

NDTMS Blood-borne virus (BBV) guidance

Supplementary guidance for recording and reporting hepatitis B, hepatitis C and HIV data

V1.0

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Purpose of this guidance

The National Drug Treatment Monitoring System (NDTMS) dataset includes a number of data items relating to blood borne virus (BBV) interventions, including hepatitis B (HBV), hepatitis C (HCV) and HIV.

This guidance has been produced to ensure treatment providers know what data is required and how to complete the data items in different situations. The document outlines the importance of the data, describes specific scenarios that providers may encounter and provides guidance notes on some of the queries that may arise when recording BBV information.

This document should be utilised by adult and young people's treatment providers in community and secure settings.

Why does NDTMS collect BBV interventions?

Hepatitis C (HCV) continues to be a major problem among people who inject drugs (PWID) in the UK, with around 18% chronically infected with HCV. Around 0.2% PWID are currently infected with Hepatitis B (see <u>Shooting Up: infections among people who inject drugs in the UK</u> for further information).

The UK Government has signed up to the World Health Organization (WHO) initiative to eliminate viral hepatitis as a major public health threat by 2030. The Office for Health Improvement and Disparities (OHID) is working with NHS England and other partners to support improvement in prevention, raising awareness, increasing testing and getting more individuals diagnosed and into treatment and care. Collecting data on BBV interventions delivered though providers of drug and alcohol treatment is key to monitoring progress towards elimination.

The government has committed to ending new HIV transmissions by 2030. The diagnosis and treatment rates of HIV in the general population are higher, and improving, compared to the rates for PWID, for whom late diagnosis and delayed (or no) treatment result in poorer clinical outcomes. Co-infection of HIV and HCV is an additional complex factor for many PWID. It is important to monitor engagement with harm reduction for PWIDs living with HIV in order to reduce onward transmission, and to promote regular HIV testing for all at risk of infection.

Recording BBV information on NDTMS

Most adult community and secure setting treatment providers will offer clients BBV screening as part of their initial and ongoing healthcare assessments. An 'opt-out' BBV testing policy has been introduced into all prisons in England. For guidance and resources about this policy is available see: Improving testing rates for blood-borne viruses in prisons and other secure settings.

When considering BBV interventions it is important to bear in mind that risks are not limited to PWID. Whilst the sharing of needles is the biggest risk factor, other risks may include sharing filters, pipes, bongs or snorters. There are also risks not associated with substance use, such as (but not limited to):

- having unprotected sex
- tattooing or piercing by an unlicensed practitioner who uses needles on multiple people
- attending botox parties where needles are used on multiple people

For further details on BBV transmission routes see: How blood-borne viruses are spread.

When recording NDTMS BBV data items, it is important to remember that the questions relate to a client's situation rather than a service's direct provision of BBV interventions. For example, if a keyworker assesses that there is a need for a client to receive hepatitis B interventions and they accept this offer then a referral to the appropriate place for provision should be made, such as a healthcare provider (either in the secure setting or in the community). In this circumstance, you would record 'offered and accepted – not yet had any vaccinations' under the 'Hep B intervention status' field at the episode level (baseline). Once the vaccination takes place, community providers should update this via the Combined Review Form (CRF), and secure setting providers should update the relevant field at episode level to 'offered and accepted – started having vaccinations'.

If you do not deliver the BBV interventions directly there may be local mechanisms in place to allow information to be shared between the service providing the intervention and your service (subject to relevant information governance protocols). However, even where this is not the case, we would expect the BBV questions to be reviewed with the client at care plan review as a matter of good practice. Community services should use the CRF to capture updates and secure setting providers should update the episode level fields.

Please refer to the following links for further information on hepatitis B:

Hepatitis B (NHS)

Hepatitis B: guidance, data and analysis (GOV.UK)

Hepatitis B: the green book, chapter 18 (GOV.UK)

Please refer to the following links for further information on hepatitis C:

Hepatitis C (NHS)

Hepatitis C: guidance, data and analysis (GOV.UK)

Please refer to the following links for further information on HIV:

HIV and AIDS (NHS)

HIV: surveillance, data and management (GOV.UK)

Guidance for community providers

The client's BBV situation should be captured during the healthcare assessment and data recorded at episode level (baseline). Change or progression in the BBV pathway should then be updated via the Combined Review Form (CRF).

Scenario 1. My client has accepted a course of hepatitis B vaccination. How do I go about recording this information as they go through their vaccination course?

If a client accepts a course of hepatitis B vaccinations upon assessment, the episode level (baseline) field 'Hep B intervention status' should be completed with the permissible value of 'offered and accepted – not yet had any vaccinations'. As the client goes through their course of vaccinations within their episode of structured treatment, updates should be recorded via the CRF. Once the client has commenced the course, a CRF should be recorded with 'offered and accepted – started having vaccinations'. Upon completion of the course, another CRF should be completed to indicate 'offered and accepted – completed vaccination course'.

At your next CRF review it is likely that you will record 'immunised already' in the 'Hep B intervention status' field.

A complete course would be 3 or 4 doses depending on the vaccine and the schedule followed. The provider should liaise with a clinician if they are unsure of local protocol.

Scenario 2. My client refused the offer of a hepatitis B vaccination and/or a hepatitis C test upon assessment but has subsequently changed their mind.

Upon assessment, if a client is offered a hepatitis B vaccination and/or a hepatitis C test and refuses, the episode level (baseline) field(s) 'Hep B /C intervention status' should state 'offered and refused'. If the client subsequently changes their mind and accepts, this should be recorded via the CRF; 'Hep B intervention status' as 'offered and accepted - not yet had any vaccinations' and/or 'Hep C intervention status' as 'offered and accepted – not yet had a test'. As the client progresses through the hepatitis B vaccination course, this should be recorded via subsequent CRFs to indicate 'offered and accepted – started having vaccinations' and 'offered and accepted – completed vaccination course'. In the case of hepatitis C this should be recorded via subsequent CRFs to indicate 'offered and accepted – had a hep C test' with the date that the test took place in 'Latest hep C test date'.

Scenario 3. My client accepts the offer of a hepatitis B vaccination and/or a hepatitis C test at assessment but subsequently refuses at later date.

If a client accepts the offer of a hepatitis B vaccination and/or a hepatitis C test at assessment then this should be recorded at the episode level (baseline) field(s) 'Hep B intervention status' as 'offered and accepted – not yet had any vaccinations' and/or 'Hep C intervention status' as 'offered and accepted – not yet had a test'. If the individual subsequently refuses then this should be recorded via the CRF as 'offered and refused' in the relevant fields. There would be an expectation that the refusal would be revisited by the service at an appropriate point in the future, if the offer is then accepted record this accordingly via the CRF.

Scenario 4. At point of assessment my client has already completed a course of hepatitis B vaccinations.

If the course took place elsewhere you may need to follow local protocols to confirm this. If a client presents to a service having already completed a course of hepatitis B vaccinations and you have confirmation, the episode level field 'Hep B intervention status' should be completed with the permissible value of 'immunised already' with further updates on the CRF unlikely.

Scenario 5. What is the difference between 'assessed as not appropriate to offer' and 'not offered' for 'Hep B intervention status' at presentation to service?

A healthcare assessment should always consider BBV. As part of this assessment if you have established that the client does not require a hepatitis B vaccination then record this as 'assessed as not appropriate to offer'.

It is now common for hepatitis B vaccination to be universally offered to all clients of all substance cohorts at presentation to service and at review if ongoing risk is identified. If you do not offer or facilitate access to BBV interventions this should be recorded as 'not offered'. We expect this to be rare and commissioners may question why there are higher than expected rates of this permissible value.

Scenario 6. When would it be appropriate to use the 'assessed as not appropriate to test/re-test' option for the 'Hep C intervention status' at presentation to service/ at client review?

As mentioned in scenario 5, a healthcare assessment should always consider BBV. As part of this assessment if you have established that the client does not require a hepatitis

C test then record this as 'assessed as not appropriate to test/ re-test'. However, it is now common for a hepatitis C test to be universally offered to all clients of all substance cohorts at presentation to service and at review if ongoing risk is identified.

Many services now offer an annual re-test for hepatitis C for their clients in treatment. If your service does have a policy of annual re-test or regular testing it may be appropriate to use the option of 'assessed as not appropriate to test/re-test' at review if the client has not engaged in risky behaviour since their last test was conducted or if a test was carried out recently.

Scenario 7. Under what circumstances would I use 'deferred due to clinical reasons' for 'Hep B intervention status'?

Deferring a hepatitis B vaccination due to clinical reasons is likely to be an exceptionally rare clinical decision. See official guidance in <u>The Green Book</u>.

Scenario 8. Under what circumstances would I use 'deferred due to clinical reasons' for 'Hep C intervention status'?

Deferring a hepatitis C test due to clinical reasons is likely to be an exceptionally rare clinical decision. Deferring hep C testing is likely to be rare but it could be justifiable if drawing sufficient blood is difficult and dry blood spot testing is not available, or if for example the service is concerned about the impact that anxiety might cause. If there are no circumstances in which a clinician/provider would defer HCV testing, they don't have to use this option.

Scenario 9. How do I record 'Hep C test date'?

'Latest hep C test date' should reflect the date that the client was last tested for hepatitis C. At the episode level (baseline) this date is most likely to be on or before the 'triage date'.

If there is no historic test or no test at assessment then leave blank. Any test that takes place post episode start should be recorded on the CRF.

Scenario 10. What do I do if a client reports that they had a hepatitis C test some time ago, but cannot recall the date?

If a client cannot remember exactly when they were tested, use an approximate date. If clients can recall the month they were tested, use the first of that month as the test date; if they can only recall the year, then use the first of January of that year.

Scenario 11. My service offers annual hepatitis C re-tests, how do I record this?

If you provide annual hepatitis C re-tests you can record the date this took place in the 'Latest hepatitis C test date' field via the CRF.

Although your service may offer annual re-tests not all clients will need one, if review/assessment establishes that the individual has not been engaged in risky behaviour since their last test was done or if a test was carried out recently then use the option of 'assessed as not appropriate to test/re-test.

Scenario 12. My client has accepted the offer of a hepatitis C test. How do I go about recording the subsequent antibody and PCR/RNA tests and possible referral to treatment?

If a client accepts a hepatitis C test upon assessment, the episode level (baseline) field 'Hep C intervention status' should be completed with the permissible value of 'offered and accepted – not yet had a hep C test'.

Once the test has been completed record 'offered and accepted – had a hep C test' in the 'Hep C intervention status' field and the date of the test in the 'Latest hep C test date' field on the next CRF completed.

Once the 'Hep C test result antibody status' is known the result of the test should be recorded on the next CRF completed.

If the antibody status is positive the client should receive a 'PCR/RNA' test. Once the result of this is know it should be recorded on the next CRF completed. Some services may complete a combined antibody and PCR/RNA test, in which case they could record both test results at the same time.

Following positive 'PCR/RNA' test there is an expectation that the client would be referred to hepatitis C treatment.

If a referral to hepatis C treatment is made following a positive PCR/RNA test, the 'Referred to hep C treatment' field should be completed using the option 'yes' on the next CRF. The 'Referred to hepatitis C treatment date' should be indicated for all those referred to treatment with the date that the client was referred to treatment following a positive test result. If the client is offered a referral for hepatitis C treatment following a positive PCR/

RNA test but declines this offer, the option of 'refused treatment' should be recorded in the 'Referred to hep C treatment' field.

Scenario 13. My client tested positive for antibodies. The PCR/RNA test is negative but they have never received treatment. How do I record this?

This may be because the infection is recent and the RNA is not yet detectable or could be due to human error in interpreting the lab results. There may be rare circumstances where the client naturally clears the hepatitis C virus. If a client does test positive for antibodies and receives a negative PCR/RNA test despite never receiving treatment the provider should discuss with a clinician what the next steps should be. If it is concluded that natural clearance is the most plausible reason record 'negative – cleared naturally' in the 'Hep C PCR/RNA status' field.

Scenario 14. My client has tested positive for PCR/RNA and through a referral to treatment has now cleared the virus. How do I record this and future updates?

Once the client has cleared the virus complete a CRF with the permissible value of 'negative (cleared by treatment)' in the 'Hep C PCR/RNA status' field.

At your next CRF review, you should assess whether it is appropriate to re-offer the client BBV testing due to continued risky behaviour. The biggest risk factor is sharing needles, but other risks (as detailed on <u>page 6 above</u>) should also be considered. If the client has engaged in any behaviour that would put them at risk of reinfection then they should be offered another HCV test. If you establish that the client has not been engaged in risky behaviour you should record this as 'assessed as not appropriate to test/re-test' in the 'Hep C intervention status' field. There are no longer restrictions on being treated for reinfection and so this should not be a barrier to re-testing.

Scenario 15. At presentation, you have confirmation from the referring provider that the client tested positive for antibodies and PCR/RNA status but had not started treatment. What do I record?

If, in accordance with local protocols, you confirmed the individual tested positive for antibodies and PCR/RNA status with the referring provider and you make a referral to hepatitis C treatment at point of assessment you would record 'yes' in the 'Client referred for hep C treatment' field at the episode level (baseline), along with the date the referral was made in the 'Referred to hep C treatment date' field (baseline). You would record 'assessed as not appropriate to offer' in 'Hep C intervention status', the date that the test took place (likely to be on or before your triage date as in this example the test was carried

out by the referring provider) in 'Latest hep C test date' and 'positive' in the 'Hep C test result antibody status' and 'PCR/RNA' fields at the episode level (baseline).

If you are not able to confirm the results or date with the service that delivered the test then it should be done again.

Scenario 16. A client has started a course of hepatitis B vaccination or had a hepatitis C test during structured drug/alcohol treatment. They completed structured treatment but go on to receive further vaccinations/test during recovery support. Should we continue to submit updated information via the CRF to reflect the vaccinations and/or tests received during recovery support?

No. BBV information should only be updated via the CRF during the client's structured treatment episode. When the client has been discharged from structured drug or alcohol treatment, you should stop submitting updated CRF forms, even if the client is still receiving recovery support.

Scenario 17. How do I record 'Latest HIV test date'?

'Latest HIV test date' should reflect the date that the client was last tested for HIV. At the episode level (baseline) this date is most likely to be on or before the 'triage date'. If there is no historic test or no test at assessment then leave blank. Any test that takes place post episode start should be recorded on the CRF.

Scenario 18. At presentation a client has previously tested negative for HIV. What should I record in 'Is client HIV positive?'

This question asks for the result of the most recent HIV test, this would include a historic test result regardless of how long ago the test was undertaken. In this scenario you should record 'No' at episode level and on subsequent CRFs. Bear in mind however that it is important to regularly review whether the client is at ongoing risk of HIV infection and consider re-testing.

'Unknown' should be used if the client has never been tested or if the client has been tested but hasn't had the result yet/cannot remember the result/the result was inconclusive.

If the individual refuses to answer record 'Client declined to answer'.

If the client is tested during treatment record updates via the CRF. Refer to local protocols regarding re-testing.

Guidance for providers in secure settings

The BBV data items in the NDTMS secure setting data set are updateable. The client's BBV situation should be captured during the comprehensive assessment and data recorded at episode level. Changes or progression are captured by updating the episode level fields. It is likely that the BBV interventions in prison will be carried out by the healthcare provider, it is important that you have mechanisms in place to allow information to be shared between the service providing the intervention and your service. However, even where this is not the case, we would expect the BBV questions to be reviewed with the client at care plan review as a matter of good practice.

Scenario 1. My client has accepted a course of hepatitis B vaccination. How do I go about recording this information as they go through their vaccination course?

If at point of assessment, the client accepts the offer of hepatitis B vaccinations, you would record 'offered and accepted – not yet had any vaccinations' in 'Hep B intervention status'. Once they start the course you can update this field to 'offered and accepted – started having vaccinations'. Once they complete the course you can update this field to 'offered and accepted – completed vaccination course'.

Scenario 2. My client accepts a course of hepatitis B vaccination/hepatitis C test but subsequently refuses. How do I go about recording this?

If at point of assessment, the client accepts the offer of hepatitis B vaccination/hepatitis C test, you would record 'offered and accepted – not yet had any vaccinations' in 'Hep B intervention status' and/or 'offered and accepted – not yet had a test' in hepatitis C intervention status. If they subsequently refuse to start the vaccinations/have the test update the field to 'offered and accepted – refused at a later date'. It's important to explore why clients refuse the BBV offer and support them in engaging – hepatitis C is curable.

Scenario 3. My client has accepted a hepatitis C test. How do I go about recording this?

If at point of assessment, the client accepts the offer of a hepatitis C test, you would record 'offered and accepted – not yet had a test' in 'Hep C intervention status'. Once the test takes place update this field to 'offered and accepted – had a hep C test' and enter the date the test took place in 'Hep C latest test date'. As the client has accepted the offer made by your service we would expect the 'Hep C latest test date' to be on or after the clients 'reception date'.

Scenario 4. The hepatitis C test establishes the client has a positive PCR/RNA status and you refer them to hepatitis C treatment. How do I go about recording this?

You can update the field 'Referred to Hep C treatment during stay within establishment or to community service at release' to 'Yes' during their episode (or at release if appropriate). You should also record the date at which this referral was made in the 'Referred to Hepatitis date C' field.

If a client has a positive PCR/RNA status but refuses to go on to hepatitis C treatment, you should update the 'Referred to Hep C treatment during stay within establishment or to community service at release' to 'refused treatment' during their episode (or at release if appropriate).

Scenario 5. How do I record 'Hep C test date'?

'Hep C latest test date' should reflect the date that the client was last tested for hepatitis C. If you have a 'test on reception' model this date is most likely to be on or around the 'reception date' /'triage date'. If it takes place at a later point during their episode of treatment update the 'Hep C latest test date' accordingly.

If the client is not tested at reception you should record the date that the most recent test took place prior to arrival. If there is no historic test or no test at assessment then leave blank.

Scenario 6. What do I do if a client reports that they had a hepatitis C test some time ago, but cannot recall the date?

If a client cannot remember exactly when they were tested, use an approximate date. If clients can recall the month they were tested, use the first of that month as the test date; if they can only recall the year, then use the first of January of that year.

Scenario 7. My client refused the offer of a hepatitis B vaccination and/or a hepatitis C test upon assessment but has subsequently changed their mind. How do I record this?

Upon assessment, if a client is offered a hepatitis B vaccination and/or a hepatitis C test and refuses, the 'Hep B /C intervention status' fields should state 'offered and refused'. If the client subsequently changes their mind and accepts, these fields should respectively be updated to 'offered and accepted – not yet had any vaccinations' and 'offered and accepted – not yet had a test'.

Scenario 8. What is the difference between 'assessed as not appropriate to offer' for 'Hep B intervention status / 'not appropriate to test/ re-test' for 'Hep C intervention status' and 'not offered'?

A healthcare assessment should always consider BBV. As part of this assessment if you have established that the client does not require a hepatitis B vaccination or a hepatitis C test then record this as 'assessed as not appropriate to offer'/ 'assessed as not appropriate to test/ re-test'.

The Public Health England BBV opt out policy guidance (in <u>Improving testing rates for blood-borne viruses in prisons and other secure settings</u>) states that BBV testing should be recommended to all prisoners including those already in prison unless:

- they have been tested in the last 12 months and have NOT subsequently put themselves at risk of infection
- they have been tested and are positive
- they are known to be positive for a BBV
- for hepatitis B: if a patient has documented evidence of a negative result and have been fully vaccinated against hepatitis B they do not require further testing for this BBV infection
- If you do not offer or facilitate access to BBV interventions this should be recorded as 'not offered'. We expect this to be rare and commissioners may question why there are higher than expected rates of this permissible value.

Scenario 9. Under what circumstances would I use 'deferred due to clinical reasons' for 'Hep B intervention status'?

Deferring a hepatitis B vaccination due to clinical reasons is likely to be an exceptionally rare clinical decision. See official guidance in The Green Book.

Scenario 10. Under what circumstances would I use 'deferred due to clinical reasons' for 'Hep C intervention status'?

Deferring a hepatitis C test due to clinical reasons is likely to be an exceptionally rare clinical decision. Deferring hep C testing is likely to be rare but it could be justifiable if drawing sufficient blood is difficult and dry blood spot testing is not available, or if for example the service is concerned about the impact that anxiety might cause. If there are

no circumstances in which a clinician/provider would defer HCV testing, they don't have to use this option

Scenario 11. How do I record 'HIV latest test date'?

'HIV latest test date' should reflect the date that the client was last tested for HIV. If you have a 'test on reception' model this date is most likely to be on or around the 'reception date' /'triage date'. If it takes place at a later point during their episode of treatment update the 'HIV latest test date' accordingly.

If the client is not tested at reception you should record the date that the most recent test took place prior to arrival. If there is no historic test or no test at assessment then leave blank.

Scenario 12. At presentation a client has previously tested negative for HIV. What should I record in 'Is client HIV positive?'

This question asks for the result of the most recent HIV test, this would include a historic test result regardless of how long ago the test was undertaken. In this scenario you should record 'No' at treatment start. Bear in mind, however, that it is important to regularly review whether the client is at ongoing risk of HIV infection and consider re-testing.

'Unknown' should be used if the client has never been tested or if the client has been tested but hasn't had the result yet/cannot remember the result/the result was inconclusive.

If the individual refuses to answer record 'Client declined to answer'.

If the client is tested during treatment this field can be updated.