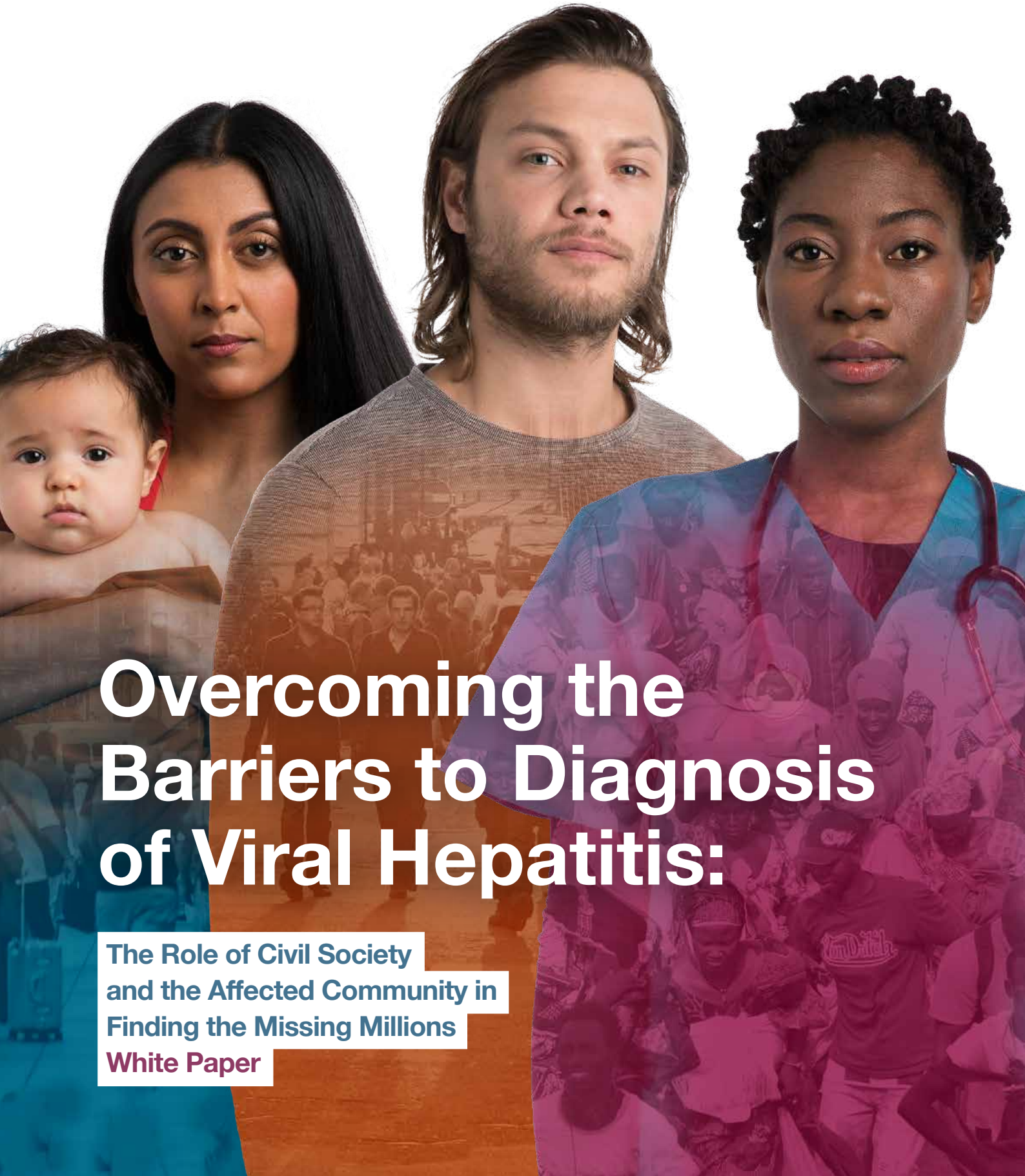
World Hepatitis Alliance

Find The Missing Millions.



Overcoming the Barriers to Diagnosis of Viral Hepatitis:

The Role of Civil Society and the Affected Community in Finding the Missing Millions White Paper

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Executive Summary

This white paper sets out recommendations for overcoming the existing barriers to diagnosing viral hepatitis B and C. It recognises the progress made since the adoption of the World Health Organization's (WHO) *Global health sector strategy on viral hepatitis, 2016–2021*, including new WHO testing guidance that many countries are starting to implement, but also that nine out of ten people around the world with viral hepatitis remain undiagnosed. The recommendations draw on a multicountry survey commissioned by the World Hepatitis Alliance (WHA) on barriers to viral hepatitis diagnosis and a global stakeholder meeting held in London in May 2018 to discuss the survey findings and the role of civil society and the affected community in addressing these barriers.

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people around the world with viral hepatitis remain undiagnosed

The five main barriers to the diagnosis of viral hepatitis B and C, according to the global survey, are:

1. **Lack of public knowledge of the diseases**
2. **Lack of knowledge of viral hepatitis among healthcare professionals**
3. **Lack of easily accessible testing**
4. **Stigma and discrimination**
5. **Out-of-pocket costs for the population**

Overcoming these barriers will be critical if we are to reach elimination. The recommendations set out in this white paper highlight that existing frameworks should be used to better educate, increase awareness and combat stigma and discrimination; targeted testing strategies with integration into existing services are required; testing must be affordable and accessible; linkage to care must occur across all screening services; and it is essential that civil society and the affected community are engaged in all of these actions.

Civil society and the affected community have a unique and important role to play in addressing the barriers to diagnosing viral hepatitis; however, to facilitate a more effective response a multi-stakeholder approach is required and governments will need to create an enabling environment that fosters collaboration. Further, all countries need to ensure that those diagnosed with hepatitis B or hepatitis C are linked to care as quickly as possible.

290

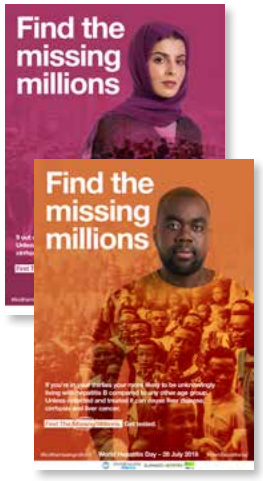
million people living with viral hepatitis B and C are unaware they have the disease

Introduction

An estimated 290 million (89%) of the 325 million people living with viral hepatitis B and C are unaware that they are infected (WHO, 2017a), irrespective of gender, age, ethnicity or geography. This puts them at risk of unknowingly transmitting the virus to others and developing extrahepatic manifestations (e.g. autoimmune diseases, diabetes), liver complications, including fatal end-stage liver disease and liver cancer. Without a massive scale-up in awareness coupled with diagnostic services, to ensure that everyone infected gets tested, treatment rates will not increase and infection rates may rise (European Union HCV Collaborators, 2017).

THE GLOBAL GOALS
For Sustainable Development

Today, there is now a policy framework to combat and ultimately eliminate viral hepatitis. The United Nations' Sustainable Development Goals (SDGs), adopted by all countries in 2015, call for combatting viral hepatitis (United Nations, 2015) and in 2016 the World Health Organization (WHO) adopted the *Global health sector strategy on viral hepatitis, 2016–2021* (GHSS), which set the goal of eliminating viral hepatitis as a public health threat by 2030 and specifically for 30% of people infected to know their status by 2020 and 90% by 2030 (WHO, 2016). Thus, without finding these "missing millions" and linking them to care, efforts to eliminate viral hepatitis will fail.



The "Find the Missing Millions" programme, initiated by the World Hepatitis Alliance (WHA) in 2018, is a three-year effort intended to assist countries to reach the diagnosis targets they committed to when adopting the WHO viral hepatitis strategy. The programme builds on the mission of WHA to "harness the power of people living with viral hepatitis to achieve its elimination" and this white paper highlights how involving civil society and the affected community can strengthen the response. While acknowledging the vast amount of work to date, including viral hepatitis testing guidance from clinical associations and technical agencies (AASLD, 2018; Chávez, 2013; EASL, 2018; Omata, 2016; WHO, 2017b), WHA, working with experts and key partners worldwide, developed a series of complementary recommendations, set out below, focusing on the role civil society and the affected community have in scaling up equitable diagnostic services to find the missing millions.

The Importance of Involving Civil Society and the Affected Community in the Response

People living with viral hepatitis and the affected community should be at the heart of every effort to eliminate viral hepatitis. Aside from fulfilling the need for trusted entities that consistently disseminate reliable information, civil society organisations bring fundamentally important perspectives and experiences which greatly enhance the effectiveness of strategies and programmes.

In the context of addressing the barriers to diagnosis, a meaningful partnership with the affected community and civil society organisations can, amongst other things, contribute to the delivery of stronger awareness campaigns; strengthen innovative approaches to finding the undiagnosed through peer support services; help identify gaps within action plans which would otherwise be missed; and offer a platform to address stigma and discrimination, ensuring an equitable response so that the most vulnerable and marginalised are not left behind in the effort to eliminate viral hepatitis. As such, policy-makers should harness the voices of those affected by viral hepatitis, recognising them as vital partners in the elimination effort.

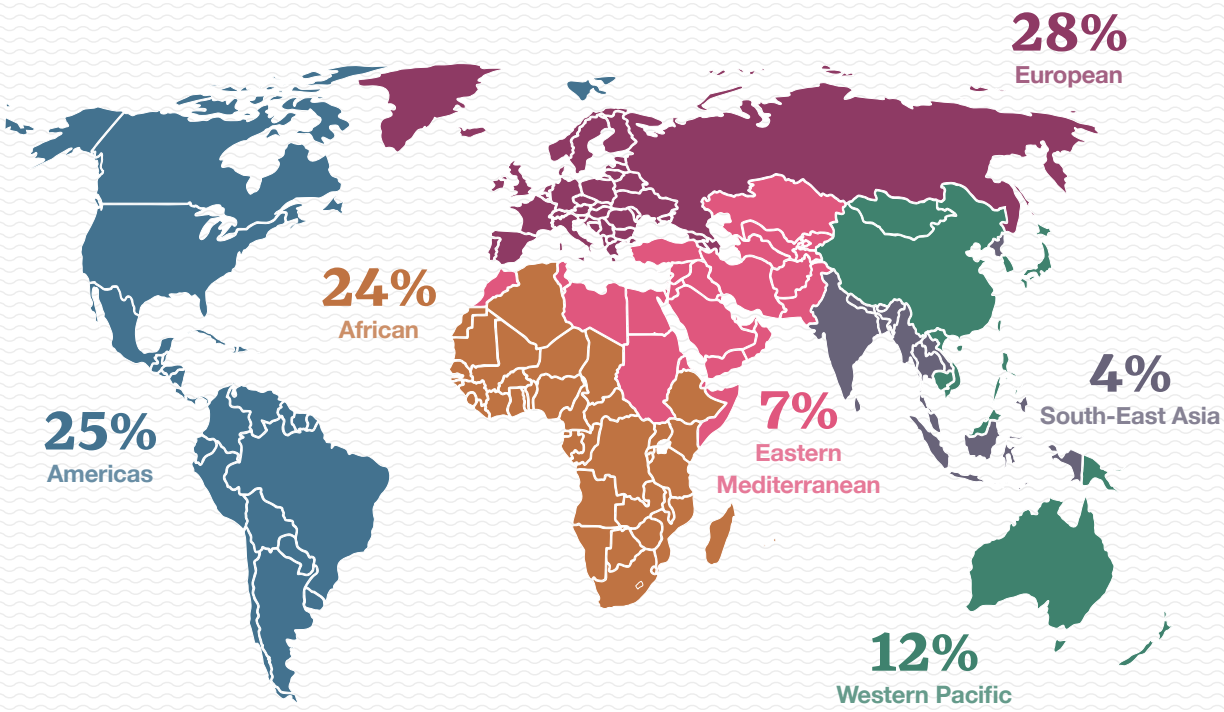
Further, as more people living with viral hepatitis are aware of their diagnosis, they and those in their social environment can be part of the drive to prevent the disease by ensuring access to services, from prevention to testing to treatment and follow-up care, and by encouraging innovation, such as health systems reforms that facilitate new, more people-centered health services.

Methodology

Available research on the barriers to diagnosis of viral hepatitis and strategies to overcome them is limited to a small number of mainly high-income countries, or specific regions and populations (Ishizaki, 2017). These studies are also limited with regard to the number and category of respondents. To address these data gaps, WHA conducted a global survey on the barriers to diagnosis of hepatitis B and hepatitis C.

WHA commissioned DJS Research, an independent research agency, to undertake a global consultation, in the form of an online survey that ran from 22 February to 21 March 2018. DJS Research sent approximately 3000 emails in English, French or Spanish to WHA member organisations, people living with viral hepatitis, medical professionals, policy-makers and other stakeholders. An open link to the survey was also provided on websites worldwide, which could be accessed by the wider hepatitis community.

Five hundred and sixty-one surveys were completed from the following regions:



Following the online survey, telephone interviews were conducted with 17 respondents from Argentina, Australia, Brazil, Canada, Cyprus, Germany, Guatemala, Mali, Portugal, Spain, Switzerland, the United Kingdom and the United States of America. The interviews were designed to gather more detailed views on the barriers that were identified as major within the online survey.

The implications of the overall small sample size are that the data from individual regions can best be regarded as indicative and do not permit comparison or robust conclusions. Further, it is important to note that geographic representation in the survey is not proportionate to the prevalence and incidence of viral hepatitis in the different regions. Nonetheless, the findings provide useful avenues for exploration which then need to be adapted to the needs of each individual region. Details on barriers to the diagnosis of viral hepatitis B and C can be found in *Find the Missing Millions: Barriers to Diagnosis Global Report* (World Hepatitis Alliance, 2018).

The focus of the two-day global stakeholder consultation, held in London on 17–18 May 2018, was to further explore the role that civil society and the affected community can play in overcoming the identified barriers to diagnosis BOX 1. Participants discussed the barriers to diagnosis identified by the survey and developed a set of recommendations; highlighting the unique role that civil society and the affected community have to play in a sustainable response.

BOX 1 · Main barriers for viral hepatitis testing according to the WHA global survey

1. lack of public knowledge
2. lack of awareness among professionals
3. lack of easily accessible testing
4. stigma and discrimination
5. out-of-pocket costs

Recommendations

These recommendations should be considered complementary to WHO guidelines for viral hepatitis testing (WHO, 2017b) and the *WHO Global health sector strategy on viral hepatitis, 2016-2021* (WHO, 2016) in that they set out to enhance the role of civil society and the affected community in overcoming the barriers to diagnosing viral hepatitis.

It is important to note that implementing these recommendations requires a multi-stakeholder response and this may mean policy-makers and other stakeholders will need to look beyond current partners. The response will be enhanced by involving not just those already engaged but also anyone who has contact with affected populations or populations at risk. This will vary depending on the setting but potential allies to consider include addiction specialists, nephrologists and haematologists, pharmacists, refugee and migrant support organisations, religious/cultural leaders who have played a role in developing and fostering health services, patient groups representing affected communities such as those with kidney disease, haemophilia or thalassemia and peers in general. Target groups may be different for efforts to combat hepatitis B versus hepatitis C, and will likely differ by country or locality.

Overcoming the main barriers to diagnosis BOX 1 requires all stakeholders to engage in three main activities:

I Raising Awareness

II Making testing more accessible

III Removing cost barriers for viral hepatitis testing

I Raising Awareness

Lack of public knowledge of the diseases, lack of knowledge among healthcare professionals and stigma and discrimination are all underpinned, in part, by a lack of awareness and so it is recommended that these three barriers should be collectively addressed.

When raising awareness, improving education and combatting stigma and discrimination, different strategies are required for different populations and, as WHO suggests, they will be dependent on the country context and may include promotion through the mass media (WHO, 2017b). In the GHSS it is stated that "Concerted advocacy efforts, particularly by political and community leaders, and a sound communication strategy are required to increase public and political awareness of the public health importance of viral hepatitis… and to mobilize action" (WHO, 2016).

Civil society and the affected community can enhance the response that WHO calls for by:

Partnering with stakeholders to advocate for:

- Health authorities to ensure continuous medical and professional education on viral hepatitis is provided from the early stages of training
- Enabling frameworks such as anti-discrimination laws and their enforcement and redress of discriminatory acts
- Decriminalisation of drug use and homosexuality as punitive laws hamper public health efforts
- National governments to join all countries in upholding the commitment made at the 63rd World Health Assembly (2010) to use World Hepatitis Day to improve education and understanding of viral hepatitis

Partnering with stakeholders to **take action** to:

Promote the use of findings from national and/or WHO monitoring and evaluation frameworks to:

- develop focused awareness strategies which target populations that are being left behind
- create civil society-led shadow reports highlighting the experiences and expertise of civil society and the affected community to add further weight to national or WHO findings

Highlight in campaign materials that viral hepatitis is potentially a cancer-causing disease

Highlight that hepatitis can cause severe extrahepatic manifestations

Find influencers beyond the usual stakeholders that can help raise awareness (e.g celebrities and political leaders)

Create enabling environments where people living with viral hepatitis are able to share their stories in order to humanise the experience of living with viral hepatitis and reduce the stigma around it

Contribute to communication and awareness-raising campaigns by helping to formulate culturally specific messaging to debunk myths, convey a sense of urgency, and reduce stigma

To ensure testing for hepatitis B and C is carried out alongside education on viral hepatitis so that awareness is increased in all people tested, not just those with viral hepatitis

Use the Find the Missing Millions campaign or other awareness-raising initiatives like World Hepatitis Day and NOhep to promote testing and improve understanding of viral hepatitis

II Making Testing More Accessible

The promotion of human rights and equity are core to both the SDGs (United Nations, 2015) and WHO initiatives to eliminate viral hepatitis. In particular these principles are evident within the guidance on access to testing, with WHO calling for testing services to be "accessible to the populations most affected" (WHO, 2017b). WHO further elaborates that: "Rapid expansion of programmes to improve coverage should not compromise the quality of services, nor contribute to inequities in access to services and health outcomes" and "Actively engaging affected populations in developing strategies and programmes should result in better targeted and acceptable services" (WHO, 2016).

Building on the foundation provided by WHO, civil society and the affected community can help national governments, national health institutions and other stakeholders to make testing more readily available by:

Partnering with stakeholders to **advocate** for:

- Development of a partnership response to viral hepatitis, where people living with the infections are included in ministerial and other global and national advisory structures
- Better data to shape testing strategies so that they are targeted and client-centred
- Available and effective testing, integrating both simple and appropriate testing technologies, while incentivising testing at the primary care level
- Provision of testing services through new models of care that allow for a "one-stop shop" experience where chronic infection can be confirmed and appropriate linkage to care implemented
- Gaps in services to be addressed, specifically at sites where testing is not available or where it is underutilised
- Broad availability of quality-assured rapid tests to screen for viral hepatitis

Partnering with stakeholders to take action to:

Participate in the design of testing policies and strategies at the national level to ensure appropriate considerations that can enhance implementation are accounted for

Build the capacity of non-governmental organisations and community-based organisations, including patient groups, to test for viral hepatitis

Stimulate political will at all levels of government for increased access to testing

Help to ensure an equitable response by setting targets, especially for vulnerable populations, as they are frequently under-represented in testing efforts

Recruit peers from the affected communities to conduct testing, act as case managers, provide pre- and post-test counselling, provide reliable information to support those newly diagnosed and address transmission fallacies

Spotlight on peers:

Peer networks span multiple and intersecting groupings and have been successful in community mobilisation. For example, peer involvement by community leaders or family members has been shown to promote access and subsequent participation in services for migrant populations, who are often cut off from services, particularly where language and a fear of using services are barriers (Seedat, 2014; Sweeney, 2015).

The role of peers could extend beyond the current focus on testing and diagnosis to also serve to provide education on viral hepatitis, including how infection/reinfection occurs (Batchelder, 2017). For example, peer-driven testing campaigns for specific populations such as people living with HIV (PLHIV), men who have sex with men (MSM), and people who inject drugs (PWID) can enable the scale up of diagnosis and treatment, as well as disseminate information on the distinct, available resources for those with a positive diagnosis to prevent stigmatisation (Crawforth & Bath, 2013; Meyer, 2015; Scott, 2014; Sharma, 2015).

III Removing Cost Barriers for Viral Hepatitis Testing

The WHA global survey found that out-of-pocket costs to patients were one of the principal barriers to diagnosis. To date, viral hepatitis testing costs have mainly been approached from a provider rather than user perspective in WHO initiatives (WHO, 2017b). However, the 4th strategic direction of the GHSS is: "Financing for sustainability: proposing strategies to reduce costs, improve efficiencies and minimize the risk of financial hardship for those requiring the services" and the proposed priority actions for countries include reducing financial barriers to patients by phasing out direct, out-of-pocket payments (WHO, 2016). A coordinated and decided approach to curb this barrier is needed and civil society and the affected community can contribute by:

Partnering with stakeholders to **advocate** for:

No, or limited and easily affordable, out-of-pocket costs for patients through inclusion of viral hepatitis services in health insurance schemes

Hepatitis testing and treatment to be included in universal health coverage packages, as set out by the Universal Health Coverage Forum in the Tokyo Declaration (2017)

The use of central procurement of quality-assured and affordable tests in order to obtain price-volume agreements

Leveraging of existing services in order to decrease investment costs for testing infrastructure and personnel, e.g. within HIV or other settings

Partnering with stakeholders to **take action** to:

Be a part of multi-stakeholder initiatives at the national level to inform the negotiation of pricing for diagnostic technologies and services

Assist in collecting and monitoring pricing data

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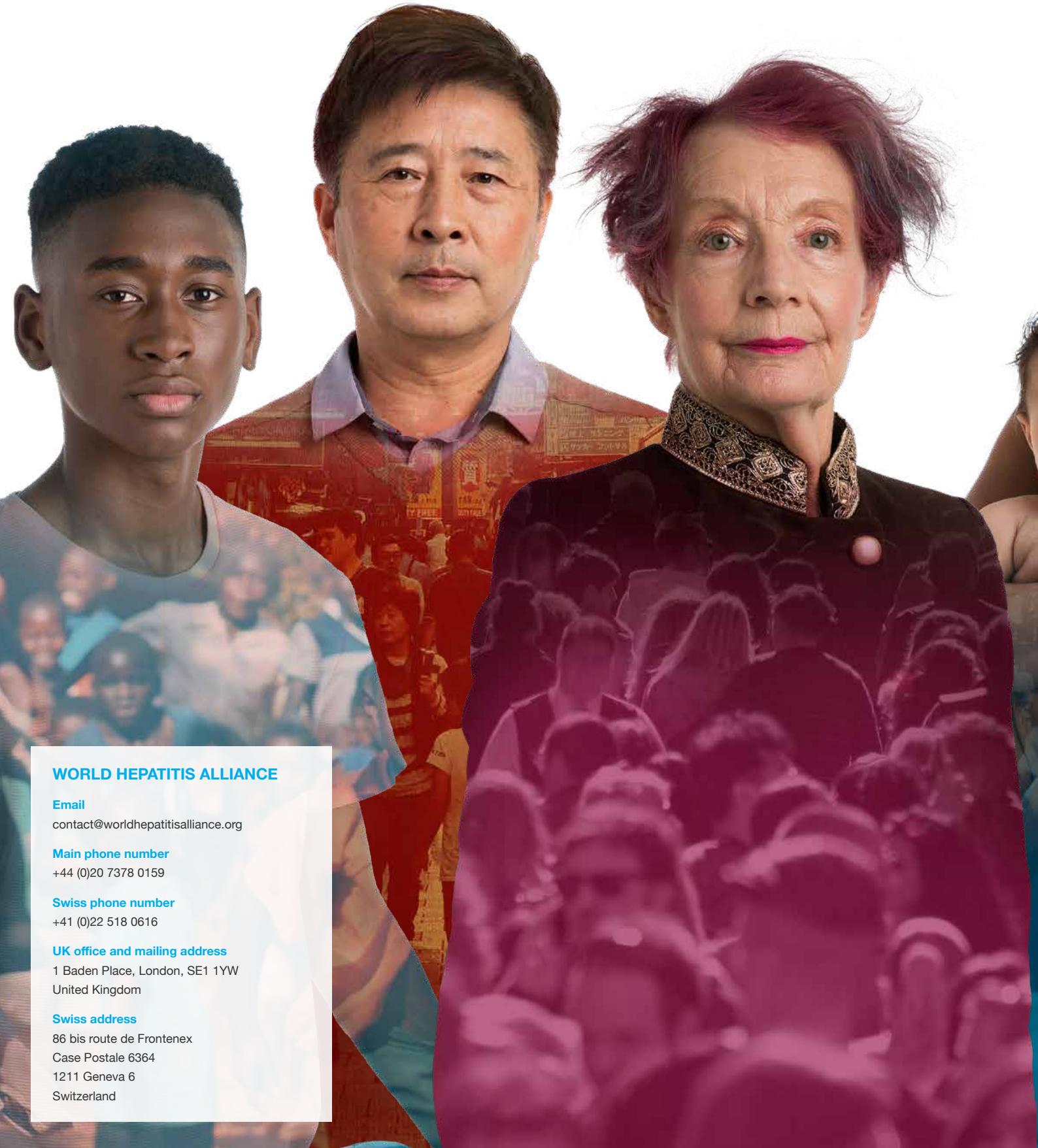

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