused Shielding advice had added stress.
2. Concerns regarding risk of exposure at work, ability to distance, poor access to Occupational Health and reluctance to disclose HIV status to employers.
3. NAT is handling a number of cases where people have been made redundant because of being HIV positive and others who have been furloughed, inappropriately, based on HIV status.
4. Consistent concerns about miscommunication of risks and shielding advice; some people with well-controlled HIV concerned they are at higher risk; PLWH and their employers not understanding the guidance (examples where employers have advised PLWH to Shield when they don't need to, not helped by the DHSC debacle.)

2.7. Question 7: Has access to HIV treatment, care and support services been affected by COVID 19? If so, can you tell us how?

66% responded yes

Themes (many overlapped with Q1):

1. Patchy home delivery and patients stuck away from home have created challenges.
2. Issues for PLWH not already registered on home delivery and lack of capacity for new sign ups as communicated by NHSE.

3. Remote care and support does not suit everyone and limits disclosure of vulnerabilities e.g. chemsex.

2.8. Question 9: Has access to HIV prevention interventions/services, including testing, been affected by COVID- 19? If so, can you tell us how?

87% responded yes

Themes

1. Responses included “suspended”, “STI capacity plummeted,” and “GUM services have been cut back to 'emergency only,' with reduced opportunities for education and opportunistic screening.”
2. PrEP access flagged by many with one respondent describing reported closure of a significant number of PrEP IMPACT sites meaning a necessity to travel further which some may be unwilling to undertake.
3. Online testing: respondents reported lack of access in general, and particularly for vulnerable groups, a lack of knowledge about online testing options and affordability issues where it is not free of charge.

2.9. UK question 1: Why are BAME communities disproportionately affected by COVID-19 and is this effect more acute for BAME people living with HIV?

23% responded yes

Themes

1. Higher prevalence of hypertension, diabetes and other co-morbidities.
2. Socio-economic factors including poverty, overcrowded/shared accommodation, immigration concerns, intimate partner violence and deprivation.
3. Many BAME PLWH work in health care; PLWH who should shield are reluctant to do so due to fears around income/job security.

2.10. UK question 4: How has your organisation adapted its HIV services and the work it does during this COVID- 19 crisis?

Themes: most responses reflect answers provided to earlier questions

1. Accelerated introduction of video technology reported by several.
2. Several described an ability to preserve face-to face consultations for the most vulnerable.
3. Streamlining of post-exposure prophylaxis.
4. Staff working from home remotely.

2.11. UK question 5: Has COVID-19 had a financial impact on your organisation or do you think it will? Are the government measures sufficient?

51% responded yes

Themes

1. Longer-term loss of research income.
2. Funding from pharmaceutical companies for BHIVA, research and service development.

3. Some described being unable to access COVID funds, others that plenty of money has been made available (including to support virtual working) and they have been assured the Government will cover any additional costs.
4. Costs related to staff absence (due to isolating, shielding or redeployment) and costs of providing cover.
5. Drug expenditure, delivery costs (many services have used Royal Mail or other providers where patients not already on home delivery.)
6. Costs of PPE.
7. Knock on effects of loss of local income eg in Luton area, reduced airport activity will have a major impact on the Council's income.
8. Some described a likely positive effect of COVID-19 on new, more efficient ways of working in the future.

2.12. UK question 6: When we move towards a gradual easing of COVID-related social measures, what do you think the priorities are for the Government around HIV?

Themes

1. HIV testing: maintaining testing rates, ensuring it is accessible, increased postal access, enforce existing guidelines with financial penalties for not meeting BHIVA and NICE standards.
2. PrEP: to ensure it is routinely commissioned, widely available in all four nations and continued education/awareness raising and to get back to eliminating new HIV transmission by 2030.
3. Virtual care: continued access and support/funds for service users to access these technologies as well as for services to run them; to ensure high quality maintained with virtual working.
4. Inequalities: recovery plans must address inequalities and prioritise restoration of services for those most in need, to understand why BAME communities at greater COVID risk.
5. COVID risk: ensure clear, consistent messaging about risk for PLWH.

2.13. UK question 7: During the COVID-19 pandemic, what further measures need to be put in place to retain the UK's progress in surpassing the UNAIDS 90-90-90 targets?

Themes

1. HIV testing: more testing in hostels, primary care; funding acute trusts and primary care to implement existing national guidance, a new public health campaign, publicity around testing (including online options) and positive media coverage of HIV issues.
2. HIV services: ensure care accessible to all and that services are prioritised/protected in terms of staff redeployment, support to ensure.

3. ADDITIONAL INFORMATION: SUMMARY OF RESPONSES TO BASHH 'CLINICAL THERMOMETER' SURVEYS

- 3.1.** Evidence gathered by BASHH in recent weeks through two UK-wide 'clinical thermometer' surveys, with responses from more than 85% of services, similarly demonstrated that services delivering HIV care have been significantly disrupted by the outbreak of COVID-19. The majority of the key themes emerging from these surveys has been captured above, however additional points of evidence have been included below.
- 3.2.** 87% of respondents to the most recent clinical thermometer survey (late April-early May) reported having less than 20% face to face HIV service provision capacity as a result of the pandemic, compared to normal levels. Whilst increased digital and telemedicine care provision has been put in place rapidly in many parts of the country, there has been considerable variation in this regard, due

to a range of local factors and barriers (often centred around limited IT infrastructure.) This has effectively resulted in a postcode lottery for HIV patients.

- 3.3.** The surveys revealed that a third of services reported having no online HIV testing capacity, whilst 43% weren't able to provide video consultations for HIV appointments. Many areas have been able to move quickly to maintain access to HIV medication through scaled-up collection and courier services, however this was also a mixed picture. Almost half of respondents (48%) said that medication collection wasn't available within their HIV setting, and only 43% of services were able to provide courier services for HIV medication. Whilst these represent considerable increases compared to the availability of these services pre-COVID, it still leaves many people living with HIV facing significant barriers to accessing key treatment.
- 3.4.** Of particular concern, and as echoed in the above sections, has been the disruptions caused to the provision of PrEP. A fifth of respondents said they were only able to maintain a 'limited' provision of PrEP, whilst 9% said they were no longer able to provide PrEP at all within their local service. This is a situation which directly jeopardises the goal of eliminating new HIV transmissions by 2030.