UPDATED RECOMMENDATIONS ON TREATMENT OF ADOLESCENTS AND CHILDREN WITH CHRONIC HCV INFECTION, AND HCV SIMPLIFIED SERVICE DELIVERY AND DIAGNOSTICS

WEB ANNEX D: VALUES AND PREFERENCES SURVEY REPORTS
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WEB ANNEX D: VALUES AND PREFERENCES SURVEY REPORTS
Updated recommendations on treatment of adolescents and children with chronic HCV infection, and HCV simplified service delivery and HCV diagnostics. Web Annex D. Values and preferences survey reports


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This publication forms part of the WHO guideline entitled Updated recommendations on treatment of adolescents and children with chronic HCV infection, and HCV simplified service delivery and HCV diagnostics. It is being made publicly available for transparency purposes and information, in accordance with the WHO handbook for guideline development, 2nd edition (2014).
Web Annex D.1: Treatment of chronic hepatitis C infection in children and adolescents: health-care workers’ values and preferences survey

This report was prepared to inform the World Health Organization guideline recommendations on treatment of children and adolescents living with chronic hepatitis C virus infection.

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2. University of Florence and Meyer Children’s University-Hospital, Florence, Italy
Background

The WHO Global Hepatitis Programme plans to release an update to the 2018 hepatitis C virus (HCV) treatment guidelines. These guidelines are scheduled for release in 2022.

Objective

As part of the evidence retrieval process, WHO commissioned an online survey of health-care workers caring for children and adolescents living with HCV infection in order to ascertain the values and preferences relating to the recommendations that may arise from these guidelines. The findings of this survey contribute to the evidence base for the recommendations contained in the guidelines.

Methods

Target population and data collection

An online survey was designed aimed at health-care workers caring for children and adolescents living with HCV infection. Survey data were collected and managed using Research Electronic Data Capture (REDCap) electronic data capture tools hosted at University College London. REDCap\(^1,2\) is a secure, web-based software platform designed to support data capture for research studies, providing (1) an intuitive interface for validated data capture; (2) audit trails for tracking data manipulation and export procedures; (3) automated export procedures for seamless data downloads to common statistical packages; and (4) procedures for data integration and interoperability with external sources.

The face and content validity of the survey instrument was assessed in consultation with the WHO Paediatric Working Group on Viral Hepatitis, and adjustments were made accordingly. The survey was made available in English.

Recruitment methods

The survey was circulated to networks providing care to children and adolescents living with HCV infection (Penta Foundation and key members of paediatric gastroenterology and hepatology societies) and the Paediatric Working Group on Viral Hepatitis members. Additionally, WHO’s regional viral hepatitis focal people circulated the survey at the regional level and other partner organizations such as the Medicines Patent Pool and CHAI circulated the survey within their networks. These groups were requested to cascade the survey to other in their networks who were involved in the care and treatment of children and adolescents with HCV.

Data analysis

Data summaries and charts were created in Stata (16.1, StataCorp LLC, College Station, TX, USA) and Microsoft Excel.

Results


It was not possible to calculate a response rate for the surveys since the denominator (the number of people to whom the survey was sent) was not available for the survey. A total of 142 individuals responded to the survey (Error! Reference source not found.). The characteristics of all 142 survey respondents are provided in Appendix 1. Characteristics of survey respondents. The analyses presented in the rest of this report are restricted to the 94 respondents who reported that they were providing care for children or adolescents over the last three years (any number); unless specified otherwise; this group will be referred to as “experienced health-care workers”.

Fig. 1. Flowchart of survey respondents
Characteristics of experienced health-care workers

Every WHO region was represented by at least five responses, with the distribution by WHO region shown in Fig. 2 and the distribution by World Bank country income classification shown in Fig. 3. The roles of respondents are shown in Error! Reference source not found.; 57% were paediatricians, paediatric infectious disease specialists or paediatric hepatologists. The majority (87%) of all experienced health-care workers were based in tertiary centres (Table 1) and had substantial experience working in paediatrics and/or viral hepatitis care (Fig. 4).

Fig. 2. Distribution of experienced health-care workers by WHO region

Fig. 3. Distribution of experienced health-care workers by World Bank income classification
Table 1. Experienced health-care workers role and facility type

<table>
<thead>
<tr>
<th>Role</th>
<th>Tertiary</th>
<th>Secondary</th>
<th>Primary</th>
<th>Private Clinic</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatologists and gastroenterologists</td>
<td>21</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>22</td>
</tr>
<tr>
<td>Infectious disease specialists</td>
<td>9</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Paediatricians a</td>
<td>49</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>54</td>
</tr>
<tr>
<td>General physician</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>82</strong></td>
<td><strong>6</strong></td>
<td><strong>4</strong></td>
<td><strong>2</strong></td>
<td><strong>94</strong></td>
</tr>
</tbody>
</table>

a Includes paediatric infectious disease specialists and paediatric hepatologists.

Fig. 4. Number of years experienced health-care workers worked in viral hepatitis or paediatrics
Caseload of experienced health-care workers

Overall, the experienced health-care workers reported a cumulative total of 1799 children and 2253 adolescents in care over the past three years. The distribution of total children and adolescents with HCV in care over past three years by WHO region is presented in Fig. 5.

*Fig. 5. Cumulative totals of children and adolescents with HCV in care over the past three years reported, by WHO region*

The largest number of children and adolescents were reported from the WHO Eastern Mediterranean Region, and this was driven by very large caseloads from respondents from Egypt, with two of the three respondents having >700 children in care over the past three years. On average, experienced health-care workers had cared for 43 children, while the majority had cared for fewer than 25 children in the previous three years (Fig. 6).
Fig. 6. Distribution of caseload per respondent, by WHO region, excluding respondents reporting ≥500 children and adolescents in care.
**Treatment experience**

Of the 94 experienced health-care workers, 82 (87%) had treated a child or adolescent with HCV over the past three years. The treatment experience of these treating health-care workers by number and age groups of children with HCV treated is depicted in Table 2. To illustrate, 52% of the health-care workers who reported ever treating a child or adolescent in the past three years had treated between 1 and 10 adolescents aged 12–17 years, and 15% had treated between 11 and 20 adolescents. Only 2% of these health-care workers had treated children younger than three years old (one from Italy and one from Brazil, both reported treating with sofosbuvir + ledipasvir). Unexpectedly, 38% of respondents reported having treated children aged under six years.

*Table 2. Treatment experience by number treated and age group*

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Number of children and adolescents treated</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–2</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>3–5</td>
<td>29 (35%)</td>
</tr>
<tr>
<td>6–11</td>
<td>33 (40%)</td>
</tr>
<tr>
<td>12–17</td>
<td>43 (52%)</td>
</tr>
</tbody>
</table>

*Outside clinical trials. The column percentages do not add up to 100% since participants could select multiple options to this question.*

The drug regimens used by treating health-care workers for paediatric HCV treatment are shown in Table 3. Sofosbuvir + ledipasvir was the most commonly used drug regimen across all age groups, with 43% of treating health-care workers reported using it to treat adolescents and 28% to treat children 6–11 years old.

*Table 3. Treatment experience by drug regimen and age group*

<table>
<thead>
<tr>
<th>Drug regimen</th>
<th>0–2 years</th>
<th>3–5 years</th>
<th>6–11 years</th>
<th>12–17 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interferon or pegylated interferon + ribavirin</td>
<td>0</td>
<td>14 (17%)</td>
<td>14 (17%)</td>
<td>9 (11%)</td>
</tr>
<tr>
<td>Sofosbuvir + interferon</td>
<td>0</td>
<td>2 (2%)</td>
<td>4 (5%)</td>
<td>6 (7%)</td>
</tr>
<tr>
<td>Sofosbuvir + ribavirin</td>
<td>0</td>
<td>6 (7%)</td>
<td>13 (16%)</td>
<td>13 (16%)</td>
</tr>
<tr>
<td>Sofosbuvir + daclatasvir</td>
<td>0</td>
<td>1 (1%)</td>
<td>3 (4%)</td>
<td>19 (23%)</td>
</tr>
<tr>
<td>Sofosbuvir + ledipasvir</td>
<td>2 (2%)</td>
<td>15 (18%)</td>
<td>23 (28%)</td>
<td>43 (52%)</td>
</tr>
<tr>
<td>Sofosbuvir + velpatavir</td>
<td>0</td>
<td>7 (9%)</td>
<td>16 (20%)</td>
<td>26 (32%)</td>
</tr>
<tr>
<td>Sofosbuvir + velpatavir + voxilaprevir</td>
<td>0</td>
<td>2 (2%)</td>
<td>2 (2%)</td>
<td>7 (9%)</td>
</tr>
</tbody>
</table>
Current HCV treatment for children and adolescents at experienced health-care workers’ facilities

21 (22%) experienced health-care workers reported that no drugs were currently available at their facilities for treating children and adolescents. These health-care workers were mostly from the Western Pacific Region (57%) and South-East Asia Region (19%) (Region of the Americas 10%, European Region 10%, African Region 5%). Table 4 indicates the drug regimens available at the facilities of the 73 experienced health-care workers who reported that treatments were available at their facilities. Current drug treatment availability was in accordance with the most frequently used drug regimens (Table 3); sofosbuvir + ledipasvir, sofosbuvir + velpatasvir and glecaprevir + pibrentasvir were the most commonly available direct-acting antiviral (DAA) regimens.

Table 4. Treatment availability at facility level

<table>
<thead>
<tr>
<th>Drug regimen</th>
<th>0–2 years</th>
<th>3–6 years</th>
<th>6–11 years</th>
<th>12–17 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interferon or pegylated interferon + ribavirin</td>
<td>7 (10%)</td>
<td>23 (32%)</td>
<td>24 (33%)</td>
<td>20 (27%)</td>
</tr>
<tr>
<td>Sofosbuvir + interferon</td>
<td>0</td>
<td>3 (4%)</td>
<td>7 (10%)</td>
<td>10 (14%)</td>
</tr>
<tr>
<td>Sofosbuvir + ribavirin</td>
<td>0</td>
<td>11 (15%)</td>
<td>13 (18%)</td>
<td>20 (27%)</td>
</tr>
<tr>
<td>Sofosbuvir + daclatasvir</td>
<td>0</td>
<td>1 (1%)</td>
<td>2 (3%)</td>
<td>15 (21%)</td>
</tr>
<tr>
<td>Sofosbuvir + ledipasvir</td>
<td>0</td>
<td>17 (23%)</td>
<td>26 (36%)</td>
<td>48 (66%)</td>
</tr>
<tr>
<td>Sofosbuvir + velpatasvir</td>
<td>0</td>
<td>10 (14%)</td>
<td>18 (25%)</td>
<td>28 (38%)</td>
</tr>
<tr>
<td>Sofosbuvir + velpatasvir + voxilaprevir</td>
<td>0</td>
<td>1 (1%)</td>
<td>1 (1%)</td>
<td>5 (7%)</td>
</tr>
<tr>
<td>Glecaprevir + pibrentasvir</td>
<td>0</td>
<td>8 (11%)</td>
<td>11 (15%)</td>
<td>27 (37%)</td>
</tr>
</tbody>
</table>

aOutside clinical trials.
The percentages do not add up to 100% since participants could select multiple options to this question.
Funding for paediatric hepatitis treatment

The main source of funding for paediatric hepatitis treatment at experienced health-care workers’ facilities was through the government or public sector 60%, patients (self-funded) 25%. A smaller proportion stated private insurance (10%), NGO (2%) and other funding as the main funding source. The main source of funding for paediatric hepatitis treatment by World Bank income classification is presented in Fig. 7.

Fig. 7. Main source of funding for paediatric hepatitis treatment, by World Bank income classification
Preferences of experienced health-care workers for future HCV treatment and DAA regimens

Sustained virological response (SVR12), long-term adverse effects, prevention of transmission to other people and preventing the stigmatization of infected children were the most important outcomes in experienced health-care workers consideration to treat children and adolescents (Fig. 8).

**Fig. 8. How important are the following outcomes or concerns when you are considering whether to treat children and adolescents?**

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Not at all important</th>
<th>Low importance</th>
<th>Neutral</th>
<th>Very important</th>
<th>Extremely important</th>
</tr>
</thead>
<tbody>
<tr>
<td>SVR12 (cure)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>85%</td>
</tr>
<tr>
<td>Measure of liver disease</td>
<td>17%</td>
<td>11%</td>
<td>48%</td>
<td></td>
<td>21%</td>
</tr>
<tr>
<td>Presence and severity of symptoms</td>
<td>8%</td>
<td>19%</td>
<td>26%</td>
<td>30%</td>
<td>18%</td>
</tr>
<tr>
<td>Measures of psychological well being</td>
<td>10%</td>
<td>24%</td>
<td>47%</td>
<td></td>
<td>16%</td>
</tr>
<tr>
<td>Measures of physical function</td>
<td>9%</td>
<td>14%</td>
<td>29%</td>
<td>41%</td>
<td>11%</td>
</tr>
<tr>
<td>Educational attainment</td>
<td>9%</td>
<td>20%</td>
<td>32%</td>
<td>26%</td>
<td>13%</td>
</tr>
<tr>
<td>Long-term adverse effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>27%</td>
</tr>
<tr>
<td>Prevention of transmission to other persons</td>
<td>9%</td>
<td>20%</td>
<td>35%</td>
<td></td>
<td>37%</td>
</tr>
<tr>
<td>Prevention of stigmatization of infected children</td>
<td>8%</td>
<td>13%</td>
<td>41%</td>
<td></td>
<td>36%</td>
</tr>
</tbody>
</table>

Experienced health-care workers’ preferences to treat by age group showed a clear trend towards treating older age groups, with the vast majority of respondents reporting that they would treat children above six years of age (Fig. 9). 63% reported they would be likely to treat children between the ages of three and five years. Around a quarter (27%) said they would be likely to treat a child younger than three years old.

The main reasons cited by respondents for not treating younger age groups were the chance of spontaneous clearance, lack of drug approvals and registration for treatment in this age group, slow disease progression and asymptomatic nature of disease in early childhood, difficulties with administering medication to young children and lack of clinical trial data (Fig. 10).
Fig. 9 If DAAs were available for treatment of HCV infection in children and adolescents in your practice/facility, how likely would you be to treat children in the following age groups:

Fig. 10. Reasons for not treating younger age groups
If DAAs were available for treatment of HCV infection in children and adolescents in your practice or facility, which DAA regimens would you prefer to use in the following age groups?

### Treatment preferences of experienced health-care workers (n=94): number and percentage of respondents’ preferences for HCV treatment, by drug regimen and age group

<table>
<thead>
<tr>
<th>Drug Regimen</th>
<th>0–2 years</th>
<th>3–6 years</th>
<th>6–11 years</th>
<th>12–17 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sofosbuvir + interferon</td>
<td>3 (3%)</td>
<td>8 (9%)</td>
<td>7 (7%)</td>
<td>8 (9%)</td>
</tr>
<tr>
<td>Sofosbuvir + ribavirin</td>
<td>3 (3%)</td>
<td>11 (12%)</td>
<td>14 (15%)</td>
<td>11 (12%)</td>
</tr>
<tr>
<td>Sofosbuvir + daclatasvir</td>
<td>3 (3%)</td>
<td>9 (10%)</td>
<td>12 (13%)</td>
<td>22 (23%)</td>
</tr>
<tr>
<td>Sofosbuvir + ledipasvir</td>
<td>7 (7%)</td>
<td>31 (33%)</td>
<td>38 (40%)</td>
<td>48 (51%)</td>
</tr>
<tr>
<td>Sofosbuvir + velpatasvir</td>
<td>7 (7%)</td>
<td>23 (24%)</td>
<td>35 (37%)</td>
<td>48 (51%)</td>
</tr>
<tr>
<td>Sofosbuvir + velpatasvir + voxilaprevir</td>
<td>2 (2%)</td>
<td>8 (9%)</td>
<td>12 (13%)</td>
<td>21 (22%)</td>
</tr>
<tr>
<td>Glecaprevir + pibrentasvir</td>
<td>8 (9%)</td>
<td>23 (24%)</td>
<td>26 (28%)</td>
<td>43 (46%)</td>
</tr>
</tbody>
</table>

**Please specify reasons for not treating a certain age group – respondent comments:**

- “Data not available and most are asymptomatic with no liver impairment.”
- “My main concern is the adherence to treatment in the youngest age groups. Even pellets may be difficult to swallow by these children. In addition, up to 40% of these patients may spontaneously clear the virus.”
- “Remote possibility of viral clearance. Lack of oral drug formulation (syrup) suited for infants and toddlers.”
- “Zero to <3 years may clear the virus spontaneously. My preference would be prevention of MTCT through treatment of pregnant women. In addition to the less likelihood of approval of medications for this age and/or production of affordable formulations particularly in LMICs.”
- “Very short follow up for long term side effects of treatment on puberty and growth-children with chronic hepatitis C are (nearly) totally asymptomatic so we can wait until end of puberty.”
Which children would you prioritise for treatment with DAAs?

**Respondent comments:**

“Wouldn't prioritize - I would treat as soon as is feasible.”

“All infected children should be treated. However, for those with significant fibrosis or HIV/HCV coinfection, there should be no delay in starting the treatment.”

“All children >3 years of age should be treated, especially those with elevated ALT or … liver fibrosis.”

“Very few cases. No need to prioritise.”

“Extra-hepatic manifestations, more advanced liver disease, any concerns about stigmatization, other medical problems that may be negatively influenced by HCV over time.”

“Children at high risk of progression of liver disease, including children with blood diseases and cancer, renal disease, diabetics and HIV-co-infected. In addition to adolescents who are using drugs and children with infected family members (treat all infected family members including children).”

“We would recommend for all children for whom DAAs are licensed, but recommend more urgently for those with advance liver disease or relevant comorbidities.”

“co-morbidities: HIV, HVB, treatment with hepatotoxic drugs, transplantation… - those returning to low income countries - risk of loss to F/U”
**Fig. 12. Which children would you not wish to treat with DAAs?**

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;3 years old</td>
<td>26,28%</td>
</tr>
<tr>
<td>None - treat all</td>
<td>15,16%</td>
</tr>
<tr>
<td>&lt;12 years old</td>
<td>6,6%</td>
</tr>
<tr>
<td>Those unable to adhere to treatment</td>
<td>5,5%</td>
</tr>
<tr>
<td>With life limiting comorbidities</td>
<td>5,5%</td>
</tr>
<tr>
<td>Other</td>
<td>5,5%</td>
</tr>
<tr>
<td>&lt;6 years old</td>
<td>3,3%</td>
</tr>
<tr>
<td>With contraindications to DAA use</td>
<td>2,2%</td>
</tr>
<tr>
<td>Without symptoms/without severe disease</td>
<td>2,2%</td>
</tr>
</tbody>
</table>

**Which children would you not wish to treat with DAAs? Respondent comments:**

“children unable to reliably take treatment if developmentally normal and likely to be able to take when older child”

“I would not avoid treatment in anyone. Of course, would have to be careful and possible consider HBV suppressive therapy for the rare child with HCV-HBV coinfection.”

“Life limiting co-morbidities”

“none unless there are absolute contraindication for use of DAAs”

“Non-compliant parents and those receiving multiple other medications with possible drug-drug interactions (if those medications cannot be replaced for the period of treatment)”

“Those suspected to be reinfected, e.g. candidates for blood transfusion, or those with fatal comorbid conditions.”

“The youngest ones (< 3 y), who can clear the virus spontaneously - In 2021, the pre-pubertal ones : cf supra. I may change my mind with more F/U”
Fig. 13. Threshold age at which treatment should be recommended in guidelines
Barriers and solutions to promoting access to HCV treatment for children and adolescents

**Fig. 14. What barriers do you face in your practice or facility in treating children and adolescents with HCV infection?**

- DAAs are available but paediatric formulations are not available: 54.57%
- Lack of national policies and guidelines: 39.41%
- Lack of awareness among patients: 37.39%
- DAAs are available but not registered for use in children and adolescents: 35.37%
- Lack of awareness among health professionals: 30.32%
- DAAs are available but not free: 23.24%
- Fear/misconceptions about the treatment: 21.22%
- DAAs are not available: 12.13%
- Others: 6.6%

**Fig. 15. What are your suggestions to facilitate access and uptake of HCV testing and treatment for children and adolescents?**

- Increased awareness: 20.21%
- Increased testing for children: 20.21%
- Guideline recommendations: 17.18%
- Improved access to DAAs: 16.17%
- Availability of paediatric formulations: 14.15%
- Reduced cost of DAAs: 14.15%
- Increased antenatal screening: 6.6%
Appendix 1. Characteristics of survey respondents

<table>
<thead>
<tr>
<th></th>
<th>Inexperienced health-care workers (N = 48)</th>
<th>Experienced health-care workers (N = 94)</th>
<th>Total (N = 142)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What best describes your role?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatologist or gastroenterologist</td>
<td>9 (18.8%)</td>
<td>22 (23.4%)</td>
<td>31 (21.8%)</td>
</tr>
<tr>
<td>Infectious disease specialist</td>
<td>9 (18.8%)</td>
<td>10 (10.6%)</td>
<td>19 (13.4%)</td>
</tr>
<tr>
<td>Paediatrician</td>
<td>19 (39.6%)</td>
<td>54 (57.4%)</td>
<td>73 (51.4%)</td>
</tr>
<tr>
<td>General physician</td>
<td>3 (6.3%)</td>
<td>7 (7.4%)</td>
<td>10 (7.0%)</td>
</tr>
<tr>
<td>Other</td>
<td>8 (16.7%)</td>
<td>1 (1.1%)</td>
<td>9 (6.3%)</td>
</tr>
<tr>
<td><strong>What best describes the type of facility where you practice?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tertiary</td>
<td>33 (68.8%)</td>
<td>82 (87.2%)</td>
<td>115 (81.0%)</td>
</tr>
<tr>
<td>Secondary</td>
<td>8 (16.7%)</td>
<td>6 (6.4%)</td>
<td>14 (9.9%)</td>
</tr>
<tr>
<td>Primary</td>
<td>5 (10.4%)</td>
<td>4 (4.3%)</td>
<td>9 (6.3%)</td>
</tr>
<tr>
<td>Private clinic</td>
<td>1 (2.1%)</td>
<td>2 (2.1%)</td>
<td>3 (2.1%)</td>
</tr>
<tr>
<td>NGO clinic</td>
<td>1 (2.1%)</td>
<td>0 (0.0%)</td>
<td>1 (0.7%)</td>
</tr>
<tr>
<td><strong>How long have you been working in the field of viral hepatitis or paediatrics?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 1 year</td>
<td>8 (16.7%)</td>
<td>1 (1.1%)</td>
<td>9 (6.3%)</td>
</tr>
<tr>
<td>1–2 years</td>
<td>4 (8.3%)</td>
<td>0 (0.0%)</td>
<td>4 (2.8%)</td>
</tr>
<tr>
<td>3–5 years</td>
<td>5 (10.4%)</td>
<td>9 (9.6%)</td>
<td>14 (9.9%)</td>
</tr>
<tr>
<td>5–10 years</td>
<td>6 (12.5%)</td>
<td>13 (13.8%)</td>
<td>19 (13.4%)</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>25 (52.1%)</td>
<td>70 (74.5%)</td>
<td>95 (66.9%)</td>
</tr>
<tr>
<td>Data missing</td>
<td>0 (0.0%)</td>
<td>1 (1.1%)</td>
<td>1 (0.7%)</td>
</tr>
<tr>
<td><strong>WHO region</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African Region</td>
<td>5 (10.4%)</td>
<td>6 (6.4%)</td>
<td>11 (7.7%)</td>
</tr>
<tr>
<td>Eastern Mediterranean Region</td>
<td>0 (0.0%)</td>
<td>5 (5.3%)</td>
<td>5 (3.5%)</td>
</tr>
<tr>
<td>European Region</td>
<td>1 (2.1%)</td>
<td>22 (23.4%)</td>
<td>23 (16.2%)</td>
</tr>
<tr>
<td>Region of the America</td>
<td>9 (18.8%)</td>
<td>18 (19.1%)</td>
<td>27 (19.0%)</td>
</tr>
<tr>
<td>South-East Asia Region</td>
<td>9 (18.8%)</td>
<td>5 (5.3%)</td>
<td>14 (9.9%)</td>
</tr>
<tr>
<td>Western Pacific Region</td>
<td>22 (45.8%)</td>
<td>38 (40.4%)</td>
<td>60 (42.3%)</td>
</tr>
<tr>
<td>Data missing</td>
<td>2 (4.2%)</td>
<td>0 (0.0%)</td>
<td>2 (1.4%)</td>
</tr>
<tr>
<td><strong>World Bank income classification</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High income</td>
<td>9 (18.8%)</td>
<td>42 (44.7%)</td>
<td>51 (35.9%)</td>
</tr>
<tr>
<td>Upper middle income</td>
<td>22 (45.8%)</td>
<td>30 (31.9%)</td>
<td>52 (36.6%)</td>
</tr>
<tr>
<td>Lower middle income</td>
<td>10 (20.8%)</td>
<td>17 (18.1%)</td>
<td>27 (19.0%)</td>
</tr>
<tr>
<td>Low income</td>
<td>5 (10.4%)</td>
<td>5 (5.3%)</td>
<td>10 (7.0%)</td>
</tr>
<tr>
<td>Data missing</td>
<td>2 (4.2%)</td>
<td>0 (0.0%)</td>
<td>2 (1.4%)</td>
</tr>
</tbody>
</table>
### Appendix 2. Data for outcome preferences

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Total n=</th>
<th>Not at all important</th>
<th>Low importance</th>
<th>Neutral</th>
<th>Very important</th>
<th>Extremely important</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>SVR12 (cure)</td>
<td>91</td>
<td>1%</td>
<td>2%</td>
<td>3%</td>
<td>29%</td>
<td>65%</td>
<td>100%</td>
</tr>
<tr>
<td>Measure of liver disease (such as biopsy, non-invasive liver fibrosis assessments)</td>
<td>90</td>
<td>3%</td>
<td>17%</td>
<td>11%</td>
<td>48%</td>
<td>21%</td>
<td>100%</td>
</tr>
<tr>
<td>Presence and severity of symptoms</td>
<td>90</td>
<td>8%</td>
<td>19%</td>
<td>26%</td>
<td>30%</td>
<td>18%</td>
<td>100%</td>
</tr>
<tr>
<td>Measures of mental well-being</td>
<td>88</td>
<td>3%</td>
<td>10%</td>
<td>24%</td>
<td>47%</td>
<td>16%</td>
<td>100%</td>
</tr>
<tr>
<td>Measures of physical function</td>
<td>90</td>
<td>4%</td>
<td>14%</td>
<td>29%</td>
<td>41%</td>
<td>11%</td>
<td>100%</td>
</tr>
<tr>
<td>Educational attainment</td>
<td>88</td>
<td>9%</td>
<td>20%</td>
<td>32%</td>
<td>26%</td>
<td>13%</td>
<td>100%</td>
</tr>
<tr>
<td>Long-term adverse effects</td>
<td>90</td>
<td>2%</td>
<td>10%</td>
<td>8%</td>
<td>53%</td>
<td>27%</td>
<td>100%</td>
</tr>
<tr>
<td>Prevention of transmission to other people</td>
<td>92</td>
<td>0%</td>
<td>9%</td>
<td>20%</td>
<td>35%</td>
<td>37%</td>
<td>100%</td>
</tr>
<tr>
<td>Prevention of stigmatization of infected children</td>
<td>91</td>
<td>2%</td>
<td>8%</td>
<td>13%</td>
<td>41%</td>
<td>36%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Data for experienced health-care workers only.

### Appendix 3. Data for age preferences
If DAAs were available for treating children and adolescents with HCV infection in your practice or facility, how likely would you be to treat children in the following age groups?

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Total n</th>
<th>Extremely unlikely</th>
<th>Unlikely</th>
<th>Neutral</th>
<th>Likely</th>
<th>Extremely likely</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–2 years old</td>
<td>91</td>
<td>36%</td>
<td>22%</td>
<td>14%</td>
<td>16%</td>
<td>11%</td>
<td>100%</td>
</tr>
<tr>
<td>3–5 years old</td>
<td>91</td>
<td>8%</td>
<td>16%</td>
<td>13%</td>
<td>30%</td>
<td>33%</td>
<td>100%</td>
</tr>
<tr>
<td>6–11 years old</td>
<td>92</td>
<td>2%</td>
<td>4%</td>
<td>4%</td>
<td>27%</td>
<td>62%</td>
<td>100%</td>
</tr>
<tr>
<td>12–17 years old</td>
<td>93</td>
<td>2%</td>
<td>1%</td>
<td>0%</td>
<td>15%</td>
<td>82%</td>
<td>100%</td>
</tr>
</tbody>
</table>
Web Annex D.2. Values and preferences on the decentralization of hepatitis C testing and treatment: results from a global community survey

Report written by:
Rosemary Delabre, Cary James, Chase Perfect and Daniela Rojas Castro

Representing:
Coalition PLUS and the World Hepatitis Alliance

Executive summary

The values and preferences of the individuals and communities seeking and receiving services are essential to robust medical and public health practice. With hepatitis C (HCV), a silent disease that disproportionately impacts marginalized populations [1–4], values and preferences regarding service delivery are particularly essential. While this assessment’s primary focus was on informants’ opinions on the delivery of services, themes around their experiences of seeking HCV services were also explored.

A multicountry rapid assessment was conducted in September 2021 to understand the values and preferences towards decentralization, task-shifting and integration of HCV services among potential end-users. The assessment was an anonymous, self-administered online questionnaire of 42 multiple-choice questions, with free text space for comments or “other” responses. The survey was distributed via civil society email networks and a limited quantity through social media.

In total, 210 people from 49 countries participated in the survey. The preliminary results presented in this report show a tendency towards support for decentralized and integrated HCV services and task-shifting.

Key messages
1. If given the choice, people with a history of HCV testing would prefer testing at a community-based centre or taking a self-test rather than accessing the service at a hospital or primary care (general public) clinic.

2. Increasing testing opportunities in a variety of settings and through self-testing would be preferable.

3. If given the choice, a large percentage of people, and particularly people who currently or formerly inject drugs, would prefer to receive HCV treatment outside traditional health-care settings such as hospitals and primary care (general public) clinics.
4. For certain populations particularly affected by HCV, having a culturally competent approach to services is more important than the location of the service or direct costs.

5. Current and former people who inject drugs indicated a preference for decentralized community-led services rather than hospitals or primary care (general public) clinics.

6. Having testing and receiving treatment in the same place is a popular preference.

7. The knowledge and expertise of trained medical professionals is valued, but so are peer or community workers and community-friendly medical personnel.

8. A range of HCV testing and treatment solutions and options would be beneficial to respond to the different needs of different populations and situations.
Background

Despite major advances in the quality and affordability of treatment in recent years, the service pathway remains particularly cumbersome for many individuals at-risk of or living with HCV. The continuum of care is marked by long delays between steps, administrative hurdles, long travel to clinics, long waits at clinics and high out-of-pocket direct and indirect costs [5]. Individually or collectively, these barriers deter people from seeking services and/or create bottlenecks to completing their path along the continuum. Moreover, marginalized communities also face barriers related to stigma and discrimination [2,6]. Community-based approaches, which engage all stakeholders affected by HCV, are well suited to identify and respond to the needs of key groups [7,8].

It is therefore important for policy discussions on the values and preferences for decentralization of services to acknowledge the added value of community-based and peer-led activities. WHO’s 2019 brief on good practices [9] provides an introduction to the scope and impact of community-based and community-led approaches in the HCV response. These include but are not limited to: general or targeted awareness campaigns, information on access to services, community-based testing, counselling and linkage to care. The role of community approaches may cover both direct examples of decentralized service delivery and complementary support to catalyse the success of decentralized services. The extent of local community capacity to provide or support decentralization may affect the values and preferences of local community members.

Within the framework of the WHO planned updated guidance on HCV simplified service delivery, an assessment was carried out through an online survey of user preferences. The development of the survey, and assumptions about the relevance of decentralization, task-shifting and integration, build on many years of evidence regarding user preferences and service feasibility of differentiated service delivery in HIV [10].

Therefore, this report presents the initial descriptive analysis of results from the values and preferences survey and specifically explores opinions on decentralization, integration and task-shifting.

Methods

Design and objectives

This was an anonymous, self-administered online survey that aimed to collect information regarding the values and preferences of people living with hepatitis C, or people likely to be exposed to hepatitis C, on simplifying delivery of care and treatment for chronic hepatitis C infection, and specifically on ways to make HCV viral testing to confirm HCV diagnosis more accessible. The results of this survey are to be used to inform key updates to HCV testing and treatment recommendations in WHO guidelines.

Survey population

This survey targeted people living with hepatitis C or people with a high likelihood of exposure to hepatitis C. This is a convenience sample, which has certain advantages, including accessibility, low cost and appropriateness for rapid surveys. The survey participants were 18 years or older, were living with or affected by hepatitis C and confirmed willingness to participate in this survey.

Survey development and promotion

The survey was developed as a collaborative effort between non-governmental organizations World Hepatitis Alliance and Coalition PLUS and WHO. The framework for the questionnaire was guided by an earlier HIV values
and preferences survey used in the HIV guidelines update in 2021 on service delivery and use of point-of-care HIV viral load assays [10] and informed by the guideline topic questions provided by WHO:

Q.1. Decentralization: Can HCV care and treatment be delivered effectively and safely in lower-level health facilities?

Q.2. Integration: Can HCV care and treatment be delivered effectively and safely integrated with other services?

Q.3 Task-shifting: Can HCV testing, care and treatment be delivered effectively and safely by non-specialists?

Q.4. Point-of-care HIV viral load: Can HCV point-of-care viral load be used as an alternative to laboratory-based assay to promote uptake of HCV viral load and treatment uptake?

The survey was then modified through extensive engagement of Coalition PLUS and the World Hepatitis Alliance with communities and their knowledge and experiences of the challenges in seeking and obtaining HCV care.

The survey consisted of a total of 42 multiple-choice questions, some of which included an “other” option for which respondents could provide more detailed information in free text. The survey also provided free text space for other comments. The survey was organized into two main sections: “about you and your experience with HCV testing and treatment” (sociodemographic information, hepatitis C testing and treatment experience) and “your preferences about how to simplify HCV services for testing and treatment” (preferences for testing location, same-day testing and treatment, integration, task-shifting). It was estimated that the survey would take 15 minutes to complete.

Due to time constraints, it was not possible to translate the questionnaire into other languages (English only). The final version of the survey was approved by all partners. Survey Monkey was used to create the online survey, collect survey data and visualize preliminary data. The survey was promoted by Coalition PLUS, the World Hepatitis Alliance, regional WHO offices and the Treatment Action Group through social media, mailing lists and direct contacts.

Data collection and preliminary analysis

The survey was launched on 8 September 2021. Data were collected over two weeks, with the survey closing on 22 September 2021. This report represents the initial descriptive analysis.

Certain results are presented by subgroups; however, note that respondents could identify with several subgroups, and therefore, for results of a given question that is stratified by subgroup, a respondent could be counted several times.

Ethics and data protection

All participants were provided with information regarding the objectives of the survey before participation. No identifying information was collected for the respondents.
Results

Description of survey respondents

In total, 210 people from 49 countries participated in the survey. 71% (n=137) of respondents were 26–55 years old. A majority of participants were male (56%, n=113), 40% were female (n=81), 1% transgender (n=2), and 2% gender non-binary (n=4).

Country of residence (Table 1): the greatest number of participants indicated they currently reside in Nigeria (23%, n=45), followed by the United States (20%, n=39), Australia and the United Kingdom (both: 7%, n=13). Close to one third (30%, n=60) of respondents came from 39 different countries that had one to three respondents.3

Table 1: What is your country of residence? (n=199)

<table>
<thead>
<tr>
<th>Answer choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nigeria</td>
<td>23%</td>
</tr>
<tr>
<td>United States</td>
<td>20%</td>
</tr>
<tr>
<td>Australia</td>
<td>7%</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>7%</td>
</tr>
<tr>
<td>Romania</td>
<td>4%</td>
</tr>
<tr>
<td>Nepal</td>
<td>3%</td>
</tr>
<tr>
<td>Ghana</td>
<td>3%</td>
</tr>
<tr>
<td>India</td>
<td>3%</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>2%</td>
</tr>
</tbody>
</table>

Country income level: a majority of participants resided in middle-income countries (52%, n=103) or high-income countries (40%, n=80), and 8% (n=16) resided in low-income countries. Participants more often reported living in an urban or large city area (68%, n=136) versus a semi-urban or small or medium city area (19%, n=39) or a rural area (11%, n=23). Most participants reported completing tertiary schooling (83%, n=165), while 11% completed secondary school.

Self-identification as a member of a key population group (Table 2, n=204): the largest representation was from people living with hepatitis C (23%), “people who formerly injected drugs” (21%), “people who inject drugs”

3 More precisely, there were three respondents from: Brazil, Malaysia, Spain, Sudan, Tanzania, and Zambia. There were two respondents each from: Burundi, Cameroon, Germany, Myanmar, Rwanda, South Africa, Uganda, Ukraine and Uruguay. Finally, there was one respondent each from: Bahrain, Belgium, Benin, Cambodia, Canada, Chad, Chile, Colombia, France, Iran Kenya, Macedonia, Malawi, Mauritius, Morocco, Netherlands, New Zealand, Pakistan, Peru, Poland, Sri Lanka, Thailand, Togo, and Zimbabwe.
(18%) and people living with HIV (16%). Of the respondents who identified as “other”, eight indicated that they were cured of HCV. Note that respondents were able to select multiple choices for this question.

Table 2. Which of the following groups, if any, do you identify with? (select all that apply) (n=204)

<table>
<thead>
<tr>
<th>Answer choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>None of the above</td>
<td>41%</td>
</tr>
<tr>
<td>People living with hepatitis C</td>
<td>23%</td>
</tr>
<tr>
<td>People who formerly injected drugs</td>
<td>21%</td>
</tr>
<tr>
<td>People who inject drugs</td>
<td>18%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>18%</td>
</tr>
<tr>
<td>People living with HIV</td>
<td>16%</td>
</tr>
<tr>
<td>Partners of someone who belongs to one of the groups above</td>
<td>8%</td>
</tr>
<tr>
<td>Men who have sex with men</td>
<td>7%</td>
</tr>
<tr>
<td>People previously in prison</td>
<td>6%</td>
</tr>
<tr>
<td>Sex workers</td>
<td>5%</td>
</tr>
<tr>
<td>Migrants</td>
<td>2%</td>
</tr>
</tbody>
</table>

Experience with hepatitis C testing and treatment: 72% (n=150) of respondents had been tested for hepatitis C, of whom 42% (n=60) tested positive. Among the 56 respondents who provided information regarding hepatitis C treatment, 91% (n=51) are currently being treated or have been treated for hepatitis C.
Values and preferences

Where were you previously tested for HCV?

Before asking the question on preference on where to be tested, participants who had indicated they had previously tested for HCV were asked where they accessed their last test (Table 3, n=142). A hospital was the most common response (24%), followed by primary care (general public) clinic (20%), “laboratory” (15%) and “community-based organization centre” (13%).

Table 3. Where did you get tested for hepatitis C? If you have been tested several times, please indicate where you had your last test (n=142)

<table>
<thead>
<tr>
<th>Answer choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>24%</td>
</tr>
<tr>
<td>Primary care (general public) clinic</td>
<td>20%</td>
</tr>
<tr>
<td>Laboratory</td>
<td>15%</td>
</tr>
<tr>
<td>Community-based organization centre</td>
<td>13%</td>
</tr>
<tr>
<td>Hospital outpatient</td>
<td>8%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>8%</td>
</tr>
<tr>
<td>Drug user support centre</td>
<td>5%</td>
</tr>
<tr>
<td>Sexual and reproductive health clinic</td>
<td>2%</td>
</tr>
<tr>
<td>Outreach, mobile or testing camp</td>
<td>2%</td>
</tr>
<tr>
<td>HIV clinic</td>
<td>1%</td>
</tr>
<tr>
<td>Hospital inpatient</td>
<td>1%</td>
</tr>
</tbody>
</table>

Where would you like to get tested for hepatitis C?

When the same group (those who had been previously tested) responded to the question: “Regardless of whether you have been tested previously or not, where would you like to get tested for hepatitis C?”, the results were different (Table 4). They were able to provide three choices. In response to this question (n=133), at a “community-based organization centre” was the most common response (44%), followed by “place of my choice using a self-test” (35%), hospital (28%) and then primary care (general public) clinic (28%).
Table 4. Comparison among participants who have been tested for hepatitis C: last hepatitis C testing site (n=142) and preference for hepatitis C testing site (n=133)\(^4\)

<table>
<thead>
<tr>
<th>Where did you get tested for HCV?</th>
<th>Where would you like to get tested for hepatitis C?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hotel/ outpatient/inpatient</td>
<td>Community-based organisation centre</td>
</tr>
<tr>
<td>Primary care (GP) clinic</td>
<td>Place of my choice, using a self-test</td>
</tr>
<tr>
<td>Laboratory</td>
<td>Hospital</td>
</tr>
<tr>
<td>Community-based organisation centre/outreach/mobile/testing camp</td>
<td>Primary care (GP) clinic</td>
</tr>
</tbody>
</table>

\(n=142\)  \(n=133\)

Key message: If given the choice, those with a history of HCV testing would prefer testing at a community-based centre or taking a self-test rather than accessing the service at a hospital or primary care (general public) clinic.

The response to this question by all participants provided similar results (Table 5, n=184). At a “community-based organization centre” was the most common response (40%), followed by “place of my choice using a self-test” and hospital (both at 33%) and primary care (general public) clinic (32%).

Table 5. Regardless of whether you have been tested previously or not, where would you like to get tested for hepatitis C? (select three answers maximum) (n=184)

<table>
<thead>
<tr>
<th>Answer choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community-based organization centre</td>
<td>40%</td>
</tr>
<tr>
<td>Place of my choice, using a self-test</td>
<td>33%</td>
</tr>
<tr>
<td>Hospital</td>
<td>33%</td>
</tr>
<tr>
<td>Primary care (general public) clinic</td>
<td>32%</td>
</tr>
<tr>
<td>Laboratory</td>
<td>29%</td>
</tr>
<tr>
<td>Drug user support centre</td>
<td>23%</td>
</tr>
<tr>
<td>Sexual and reproductive health clinics</td>
<td>14%</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>11%</td>
</tr>
<tr>
<td>No preference</td>
<td>7%</td>
</tr>
<tr>
<td>Other – please specify</td>
<td>5%</td>
</tr>
<tr>
<td>HIV clinic</td>
<td>5%</td>
</tr>
</tbody>
</table>

\(^4\) A maximum of three choices were possible
When given the choice, non–health care community settings were among the preferred choices for HCV testing. Self-testing, which is not yet available, was expressed as a preference in addition to primary care and laboratories. Similar preferences were expressed by participants who identified as people living with hepatitis C and, thus, have real-life experience of testing.

**Key message:** Increasing testing opportunities in a variety of settings and through self-testing would be preferable.

Among people who inject drugs, those who identified as current or previous people who inject drugs, “community-based organization centre” (54%) and drug user support centre” (50%) were preferred by a much higher percentage, followed by self-testing (39%). This highlights a very strong preference for decentralized services for this group. Traditional health-care settings did not feature in their top three preferences.

One respondent from Australia who identified as a current person who injects drugs commented: “I would like to be tested by someone with living experience of drug use (not past experience) and lived experience of hepatitis C. A place where there is no discrimination. So no to hospital, laboratory, pharmacy …”

A respondent from the United Kingdom who identified as someone who formerly injected drugs expressed the preference to be tested “by trained peers in community or home setting”.

**If you were previously treated for hepatitis C, where were you treated?**

Participants who had been treated for hepatitis C provided information on where they received hepatitis C treatment (Table 6, n=45). Most were treated at a hospital (64%) or “primary care (general public) clinic” (22%). Some participants indicated receiving their treatment at a “drug user support centre” (7%), “community-based organization centre” (4%) or HIV clinic (2%). None reported receiving treatment at a “sexual and reproductive health clinic”.

**Table 6. Where did you receive your hepatitis C treatment? (n=45)**

<table>
<thead>
<tr>
<th>Answer choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>64%</td>
</tr>
<tr>
<td>Primary care (general public) clinic</td>
<td>22%</td>
</tr>
<tr>
<td>Community-based organization centre</td>
<td>4%</td>
</tr>
<tr>
<td>Drug user support centre</td>
<td>7%</td>
</tr>
<tr>
<td>HIV clinic</td>
<td>2%</td>
</tr>
<tr>
<td>Sexual and reproductive health clinics</td>
<td>0%</td>
</tr>
</tbody>
</table>

**Where would you like to receive your treatment?**
All participants were later asked, “Regardless of your treatment status (treated, not treated), where would you like to receive your treatment?” and they were allowed to choose up to three options (Table 7, n=175). The most popular sites chosen were “community-based organization centre” (50%), followed by hospital (39%) and general practitioner (29%). “Same as testing site” was also proposed, which was chosen by 54%, suggesting interest in integration of services.

**Table 7. Regardless of your treatment status (treated or not treated), where would you like to receive your treatment? (select three answers maximum) (n=175)**

<table>
<thead>
<tr>
<th>Answer choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same site as testing site</td>
<td>54%</td>
</tr>
<tr>
<td>Community-based organization centre</td>
<td>50%</td>
</tr>
<tr>
<td>Hospital</td>
<td>39%</td>
</tr>
<tr>
<td>General practitioner’s cabinet</td>
<td>29%</td>
</tr>
<tr>
<td>Drug user support centre</td>
<td>21%</td>
</tr>
<tr>
<td>Sexual and reproductive health clinics</td>
<td>10%</td>
</tr>
<tr>
<td>HIV clinic</td>
<td>8%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>7%</td>
</tr>
<tr>
<td>No preference</td>
<td>5%</td>
</tr>
</tbody>
</table>

Among people who inject drugs, while this order of preference is consistent across most groups, when focusing on the preferences of current and former people who inject drugs together (n=54), there is a clear preference for receiving treatment at a “drug user support centre” (n=25, 46%), which is higher than the preference for this site among all the respondents (21%).

**Key message: If given the choice, a large percentage of people, and particularly current and former people who inject drugs, would prefer to receive HCV treatment outside traditional health-care settings such as hospitals and primary care (general public) clinics.**

**Most important considerations regarding HCV testing and HCV treatment locations**

In two separate questions, participants were asked “what are the most important considerations regarding” (a) HCV testing (n=186) and (b) HCV treatment locations (n=175). Participants could choose up to three options. For both questions, the location of the service being close to their home or office was the most commonly chosen option (a: 53%; b: 56%), followed by “direct costs” (a: 38%; b: 40%) and thirdly, the service having a non-judgemental and non-stigmatizing approach or atmosphere (a: 37%; b: 39%).

However, for current and former people who inject drugs (n=57) and people living with HIV (n=31), having a non-judgemental and non-stigmatizing atmosphere was the consideration most commonly indicated for both questions.
Key message: For certain populations particularly affected by HCV, having a culturally competent approach to services is more important than the location of the service or direct costs.

Preference for testing and treatment in the same place
All participants (n=172) were asked, “Would you like to be tested and receive treatment in the same place?” - 91% responded “yes”. When asked the main reason for wanting to be tested and receive treatment in the same place (n=158), the most frequent choices were “convenience” (34%) and “continued follow-up from testing to treatment” (33%). This suggests that having testing and treatment services together wherever they occur would be preferable to many.

Key message: Having testing and receiving treatment in the same place is a popular preference.

Participants were asked what they felt was “most important to make it easier for a person to be tested and treated for hepatitis C?”:

One participant from Nigeria said: “Having HCV services in one place; integrated with other health condition services; provided by non-specialists will increase accessibility.”

A participant from the United States who identified as transgender and as a sex worker wrote that she “believed” in a site that “can offer all-around adequate care services – health navigation, testing, treatment, follow-up and other services or testing options.”

A participant from the United States who identified as a person “who uses drugs” wrote: “most important is having test and treat in same place on same day for convenience. Then if there is testing and treatment in existing service centres, outside urban areas and by non-specialist health workers, [it] is all part of making that possible.”

With whom would you prefer to discuss your health needs related to hepatitis C?
Although the participants showed a preference for testing and treatment outside hospitals and general public clinics, participants did show a preference for seeing specialists when discussing health needs related to hepatitis C. In response to the question “With whom would you prefer to discuss your health needs related to hepatitis C?” (Table 8, n=166), “specialist doctor” was the most popular choice (48%), followed by “community-friendly medical personnel” (23%), “general practitioner” (11%) and “community or peer worker” (10%).

Table 8. With whom would you prefer to discuss your health needs related to hepatitis C? (n=166)

<table>
<thead>
<tr>
<th>Answer choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist doctor</td>
<td>48%</td>
</tr>
<tr>
<td>Community-friendly medical personnel</td>
<td>23%</td>
</tr>
<tr>
<td>General practitioner</td>
<td>11%</td>
</tr>
<tr>
<td>Community or peer worker</td>
<td>10%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>4%</td>
</tr>
<tr>
<td>Nurse</td>
<td>2%</td>
</tr>
<tr>
<td>Community leader</td>
<td>1%</td>
</tr>
</tbody>
</table>
For current or former people who inject drugs (n=52), 21% showed a greater preference for “community or peer workers”, while only one in this group reported a preference to discuss HCV with a “general practitioner”. This is consistent with the information available among other groups that also expressed preference to access testing and treatment outside of traditional health-care settings.

In response to the question “Who would you prefer to perform your hepatitis C test?” (Table 9, n=165), “specialist doctor” (26%) and “trained community or peer worker” (22%) were the top choices, followed by “community-friendly medical personnel” (18%). “General practitioner” and “trained nurse” were less popular options (both at 10%).

**Table 9. Who would you prefer to perform your hepatitis C test? (n=165)**

<table>
<thead>
<tr>
<th>Answer choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist doctor</td>
<td>26%</td>
</tr>
<tr>
<td>Trained community or peer worker</td>
<td>22%</td>
</tr>
<tr>
<td>Community-friendly medical personnel</td>
<td>18%</td>
</tr>
<tr>
<td>No preference</td>
<td>11%</td>
</tr>
<tr>
<td>General practitioner</td>
<td>10%</td>
</tr>
<tr>
<td>Trained nurse</td>
<td>10%</td>
</tr>
<tr>
<td>Other – please specify</td>
<td>3%</td>
</tr>
</tbody>
</table>

A participant from Malawi who preferred a “specialist doctor” said of her preference “because they are the ones well knowledgeable of the infection.”

A participant who also preferred a “specialist doctor” also indicated a preference for follow up from a different provider: “It’s normal in this situation you visit your specialist to secure your next step and after, you can approach to community-friendly medical person.”

A participant who identified as living with HCV, people who inject drugs and previously in prison preferred “Trained community or peer worker” and commented, “especially one with lived experience, there’s power in that”.

A participant from Australia who identified as a person who injects drugs said, “I am more comfortable with peers, they are way less stigmatizing.”

This suggests that the knowledge and expertise of trained medical professionals is valued by this group, but so are trained peer and community workers. The provision of culturally competent services by community-friendly medical personnel was also valued.

**Key message: The knowledge and expertise of trained medical professionals is valued, but so are peer and community workers and community-friendly medical personnel.**

Specialists have an essential place in the care for people living with hepatitis C and those affected by hepatitis C;
however, to meet the needs among these populations, it is important that a wide variety of options for service delivery be available to meet populations where they are, or where they feel most comfortable, to provide the most efficient and effective care.

**Key message:** A range of HCV testing and treatment solutions and options would be beneficial to respond to the different needs of different populations and situations.

**Limitations**

Some limitations should be noted regarding this survey. Due to the sampling method and small sample size, generalization of these results to the target population should be made with caution. Furthermore, online surveys may not reach populations that do not have regular Internet access such as those who are homeless or experience marginalization. In addition, since most participants lived in an urban area, it is possible that they are less affected by centralization of care. This survey was only available in English and therefore prevented a wider participation in non-anglophone countries. Although effort was made to use simple language in the questionnaire, it cannot be excluded that some individuals were unable to respond to the survey due to limited English comprehension or literacy. Due to time constraints, it was not possible to extensively pilot the survey before diffusion. A fully participatory approach, which implicated those concerned directly in the development of the survey, would have added to the robustness of the results.

Additional work is needed to collect information regarding values and preferences among marginalized populations that are most likely not reached by traditional health systems and likely to encounter barriers to health services delivery. Methods that are more adapted to marginalized populations, such as administration of the questionnaire by trained community-based workers during outreach activities, would complement the data presented in this report.

**Conclusions and recommendations**

Preferences for testing in community-based organizations or self-testing support increasing testing opportunities in a variety of settings (including through self-testing). For current and former people who inject drugs in particular, decentralized services seem to be particularly advantageous. The same is true regarding treatment; these results suggest that, if given the choice, many people would prefer to receive HCV treatment outside traditional healthcare settings such as hospitals and general public clinics – and that this may even be a strong preference for certain groups. Additionally, having a culturally competent approach to services is more important than the location of the service or direct costs for certain groups.

In terms of integration of services, preference for accessing testing or treatment through community-based centres was more popular than hospitals and primary care services throughout the survey. Strong preferences were observed for having testing and receiving treatment in the same place, not only for convenience but also to have continued follow-up from testing to treatment, thus potentially increasing linkage to care following diagnosis. Regarding task-shifting, these results suggest that the knowledge and expertise of trained medical professionals is valued by the study participants but so are trained peer and community workers and community-friendly medical personnel.

These results indicate the need to deliver a range of HCV testing and treatment solutions and options to respond to the different needs of different populations and situations. Note, however, that implementing integration in the
traditional settings or in community-based settings, enlarging task-shifting and decentralizing certain services requires increasing capacity, including human and financial resources, to adequately conduct testing and meet treatment needs.
References


Acknowledgements

We thank all survey participants who took the time to answer this survey and share their thoughts and experiences. We also thank the nongovernmental organizations and community-based organizations that helped to promote this survey.
Appendix. Survey tool

Below is the full text of the online survey. Note that the survey included logic, which meant that at several points, the response to a specific question would result in variation in the subsequent questions so that not all participants were asked all questions.

Welcome to the values and preferences survey. You are being invited to participate in an online survey about different ways to simplify delivery of care and treatment of chronic hepatitis C virus (HCV) infection, including ways to make HCV viral testing to confirm HCV diagnosis more accessible. This survey is being conducted to understand the preferences of people living with hepatitis C and people with high-risk exposure to hepatitis C. The results from this survey will be used to inform forthcoming WHO guideline recommendations on HCV service delivery.

The survey should take no more than 15 minutes to complete. The first part covers questions about your own experience with testing and treatment for hepatitis C; the second part addresses your preferences for the different ways of delivering HCV services and your reasons: These include decentralized HCV testing and treatment; making viral load testing more accessible; integration of testing and treatment with other services; and task-shifting of care and treatment to non-specialists.

The survey is completely anonymous, and we will not be asking for any identifying information such as your name, address or the organization you work for.

We very much appreciate your time in completing this important survey.

Section A: About you and your experiences with HCV testing and treatment

We will start by asking a few general questions to get to know you better.

1. What is your age? (years) [free text]

2. What is your gender?
   o Male
   o Female
   o Transgender
   o Gender non-binary
   o I do not wish to respond
   o Other (please specify)

3. What is your country of residence? [drop-down menu]

4. Currently, you live in:
   o Urban area/large city/near a large city
   o Semi-urban area/small or medium city#
   o Rural area/village
   o Other (please specify)
5. What is the highest level of education that you have completed?
- I never went to school
- Primary
- Secondary (middle school/high school)
- Tertiary (college, university, or vocational training)
- Other (please specify)

6. Which of the following groups, if any, do you identify with? (Select all that apply)
- People living with hepatitis C
- People who inject drugs
- People who formerly injected drugs
- Men who have sex with men
- People previously in prison
- People living with HIV
- Sex workers
- Migrants
- Partners of someone who belongs to one of the groups above
- None of the above
- Other (please specify)

7. Have you ever been tested for hepatitis C?
- Yes
- No
- I do not know

8. Why haven’t you been tested? (select 3 answers maximum)
- I do not feel that I am at risk
- I do not know about hepatitis C
- I do not want or am afraid to know my status
- I do not feel comfortable asking for a hepatitis C test from my doctor or health-care provider
- I do not want to know as treatment is not available to me
- I have other concerns more important than hepatitis C
- I think hepatitis C testing is too complicated
- Other (please specify)

9. Where did you get tested for hepatitis C? If you have been tested several times, please indicate where you had your last test.
- Hospital
- Primary care (general public) clinic
- Community-based organization centre
- Drug user support centre
- Sexual and reproductive health clinic
- Laboratory
- HIV clinic
- Hospital inpatient
- Hospital outpatient
- Outreach/mobile/testing camp
- Other (please specify)
10. Why did you have a hepatitis C test?
   o Doctor recommended
   o Nurse recommended
   o Health worker recommended
   o I felt I was at risk of hepatitis C
   o Community/peer worker recommended
   o Testing campaign
   o Other (please specify)

11. Have you ever tested positive for hepatitis C?
   o Yes
   o No
   o I do not know

12. Did you have an HCV viral load (PCR) test to confirm your diagnosis?
   o Yes
   o No
   o I do not know

13. Why did you not take a confirmation test? (select three answers maximum)
   o I have other concerns more important than hepatitis C
   o I think it is too difficult or inconvenient to have the confirmatory test
   o I was not informed about it
   o I am scared to learn of my status
   o Other (please specify)

14. How much time passed between your first (antibody test) and your confirmatory (PCR) test?
   o The same day
   o The next day
   o A few days
   o A few weeks
   o Longer than a few weeks
   o Other – please specify
   Comments

15. Are you being or have you been treated for hepatitis C?
   o Yes
   o No

16. How much time passed between your confirmatory test and when you started treatment?
   o The same day
   o The next day
   o A few days
   o A few weeks
   o Longer than a few weeks
   o Other – please specify
   Comments
17. Who has prescribed your treatment?
   o General practitioner
   o Specialist (hepatologist, gastroenterologist, other)
   o I do not know
   o Other (please specify)

18. Where did you receive your hepatitis C treatment?
   o Hospital
   o Primary care (general public) clinic
   o Community-based organization centre
   o Sexual and reproductive health clinics
   o Drug user support centre
   o HIV clinic
   Comments

19. Did you receive your hepatitis C treatment prescription in the same place where you were tested for hepatitis C?
   o Yes
   o No
   Comments

Section B: Your preferences about how to simplify HCV services for testing and treatment

Health service decentralization involves making health services more available outside hospitals in cities/towns closer to the users. This may mean HCV services (testing and/or treatment) are delivered in primary care/general public practices or community sites, drug treatment sites, HIV clinics and prisons.

20. Regardless of whether you have been tested previously or not, where would you like to get tested for hepatitis C? (select three answers maximum)
   o Hospital
   o Primary care (general public) clinic
   o Community-based organization centre
   o Sexual and reproductive health clinics
   o Drug user support centre
   o Laboratory
   o HIV clinic
   o Pharmacy
   o Place of my choice, using a self-test
   o No preference
   o Other – please specify
   Comments

21. According to you, what are the most important considerations regarding hepatitis C testing locations? (select three answers maximum)
   o Close to your home or workplace
   o Service hours
   o Waiting time
   o Direct costs (test costs, medical fees)
   o Indirect cost (loss of wages, transportation, etc)
o Presence of community/peer workers
o Presence of community-friendly medical personnel
o Non-judgemental atmosphere
o Ability to remain anonymous
o Other (please specify)

22. If your initial antibody test is positive, a further blood test for a confirmatory viral load test is necessary to assess whether you need to receive hepatitis C treatment. Until recently, these viral load tests were mainly only available in a laboratory in a hospital setting. If it were possible to conduct this viral load test outside the hospital (sometimes called point-of-care tests), where would you prefer to conduct them? (select three answers maximum)
  o Primary care (general public) clinic
  o Community-based organization centre
  o Drug user support centre
  o Laboratory
  o Sexual and reproductive health clinics
  o HIV clinic
  o In the same place where I had my initial antibody test
  o In the same place where I shall have my treatment
  o No preference
  o Other (please specify)

Comments

23. Would you prefer to do your initial and confirmatory viral load tests on the same day?
  o Yes
  o No
  o I do not know
  o No preference

24. What are your most important reasons? (select three answers maximum)
  o Possibility to confirm my status more quickly
  o Possibility to start treatment more quickly
  o Save time
  o Avoid extra costs (loss of wages, transportation)
  o Avoid additional travel
  o Reduce time my family and friends are exposed
  o Other (please specify)

25. What is the reason? (select two answers maximum)
  o I need more time to prepare myself for the results
  o I am scared to learn of my status
  o I am not confident in the centre’s capacity to perform both tests
  o I would like more information before deciding
  o Other (please specify)

26. Would you prefer to do both the hepatitis C tests at the same place?
  o Yes
  o No
  o I do not know
  o No preference
27. What is the reason? (select two answers maximum)
   o I am concerned about confidentiality
   o I am concerned about cost
   o I am concerned the staff is not adequately trained to perform both tests
   o I am concerned about stigma and discrimination
   o Other (please specify)

28. What is the reason? (select three answers maximum)
   o Community-friendly site
   o Convenience
   o Avoid additional administrative procedures
   o Continued follow-up
   o Other (please specify)

29. If the viral load is positive (indicating current hepatitis C infection), would you like to receive treatment on the same day?
   o Yes
   o No
   o I do not know
   o No preference

30. What is the main reason?
   o Community-friendly site
   o Convenience
   o Avoid additional administrative procedures
   o Continued follow-up from testing to treatment
   o Avoid exposing my family and friends to hepatitis C
   o Other (please specify)

31. What is the main reason?
   o I do not have symptoms
   o I think hepatitis C treatment is too complicated
   o I would like more information before deciding
   o I would like to discuss treatment with my general public before deciding
   o Other (please specify)

32. Regardless of your treatment status (treated, not treated), where would you like to receive your treatment? (select three answers maximum)
   o Hospital
   o HIV clinic
   o Drug user support centre
   o Community-based organization centre
   o Sexual and reproductive health clinics
   o General practitioner’s cabinet
   o Same site as testing site
   o No preference
   o Other (please specify)

33. According to you, what are the most important considerations regarding hepatitis C treatment locations? (select three answers maximum)
34. If the viral load is positive (indicating current hepatitis C infection), when would you prefer to receive treatment?
- The same day
- Next day
- Several days later
- Few weeks later
- More than a few weeks later

Please comment

35. Would you like to be tested and receive treatment in the same place?
- Yes
- No
- I do not know

Please comment

36. If yes, what is the main reason?
- Community-friendly site
- Convenience
- Avoid additional administrative procedures
- Continued follow-up from testing to treatment
- Other – please specify

Comments

37. If no or you don’t know, what is the main reason?
- I would like to discuss treatment with my general practitioner before deciding
- I am concerned about confidentiality
- I am concerned about the cost of treatment
- I am concerned the staff is not adequately trained
- I would like more information before deciding
- I am concerned about stigma and discrimination
- Other – please specify

Comments

Task shifting is the process in which certain tasks in testing and treatment of hepatitis C, are performed by a wider group of trained individuals and do not rely on specialists. The main aim of task shifting is to make services more widely available to communities.
38. With whom you would prefer to discuss your health needs related to hepatitis C?
   o Specialist doctor
   o General practitioner
   o Nurse
   o Community-friendly medical personnel
   o Community/peer worker
   o Community leader
   o No preference
   o Other (please specify)

39. Who would you prefer to perform your hepatitis C test?
   o Specialist doctor
   o General practitioner
   o Trained nurse
   o Trained community or peer worker
   o Community-friendly medical personnel
   o No preference
   o Other – please specify
   Please give reasons for your choice:

Closing questions

40. Which of the following best explain your reason to get tested and, if applicable, eventually treated?
   o Better personal health
   o Avoid exposing my family and friends to hepatitis C
   o Be in good health to provide and be there for my family
   o Proximity of services
   o Speed of services
   o Trust in community or peer workers
   o Trust in health-care workers
   o Trust in community leaders
   o National awareness campaign
   o Other (please specify)

41. Which of the following best explain your reason to not get tested and, if applicable, eventually treated?
   o I do not feel that I am at risk
   o I am scared to learn of my status
   o I fear experiencing stigma and discrimination from my family and friends
   o I fear experiencing stigma and discrimination from health personnel
   o Direct costs (treatment, health-care professional fees)
   o Indirect costs (loss of wages, transportation)
   o Distance of services
   o Wait times
   o Other (please specify)

42. Please rank the following according to which you think is the most important to make it easier for a person to be tested and treated for hepatitis C? (Please rank from 1 (most important) to 7 (least important).
   o Having all necessary testing and treatment services in the same place
o Having all necessary testing and samples taken just once (if first test is positive, a second, confirmatory test is automatically done on the same sample).
o Having all necessary testing and starting treatment on the same day
o Having more local hepatitis C testing and treatment services (increasing the hepatitis C services available outside big cities and hospitals)
o Having hepatitis C testing and treatment services available where care is already received for other health needs (primary care/general practitioner, HIV clinic, opioid substitution therapy centres, community-based organization centres etc.)
o Having hepatitis C testing and treatment services which are provided by trained non-specialist health workers
o Having more information on hepatitis C, testing and treatment

Please share your reasons for this ranking.

Thank you for completing the survey!
If there is anything else you would like to share, please contact us at contact@worldhepatitisalliance.org.
Web Annex D.3. Key populations’ values and preferences for HIV, hepatitis and sexually transmitted infection services study: brief summary for HCV guidelines meeting

Report written by members of INPUD

Introduction

What is INPUD?
The International Network of People Who Use Drugs (INPUD, www.inpud.net) is a global, peer-based network that seeks to promote the health and protect the rights and dignity of people who use or have used drugs, including people who inject drugs.

Background to the study
In April 2021, INPUD and other key population networks agreed to collaborate with the WHO Department of Global HIV, Hepatitis and Sexually Transmitted Infection Programmes in a global qualitative study to inform the updating of the WHO 2016 consolidated guidelines for HIV prevention, diagnosis, treatment and care for key populations. The four key populations that participated in the study were: gay and bisexual men and other men who have sex with men, female, male and transgender sex workers, people who inject drugs and transgender people. Although the 2016 consolidated guidelines specifically focus on HIV, the updated guidelines will (for the first time) also address viral hepatitis and STIs.

Across April–June 2021, each of the four key population global networks conducted separate peer-driven qualitative research studies into the values and preferences of their communities in relation to HIV, viral hepatitis and STI interventions and programmes. The research questions for the qualitative study were based on seven PICO questions that formed the basis of the systematic evidence-informed review component of the guideline updating process. These questions were investigated in relation to key population members’ values and preferences for how services and interventions are provided, where they are provided and by whom as well as perceived harm, disadvantages and advantages of different service modalities and approaches. Additionally, values and preferences were also assessed in relation to structural and other barriers and interventions to provide an understanding of the context of implementation for HIV, HCV and STI interventions. This report represents a very brief summary of selected key topics and findings from both the INPUD specific and the combined key population networks research reports with relevance for the HCV guidelines meeting.

Methods

Summary of study design and research method

Data were collected both through individual semistructured interviews and focus group discussions. Separate guides were developed for the semistructured interviews and the focus group discussions, and all research materials were piloted to improve the validity, accessibility and suitability of all research materials used. The numbers of semistructured interviews and focus group discussions conducted were set to ensure thematic saturation, which was 8–15 focus group discussions, with a minimum of 5 and maximum of 10 participants per focus group discussion, and 10–20 semistructured interviews. The WHO Research Ethics Review Committee provided ethics approval.
The participants were recruited using a generic purposive sampling approach informed by the aims and purpose of the study and the key research questions. The eligibility criteria were designed to ensure diverse geography, gender and age demographics. All research participants were required to meet the following criteria: be over 18 years of age; able to provide oral informed consent for participation; able to communicate in English, French, Spanish or Russian (or able to communicate via an interpreter); and identify as a member of a key population and/or as a member of a key population organization or network.

All semistructured interviews and focus group discussions were conducted virtually over Zoom, WhatsApp, Skype or other secure communication platforms. Data were collected by community experts engaged by the global key population networks as consultants. Participant responses were documented, electronically recorded and transcribed verbatim (resources permitting). The responses were then collated and coded using an inductive, thematic analysis approach. Data summaries from each of the key population studies were prepared by a principal investigator from each network, entered into a joint draft and analysed to create a consolidated key population report. Each key population network also developed a separate network report with further detail and in-depth analysis.

In total, 230 individuals participated in either a semistructured interview or focus group discussion from all six WHO regions and 68 countries. A total of 61 semistructured interviews and 32 focus group discussions were conducted. Further details on participant characteristics, including WHO region, country of residence and gender and age breakdowns are provided in the consolidated key population report and in the individual network reports.

Study limitations
Due to the heterogeneity of the key populations involved in this study and the inherent subjectivity of values and preferences, the results of this study are neither representative nor generalizable. Nevertheless, this study offers a range of important insights into the values, preferences and perceptions of the individuals from the key populations who participated in the study and, in doing so, provides useful data to inform the updating of the consolidated guidelines. The insights may also supplement existing research evidence and guide future research and may be valuable for other process with an interest in how services and interventions are provided for these key populations.

Results

Summary of topics and findings relevant to the HCV guidelines meeting

Drawing on the analysis and results from the INPUD specific report and the consolidated key population networks report, we have identified and summarized below some of the key topics and findings from the research relevant for the HCV guidelines meeting. Specifically, we have organized these points under four key headings: decentralization; integration; the role of peer workers; and stigma and discrimination.

Decentralization

- One key finding identified in both the INPUD-specific and the broader consolidated reports is an overwhelming preference for community-led responses and service delivery for HIV, STIs, and HCV.
  - Community-led services were unanimously endorsed and preferred by participants across all four key population networks.
  - Participants described community-led services as being critical to promoting the health and human rights of marginalized groups, especially as a counterbalance to stigmatizing health-care environments.
  - Participants discussed a range of advantages to community-led services, including their comprehensive approach to key populations’ well-being; specific understanding of community health needs; greater accessibility of services and referrals; confidentiality; and safe spaces for communities to gather, self-organize and advocate.
Participants also identified community-led services playing a key role in addressing the need for more information on new and emerging testing, treatment and prevention interventions and technologies. In particular, participants discussed how community-led services know how to provide information to their communities in ways that are credible, relevant, non-judgemental, trustworthy and accessible.

Effective community-led service models mentioned by participants included drop-in centres, mobile clinics, peer outreach and one-stop-shop models.

INPUD participants from the global North also discussed using peer-led point of care (PoC) RNA testing models through needle and syringe programmes, peer-clinic, drop-in, outreach and online services for peer-supported testing.

Financial and other incentives are also being used in these peer-led models to encourage testing, getting the result, commencing treatment, achieving SVR and bringing in or referring a peer or buddy.

Participants engaged in these community-led HCV services also highlighted the critical importance of training, support and adequate resourcing and infrastructure support to ensure high-quality service provision and best-practice approaches to clinical governance matters.

Integration

INPUD participants emphasized the importance of embedding HCV testing within a broader harm-reduction approach, including offering pangenotypic DAA treatment and HCV prevention for people in prisons.

“Hepatitis C treatment and harm-reduction services go hand-in-hand. People talk about access to [HCV] treatment and leave the prevention side out or they expect that once someone gets [HCV] treatment they will remain abstinent, and that’s not always the case. So, prevention always needs to be linked to treatment because health services and treatment don’t exist in a vacuum.” (Female drug user, Europe)

In relation to strategies to address barriers to HCV treatment, there was strong support among participants for opening up HCV DAA treatment through a wide range of treatment options and settings, including at needle and syringe programmes, harm-reduction services, health services, drop-in centres, OAT clinics as well as general public and hospital settings to maximize access and reduce barriers.

Integration or efforts towards integration should always give priority to increased access and quality of services for people who use drugs and should keep in mind that not all health-care centres are equipped to deal with the specialist needs of people who use drugs and, in such instances, may increase experiences of or fear of experiencing stigma and discrimination.

Finally, although prisons were not a specific focus in this study, participants from several regions also emphasized the importance of offering HCV DAA treatment (and HCV prevention and harm reduction) for people in prisons, particularly in the context of an overwhelming lack of access to sterile injecting equipment and other harm-reduction measures in most prisons globally, coupled with the levels of incarceration associated with drug-related offences.
The role of peer workers

We note the current recommendation on the role of trained peer workers to promote linkage to care in the existing viral hepatitis testing guidelines. We have therefore identified some specific issues from our research that may be useful towards the further implementation of this recommendation.

- Our research identified the need for a greater focus on peer-led education, information, counselling and outreach surrounding condom usage, harm reduction and treatment adherence to reduce vulnerability to HIV, STIs and HCV.
- It also identified the need for more specific ongoing peer-based and community-led HIV, STI and HCV education delivered through a variety of mechanisms and formats including:
  - the practice of peers assisting with health service access, information, education and referral was greatly valued by participants across all four key population networks;
  - across key population networks, the positive impact of peer navigators was observed throughout the testing and treatment cascade – including treatment linkage, continuity and re-engagement; and
  - peer-based testing models were viewed as critical for a group of people who are highly criminalized, often marginalized and disaffected from the mainstream health system and frequently living in poverty:

  “It all goes back to us as peers, to educate them about these things and offering incentives.” (Other gender-non-conforming drug user, African Region)

  “Access to tests is needed that is not associated with visiting medical institutions. If a peer-to-peer counsellor and the drug user himself can do this on their own, it is much more convenient and effective.” (Female drug user, European Region)

- Female participants also identified preferences towards and a valuing of peer-based services and their role in making HIV, STI and HCV services attractive, accessible and, ultimately, effective and safe:

  “If it was provided by a peer, I would be more willing to listen” (Female drug user, African Region)

- For the majority of participants in this study, regardless of country or region, peer navigators were viewed as “essential due to their lived experience”. There was a very high regard and valuing of peer navigators, peer workers and peer educators in the context of HIV, STI and hepatitis prevention treatment and care.

- Despite the clear preferences and values of participants towards peer workers, participants also highlighted what they viewed as ongoing problems associated with peers being “not seen as professional”, “undervalued”, “unpaid” and not recognized in the same way as other health-care workers and not given adequate training and support:

  “Peer workers need to be trained and supported and properly paid so that they can avoid exposing people to burnout and stress.” (Female drug user, European Region)

- One participant summed up why they value peer-based services in the following way, which speaks directly to the potential value of decentralized approaches to HCV service delivery:

  “I am a really big believer in recognizing peers as experts or professionals in their own lives, because one, they’ve got the empathy, support and connection already – peer to peer, and then two, give them the tools like motivational interviewing, even [cognitive behavioural therapy] and suddenly, you’ve got access to injecting equipment and safer using done, naloxone provision done, HCV testing and treatment done, I could go on… but I mean, it’s amazing.” (Male drug user, Western Pacific Region)
Other participants spoke about the unique capacity of peer workers to not only be flexible and “meet people where they are” and therefore be truly “person-centred” but also their capacity to reach and gain the trust of people from various backgrounds, identities and experiences. Again, participants gave concrete examples of how decentralization and integration models in relation to HCV services can work in practice:

“We have a drop-in that is managed by peers. It’s a super drop-in centre that mixes populations, you know, non-binary people and women and sex workers and migrants. It’s managed by peers and already agreed with a hospital that a team with a doctor is going there with Fibroscan and with everything to test and begin treatment. They managed to take the medicine out of the hospital to the community. So, it is a super great example.” (Male drug user, European Region)

In relation to integration and the potential for more collaboration between mainstream health services and community-led services, participants raised the need for stigma and discrimination training for health service providers as a prerequisite to working with peers:

“Peer workers are often treated really poorly by mainstream services. I mean, what’s the point of sending peers into a service where they are not wanted, to work with people who don’t really want to be treated in that service? Ultimately, there is a real need for stigma training for frontline services in working with and respecting peers before they have access to peer workers.” (Female drug user, Western Pacific Region)

Stigma and discrimination

In addition to highlighting the need for stigma and discrimination training for service providers working with peer workers, participants also emphasized the importance of sensitizing health-care providers to provide non-stigmatizing, non-discriminatory health care to key populations.

As already identified above, INPUD participants highlighted the importance of the underpinning philosophy or approach of mainstream health services and in particular the importance of taking a harm-reduction approach.

In relation to health-care providers, INPUD participants also highlighted the importance of the attitudes and values of individual health-care workers and the extent of stigma and discrimination experienced by people who inject drugs in the context of criminalization.

Indeed, research has found that in the context of criminalization, experiences of stigma and discrimination are so pervasive that they are almost a universal experience for people who use drugs. It is hardly surprising then that participants routinely described stigma and discrimination as being at the heart of the barriers and problems experienced by people who inject drugs in relation to accessing services and being able to stay in HCV or HIV treatment:

“There are the barriers to service access; if you take away the stigma, then I will not be ashamed to present myself.” (Female drug user, African Region)

Barriers to HCV treatment specifically due to the poor attitudes of health professionals were raised by several INPUD participants as an ongoing problem.

Despite large and growing literature showing high HCV DAA treatment adherence, SVR and completion rates among people who inject drugs and/or on opioid agonist therapy and that “reinfection” should not be used as a reason to withhold therapy from people with ongoing injecting drug use, alcohol and other drug clinicians in some contexts continue to use cessation of injecting drug use (and sometimes even cessation of opioid agonist therapy) as a treatment access criterion:
“We had a physician at a big hospital here, where people had to be off methadone in order to qualify for hep C treatment.” (Male drug user, Americas)

“They also want you to stop using for you to get treatment. They also say things like if you get reinfected, they will not treat you again.” (Female drug user, African Region)
Report written by Guillermo Z. Martínez-Pérez and Sonjelle Shilton
FIND, the global diagnostics alliance

Background

A rapid qualitative assessment on hepatitis C self-testing

A multicountry rapid qualitative assessment was conducted in 2020 to understand the values and preferences towards hepatitis C (HCV) self-testing among potential end-users and health-care workers. While the assessment’s primary focus was on informants’ opinions on HCV self-testing, themes around their understanding of HCV and around their perspectives on current HCV testing services were also explored. This was an assessment that was part of the HCV self-testing research portfolio supported by the Foundation for Innovative New Diagnostics (FIND). The 2020 rapid assessment’s findings on the theoretical acceptability of HCV self-testing, which are available elsewhere,1,2,3 help to understand findings from other recent FIND-supported HCV self-testing usability, performance and empirical acceptability studies conducted in other low- and middle-income countries.4,5,6

The body of literature on HCV self-testing demonstrates that this is an innovation that is perceived as user-friendly and that holds the potential to increase affected populations’ awareness of their HCV status. WHO issued guidance in mid-2021 to recommend the use of HCV self-testing as an additional testing approach; in collaboration with actors such as civil society organizations that support HCV care provision to the communities; ensuring that devices are distributed with clear user instructions and indications for linkage to confirmatory testing; and, taking care not to add further stigma to groups that have been traditionally made vulnerable in many contexts for their gender or sexual identities, their serological status or their drug consumption practices.7

HCV self-testing is just one of the many technological solutions that can bring HCV diagnosis and care closer to affected communities in HCV-prevalent settings. Other innovations (such as mobile testing vans, reflex testing, dried blood spot-based testing and point-of-care nucleic acid testing) have been proposed to eliminate populations’ social and physical barriers to uptake HCV testing and, for those identified as HCV-infected, to progress along the HCV cascade of care.8 Nevertheless, most of these innovations can have stronger impact in HCV elimination if implemented in decentralized HCV care services that are staffed by the same health-care workers that routinely cater for the communities’ basic health needs.8,9 As informants in our rapid qualitative assessment reported, HCV self-testing would have added value if users who obtain a reactive result can easily access confirmatory testing and if health systems are prepared to facilitate their access to treatment for those confirmed positive on the spot. To enable one-stop-shop services, decentralizing viral load testing to community-level health spaces is crucial to enrol patients in HCV care at the very point of confirmation of a positive result.
During Autumn 2021, the analyses and reports resulting from the multicountry rapid qualitative assessment have been re-reviewed with the aim of synthesizing the qualitative data on the values and preferences among potential end-users of HCV self-testing (health-care workers included) towards task shifting, integration, simplification and decentralization of HCV testing and treatment delivery. This Report will provide guidance, supported by informants’ emic perspectives, to the planned roll-out of point-of-care viral load testing technologies in low- and middle-income countries for the purpose of: confirmatory testing, assessing patients’ eligibility for HCV treatment and determining viral clearance among treated patients.

**Methods**

**Study sites and populations.** This was a qualitative inquiry conducted in 2020 in Brazil, Costa Rica, India, Indonesia, Kyrgyzstan, Philippines, Rwanda, South Africa, Thailand and Ukraine. To harmonize institutional engagement in the assessment, FIND developed a master assessment protocol. Three main populations were involved as participants: (a) health-care workers (in India, Indonesia, Rwanda, Thailand, Ukraine), (b) the general public (in Rwanda, Thailand, Ukraine) and (c) groups made vulnerable such as men who have sex with men (in Brazil, India, Philippines), people who live with HIV (in India, Indonesia), people who use drugs (in Costa Rica, India, Indonesia, Kyrgyzstan, South Africa), and transgender people (in Costa Rica, India).

**Sampling and recruitment.** Informants were to be over 18 years old, to self-identify as members of the group of interest and to provide consent. In sampling potential informants, men who have sex with men, people living with HIV, people who use drugs and transgender people were categorized based on WHO definitions. Specific criterion for health-care workers’ participation included being engaged in HCV care. For the general public, Thailand and Ukraine did not use any exclusion criteria. In Rwanda, the general public included those who identified as gender-conforming people, who were not living with HIV and who did not report same-sex practice, sex work or drug use.

While the sampling techniques (convenience, purposive and snowballing) and recruitment agents (community peers, institution staff and health-care workers) varied in each country, the principle of maximum variation sampling was applied. Across sites, diversity of age groups, gender identities and areas of residence were pursued. A minimum sample size of 24 individuals per group was proposed. In each site, potential informants were approached by local teams, informed of the assessment goals and, if interested in participating, were required to go through an informed consent process before data collection.

**Data collection and analysis.** Individual and group interviews were conducted before participatory action research. When feasible, interviews were conducted face to face. Most group interviews had five to seven participants. Interviews were guided by a 42-item structured guide. Interviews recordings were transcribed by the site teams into a single question-by-question Microsoft Excel® matrix. Participatory action research was done in all countries with all groups except health-care workers. Participatory action research sessions had between 6 and 20 attendees. In each session, organizers assigned attendees to small subgroups of 3–5 people each. Subgroups engaged in the exercises “roles and responsibilities”, “mapping”, “decision-taking” and “piling-up”.

Data collection and analysis took place concurrently. A thematic analysis approach was used. Data were analysed in a question-by-question manner and then revised in a theme-by-theme manner filtering by informants’ sex, education and area of residence. Finally, interview data were compared with the results from the participatory action research exercises. Each implementing institution produced a country report in which key findings were discussed. These reports (n=11) were subsequently coded and analysed in Dedoose® by the lead social scientist.
**Ethics.** The assessment complied with all national norms and regulations for conducting formative research and protection of private personal data.
Results

Participants’ characteristics

A total of 460 interviewees, 220 group discussants and 257 participatory action research session attendees participated as informants in the assessment (see Table 1 below for detailed country disaggregated demographics). In total, 990 informants participated. 329 (36%) of these were cis-women and 71 (8%) were trans-women. 683 (74%) were inhabitants of urban areas. The majority were in 26–35 years old (296, 32%) and 36–49 years old (392, 43%). The informants’ education profile varied significantly among countries. For instance, the percentage of postgraduates ranged from 1% in Rwanda to 65% in Ukraine, and the percentage of informants with secondary school studies ranged from 1% in Thailand to 60% in Indonesia.

Data collection encounters were well participated by 607 members of vulnerable groups (153 men who have sex with men, 132 people living with HIV, 280 people who use drugs and 42 transgender people), 150 members of the general public and 163 health-care workers.

The assessment group categories were not exclusive. Informants were considered as members of a specific group depending on their other preferences or primary identities. Many individuals could have been considered informants in more than one assessment group (such as health-care workers who were living with HIV; transgender people who used drugs; and members of the general public who engaged in same-sex practices). Further, across all countries, some informants disclosed living with HCV, but their identity as HCV-infected people was not captured for analysis.

<table>
<thead>
<tr>
<th>Group</th>
<th>Rwanda (n=72)</th>
<th>South Africa (n=47)</th>
<th>Brazil (n=72)</th>
<th>Costa Rica (n=49)</th>
<th>India (n=283)</th>
<th>Indonesia (n=115)</th>
<th>Kyrgyzstan (n=47)</th>
<th>Philippines (n=47)</th>
<th>Thailand (n=105)</th>
<th>Ukraine (n=100)</th>
<th>Total (n=920)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men who have sex with men People living with HIV</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>51, 18.0%</td>
<td>42, 28.9%</td>
<td>50, 43.5%</td>
<td>-</td>
<td>47, 100%</td>
<td>-</td>
<td>53, 10.0%</td>
</tr>
<tr>
<td>People who use drugs</td>
<td>-</td>
<td>-</td>
<td>47, 100%</td>
<td>-</td>
<td>49, 100%</td>
<td>42, 14.8%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>58, 63.9%</td>
</tr>
<tr>
<td>Transgender Health-care workers General public</td>
<td>36, 50.0%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>21, 7.4%</td>
<td>42, 14.8%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>55, 58.9%</td>
</tr>
</tbody>
</table>

Informants per encounter

<table>
<thead>
<tr>
<th>Gender</th>
<th>Cis F</th>
<th>Cis M</th>
<th>Trans F</th>
<th>Trans M</th>
<th>Non-binary</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>14, 29.8%</td>
<td>33, 70.2%</td>
<td>14, 29.8%</td>
<td>33, 70.2%</td>
<td>1, 1.8%</td>
</tr>
<tr>
<td>Age group</td>
<td>12, 25.5%</td>
<td>18, 22.7%</td>
<td>12, 25.5%</td>
<td>18, 22.7%</td>
<td>1, 1.8%</td>
</tr>
<tr>
<td>Location</td>
<td>50, 69.4%</td>
<td>47, 100%</td>
<td>17, 23.6%</td>
<td>12, 24.5%</td>
<td>14, 19.4%</td>
</tr>
<tr>
<td>Education</td>
<td>8, 11.1%</td>
<td>8, 11.1%</td>
<td>8, 11.1%</td>
<td>8, 11.1%</td>
<td>8, 11.1%</td>
</tr>
</tbody>
</table>

Web Annex D: Values and Preferences Reports
Perspectives on decentralized HCV testing and care

During the interviews, all informants reflected on their experiences with current HCV testing and treatment in their contexts. During the interviews and the participatory action research, they were also asked to propose how current services could be reorganized to eliminate the access barriers they had identified. In this section, an overview of how informants considered that some of the key interventions proposed to increase HCV testing and treatment\textsuperscript{11} could help to mitigate people’s most common barriers to demand, access and utilize HCV care and to increase HCV care clients’ retention in care and satisfaction with health-care provision. Specifically, narratives around the theoretical benefits of decentralization, simplification, integration and task-shifting are explored. Unless stated otherwise, the insights below were voiced by all assessment groups of people.

The degree to which the barriers affected people at risk of HCV depended on their gender, education and area of residence. In Indonesia, some informants claimed that women people who use drugs would be the ones facing the greatest difficulties in accessing HCV testing and treatment, whereas some Ukrainian informants stated that, regardless of gender or education, older people and those living in rural areas could face most problems in accessing HCV testing and treatment. In Costa Rica and Brazil, income seemed to be a decisive factor, since those with more money would contract private insurance to see their health-care needs met, including HCV testing and treatment.

Overwhelmingly, in all sites there were mentions of people avoiding health-care spaces just to avoid being “mistreated” by health-care workers who were described as discriminatory, prejudicial, and unjust. Health-care workers’ attitudes were described as one of the major deterrents to demand, access and accept care. This was shared by a few health-care workers who recognized the disconnect between professionals and clients in some settings. However, on the other hand, in all sites there were informants who also opined that HCV testing and treatment uptake could improve if these were not provided by health-care workers in remote hospital facilities but by the health-care workers who are working with local communities.

All sites mentioned that HCV testing and treatment were inconvenient, because they were far from their residence or because of the long queues, the informal fees expected by some staff or the conflicting schedules. People who use drugs and people who engage in sex work were the ones who most insisted that schedules need to be more convenient for their daily activities. Similarly, in all sites there were voices expressing how complicated the processes for accessing treatment were for those who tested HCV positive. The people who use drugs were concerned that they might be denied treatment just for their consumption of drugs. All other groups were concerned that they could be rejected for treatment if they did not have sufficient funds or lacked health insurance. In their opinions, many people would reject testing – even if offered free of charge – just to avoid having to live with the stress of being an HCV patient with no possibility of treatment.

Fear was a common concern. Fear of stigma: many vulnerable people were suffering the effects of social stigma, and many expressed that they would not want to add further opportunities for stigmatization. Fear may be driven by marginalization of affected groups but also by lack of awareness on what HCV is, how it is transmitted and how it can be diagnosed and treated. Fear of disability or death: the majority agreed, and including health-care workers, that there is little knowledge that an effective cure for HCV exists. Some health-care workers claimed that there is also limited knowledge among some health-care workers, even if they are also at risk of HCV.

Decentralization of HCV testing and treatment and bringing it near to the communities was emphasized as a means to increase knowledge on HCV care; empower health-care workers in their task to create awareness on HCV; ensure that health-care workers can offer testing to their usual clients based on their behaviour (and not on their identities); and to fast-track access to treatment, where necessary, and engage community networks to promote patients’ adherence to treatment. Many informants did know where testing services were located, but the majority were confused about where treatment is provided when a reactive test is confirmed.
To many, partial decentralization of HCV care is not a good means to encouraging testing to become aware of one’s HCV status. To help populations understand the processes to progress from screening to confirmatory testing to treatment, once all HCV testing and treatment services are decentralized to the community level, these need to be simplified. The concept of a one-stop shop was mentioned by informants who knew of this approach in harm-reduction sites, HIV clinics or maternal health services. Many were aware that, with good organization, education in prevention, diagnosis and treatment can be offered at the same time. Simplification, in decentralized sites, was also proposed for people to disregard the inconveniences commonly associated with testing. If people had screening, confirmatory testing and assessment for treatment done by the same provider, on the same day and at the same site, many people would – in the informants’ opinion – not be very concerned about the time they lose, the queues they endure, the expenditure they incur or the daily wages they lose. The simpler the processes, the easier it will be for people at risk of HCV to demand testing. Furthermore, the more transparent the processes for accessing treatment, the better it will be for recently diagnosed people to cope with the psychosocial stress of learning their HCV status. Many informants insisted on the need to simplify test-to-treatment pathways and in the need for health-care workers to be clear about the mechanisms for infection confirmation and access to treatment. Transparency was especially relevant for people who use drugs and transgender people, many of whom explained that they feel that some health-care workers neglect them care for no sound reason.

A proposed strategy to simplify HCV testing and treatment provision was its integration with other services that are provided at the community level by the health-care system or by other civil society organizations. Integration would expand the concept of a one-stop shop for a single disease to a one-stop shop for a variety of conditions. HCV testing and treatment could be provided at HIV, malaria, maternal or mental health services. Integration could palliate the lack of awareness on HCV, since many community-based organizations do conduct education in prevention alongside clinical care. However, if integration be done only in HIV clinics or in spaces for people who use drugs, as some informants opined, this could have a negative effect, as some at-risk people who fear stigma intentionally avoid these spaces. Although the people who use drugs largely supported integration of HCV testing and treatment in harm-reduction sites, many men who have sex with men and transgender people thought that many people – especially bisexual men in partnerships with women – would not test for HCV if this were only available in people living with HIV– or LGBT+-friendly spaces.

Task-shifting of HCV testing and treatment to non-specialists was the aspect where insights were more diverse. It was appreciated that non-specialists are already engaged in HCV testing and treatment. Primary care physicians, nurses, community health workers, pharmacists and social workers were among the health-care workers mentioned as cadres who could play a role alongside the HCV cascade of care. Many informants expressed that testing uptake and linkage to care would increase if people had the chance to go to the health-care workers that look after them for other conditions. However, to others, this approach would deter testing due to their poor perception of the health-care workers’ attitudes towards them. This was emphasized by people who use drugs, transgender people and informants who engaged in sex work. The people who engage in same-sex practice expressed that they preferred to pay for private health care in which there was, allegedly, less risk to be looked down at by health-care workers. Only the people living with HIV in Indonesia expressed that health care to them has improved recently. Unanimously, whether in favour or against task-shifting of HCV testing and treatment to community-based health-care workers, all sites insisted in the need to sensitize the general public and the health-care workers. To the majority, task-shifting would not increase people’s access to test and treat if health-care workers’ attitudes do not improve.
Conclusion

Although this was an assessment of values and preferences towards HCV self-testing, the informants’ narratives are invaluable to support the decentralization of HCV testing and treatment to facilities other than tertiary hospitals and specialist clinics; to task-shift the confirmation of HCV infection and initiation into HCV treatment to other cadres of health-care workers; to simplify processes to avoid patients avoiding HCV care; and to integrate HCV testing and treatment in health services that are provided both in routine health-care provision to the general public (such as family medicine) and in other services that target specific groups (such as maternity, harm-reduction, tuberculosis or HIV clinics) (see diagram above). The informants’ recommendations align with the 2016–2021 WHO global health sector strategy on HCV. 11 Although these recommendations were made with the aim to offer suggestions to overcome barriers for accepting HCV testing and treatment in their countries, informants also suggested that new access barriers could be created if these strategies (decentralization, task-shifting, simplification and integration) were implemented with improper planning and insensitive consideration to communities’ needs and preferences. If clinics with inappropriate infrastructure and poor organization are decentralized, people will not accept them. If tasks are shifted to health-care workers who are currently being avoided by affected people, HCV testing will not increase. If services that are avoided by at-risk groups (such as HIV clinics avoided by some LGBT+ people) are integrated, HCV testing might not increase. In all these steps, PoC or near-PoC will be needed. The informants in the assessment did not mention “viral load”, but there were numerous mentions to the need to receive confirmatory testing straight away – for which PoC VL will be needed; to receive confirmation of eligibility for treatment based on data (for which PoC VL is necessary) and not on staff prejudice; to stay in care and not drop treatment (and VL will be needed to confirm successful cure).
Acknowledgements

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Guillermo Z. Martínez Pérez (FIND) developed the protocol and guiding materials for the conduct of the rapid qualitative assessment, provided technical support for in-country consultants and developed this report in cooperation with Sonjelle Shilton, who conceptualized the initial assessment (FIND).

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