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Increasing access to hepatitis C testing and care for people who inject drugs

Identifying barriers to and opportunities for supporting hepatitis C testing and care in drug services: a participatory diagnostic process

12

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Preface

Although preventable and curable, hepatitis C virus (HCV) infection is highly prevalent among people who inject drugs in Europe. The elimination of hepatitis C as a public health threat by 2030 is a target under Sustainable Development Goal 3 (SDG 3) on health, to which all EU countries have signed up. To achieve this target in the EU, it is crucial for services to reach people who currently inject drugs and who have done so in the past. This key population has a high disease burden and their access to HCV testing and treatment, as well as to other effective interventions that prevent and reduce the transmission of the virus, needs to be increased.

The importance of addressing the needs of people who inject drugs as part of action to achieve the elimination of hepatitis C cannot be overstated. Most studies in Europe find HCV antibody prevalence levels among this group of over 50 %, while surveys among people entering drug treatment show low rates of testing. Many barriers may prevent people who inject drugs from being tested for HCV, resulting in a reduced likelihood of them accessing treatment. Testing services are still mostly located in tertiary clinical settings, such as hospitals or specialist clinics, and thus may remain 'out of reach' for people who inject drugs. On the other hand, providers of harm reduction and drug treatment services are in close, often daily, contact with a large number of people who use drugs and could play a pivotal role in bringing HCV screening closer to this population, but often lack adequate training, equipment and resources.

This document has been produced as part of a wider initiative that the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) is undertaking to support countries in the prevention and control of infectious diseases among people who inject drugs. It provides a step-by-step guide for those involved in planning and managing infectious diseases and drug services, focusing on how to identify barriers to and opportunities for improving provision of HCV testing and access to treatment for people who use drugs. In particular, it focuses on HCV testing in harm reduction and drug treatment settings. Based on work conducted by the EMCDDA, consultation with European partner organisations and pilots conducted in Luxembourg and Poland, it incorporates practical guidance on how to conduct a diagnostic process. It includes tools for assessing the need for and scale of HCV-related prevention responses and for ascertaining whether or not system-, provider- and client-level barriers to HCV testing exist. Importantly, this process has been undertaken with the full participation of all key stakeholders, allowing joint solutions to be developed and relevant actions to be planned together.

The piloting of the diagnostic process has demonstrated what can be achieved through working in partnership on this issue and we hope that this report will enable others to follow suit and, as a result, make good progress towards achieving the elimination of hepatitis C as a public health threat in our communities.

Alexis Goosdeel
Director, EMCDDA

Increasing access to hepatitis C testing and care for people who inject drugs: why is it so important?

Hepatitis C is widespread among people who inject drugs

Hepatitis C is a liver disease, which is caused by the hepatitis C virus (HCV), a blood-borne virus that is widely prevalent globally. In 60-85 % of those infected, hepatitis C becomes a long-term chronic disease, which can have fatal consequences due to the development of liver cirrhosis and hepatocellular carcinoma (Hofstraat et al., 2017). People who inject drugs remain a key group at risk of HCV infection in most European countries, as a result of insufficient awareness and widespread unsafe injection practices such sharing injection equipment. Available national estimates of antibody prevalence among this group suggest that more than one out of two people who inject drugs in Europe may have been in contact with HCV (EMCDDA, 2020). Transmission through injecting drug use is ongoing and accounts for a substantial proportion of newly reported HCV infections where transmission mode is known (ECDC, 2019).

Safe and highly effective treatment in the form of direct-acting antiviral (DAA) regimens for hepatitis C is now available. This progress has prompted many European countries to adopt new viral hepatitis strategies and update guidelines to broaden access to HCV testing and treatment. The reduction in the price of direct-acting antiviral medicines has enabled treatment to be rolled out rapidly in a number of European countries. The challenges that remain are low levels of HCV testing and unclear referral and treatment pathways, both of which pose particular barriers for people who inject drugs.

The elimination of hepatitis C as a global policy goal

Health features prominently in the 2030 Agenda for Sustainable Development and one of its 17 global Sustainable Development Goals (SDGs) is to ‘ensure healthy lives and promote wellbeing for all at all ages’ (^{1}). Within this goal, a specific target on health addresses HIV, hepatitis and tuberculosis as globally relevant communicable diseases:

> ‘By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases’ (^{2}).

To accelerate progress towards the health-related SDGs, close cooperation between health, development and humanitarian agencies at the global level has been established (WHO, 2019).

(^{1}) UN Sustainable Development Goals website: https://www.un.org/sustainabledevelopment/health/

(^{2}) Ibid

The EU is fully committed to being a frontrunner in implementing the 2030 Agenda for Sustainable Development, together with its Member States. Several EU 'initiatives on health and the EU Cohesion Policy support and complement national governments in their efforts to improve and protect human health, to reduce inequalities in health status and promote social inclusion. The European pillar of social rights underlines the right of every individual to timely access to affordable, preventive and curative health care, long term care and good quality essential services. It also covers social protection, including healthcare and sickness benefits' (European Commission, 2020).

To incorporate the health target into a global operational policy framework for hepatitis, the World Health Assembly endorsed in May 2016 the global health sector strategy on viral hepatitis, which aims to eliminate hepatitis as a public health threat by reducing the incidence of chronic infections by 90 % and mortality by 65 % by 2030 (WHO, 2016a). To support the implementation and monitoring of this strategy, a framework with 10 core indicators has been proposed by the World Health Organization (WHO). These include a mix of epidemiological and programmatic indicators (WHO, 2016b). This framework also stresses the importance of including comprehensive harm reduction services for people who inject drugs in the strategy (see box).

Testing and linkage to treatment is a core component of a hepatitis C elimination strategy, because of both the direct benefits of treatment for the infected individual and the indirect impact of treatment on reducing transmission in the community. Achieving elimination among people who inject drugs will require a significant scale-up of prevention interventions within drug services, including increased testing (see box). In line with the EU's commitment to achieving the SDGs, the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) and the European Centre for Disease Prevention and Control (ECDC) collaborate closely with the WHO to support EU countries in their elimination efforts through monitoring, public health guidance and best practice dissemination (Duffell et al., 2017; EMCDDA, 2019a). The work of the EMCDDA is focused on people

Harm reduction as part of a comprehensive response

'A package of harm reduction services for PWID [people who inject drugs] can be highly effective in preventing transmission and acquisition of viral hepatitis A, B and C, as well as HIV and other blood borne infections. Such a package should be integrated into a comprehensive set of services for the prevention and management of substance use disorders.' (WHO, 2016a, p. 21).

The comprehensive package consists of the following interventions:

1. needle and syringe programmes
2. opioid substitution therapy and other drug dependency treatments
3. HIV testing and counselling
4. antiretroviral therapy
5. prevention and treatment of sexually transmitted infections
6. condom programmes for people who inject drugs and their sexual partners
7. targeted information, education and communication
8. prevention, vaccination, diagnosis and treatment of viral hepatitis
9. prevention, diagnosis and treatment of tuberculosis.

For more information see: https://apps.who.int/iris/bitstream/handle/10665/246200/9789241511124-eng.pdf?sequence=8 who inject drugs, one of the population groups that are particularly vulnerable to hepatitis C and frequently lack adequate access to services. Following the WHO framework of indicators, the agency monitors developments in national policies that target this group, the epidemiological trends in regard to hepatitis B and C, as well as the level of access to core harm reduction measures such as the provision of clean drug injection equipment and drug treatment (EMCDDA, 2019b).

Drug services as priority settings for hepatitis C virus testing

Testing is the gateway to accessing treatment and, to achieve HCV elimination, particular efforts are needed to reach those at risk and undiagnosed. Because people infected with HCV often do not have any symptoms, people who inject drugs infected with HCV may be unaware of their infection. The importance of testing, early diagnosis and treatment of all people who are chronically infected is highlighted in current international guidelines (EASL, 2018; WHO, 2018).

The latest European testing guidance (ECDC, 2018) stresses the importance of a stronger focus on people who inject drugs and other groups most at risk, to interrupt viral hepatitis transmission chains and prevent further infections.

> ‘In order to interrupt existing transmission chains and prevent further infections, Europe needs a stronger focus on working closer with vulnerable populations to help better detect those with undiagnosed infections, then link them to appropriate health care services. Increasing testing coverage and uptake, especially for those most at-risk, is an essential element of any strategy to eliminate HBV [hepatitis B virus], HCV and HIV in the European Union and European Economic Area (EU/EEA)’ (ECDC, 2018, p.1).

The past decade has seen important biomedical advances that have made a significant contribution to promoting the early diagnosis of HIV and viral hepatitis, and new medications have significantly enhanced the effectiveness of treatment of chronic hepatitis. New testing technology is available that makes testing outside specialist settings easy, and new direct-acting antiviral treatments for hepatitis C, which cure the disease within 12 weeks with fewer side effects than previous treatment options, are available.

Bringing health services to those who have a particular need for them is part of ensuring a people-centred approach to health (EMCDDA, 2017), and these technological developments provide an opportunity for new models of care to be developed that provide a more adequate and timely response for hard-to-reach groups, such as people who inject drugs. However, taking advantage of these opportunities may need a reorientation of service provision and a range of barriers may exist that need to be addressed to enable successful implementation.

The diagnostic process described in this document provides a way of identifying barriers to and opportunities for improving the provision of HCV testing and care for people who use drugs and, at the same time, making progress towards meeting the HCV elimination targets.

Introducing the diagnostic process

As highlighted in the previous section, people who inject drugs are at particularly high risk of HCV infection but tend to have low rates of access to testing and treatment in Europe. The diagnostic process for identifying barriers to and opportunities for improving HCV testing and referral to care for people who inject drugs described in this document brings together a variety of stakeholders to identify problems and areas for improvement.

The main mechanism and core activity of the diagnostic process for identifying barriers to HCV testing in drug services (the 'problem') is to use a participatory dialogue between stakeholders as a basis for identifying actions to improve the situation ('solving' the problem).

While the focus and the objectives of the diagnostic process, as well as which participants should be invited to take part, will differ according to the needs and situation in a given national or local context, the process and steps to consider while planning the implementation of the diagnostic process are similar. This document discusses the key issues to be considered, regardless of the country and context-specific situation.

The diagnostic process consists of three main steps (see Figure 1).

The starting point for the diagnostic process is the mapping of information on the current situation, including the assessment of the need for HCV testing in drug services. This may include in particular an assessment of available data on the prevalence of HCV antibodies among people who inject drugs and of acute and chronic HCV infections. Common risk behaviours and prevention coverage should also be assessed, as well as national or local testing policies for this key population. It will be important to map the infrastructure of testing currently available to people who inject drugs, including opportunities for HCV testing in drug services. A checklist (see Figure 3 and Appendix 1) should then be used to identify system-, provider- and client-level barriers to testing in drug services. This is discussed in more detail in the section on Step 1 below.

FIGURE 1
The main steps in the diagnostic process

The core element of the process is a multi-stakeholder round-table meeting (Step 2), bringing together representatives from:

- the system level, such as policymakers and service planners;
- the provider level, that is, providers of infectious disease and drug services;
- the client level, to ensure that the experiences of people who use drugs are also taken into account.

The aim of this meeting is to identify the barriers to HCV testing and treatment for people who inject drugs, to clarify the key target areas for improvement of HCV testing in drug services and to identify priority actions to address the most important issues (see *EMCDDA guide to holding a stakeholder round table on supporting HCV testing and care in drug services*).

The final element of the diagnostic process (Step 3) is dedicated to ensuring monitoring and the evaluation of outcomes. It typically involves preparing a report on the stakeholder meeting, linking the activities aimed at removing barriers to HCV testing for people who inject drugs that were proposed by stakeholders to local or national policies, such as the hepatitis elimination strategy, and defining the expected results of implementation, ideally linked to pre-defined indicators.

Importantly, the diagnostic process can be flexible and tailored to national or local needs and situations. In many cases, it will not be possible to get all relevant stakeholders together at one time, or to consider barriers to community-based testing and care at all levels (3), because of missing information. However, a start can be made and areas for action to improve the situation can be identified. It can be useful to repeat the diagnostic process or one or more of its steps to identify further issues to be addressed over time.

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(3) This manual covers the promotion of HCV testing and care in drug services in the community. It does not address HCV testing in prison settings, which requires a different approach.

1

Assessing the need for hepatitis C testing in drug services

The EMCDDA tools available to support the mapping exercise are as follows:

- EMCDDA elimination barometer
- checklist of potential barriers to HCV testing among people who inject drugs (Appendix 1)
- knowledge questionnaire on viral hepatitis for drug service staff.

The diagnostic process starts with a needs assessment exercise, aimed at mapping the situation and describing the context in which the stakeholder round table will take place. Understanding what is known about the extent and nature of the HCV problem is important background knowledge and contextual information for successfully implementing the stakeholder round table. Knowing the size of the key population, as well as the policies and available infrastructures for testing and linkage to hepatitis care in the country or region, will help in preparing the dialogue for the relevant stakeholders and selecting the target audience, and will help stakeholders to choose the appropriate objectives. However, if the available information is very limited, it may also be possible to collect some information directly from experts, either beforehand or during the introductory session at the stakeholder meeting.

The EMCDDA elimination barometer

The EMCDDA elimination barometer (EMCDDA, 2019b) was developed by the EMCDDA together with its expert network on drug-related infectious diseases as a follow-up to the first global health sector strategy on viral hepatitis, endorsed by the World Health Assembly in 2016. It reflects the global WHO indicators for monitoring progress towards the elimination of viral hepatitis, according to the global health sector strategy monitoring and evaluation framework, and includes 17 indicators relevant for the key population, people who inject drugs (Figure 2).

A first technical report published in September 2019 presents data from the EU countries, Norway, Turkey and the United Kingdom relating to the 2020 targets of the WHO's regional action plan for viral hepatitis in the European region (EMCDDA, 2019b). Data sources include the EMCDDA's national focal points and its European network of experts in the field of drug-related infectious diseases as well as published reports and studies. The indicators cover, among other things, the burden of HCV and HBV infection among people who inject drugs in each country; the level of coverage of selected prevention interventions, namely of opioid substitution treatment for those dependent on opioids; the level of coverage of clean injecting kits for those who inject drugs; and the availability of

HBV vaccinations for people in prison. Furthermore, the percentage of people who inject drugs entering drug treatment services who report having been tested for HCV antibodies in the past 12 months is used to highlight potential missed opportunities for diagnosing HCV infection in people who inject drugs. Finally, national HCV policies and clinical guidelines are assessed to check if they include barriers among people who inject drugs to accessing direct-acting antiviral treatment.

The data compiled in the national 'elimination barometer' for a specific country provide a useful overview of the information that is routinely reported and also show the indicators for which data are lacking. It is also worthwhile gathering additional data and contextual information beyond the 17 indicators, for example data relating to the national drug treatment system, and on drug and infectious disease policies and regulations.

A collection of other potentially valuable sources of information can be found in the resources section of the web page dedicated to the EMCDDA initiative on increasing access to hepatitis C care through drug services. In addition, there may be local and national studies, both published and unpublished, that have some information that helps to provide a picture of both the need for HCV testing and the current provision.

It is useful to collaborate with researchers in the field to prepare an overview of the current situation, as this can provide an opportunity to share the latest findings from relevant research. The round-table meeting will also offer an opportunity for the stakeholders invited to present additional formal and informal data, including activity reports from local

FIGURE 2

Indicators and targets in the EMCDDA hepatitis elimination barometer

Area	Indicator	Related 2020 target
CONTEXT AND NEED	▪ Number of injectors entering drug treatment and number of PWID ▪ Main drugs injected ▪ Sharing of needles/syringes ▪ Prevalence of HCV and HBV	✓ Indicators available and context documented
INPUTS	▪ Hepatitis national policy/action plan inclusive of PWID	✓ National policy adopted
PREVENTION	▪ Sterile needles/syringes distribution ▪ Opioid substitution treatment coverage ▪ HBV vaccination ability in prison	✓ 200 per PWID per year ✓ 40 % in treatment ✓ HBV vaccination available
TESTING AND LINKAGE TO CARE	▪ HCV/HBV testing availability in drug facilities/prisons ▪ Proportion of PWID tested for HCV in the last year ▪ Notifications of acute and chronic HCV/HBV cases ▪ DAA treatment availability for PWID	✓ 50 % of PWID with chronic ✓ HCV/HBV diagnosed ✓ 75 % of eligible patients treated
IMPACT	▪ Prevalence of HCV among young and new PWID (proxy for incidence)	✓ 30 % reduction (baseline = 2015)

Note: DAA = direct-acting antiviral

Source: EMCDDA (2019b) (based on WHO, 2016b). PWID, people who inject drugs.

service providers, or reports about the clinical management of patients or the cascade of care for hepatitis (4).

The overview of the situation should be as comprehensive as possible, but a lack of certain data should not be seen as a barrier to progress in the diagnostic process or to the organisation of a stakeholder meeting. Information gaps can be an important element for discussion and may be one of the barriers to improving provision.

The checklist of potential barriers to hepatitis C testing among people who inject drugs

A second core input for the diagnostic process is a checklist of potential system-, provider-, and client-level barriers to HCV testing (see Appendix 1) (Sperle-Heupel et al., 2018). The checklist is based on the available literature and expert knowledge, and structured into three parts, one for each type of barrier: system-level, provider-level and client-level barriers. Barriers are then organised into sub-categories within each of the three levels (see Figure 3 and Appendix 1). The checklist is a useful tool for organising and focusing the discussions at the stakeholder meeting, and the barriers listed can also be the basis for statements or questions that may be used in preparation for the meeting, as part of a survey, or at the meeting itself in plenary sessions or workshops to stimulate discussions. However, it is important to note that the checklist topics are by no means exhaustive and it is advisable to ensure that the discussion is facilitated in a way that allows the identification of additional barriers that may be of particular importance in the country and/or settings under discussion but that may be missing from the EMCDDA checklist.

The checklist is therefore a very flexible tool (see the scenarios in the accompanying *EMCDDA Guide to holding a stakeholder round table on supporting hepatitis C testing and care in drug services*). Depending on circumstances, an online version of the checklist may be preferred, using an online survey tool such as EU Survey, or the survey could simply be printed and distributed. The checklist questions can be answered individually or as a group. Sending the checklist out before the stakeholder meeting may allow the consultation to involve a larger number of people than could be accommodated at the event itself, with the results being brought together for discussion at the meeting. Having an anonymous online version may be useful if there are concerns that some groups, for example service staff or people who inject drugs, may not feel comfortable speaking openly at a large group meeting.

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(4) A cascade of care for hepatitis is commonly determined by the number of patients with chronic HCV infection, the number of patients diagnosed with chronic HCV infection, the number of patients linked to HCV care, the number of patients being treated with antiviral medication for HCV infection and the number of patients with a sustained virological response.

FIGURE 3
Checklist at a glance

System level

National regulatory framework	
No national policy for HCV treatment for infectious diseases	No national policy in place for unrestricted access to HCV treatment
No national screening strategy in place for HCV testing of PWID	No public funding available for HCV screening
National drug laws identified as a barrier	No public funding available for HCV treatment

Society level/ discrimination
Stigma and discrimination against PWID
Stigma and discrimination against people with HCV
Restriction to access to any services due to HCV status
Breach of confidentiality – (link to other systems, e.g. police registries)

Organisation of testing and treatment on national level	
Testing for HCV is not provided by OST services	Testing for HCV is not provided by other drug services
Medical doctor required for HCV testing	No screening plan/ government guidelines for HCV testing of PWID
HCV treatment provision only by approved centres	No programmes implemented for HCV testing of PWID

Epidemiological situation
Lack of evaluation and monitoring of indicators of national HCV plan
Lack of HCV prevalence data for PWID
Lack of HCV incidence data for PWID
Lack of data on HCV testing of PWID

Provider level

Internal barriers
Low level of knowledge of HCV among staff in harm reduction agencies
Low level of knowledge of HCV among staff in drug treatment, including OST services
HCV testing is not perceived as the area of responsibility of the staff in drug services
Scared of stigmatising client when asking about HCV
Assumption by staff: HCV testing is too complicated
HCV treatment not offered if current drug use

External barriers	
Insufficient staff available to offer HCV testing services	High fluctuation of staff in drug services
Insufficient availability of information materials	Service not set up to support minority populations (e.g. lack of translated materials, no interpretation)
Lack of time to offer HCV testing	Lack of referral pathways to HCV care and treatment
Lack of available funding to offer HCV testing services	Lack of available equipment to perform testing services
Point-of-care (POC) HCV testing not available in drug treatment services	No existing collaboration with laboratories for confirmatory HCV testing

Client level

Knowledge
Insufficient knowledge of HCV
Insufficient knowledge of hepatitis C treatment options
Myths about HCV e.g. "I have no symptoms so I have no problem"
Fear that drawing blood will damage veins
Perception of HCV
Perceive risk of HCV as low and not as serious as HIV
Cultural attitudes towards infection/no need to avoid infection

Stigma
Fear of stigma if tested HCV positive
Negative experiences with health care or drug service staff/stigmatised when tested for HCV
Stigma/shame of using drugs
Competing problems
Other health problems (e.g. mental health problems)
Lack of housing
Lack of sufficient food
Lack of financial resources

Access
It takes too long time to get tested
The service is too far away (location)
The hours where you can get tested do not fit the schedule of the client
Language barrier
Lack of/poor available transportation to the service
HCV services restricted to those in addiction care (OST)
Two step testing (HCV serology and HCV RNA)

Consequences of a positive test result
No hepatitis C treatment available if tested positive
Fear of losing children (to child services)
Fear of negative impact on the asylum procedure (for migrants)
Fear of HCV testing/knowing results
Fear of HCV treatment side effects

Note: For more information, see full checklist in Appendix 1.
OST, opioid substitution therapy; PWID, people who inject drugs.

Knowledge questionnaire on viral hepatitis for drug service staff

The EMCDDA published a knowledge questionnaire as part of its initiative to increase access to hepatitis C care through drug services. The main aims of the knowledge questionnaire are to refresh knowledge on HCV and HBV transmission, testing and care for people who inject drugs among those working in drug treatment settings, and to increase awareness among staff of the importance of knowing their own status.

The knowledge questionnaire covers a wide range of aspects regarding viral hepatitis B and C, such as prevalence, routes of transmission, prevention measures, treatment and testing options, and international recommendations on testing and treatment.

The literature shows that knowledge about new hepatitis treatment and testing methods among staff working in harm reduction settings is not always sufficient or up to date. This may have implications for the clients, who may not be informed by staff about new developments in this area and, as a result, may be less willing to be tested and/or treated. Therefore, in the context of the diagnostic process, the knowledge questionnaire can be used to identify existing barriers at the level of service providers. The knowledge questionnaire can be implemented at the beginning of the diagnostic process in selected drug treatment services, and the results of the exercise can inform discussions at the stakeholder meeting when system-level barriers and opportunities are considered. If the level of knowledge is low, the information collected and documented could lead to the inclusion of a training provision for staff of drug treatment centres in the document summarising outcomes or in an action plan. If the situation is the opposite, and staff are well informed about recent developments in HCV treatment and testing for people who inject drugs, any investment can go into other areas of work. Moreover, at a later stage, the information collected through the knowledge questionnaire can serve as a basis for monitoring and evaluation (see also Step 3 below).

2

Multi-stakeholder consultation to identify barriers and solutions

The EMCDDA tools available to support the stakeholder round table are as follows:

- a guide to holding a stakeholder round table, including:
    - a draft agenda of the meeting
    - case study examples of conducting a stakeholder meeting in two EU Member States
    - an example of a meeting evaluation questionnaire.

The core element of the diagnostic process is a structured round-table discussion. This format is well suited to the purpose of bringing together different groups of stakeholders, with different perspectives, backgrounds and knowledge. The participatory approach aims to foster a better understanding of the current situation and needs in regard to the HCV testing of people who inject drugs at the national or sub-national level, and to help stakeholders to identify opportunities and make concrete and realistic plans for actions that will promote HCV testing and access to care for people who inject drugs.

There are three main stages to organising a stakeholder event that need to be considered.

The first stage is related to planning and preparation for the stakeholder meeting, which involves key elements such as establishing a core team composed, at a minimum, of a drug specialist and an infectious disease expert, and formulating the objectives of the meeting. The latter should be supported by the review of the needs assessment for HCV testing and care in drug services (carried out in Step 1 of the diagnostic process), and consideration of what can realistically be achieved within the time frame and at a single stakeholder meeting. Identifying a small number of priority objectives that should be addressed at the meeting and selecting which level of government (local, regional, national or a combination) will impact on the implementation of change will help to determine which partners should be invited to the meeting, that is, which partners are most suited to addressing the topics in question successfully and covering areas outside the areas of expertise of the core team.

The first stage can be quite time consuming, as it also involves a needs assessment exercise, consultations with experts, agreeing on the date and place of the meeting, and selecting the facilitator and presenters. There is no single mix of people best suited to these events, and the final choice will depend on the local and regional contexts,

FIGURE 4
Who to consider inviting to the stakeholder meeting to identify barriers and solutions to HCV testing and care among PWID in drug services

System level	✓ Local politicians ✓ Policymakers ✓ Community/advocacy group representatives ✓ Treatment fund/insurance fund representatives	
Provider level	✓ Staff involved in diagnostic testing ✓ Staff from hospital/clinic settings (link to care) ✓ Drug treatment and harm reduction staff ✓ Community/advocacy group representatives ✓ Prison physicians	
Client level	✓ Community/advocacy group representatives (for people who inject drugs or with HCV infection) ✓ Clients in contact with harm reducton services ✓ Community/advocacy group representatives ✓ Clients in drug treatment	

the objectives of the event and the available resources. Yet, it is crucial to ensure that there is representation from all three levels (system, provider and client; see Figure 4), with participants with appropriate competences in decision-making, sound technical knowledge and a client perspective.

The second stage is related to holding the stakeholder round-table meeting. The length and the structure will be determined by the objectives of the meeting and the availability of the experts. However, a minimum of half a day should be set aside to address the topic. Preparatory work, including the collection of information ahead of the meeting, may facilitate the organisation of the day. It can be useful to start meetings with a brief illustration of the situation based of the needs assessment exercise (Step 1 of the diagnostic process), to ensure that participants have a common understanding of the situation and the baseline. The format selected is a round table, a technique that allows the building of consensus and seeking of solutions among formal decision-makers and representatives from other sectors of society. By definition, it is a closed meeting that should aim to confront issues rather than people and create a win-win situation for all participants. There is a lot of flexibility for meeting organisation, as shown by the three different scenarios provided in Appendix 2 and in the *EMCDDA Guide on holding a stakeholder round table on supporting HCV testing and care in drug services*. These scenarios are based on the experience of several EU Member States that have already organised their first consultations in line with the EMCDDA guidance. All the scenarios include an important session where solutions, including existing good practices, are discussed. This session could potentially be scaled up or replicated.

The third and final stage of the stakeholder round-table meeting is dedicated to ensuring that the meeting produces useful outputs. This can to some extent be done during a review session at the meeting, but it may be helpful to agree with the meeting participants on a follow-up process in which they formally agree on and sign up to contributing to a report on the meeting. The meeting report, including — if applicable — any actions and indicators agreed on, will later provide valuable input to Step 3 of the diagnostic process, which is dedicated to monitoring and evaluating changes.

3

Ensuring monitoring and evaluation

The EMCDDA tools available to support monitoring and evaluation are as follows:

- EMCDDA elimination barometer
- knowledge questionnaire on viral hepatitis for drug service staff

The final step in the diagnostic process aims to ensure that the results of the stakeholder round table are followed up and that the implementation of any actions that the stakeholders at the meeting agreed on is monitored and that results are evaluated. The content of this step can vary, as it depends entirely on the objectives of the meeting. For example, if the objective was to simply get consensus on the main barriers to HCV testing for people who inject drugs in drug treatment services, then a report listing the barriers identified will suffice. However, if the objective of the meeting was to identify potential actions to overcome these barriers, then the development of an action plan might be the most appropriate outcome; an action plan might include plans on how to address potential information gaps.

If an action plan is developed, it will be important to be realistic about what can be achieved, as it may not be possible to address all barriers at once. It can be useful to structure action plans so that consideration is given in turn to actions that can be taken immediately — the ‘quick wins’ — which will often be small changes made by individual participants; medium-term actions, which can be achieved reasonably quickly; and longer-term actions, for example if legislative changes are needed.

To ensure that the diagnostic process, including the outcomes of the round-table discussion, have an impact and help to improve current practice, it is important to produce a report on the stakeholder meeting and ensure that it is disseminated widely.

Ideally, the meeting report will include a list of actions and the actors responsible for taking these actions, and indicators against which to measure progress. The indicators should link to the indicators in the EMCDDA elimination barometer, based on the global evaluation framework and comparable across all EU Member States (see Step 1). Table 1 shows an example of how action points can be listed and included in an outcome report.

TABLE 1

Suggested table with action points from the round-table discussion

Action point (what do we want to achieve?)	Strategy (how to achieve this?)	Responsible person	Deadline	Indicator (how can success be measured?)	Progress update (what has been achieved?)

It is good practice to arrange a consultation process (online or face to face) to discuss and review the meeting report, and the actions, indicators and intended outcomes agreed on. This consultation should involve all stakeholder levels and serve as an opportunity to modify and improve the report, to ensure maximum impact through endorsement by all stakeholders.

Different tools can be used to monitor and evaluate progress, including the EMCDDA elimination barometer (see Step 1) and the knowledge questionnaire for staff working in drug services. These tools allow the assessment of changes in the epidemiological situation, in response measures and in HCV knowledge by comparing the results at the beginning of the diagnostic process with the situation at the end of the process.

Appendix 1

Checklist of barriers for HCV testing

	National regulatory framework		Society level/ discrimination	Organisation of testing and treatment on national level		Epidemiological situation
System level	No national policy for HCV treatment for infectious diseases	No national policy in place for unrestricted access to HCV treatment	Stigma and discrimination against PWID	Testing for HCV is not provided by OST services	Testing for HCV is not provided by other drug services	Lack of evaluation and monitoring of indicators of national HCV plan
			Stigma and discrimination against people with HCV			Lack of HCV prevalence data for PWID
	No national screening strategy in place for HCV testing of PWID	No public funding available for HCV screening	Restriction to access to any services due to HCV status	Medical doctor required for HCV testing	No screening plan/ government guidelines for HCV testing of PWID	Lack of HCV incidence data for PWID
	National drug laws identified as a barrier	No public funding available for HCV treatment	Breach of confidentiality – (link to other systems, e.g. police registries)	HCV treatment provision only by approved centres	No programmes implemented for HCV testing of PWID	Lack of data on HCV testing of PWID

	Internal barriers	External barriers	
Provider level	Low level of knowledge of HCV among staff in harm reduction agencies	Insufficient staff available to offer HCV testing services	High fluctuation of staff in drug services
	Low level of knowledge of HCV among staff in drug treatment, including OST services	Insufficient availability of information materials	Service not set up to support minority populations (e.g. lack of translated materials, no interpretation)
	HCV testing is not perceived as the area of responsibility of the staff in drug services	Lack of time to offer HCV testing	Lack of referral pathways to HCV care and treatment
	Scared of stigmatising client when asking about HCV	Lack of available funding to offer HCV testing services	Lack of available equipment to perform testing services
	Assumption by staff: HCV testing is too complicated	Point-of-care (POC) HCV testing not available in drug treatment services	No existing collaboration with laboratories for confirmatory HCV testing
	HCV treatment not offered if current drug use		

	Knowledge	Stigma	Access	Consequences of a positive test result
Client level	Insufficient knowledge of HCV	Fear of stigma if tested HCV positive	It takes too long time to get tested	No hepatitis C treatment available if tested positive
	Insufficient knowledge of hepatitis C treatment options	Negative experiences with health care or drug service staff/stigmatised when tested for HCV	The service is too far away (location)	Fear of losing children (to child services)
	Myths about HCV e.g. “I have no symptoms so I have no problem”	Stigma/shame of using drugs	The hours where you can get tested do not fit the schedule of the client	Fear of negative impact on the asylum procedure (for migrants)
	Fear that drawing blood will damage veins	**Competing problems**	Language barrier	Fear of HCV testing/knowing results
	Perception of HCV	Other health problems (e.g. mental health problems)	Lack of/poor available transportation to the service	Fear of HCV treatment side effects
	Perceive risk of HCV as low and not as serious as HIV	Lack of housing	HCV services restricted to those in addiction care (OST)	
	Cultural attitudes towards infection/no need to avoid infection	Lack of sufficient food	Two step testing (HCV serology and HCV RNA)	
		Lack of financial resources		

Checklist (statements and questions): Overcoming barriers to HCV testing among PWID at **SYSTEM LEVEL**

National regulatory framework	1. Does my government have a national screening strategy in place for HCV testing of PWID?	2. Does my government have a national policy in place for unrestricted access to HCV treatment?	3. Does this policy include treatment of HCV for active PWID?
	4. Is public funding available for HCV screening of PWID?	5. Is public funding available for HCV treatment of PWID?	6. Is the national drug policy having an impact on PWID's access to HCV testing and care?

Society level/ discrimination	1. In my country, stigma and discrimination against PWID are not a problem	2. In my country, stigma and discrimination against people living with HCV are not a problem	3. In my country, people diagnosed with HCV are restricted from accessing some types of services or functions e.g. workplaces or public institutions

Organisation of testing and treatment on national level	1. In my country and setting, is HCV testing permitted without a medical doctor?	2. In my country, is testing for HCV provided by opioid substitution treatment (OST) services?	3. In my country, is testing for HCV provided by most drug services?	4. In my country, is HCV treatment provision decentralised?	5. Is there consensus nationally regarding HCV screening and treatment guidelines?
	6. Are there data on the prevalence of HCV for PWID?	7. Is there political support from my government to increase HCV testing and treatment?	8. Is there financial support from my government to increase HCV testing and treatment?	9. Are there programmes implemented for HCV testing of PWID?	10. National HCV plan is followed up regularly in my country

Epidemiological situation	1. Is HCV national action plan being monitored and evaluated?	2. Is data on HCV prevalence among PWID available?	3. Is data on HCV incidence among PWID available?	4. Is data on HCV testing among PWID available?

Checklist (statements and questions): Overcoming barriers to HCV testing among PWID at **PROVIDER LEVEL**

Internal barriers

1. Is the level of knowledge of HCV among the staff working in drug treatment services known?
2. Is the level of knowledge of HCV among the staff working in OST services known?
3. Is knowledge of HCV among staff sufficient to address HCV with clients?
4. Is HCV testing perceived as the responsibility of the staff in drug treatment services?
5. HCV-related stigma is not an issue among staff in drug treatment services
6. HCV testing is considered easy and straight forward among the staff in drug treatment services
7. The staff in drug treatment services have other priorities which get in the way of offering HCV testing.

External barriers

1. Is there sufficient staff to offer HCV testing in drug treatment services?
2. Is the staff in drug treatment services sufficiently trained to offer and provide HCV testing?
3. Is there sufficient funding to perform HCV testing services?
4. Is equipment available to perform HCV testing in drug treatment services?
5. Does a collaboration with laboratories exist for confirmatory HCV testing?
6. Is POC testing available in drug treatment services?
7. Are drug treatment services sufficiently provided with information materials?
8. Is there stability in the staff so that those trained in HCV testing services are there for a longer period of time?
9. Is there sufficient time for staff in drug treatment services to offer testing?
10. Are there sufficient supporting materials available for conducting counselling also in different languages?
11. Do pathways exist for referral to HCV care?
12. Is the staff in drug treatment services aware of the HCV care pathways and how to link people to care?

Checklist (statements and questions): Overcoming barriers to HCV testing among PWID at **CLIENT LEVEL**

Knowledge

1. Are clients in drug treatment services well informed about the hepatitis C virus?
2. Cultural beliefs among clients prevent or delay HCV testing
3. Myths such as "my HCV is incapsulated" exist among clients
4. Are clients in drug treatment services well informed about hepatitis C treatment?
5. Is the idea that drawing blood 'harms their veins' common among PWID?
6. Do clients know that the risk of HCV infection is higher than HIV among clients in drug treatment services?
7. Is HCV infection perceived as serious as HIV among clients in drug treatment services?

Stigma

1. Fear of stigma if tested positive is an issue among clients in drug treatment services
2. Negative experiences with health care or drug treatment service personnel prevent clients in drug treatment services seeking health care?
3. Stigma and shame related to using drugs is an issue in my country.

Access

1. It takes too long to get tested
2. Testing services are not easy to reach
3. Opening hours of testing services do not fit clients' needs.
4. Language barriers exist.
5. Transportation options to reach the service are insufficient.
6. Hepatitis C treatment is restricted to those in addiction therapy (current PWID cannot access)
7. Two-step testing prevents clients from getting tested

Competing problems

1. Other health problems prevent PWID from getting the HCV test
2. Lack of housing prevents PWID from getting the HCV test
3. Lack of sufficient food prevents PWID from getting the HCV test
4. Lack of personal financial resources prevents PWID from getting the HCV test

Consequences of positive test result

1. Is treatment available for those with hepatitis C?
2. Are clients assured that they will not lose their child if they are tested positive?
3. Are clients assured that they will not be deported if they are tested positive?
4. Do clients fear getting tested and knowing their result?
5. Do clients fear treatment side effects?

Appendix 2
Three round-table scenarios

Scenario 1

Description of the situation

There is a high prevalence of HCV among people who inject drugs in country X (60 %). There is no law that prohibits HCV testing from being implemented in drug services, and a national plan, which includes testing of people who inject drugs, has been in place since 2017. Data on people who inject drugs are difficult to collect from country X, but surveys suggest that HCV testing rates among people who inject drugs and the proportion diagnosed and linked to care are low. HCV testing is implemented in very few drug treatment services, and these services are located in or close to the country's capital city. The reasons why few drug services have implemented HCV testing are unknown.

Objectives

The objectives are to identify the main barriers at the provider and client levels (the five most important barriers at each level) that hinder implementation of HCV testing, and to identify possible solutions to overcome each of the barriers identified.

Participants

- Four representatives from the provider level: two from a drug service that implements HCV testing and two from a drug service that has not implemented HCV testing.
- Four representatives from the client level: two who attend the drug service that offers HCV testing and two who do not attend and have not been tested for HCV.

Structure of the discussion and use of checklist

After a round of introductions and the presentation of basic ground rules and the objectives of the meeting and the agenda, the discussion could start with the consideration of provider-level barriers, by addressing, together with the participants, the questions related to the provider level in the checklist, for example:

- Is knowledge of HCV among staff sufficient to address HCV among clients?
- Is HCV testing perceived as the responsibility of the staff in drug treatment services?

The meeting facilitator could discuss the questions (choose a number that time will permit) with the participants. Once the facilitator has gone through the checklist and the questions, a list of barriers, in order of priority, could be made and the five most important at the provider level identified. Before starting the prioritisation, the barriers identified could be grouped according to level. For the prioritisation of barriers, participants could be asked to mark the most important barrier (e.g., with a red sticker) to see which of the barriers receive the most votes. Once this step is complete, possible solutions to overcome the most important barriers identified could be discussed. For this, it would be a good idea to draw on the experience of the participants from drug services that have already been successful in implementing HCV testing.

The next step (which could be after a break) would be to identify the barriers at the client level by going through the same steps as above and answering the questions in the checklist for the client level. Once the barriers have been identified and listed in order of priority, possible solutions for overcoming these barriers can be identified.

Scenario 2

Description of the situation

In country Y, it is believed that the HCV epidemic is mainly concentrated among people who inject drugs, but up-to-date figures are unavailable. Despite the existence of a national hepatitis action plan, there are still barriers at the system level that prevent the efficient scale-up of HCV testing among people who inject drugs. However, exactly which barriers play the most significant roles, and which can be overcome, is unknown. Data on HCV prevalence among people who inject drugs are available, and so are data on testing uptake, which is low. Some drug services offer HCV testing, but this has not improved testing uptake among people who inject drugs. The reasons for this are unknown.

Objectives

Objectives include identifying the main barriers at the system, provider and client levels (the five most important at each level) that hinder implementation of HCV testing, but the main objective is to identify solutions to overcome these barriers.

Participants

- One representative from the policy level/political scene.
- One representative from a national or regional/local public health institute.
- Four representatives from the provider level: two from a drug service that implements HCV testing and two from a drug service that does not offer HCV testing.
- Four representatives from the client level: two who attend the drug service that offers HCV testing and two who do not attend and have not been tested for HCV.

Structure of discussion and use of checklist

Since barriers at all levels should be identified, but the main focus is on identifying solutions, to save time and ensure constructive discussion, in this case the checklist, with some brief instructions, could be shared with the participants before the round-table discussion. Participants could be asked to complete the checklist and send it back some time before the round-table discussion takes place, to leave enough time to summarise the answers and barriers identified at each of the three levels.

After a round of introductions of the participants and the presentation of basic ground rules and the objectives of the meeting and the agenda, the discussion could start with the facilitator providing a brief summary of the results from the participants' responses to the checklist and presenting the most commonly identified/agreed on barriers. These prioritised barriers could then be discussed with the participants, with a focus on identifying solutions for overcoming these. While the answers to the checklist received and summarised at the start of the meeting will allow discussions to be focused more directly on the topic, it is possible that more or other barriers will be identified when discussing the results and looking for potential solutions. There should be room for alterations of the initial results, as participants getting together at a round-table discussion may stimulate more thoughts and ideas than participants completing the checklist by themselves.

Scenario 3

Description of the situation

It is known that the HCV epidemic is mainly concentrated around people who inject drugs, and this group represents the majority of new HCV cases in country Z. The country has just begun to implement its first 4-year national hepatitis action plan and, according to recent data, the uptake of HCV testing among people who inject drugs is high, but the proportion of people who inject drugs who access hepatitis C treatment is low. Prior to the round-table discussion, another stakeholder consultation had been held to discuss access to hepatitis C treatment among healthcare practitioners working in drug treatment centres. This means that most of the current round-table participants had already discussed existing barriers together and are familiar with each other.

The planning of the round table is led by a core coordination team that consists of the EMCDDA national focal point and two other experts with technical backgrounds in and knowledge of hepatitis C/HIV and people who inject drugs in the country, linked to the national infectious diseases department. Members of the team take turns chairing and presenting at the round table, depending on content.

While some main barriers to testing and access to HCV treatment and explanations for these barriers are known and may have been addressed previously, others are less evident. There is a need to gather people from different levels to reach a consensus and an understanding regarding the existing barriers and develop possible solutions for these barriers at different levels (service provider/practitioner and client levels).

Objectives

1. To have a clearer and common view of the barriers and solutions to HCV testing:

- to achieve common ground (consensus) regarding the main barriers to testing at each level;
- to suggest a list of solutions per barrier and organise them into a hierarchical order according to their feasibility.

2. To have a clearer and common view of what a barrier is and what facilitates linkage to care:

- to achieve common ground (consensus) regarding the main barriers to linkage to care;
- to suggest a list of solutions per barrier and organise them into a hierarchical order according to their feasibility.

Participants

- Prison psychiatrist
- Infectious disease physicians
- Infectious disease nurses
- Directors and healthcare practitioners from drug treatment centres
- Directors and healthcare practitioners from low-threshold centres
- Representatives from the Directorate of Health, including the coordinator of the current and future national strategy and action plan against illicit drugs and associated addictions
- Coordinator of the national hepatitis action plan
- Deputy head of the National Infectious Diseases Research Unit and president of the Surveillance Committee for AIDS, Hepatitis and Sexually Transmitted Diseases.

Structure of discussion and use of checklist

Since barriers at all levels should be identified, the checklist could be circulated prior to the round-table discussion. Participants could be asked to complete the checklist and submit their replies to the coordination team before the meeting, to save time and ensure constructive discussion. The barriers identified in the replies to the checklist submitted could be presented briefly, as well as barriers identified during the earlier consultation meeting. They could then be discussed in more detail: first in small groups and then in plenary.

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About this publication

This manual provides a step-by-step guide for those involved in planning and managing infectious diseases and drug services, focusing on how to identify barriers to and opportunities for improving provision of HCV testing and access to treatment for people who use drugs. In particular, it focuses on HCV testing in harm reduction and drug treatment settings.

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