BHIVA 2021 Survey: HIV clinical services: lessons from the pandemic
Summary of findings

This report summarises findings of a survey of HIV specialist clinical services conducted in May-July 2021 with the aims of:

- Describing how UK HIV specialist clinical services adapted and responded to the covid-19 pandemic
- Sharing lessons that may be learnt from this for the future development of NHS care.

Number of responses: 100

Key points

The pandemic had a substantial impact on HIV services and led to changes in care delivery, for example:

- Less frequent routine monitoring for some stable patients
- A shift towards remote/virtual consultation methods
- Taking bloods separately from clinician consultations, and in different locations
- Different methods of ART supply/delivery.

Some of these changes are likely to be maintained post-pandemic, but HIV services should:

- Enable access to face-to-face consultations for individuals whose needs cannot be met remotely
- While encouraging people living with HIV to register with and disclose their status to GPs, ensure appropriate care access for the minority who choose not to do so.

Further guidance from BHIVA may be of value as regards selection of individuals suitable for less frequent monitoring, including implications for U=U.

Detailed results: report sections

Qualitative write-in responses provided useful learning, and selected quotes can be found via these links:

About your HIV service

Which of these best describes your HIV clinical service:

	Number/percentage
Integrated HIV service involving infectious diseases and sexual health/genito-urinary medicine departments	22
Standalone HIV service	10
Infectious diseases service	1
Sexual health/genito-urinary medicine service, at or immediately adjacent to a hospital providing acute medical care	22
Sexual health/genito-urinary medicine service, sited separately from acute medical care	38
Other	6
Not answered	1

How many adults receive HIV care from your service?

	Number/percentage
500 or fewer	60
501 to 1000	26
1001 to 2000	10
2001 to 4000	4
Over 4000	0

Does your service provide in-patient HIV care?

	Number/percentage
Yes, with 24/7 HIV specialist consultant cover	41
Yes, but without 24/7 HIV specialist consultant cover	16
No, out-patient service only	43

What changes did your HIV clinical service experience in response to the covid-19 pandemic?

	Ongoing	Happened, not ongoing	Did not happen	Not sure/not answered
Capacity for routine bloods (eg HIV viral load monitoring) substantially reduced	3	75	22	0
Capacity for urgent bloods substantially reduced	1	15	84	0
Capacity to see HIV patients face to face physically substantially reduced, even if urgent	7	48	45	0
Department/building closed, but staff remained able to access HIV patient records remotely (eg while working from home)	3	10	86	1
Department/building closed, and access to HIV patient records unavailable	0	1	98	1

Did your service streamline care with other specialties and/or primary care for patients requiring monitoring for other conditions alongside HIV, so as to need fewer face- to-face interactions? Please comment on what this involved:

	Number/percentage
Yes, other specialties took bloods for HIV monitoring when seeing our patients	23
Yes, primary care took bloods for HIV monitoring when seeing our patients	28
Yes, we took bloods/other samples or did measurements for other specialties when their patients attended the HIV service	35
Yes, we took bloods/other samples or did measurements for primary care when their patients attended the HIV service	27
We streamlined care in other ways	30
*No reported streamlining**	*38*

NB: Multiple responses possible. *41 services ticked "No, we did not streamline care with other specialties or primary care" but 3 of these also selected options suggesting they had done so.

Staff deployment and training

Were specialist health care workers re-deployed or diverted away from care of adults with HIV to other work during the pandemic?

	Number/percentage
Yes, all HIV specialist staff were re-deployed or diverted to other work	1
Yes, most HIV specialist staff were re-deployed or diverted to other work	13
Yes, some HIV specialist staff were re-deployed or diverted to other work	42
No, HIV specialist staff were not re-deployed or diverted to other work	44

To what type(s) of work were specialist HIV clinical staff re-deployed or diverted?

Of 56 sites reporting re-deployment:

	Number (percentage)
ITU for covid-19 patients	15 (26.8)
Other covid-19 in-patient care	44 (78.6)
Covid-19 testing	10 (17.9)
Covid-19 contact tracing	3 (5.4)
Covid-19 vaccination	14 (25.0)
Cover (back-fill) in non-covid-19 clinical areas for other staff who were re-deployed, shielding or in isolation	15 (26.8)
Other area(s)	14 (25.0)

NB: Multiple responses possible.

During which time period(s) was the HIV service significantly affected by staff re-deployment/diversion to other roles?

Of 56 sites reporting re-deployment:

	Number (percentage)
First peak of pandemic (approximately March-May 2020)	51 (91.1)
Summer and/or early Autumn 2020	14 (25.0)
Second peak of pandemic (approximately October-December 2020)	21 (37.5)
Third peak of pandemic (approximately January-March 2021)	22 (39.3)
April 2021 and beyond	3 (5.4)

NB: Multiple responses possible.

Implications of the pandemic for specialist registrars:

	Yes	Not sure	No	Not applicable/ not answered
Will re-deployment to ITU/general medicine during the pandemic be counted towards dual accreditation?	7	5	10	78
Has ITU/general medicine experience during the pandemic encouraged trainees to seek dual accreditation?	2	6	12	80
If opportunities for training/experience have been limited because of the pandemic, are there plans to make up for this (eg via extended training/additional placements)?	16	27	42	15

Regarding staff mental health/well-being, has your hospital/trust/organisation:

	Yes	Unsure	No	Not answered
Assessed how the pandemic has affected mental health/well-being?				
For staff directly involved in covid-19 care:	57	28	10	5
For other staff including the HIV service:	56	15	27	2
Provided additional mental health/wellbeing support or services?				
For staff directly involved in covid-19 care:	79	12	3	6
For other staff including the HIV service:	83	6	6	5

Individual clinical care and monitoring

What method(s) has your service used to notify HIV patients about changes in provision and how to access care during the pandemic?

	Number/percentage
Newsletter (eg via email) circulated to consenting HIV patients	9
Text/SMS updates to consenting HIV patients	73
Updates to clinic website	64
Briefing/information for peer support/community organisations to disseminate via their own networks	24
Other	44

NB: Multiple responses possible. “Other” answers included phone (21), letters (6) and social media (4).

How has your service used different methods of clinician consultation during the pandemic:

	Main method used	Sometimes used	Available but used rarely or not at all	Not available	Not answered
Video remote consultation	2	22	36	34	6
Telephone or audio-only remote consultation	78	21	0	0	1
In person, via patient attending clinic	28	65	4	0	3
In person, via home visit (eg by HIV specialist nurse)	0	29	23	41	7

Does your service intend to use remote consultation for review of stable patients in future, post-pandemic?

	Number/percentage
Yes, use routinely unless in person consultation is required, eg because of need for examination or communication issues	27
Yes, use in some circumstances eg if patient prefers	53
No or only exceptionally	12
Other	8

Through the pandemic, how frequently has your service aimed to monitor stable patients with well-controlled HIV undetectable on ART:

	Six monthly	At least annually	Less frequently if stable and no cause for concern
HIV viral load monitoring	19	79	2
Other routine monitoring eg renal/liver profile	19	78	3
Clinician review	50	46	4

Did your service discuss with patients the potential risks of continuing ART with no or infrequent monitoring, and document patients' consent to this?

	Number/percentage
Yes, routinely discussed and documented	31
Yes, in some cases	41
No	11
Not applicable because usual frequency of monitoring was maintained	15
Not sure	2

In the future, post-pandemic, do you expect that some stable patients will be selected for annual (rather than 6- monthly) blood monitoring as part of an agreed care pathway?

	Number/percentage
Yes	53
Not sure	28
No	18
Not answered	1

What criteria will your service use to select patients eligible for annual blood monitoring?

	Number/percentage
On regimen with high genetic barrier to resistance	31
Low expectation of long term side effects	28
No or stable co-morbidit(ies)	34
Criteria have not yet been decided	18
Other	15

NB: Multiple responses possible.

During the pandemic, has your service provided welfare checks or mini-reviews, eg phoning patients to ask about their health in between full clinician reviews?

	Number/percentage
Yes, we have tried to do this for all adult HIV patients	23
Yes, for patients with mental health/well-being concerns	38*
Yes, for complex patients, eg with uncontrolled HIV or co-morbidities	48*
Yes, for other patient group(s)	21*
No, we have not done this	25

NB: Multiple responses possible: * number shown excludes those also selecting all adult patients.

Other than individual enquiry during clinician reviews or welfare checks, has your service attempted any systematic assessment of mental health/well-being of adult patients living with HIV during the pandemic?

	Number/percentage
Yes	19
Not sure	2
No	78
Not answered	1

Has your service remained able to ensure the following for individuals newly diagnosed with HIV:

	Yes	Not sure	No	Not applicable – no new diagnoses	Not answered
Specialist clinician review within 2 weeks of positive test (eg by clinical nurse specialist or HIV physician)	99	0	0	0	1
Access to health advisor or specialist nurse support	96	0	3	0	1
Rapid initiation of ART where clinically appropriate and/or preference of patient	97	0	1	1	1
Access or referral to peer/community support service	69	11	18	1	1

During the pandemic, how did the number of patients disengaging from HIV care/becoming lost to follow up compare with the previous year?

During the pandemic, how did the number of patients re- engaging in HIV care after previous disengagement compare with the previous year?

	Increased	No real change	Decreased	Not sure/not answered
Disengaging from care	7	56	20	17
Re-engaging in care	38	49	2	11

Anti-retroviral (ART) medication supply

What methods has your service used to provide ART medication to stable patients during the pandemic?

	Used routinely	Sometimes used	Not available	Not answered
Home care service	70	15	7	8
Royal Mail or similar	17	34	28	21
Patient collection from HIV clinic/on- site pharmacy	58	35	1	6
Patient collection from other (eg local) pharmac(ies)	21	25	36	18
Other method(s)	9	22	26	43

NB: Multiple responses possible.

If new methods were used for ART supply, how effective were they?

	Number/percentage
Highly effective, few or no problems such as non-delivery	46
Some problems	17
Frequent or serious problems	0
Not sure/not answered	2
Not applicable because did not change methods	35

What are your expectations regarding ART supply methods in future, post-pandemic?

	Number/percentage
Most patients will collect from HIV clinic/on-site pharmacy	31
Most patients will use other methods	58
Not sure	11

Vaccination against covid-19

What methods has your service used to inform HIV patients about the benefits of covid-19 vaccination and encourage uptake?

	Number/percentage
Routinely asking about vaccination during consultations	98
Booking/arranging vaccination appointments for patients requiring this	46
Phone calls to individual patients	44
SMS/text messages to individual patients	33
Information in patient newsletter	11
Clinician liaison with peer support/community organisations	18
Other	22

NB: Multiple responses possible

Adults with HIV are in priority group 6 for covid-19 vaccination (unless at higher priority because of age or clinical vulnerability) and should have been offered a first dose around the second half of February. If there were any issues or problems regarding prioritisation or vaccine offer for your patients, please comment here:

77 services replied although in several cases this was to say there were no problems.

Where issues were reported, these most often related to patients not registered with a GP or not disclosing their HIV status to their GP. Several services made special arrangements for such patients, eg:

> *For younger patients who haven't disclosed to primary care we had great support from the local vaccination hub to allow direct referral in for provision of the vaccination, despite HIV status not being formally documented.*
>
> *We were able to provide them with a vaccine at the Hospital vaccination hub, usually only available to staff.*
>
> *We were able to organise vaccination for these through Public Health liaising with their local health board.*

Other issues related to prioritisation, including work done by HIV services to ensure this, eg:

> *I had patients advised they were extremely clinically vulnerable and advised to shield (with consequent job loss, financial difficulties and mental health consequences) and yet they were unable to book vaccination, either through their GPs or by putting in their NHS number on the self book website. The clinical coding to suggest vulnerability and shielding worryingly didn't correlate with vaccine eligibility and invitation...*
>
> *We proactively reviewed out-patient lists, and established which patients were priority group 4, and then contacted them and their GPs regarding this.*
>
> *We contacted GPs of all pts felt to be at increased risk (group 4) to highlight this and also all GPs of other patients to highlight need to be placed in group 6.*

Despite this, some services reported that a few individuals with HIV were not prioritised:

We had small number who were not going to be called early as gp wasn't aware and no other reason for them to have it early. Some of these patients agreed to finally allow us to write to gp but a few didn't so they had to wait until they could get vax with their whole age group.

In the end there was only one patient <40 who wouldn't let the GP know, and they decided to wait until they were called routinely. We do have the facilities now to refer if needed, but haven't needed to as yet.

A few services reported vaccine hesitancy as a significant concern:

The vast majority of patients were convinced the COVID-19 vaccine was not designed for them. Dismissing and alleviating their fears and concerns remains an ongoing challenge.

At least 3 of my patients are anti vaxxers.

Vaccine hesitancy has been and remains a concern, especially for certain vulnerable groups, including ethnic minorities.

Lessons learnt

If there are key lessons to share from your service's experience of and response to the pandemic, then please write them here. Examples might be:

- What worked?
- What did not work? Unforeseen issues?
- Positive changes that you plan or intend to maintain post-pandemic?

86 services responded. Key themes are highlighted below, with selected illustrative comments.

Remote consultations: Strongly supported, although several respondents stressed that face-to-face options should remain available:

> *Telephone consultations will now become the norm!*
>
> *We have a geographically disperse population and the T-cons were very well received. Most patients who have been asked have expressed a wish to continue with these.*
>
> *Patients would like to attend the clinic less frequently*
>
> *Phone consultations reduced DNAs!*
>
> *Telephone consultations have worked well for many patients, particularly those who are very stable but also those who have often missed face to face appointments.*
>
> *There are a group of patients however I feel in my clinic who need face to face eg transition, cognitive difficulties , complex*
>
> *Altering proformas to whats important to capture via remote consultation, catching up on important issues when getting back to normal, using communication skills to pick up on Q's*
>
> *Use of MS Forms as means of conducting remote consultations for very stable patients.*
>
> *This service is continuing with telephone triage for all patients (HIV, GUMed and Contraception) as it has shown that it is a much more time efficient system and optimises staff usage. Many patients can be seen same day, as face-to-face appointments are not booked with inappropriate attendances e.g. things that should be done in Primary Care, directly signposting to A&E (with emailed letter) a PID with sepsis, etc.*

Phone or video: Phone was mostly preferred, but there were some specific points about video:

> *Video consultations have been very useful for the pharmacists doing switches as they can actually show the pt the meds.*
>
> *What did not work: - Remote consultations for people who did not have access to data for video calls*

Separate appointment for bloods etc (on or offsite): Useful although some problems were noted:

> *Working with up to date blood results (quick 10 min blood test visit 2/52 prior to T-con) rather than bloods taken on same day as F2F consultation and working with 6/12 old results on that day then chasing if any abnormals was a major improvement.*
>
> *Express clinic for bloods/weight/BP/urine followed by VC if eligible, FTF if not or patient preference.*
>
> *Flexibility of where patients can attend for phlebotomy has improved patient choice, decreased DNA's.*
>
> *Offsite bloods (we are based on a main hospital site) - favoured location, but some teething problems e.g. wrong bloods taken, viral loads missed off.*
>
> *Community phlebotomy service at local park and ride worked really well but limited to those in a car*
>
> *Specific blood / medication collection clinics implemented.*

Home visits: Highly rated by services able to offer them:

> *Home visits for those who were shielding- very positive. Also helped with getting the disengaged back into service. Home visits are something that will remain.*
>
> *There was good team work with our community nurses who visited elderly and vulnerable patients*

New methods of ART delivery: Mostly seen positively:

> *Home delivery services increasingly useful and encouraged.*
>
> *The home delivery and drive thru pharmacy for prescription collection worked very well.*
>
> *Issues with home delivery of ART which was introduced in October 2020 due to the sudden increased workload for the home delivery company.*
>
> *Mailing of ARVs worked really well. Pharmacy courier service for ARVs worked really well*
>
> *More patient have signed up for the home care option for the delivery of their medication, less risk of running out. We created a dedicated email for patients to contact the service to request a repeat script.*

Effect of lockdown/restrictions: Some of the success of remote consultations, home visits and ART home delivery may have been due to pandemic restrictions:

> *Home delivery easier as most patients were at home.*
>
> *During full lockdown it worked well as it was easy to get hold of the patients but once lockdown lifted sometimes we couldn't get hold of patients and had to try*

several times. .. suspect the DNA rate on tel appts will go up once things go back to normal so tel appts may not be so time efficient for hiv staff in future

Hospital or community clinic:

Being a hospital based service meant some patients wanted to move care to a community service for fear of contracting COVID-19

We were seeing HIV patients in our town centre clinic rather than the hospital in March/April/May but we had issues with blood specimen transportation and pharmacy as path lab and pharmacy based at hospital.

HIV clinic moved to off-site Sexual Health clinic - some delay in bloods being processed, leading to haemolysed samples and false readings (ie high potassium levels)

Communicating with patients:

Some patients thinking we had shut even when we remained open throughout and had this communicated in lots of different ways.

What did not work: Keeping the website updated quickly enough with the changing advice. Ensuring those not with English as a first language were kept updated.

Peer support:

Hope to see a return of on site peer support soon! For many of most vulnerable they were reluctant to access remotely.

We lost our health-advisors during service reconfiguration, specialist nurses were redeployed and we do not have peer support. We felt the need more than usual when patients were going through psychological difficulty.

Implement peer support as this would have been beneficial during the pandemic.

Online/remote access to patient records: Enabled staff to provide care while isolating/quarantining, may remain valuable for flexible working post-pandemic:

…access to patients records via electronic notes... This has also allowed the staff some flexibility for working from home when self isolating or looking after children.

We were lucky in that we had a good solid foundation team of experienced staff, the main problems arose from sick leave, quarantine, and some senior staff being included in the extremely clinically vulnerable group and so having to work remotely from home via laptop & phone. There were Trust level issues early on with remote access to IT support as HIV was not prioritized above ITU, ED, AMU, etc. which was understandable on most occasions when problems with remote access arose but overall there was reasonably good support.

Shielding staff limited options for HIV remote clinics as no EPR or access to notes. HIV EPR planned…

Moving onto online INFORM HIV records have helped, including online access to hospital electronic patient record.

Reduced frequency of monitoring: Mostly worked well but identifying suitable stable patients could be time-consuming, plus need for formal guidance:

Initial weeks involved a lot of work going through all records and upcoming appointments to work out if they could defer bloods and arrange prescriptions. Future system in place to flag up patients stable to defer bloods if required would be helpful.

We are waiting for the BHIVA guidelines to change to reflect when monitoring can be yearly (other than those on PI's).

I would like clarity from BHIVA regarding the safety of not routinely monitoring viral loads/ biochemistry 6 monthly and the potential impact on U=U discussions/potential toxicity issues.

Moving to yearly bloods for stable patients appears to be low risk - we would value a national analysis on this and updated monitoring guidance from BHIVA.

Deferring routine bloods has resulted in delayed diagnosis of CKD,T2DM.

Mental health concerns:

Mental health much worse for patients overall in lockdown and we have strengthened our mental health support services and information on how to access services which is useful going forwards.

More difficult to assess psychological issues via telephone consultation.

[Redacted comment re an individual who died, with complex mental health issues - care "felt disjointed"]

Special needs and unwell patients:

Delayed diagnoses of opportunist infection has been a concern for patients with a new but late HIV diagnosis. We have seen delayed PCP cases treated as presumed Covid, with steroid and non-invasive ventilation, where appropriate treatment has been delayed.

What did not work - urgent issues and vulnerable clients, unwell patients , urgent medication request, walk- in facilities, patients with language problems ,

Primary care:

Many patients would not see their GP and so asked for help with more routine GP issues.

What did not work- communicating with primary care

Proactively encouraged patients to discuss their HIV status with their GPs to access timely vaccination - can only be a good thing.

Support primary care help with doing monitoring blood tests.

Remote consultation and monitoring (by GP or referral to local investigation and treatment room) works well for some of our remote and rural patients.

Laboratory services: Changed arrangements led to some difficulties:

Genotypic resistance results were delayed during first lock down due to PHL covid- 19 work load. had to use alternative private lab until PHL re-start

Considerable delay in getting viral loads and CD4 counts done as the local lab referred them to regional labs.

We had our HIV viral load tests and some routine tests delayed because of reagents and swabs shortages. In addition our local laboratory farmed out their HIV viral load tests out to the local university without telling us and their cut off for the virus is different from the kit our laboratory normally uses.

Prisons: Worked well where phone consultations permitted:

What didn't work: Prison sexual healthcare - not allowed in due to restrictions and no options for other consultation methods eg phone/VC - had to rely on prison staff to deliver care under our supervision.

Change to management of HMP inmates has improved. Now phone consultations (used to attend in person with DNAs) with blood monitoring by HMP health care team 2 weeks beforehand. Has improved the engagement of the small number of inmates at the two local prisons. Better working relationship with the HMP healthcare staff developed.

Staffing:

What did not work - expectation that we would manage for months on end with extremely high levels of redeployment. Affected staff wellbeing, notable loss of experienced workforce during the pandemic esp. 2/3rd wave

Early and rapid planning for covering and managing staff redeployment, instigated by the service, not the Trust

Staff dedication to finding new ways of working and going the extra mile e.g. doing ward cover and still covering clinics

Staff redeployment exposed the scarce resource available for HIV overall and the difficulty in getting a backup with reasonable expertise. … Succession planning and training is one of our priority

shortage of staff & clinicians

Staff sickness and isolation periods really affected the service.

Biggest problem was staff having to shield and the knock on effect on those who didn't

Training:

Negative impact on training opportunities for trainees - aim to return to teaching clinic model

Liaison among clinicians: Value of MDT and wider networking, including BHIVA:

Maintaining monthly MDT meetings has been valuable in maintain co-ordinated patient care and assessing who would benefit consultant face to face.

What worked well:- daily MDT briefings to know who was available/sick/what was new. …BHIVA updates e.g. on Covid vaccine, isolation guidelines

Liaising with other medical colleagues benefits all and this can be done very discretely to maintain confidentiality by using specific clinician nhs.net email

We had an excellent BCP in place, regular operational meetings, enhanced communication, learning from other clinics across UK though BASHH/BHIVA network etc. put us in good place

Pride in the HIV service:

The HIV team made a significant contribution to the trust's pandemic efforts - eg PI for treatment trials, ICU cover, helping set up staff testing and the vaccination hub.

We were part of a larger London service [service name redacted] which had a rapid timely response to changes throughout the pandemic.

Absolutely minimal number of incidents given the sheer volume of patients managed.

I am pleased that we maintained a full service throughout the pandemic but were able to offer flexibility to patients who were shielding or anxious about visiting the clinic.

Patients valued our ongoing concern about their health and well-being

Patients being heroes.

Scope for further work

Finally, 51 individuals gave their names as being willing to be invited to provide more in depth information via an online focus group or qualitative interview.