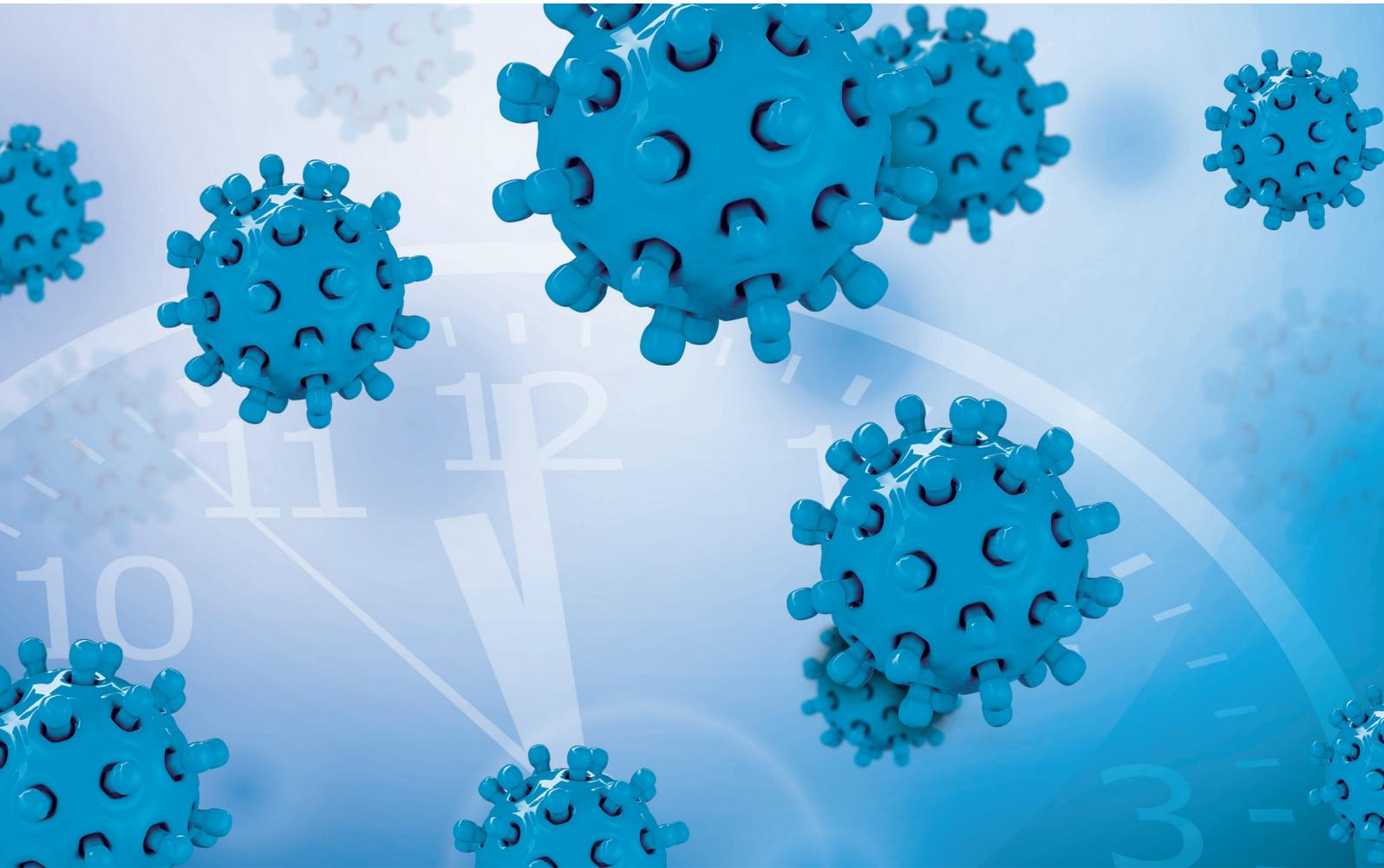


A report from the Economist Intelligence Unit.

TACKLING HEPATITIS C: MOVING TOWARDS AN INTEGRATED POLICY APPROACH



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Executive summary

Over a year after the publication of *The silent pandemic: Tackling hepatitis C with policy innovation*, The Economist Intelligence Unit's previous report on the subject, the hepatitis C virus (HCV) continues to pose a rising threat to healthcare systems worldwide.

As many as 170m people, or 2.4% of the world's population, are infected with HCV, according to the World Health Organisation (WHO), nearly five times the number estimated to be living with HIV.¹ While mortality rates as a result of acute hepatitis have remained relatively constant over the past ten years, deaths from HCV complications, such as cirrhosis of the liver, have seen a much sharper upward trajectory.

There are countries in each region of the world that suffer from high rates of infection: Georgia and Romania in Europe, Brazil and Argentina in Latin America, Mongolia, Indonesia and Taiwan in Asia, Egypt and Sub-Saharan countries in Africa, and the United States in North America. As a result, a number of these countries have played a leading role in multinational efforts to combat HCV.

In our earlier report we found that the lack of sufficient knowledge and data about the disease and its prevalence, poor public awareness, the failure to follow through consistently with treatment where testing is available, and high

rates of infection among marginal populations had created significant barriers to tackling HCV. In this update, we look at what progress has been made and the barriers that remain.

The key findings include the following.

Epidemiological data remain scarce, but awareness of the disease is growing. The continued lack of data remains a problem, with 2010 being the most recent year for which comprehensive global data are available. A number of governments as well as non-governmental organisations (NGOs) in countries ranging from Thailand to Brazil are accelerating efforts to improve education (particularly of high-risk groups), increase outreach programmes and make testing for the virus more accessible. Yet the number of those providing free testing remains small, eliminating another potential source of data about the spread of the disease. In addition, the relatively recent emergence of HCV means that many awareness campaigns and multinational initiatives are still focused on viral hepatitis more broadly, making it difficult to assess the extent to which national health authorities are addressing HCV separately from other strains of viral hepatitis.

NGOs and patient groups are taking the lead. Patients and advocacy organisations are

¹ *Bulletin of the World Health Organisation, 2012; 90:540-550; Guidance on prevention of viral hepatitis B and C in people who inject drugs, World Health Organisation, July 2012.*

playing a key role in shaping the policy agenda to tackle HCV. On a multinational level, groups such as the World Hepatitis Alliance (WHA), the European Liver Patients Association (ELPA) and the Coalition to Eradicate Viral Hepatitis in Asia Pacific (CEVHAP) have mobilised lawmakers and officials from the WHO to commit to a more integrated policy approach to help developing countries cope with what is expected to be an explosion of HCV cases over the next decade. “It’s an odd dynamic, where people are becoming more aware, but that hasn’t yet translated into real concrete action,” says Stefan Wiktor, team lead for the Global Hepatitis Programme at the WHO. “The idea is to try to harness some of this excitement and start moving it in a more aligned direction.” As a result, many initiatives during the past couple of years have focused on establishing multiple official pathways for the exchange of information and advice between the WHO, technical advisers, patient groups and national governments, including the WHO’s Framework for Global Action in 2012.

A better knowledge of the disease underscores the need for a co-ordinated response covering a range of areas. Healthcare stakeholders are becoming more aware of the way in which HCV progresses and of the potential for curing a

significant percentage of those who are infected if they are identified sufficiently early. As a result, more rapid testing and earlier diagnosis have become a priority for patient groups and health officials, as well as an important component of prevention. “What we see in general is that detection rates are slowly increasing, largely thanks to the activities of NGOs,” says Achim Kautz, vice president of ELPA. Initiatives with the greatest success rate so far tend to focus on HCV in a holistic way, rather than on one individual aspect.

Global variations in addressing HCV persist.

The ways in which governments deal with the threat posed by HCV vary substantially, with only a minority of countries—such as Egypt, which has the worst-affected national population (nearly one in five people have the virus)—taking a more aggressive approach to testing, surveillance and treatment. On a regional basis, countries in Africa (with the exception of Egypt), eastern Europe and Central Asia have begun to expand access to testing and diagnosis of the disease only relatively recently. By contrast, larger middle-income countries in Latin America and South-east Asia appear to be mobilising resources more successfully.

About this report

Tackling hepatitis C: Moving towards an integrated policy approach is an Economist Intelligence Unit report, commissioned and funded by Janssen, which investigates national and multinational policy initiatives to combat the hepatitis C virus (HCV). The findings of this report are based on desk research and interviews with a range of healthcare experts.

Our thanks are due to the following for their time and insight (listed alphabetically):

- Andrew Amato, head of the HIV/AIDS, STI and viral Hepatitis programme at the European Centre for Disease Prevention and Control
- Professor Adrian Streinu Cercel, National Infectious Diseases Institute “Prof. Matei Bals”, Romania

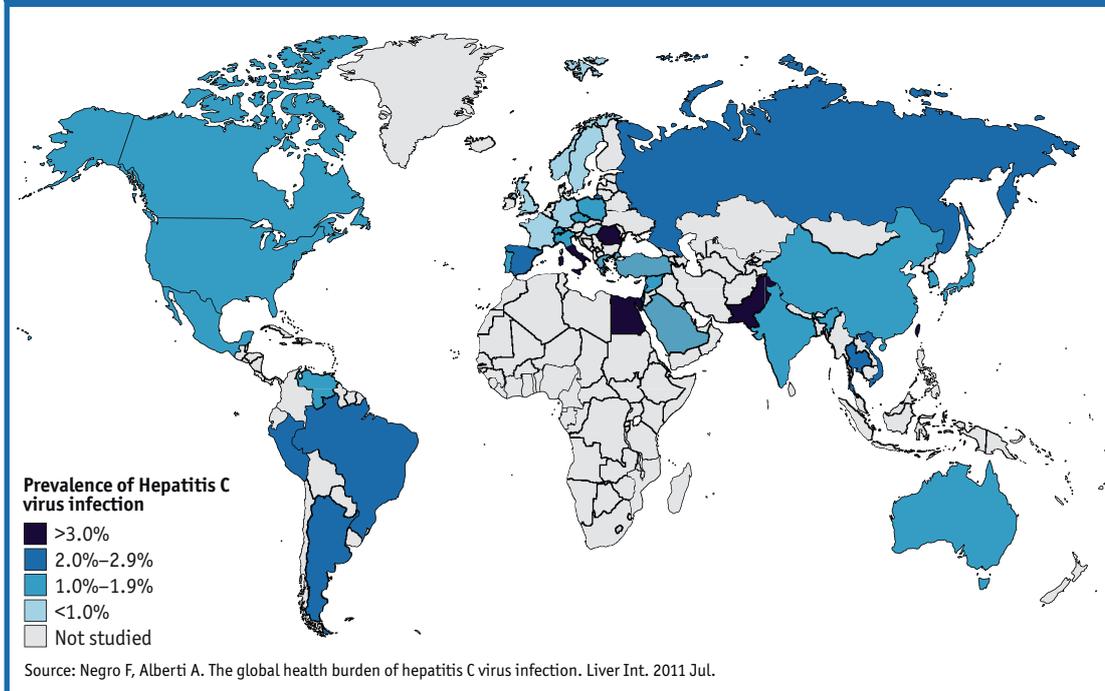
- Charles Gore, president, World Hepatitis Alliance
- Karyn Kaplan, director of International Hepatitis/HIV Policy & Advocacy, Treatment Action Group, New York
- Achim Kautz, vice president, European Liver Patients Association
- Els Torreele, director of the Access to Essential Medicines Initiative of the Public Health Programme, Open Society Foundation, New York
- Stefan Wiktor, team lead for the Global Hepatitis Programme, World Health Organisation

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1

Effective disease surveillance: The road to a joined-up solution

Prevalence of chronic HCV infection



The failure to adequately measure levels of chronic HCV in more than half of the countries surveyed by the WHO means that policymakers are missing the larger pool of undetected cases.

Elements of effective HCV control

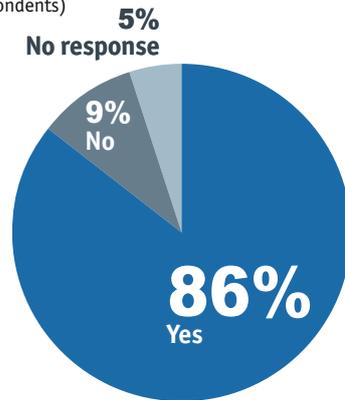
The hepatitis C virus (HCV) is usually symptomless for decades, all the while slowly damaging the liver and making treatment more costly and complicated. With most of those infected in the prime of their working life, HCV puts a heavy burden on healthcare systems and adds to the overall economic cost of the disease from missed days of work and health visits. These costs rise even further in the case of severe liver problems, which can require transplants or other treatments and procedures. As the disease peaks in many of the worst-affected regions in the next decade, these costs are likely to rise exponentially.

Yet HCV is largely curable, and early treatment can greatly diminish the level of cirrhosis and primary liver cancer. Good surveillance is thus a key part of the fight at both the national and the international level, and some countries have indeed made progress since our 2012 report. More than 85% of member states surveyed by the World Health Organisation (WHO) in its 2013 *Global policy report on the prevention and control of viral hepatitis* said they were conducting routine surveillance for acute HCV, although just 49% (such as Argentina, South Africa and Croatia) conducted surveys for the chronic form of the disease. In Africa, South-east Asia and the Americas the levels of HCV are 25%, 33% and 38%, respectively.

Types of surveillance in member states reporting the existence of routine surveillance for hepatitis C

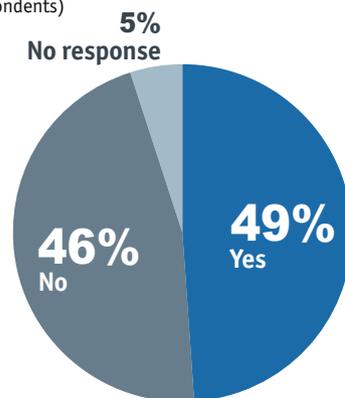
There is a national surveillance system for acute hepatitis C infection

(% respondents)



There is a national surveillance system for chronic hepatitis C infection

(% respondents)



Source: Global policy report on the prevention and control of viral hepatitis, World Health Organisation, 2013.

While the identification of acute cases can improve outcomes for those infected, it ignores the more significant threat facing many countries. Most governments, especially in poorer countries, are focusing on the incidence of the disease with initiatives that focus on marginal populations where the virus is concentrated, rather than dealing with the prevalence of the disease in the broader population. The failure to adequately measure levels of chronic HCV in more than half of the countries surveyed by the WHO means that policymakers are missing the larger pool of undetected cases. These are likely to be the biggest drain on government resources owing

to the cost of managing the complications of advanced liver disease.

“[European] member states have made huge progress in cleaning up their data,” says Andrew Amato, head of the HIV/AIDS, STI and viral Hepatitis programme at the European Centre for Disease Prevention and Control (ECDC), an independent EU agency, adding that many countries now separate acute and chronic HCV surveillance and more than half follow standard case definitions.

Patient and advocacy groups in the front seat

Where national governments have lagged behind, non-governmental organisations (NGOs) and patient advocate groups have increasingly stepped in to fill the gap. Groups such as the New York-based Treatment Action Group (TAG), which emerged from the HIV/AIDS activist movement, and the World Hepatitis Alliance (WHA) have helped advocates lobby for better awareness of the disease and better access to treatment and diagnosis options, as well as more simplified forms of care.

The European Liver Patients Association (ELPA) recently launched a project in conjunction with the WHA to work with European countries, analysing their current policies for addressing HCV and helping stakeholders to develop national strategies, according to Achim Kautz, vice president of ELPA. The programme has been completed in Romania and Germany and is currently running in Greece, with six more countries expected to participate by the end of 2014.

Regionally, the involvement of external stakeholders has taken a variety of forms. In western Europe and North America, charities and other organisations, such as the Hepatitis C Trust and ELPA, offer information and support to patients and, in the case of ELPA, analyse existing national and Europe-wide action plans to develop an advocacy strategy.

“

There are many barriers to tackling the disease that need to be taken into account. One is awareness, another is testing, and the healthcare system in a lot of countries isn't set up for it.

”

Stefan Wiktor, team lead for the Global Hepatitis Programme, World Health Organisation

In Asia, where patient groups have traditionally been less mobilised, the Coalition to Eradicate Viral Hepatitis in Asia Pacific (CEVHAP) raises awareness of the disease, builds ties between key regional stakeholders and conducts research to support evidence-based policy. In other regions, such as Africa and Latin America, however, there is little in the way of regional co-ordination of projects aimed specifically at those infected with hepatitis C.

Governments under pressure to confront HCV

A new generation of medicines has been shown to cure HCV infection in as many as 90% of patients, according to Stefan Wiktor, team leader for the Global Hepatitis Programme at the WHO. Against this backdrop, improving access to treatment creates a significant opportunity and underscores the need for broader national policies and consistent management protocols to tackle HCV.

Consequently, campaigners are putting more pressure on governments to improve data, testing and diagnosis procedures in order to widen access to treatment.

“There are many barriers to tackling the disease that need to be taken into account,” says Dr Wiktor. “One is awareness, another is testing, and the healthcare system in a lot of countries isn’t set up for it.”

A number of Latin American countries, including Argentina, Brazil, Costa Rica, El Salvador and Nicaragua, now offer free HCV testing to all individuals, as do other countries around the world such as Belarus, India, Iraq and Sudan. In Brazil, Georgia and Thailand, there has been a focus on ensuring that treatments are defined as “essential medicines” or covered by national health plans. Meanwhile, Egypt is continuing to develop its HCV patient registry, which launched in October 2012 with 32,000 patients. ■

Case study: Towards an action plan in Romania

In Romania, the road to a co-ordinated plan starts with a failure of sorts and is in many ways typical of developing countries in the obstacles the country faces in establishing an integrated approach to HCV.

There is an absence of reliable data regarding HCV prevalence, according to the Romanian Hepatitis Action Plan, which notes that this is largely due to “the lack of harmonised efforts to identify transmission channels and infection rates”.² The country is ranked 25th out of 30 countries in the European Hepatitis Index 2012, which measures hepatitis care delivery. A significant number of infections are believed to stem from the period before 1989, when blood supply was not routinely screened and reuse of needles was common, according to Professor Adrian Streinu Cercel of the National Infectious Diseases Institute “Prof. Matei Bals” in

Romania. Around 3.4% of the total population is estimated to be infected with the virus, although this rises to 12% in some regions, according to Mr Kautz of ELPA.

This has motivated the Romanian Liver Patients Association (APHO) to launch a national strategic plan to combat HCV. In June 2013 the group published a white paper looking at four main courses of action: prevention, detection, monitoring and treatment.

Campaigners are now seeing the first fruits of their efforts. A national registry for viral hepatitis, established in February 2014, will, when fully operational, screen patients for all varieties of the disease and also provide individual therapy and treatment protocols for patients. The number of patients estimated to need therapy is 300,000. ■

² *Romanian Hepatitis Action Plan*. Available at <http://www.elpa-info.org/elpa-news---reader/items/strategic-action-plan-against-hepatitis-in-romania-2013.htm>

Euro Hepatitis Index 2012 (comparison of hepatitis B and C care performance)

1 (top performer)	France
2	Slovenia
3	Germany
4	Sweden
5	Portugal
6	Italy
7	UK
8	Croatia
9	Norway
10	Spain
11	Ireland
12	Switzerland
13	Belgium
14	Netherlands
15	Austria
16	Denmark
17	Finland
18	Poland
19	Luxembourg
20	Malta
21	Bulgaria
22	Greece
23	Cyprus
24	Slovakia
25	Romania
26	Czech Republic
27	Hungary
28	Latvia
29	Estonia
30	Lithuania

Source: Health Consumer Powerhouse

2

The prevention imperative

Identifying the gaps

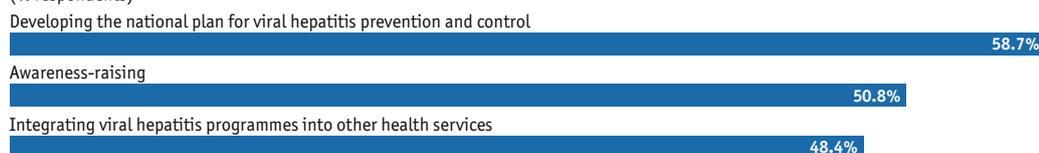
Improving prevention measures is crucial to reducing the impact of HCV, particularly as the potential to cure a large number of infected patients could relieve cash-strapped governments of the cost of expensive medical interventions resulting from long-term liver

damage and liver cancer. Initiatives worldwide range from primary prevention, such as limiting unsafe health practices or providing needle exchanges for people who inject drugs (PWIDs), to secondary prevention, such as testing for the disease and early treatment, which can identify those infected and improve their prospects of being cured.

"Viral hepatitis control and prevention: areas in which member states indicated interest in receiving WHO assistance "

Awareness-raising partnerships and resource mobilisation (first WHO strategic axis)

(% respondents)



Evidence-based policy and data for action (second WHO strategic axis)

(% respondents)



Prevention of transmission (third WHO strategic axis)

(% respondents)



Screening, care and treatment (fourth WHO strategic axis)

(% respondents)



* N = 113 (This response option was not included in the survey completed by Belarus, Columbia and countries in the South-east Asia Region. Source: Global policy report on the prevention and control of viral hepatitis, World Health Organisation, 2013.

“

The more we do awareness campaigns, the more countries are interested in discussing the hepatitis problem itself.

”

Achim Kautz, vice president, European Liver Patients Association

Prevention also requires better co-ordination within healthcare systems, particularly with regard to addressing low levels of knowledge about HCV among healthcare workers. The health system has been a major route for the transmission of HCV, primarily in developing countries, and while awareness of the need to screen blood products and avoiding the reuse of needles and other equipment has improved in countries such as Russia and Bulgaria (which both have national policies on injection safety and infection control for blood banks), progress towards eliminating dangerous behaviour remains mixed. Even in Egypt, which has the world's largest HCV treatment programme, there are some 500,000 new cases of HCV infection each year, according to F DeWolfe Miller, professor of epidemiology at Hawaii University. Scotland's Hepatitis C Action Plan is often cited as a leading example of making the prevention and treatment of HCV a mainstream healthcare matter [see case study in our 2013 report].

While different regions face very different levels of HCV infection, individual countries have worked together to provide leadership on international initiatives. Delegates from Brazil, Egypt, Indonesia and Mongolia spoke at the 66th meeting of the World Health Assembly, the decision-making body of the WHO, in 2013 and drafted a new resolution in January 2014 to push for more concrete progress in fulfilling the original 2010 WHO resolution, explains Charles Gore, president of the World Hepatitis Alliance (WHA). The new resolution calls for greater “synergies” between viral hepatitis prevention and control measures as well as between viral hepatitis and non-communicable diseases in the WHO Global Action Plan for 2013-20.

Patient groups and health authorities are nevertheless putting forward more specific recommendations to health bodies. ELPA's recent manifesto on policy measures to combat chronic liver disease in 2014-19 recommends that general practitioners make liver enzyme tests mandatory in routine medical check-ups

for people between the ages of 20 and 60, and that patients with elevated liver enzyme levels be tested for possible causes, including HCV. The American Association for the Study of Liver Disease (AALSD) recommends HCV testing at least once for anyone born between 1945 and 1965, a guideline also used by the US Centers for Disease Control and Prevention (CDC), as well as for healthcare workers exposed to blood products through contact with needles and patients who received blood transfusions or organ transplants before July 1992. It also advises annual testing for those with increased risk factors for HCV, such as PWIDs. “The more we do awareness campaigns, the more countries are interested in discussing the hepatitis problem itself,” says ELPA's Mr Kautz. Not only will information about HCV then filter through to the public at large, but it will also improve the ability of healthcare professionals to recognise and treat the disease.

HIV/HCV co-infection helps to channel campaigns

Globally, around 20% of people with HIV are also infected with HCV, estimates Dr Wiktor from the WHO. While research on the outcomes for co-infected patients remains limited, there is evidence that being HIV positive causes faster liver damage from viral hepatitis; co-infected patients are also twice as likely to develop cirrhosis as people who only have HCV, according to the Treatment Action Group (TAG).⁴

Many activists are taking lessons from the efforts of HIV/AIDS campaigners to demand earlier treatment. “One of the main things about the HIV-AIDS movement has been global solidarity, and HIV-AIDS advocates are now getting more interested in HCV because everyone realises that this is the new frontline,” says Els Torreele, director of the Access to Essential Medicines Initiative of the Public Health Programme at the Open Society Foundation in New York.

Both Karyn Kaplan, director of international Hepatitis/HIV Policy and Advocacy at the TAG, and Mr Gore of the WHA note that the WHO's

Globally, around 20% of people with HIV are also infected with HCV.

Source: WHO

³ <http://who.int/hiv/pub/guidelines/hepatitis/en/>

⁴ Karyn Kaplan and Tracy Swan, *Training Manual for Treatment Advocates: Hepatitis C Virus and Coinfection with HIV*, Treatment Action Group (TAG), New York, November 2013.

recent decision to include its viral hepatitis programme in its HIV programme will help to raise the profile of HCV. "Where HIV overlaps, there is quite a lot of expertise in things like guidelines," highlights Mr Gore, adding that there are potential synergies in diagnosis and treatment of both diseases. As an example he refers to the potential to share the costly laboratory equipment that the President's Emergency Plan for AIDS Relief (PEPFAR) of the US government has donated to HIV-ravaged developing countries. "You just need to change

the reagents and you can use 20% extra capacity in some countries," says Mr Gore. "Given the high risk of liver cancer in HCV patients, similar funding could be available from cancer prevention budgets." "We will need to integrate the hepatitis programme into a lot of existing programmes," he adds. "People have got to stop saying, can we afford a hepatitis programme and start saying, how can we afford it?"



3

Reaching out to vulnerable populations

Between 60% and 80% of people who inject drugs are infected with HCV worldwide.

Source: WHO

With surveillance still inconsistent in many countries, activists and healthcare providers are increasingly looking to reach out to those who are at particularly high risk of becoming infected with HCV. For activists and governments alike, the process of reaching out involves the recognition that socially marginalised populations have different needs, respond to different messages and frequently face stigma when dealing with healthcare staff that can dissuade them from getting tested or treated.

Against that backdrop, much of the activism and outreach in the past couple of years has targeted three separate groups: PWIDs, prisoners and vulnerable ethnic or national groups such as South Asian populations in the UK.

Between 60% and 80% of PWIDs are infected with HCV worldwide, according to the WHO.⁵ Working with PWIDs has often involved harm-reduction initiatives, which range from needle exchanges to the supply of methadone.

However, the global economic crisis has reduced government funding for some of these programmes. "There are countries that are managing to weather the economic crisis relatively well in funding their health services and countries where it is adversely affecting the prevention side of their work," says Dr Amato of the ECDC. He notes that a reduction in funding for harm reduction programmes targeted at PWIDs in countries such as Greece and Romania

could lead to an upsurge of both HIV and HCV in these countries.

Prisoners also tend to have a high prevalence of HCV, especially in developing countries, because of intravenous drug use and other risky behaviour such as tattooing. In Georgia, where 6.7% of the national population is infected—one of the highest rates in Europe—pressure from patient groups led the Ministry of Corrections to launch a programme in March 2014 to treat HCV-infected patients in the country's prisons, where 18% of deaths are the result of cirrhosis caused by HCV.⁶ The government has committed to extending the programme to universal national coverage by 2016.

"Everyone [in Georgia] knows someone who is affected by HCV, but until recently there was no treatment available whatsoever," explains Dr Torreele of the Open Society Foundation. "Once patient groups started raising awareness, people were very attentive, and there was a lot of pressure on the government to start looking into it."

Elsewhere, campaigns have focused on high-profile public messages. In the UK, the Hepatitis C Trust runs a mobile outreach van that travels around the country offering free testing and onward referrals to those who test positive. The van focuses its efforts on events or areas with target populations, including PWIDs, the homeless and South Asian populations.

⁵ *Prevention & Control of Viral Hepatitis Infection: Framework for Global Action*, World Health Organisation, 2012.

⁶ The 18% figure is from "Fight for C Hepatitis treatment in full force", by Irma Kakhurashvili, *Georgia Today*, Issue 676, August 2013.

Case study: The benefits of peer education in Thailand

In Thailand, up to 90% of people who inject drugs (PWIDs) have been found to be infected with HCV.⁷ But with testing and treatment services still not widely available and PWIDs facing high levels of stigma and discrimination in healthcare settings, many are unable to find out about their HCV status.⁸

The Mitsampan Community Research Project conducted a study from July through October 2011 to see how these barriers might be overcome.⁹ The researchers trained 440 community-recruited intravenous drug users as peer educators and taught them how to administer surveys. Although the study generally found that only one-third of participants were aware of their status, those who had received peer-based education on HCV were significantly more likely to have had an HCV test.

The Thailand Treatment Action Group has also developed a peer-education curriculum with other NGOs, which has been employed in harm reduction drop-in centres in most regions of Thailand, reducing the harmful consequences of activities such as intravenous drug use. Part of this process could ultimately involve integrating HCV into the training and treatment programmes of Population Services International, a global health organisation, and the Global Fund, an international financing organisation, which are already available to HIV-infected PWIDs, according to Karyn Kaplan, director of international Hepatitis/HIV Policy and Advocacy at the TAG in New York. However, the peer education model has remained largely the preserve of NGOs and international organisations, with the Thai government still reluctant to support such programmes.

In Thailand, up to 90% of people who inject drugs (PWIDs) have been found to be infected with HCV.

⁷ L Ti, K Kaplan, K Hayashi, P Suwannawong, E Wood, T Kerr, "Low rates of hepatitis C testing among people who inject drugs in Thailand: implications for peer-based interventions", *The Journal of Public Health*, Vol. 35, No. 4, pp 578-584, January 18th 2013.

⁸ Ibid.

⁹ The project is a collaboration between the Mitsampan Harm Reduction Centre in Bangkok, the Thai AIDS Treatment Action Group, Chulalongkorn University and the British Columbia Centre for Excellence in HIV/AIDS.

Conclusion

Awareness of the scale of the HCV problem has clearly grown since our last report, and with it the determination of governmental and non-governmental groups to lay the groundwork for both closer consultation and a route to more co-ordinated national strategies for dealing with the virus. Yet concrete initiatives remain thin on the ground, and a continued lack of resources, including scarce data about the scale of the problem in individual countries, is impeding further progress.

This is particularly dangerous as inaction is arguably the riskiest form of behaviour associated with HCV, leading to increased cases of liver cancer, with costlier treatment and worse outcomes, as well as higher rates of transmission of the virus. ELPA's recent manifesto on chronic liver disease notes that undiagnosed and untreated cases of HCV will lead to further deterioration in patients' conditions and an increasing burden on European health systems. "The peak is expected for 2020 to 2025," it concludes. "If Europe wants to avert this peak, it must act now."

Patient groups and other advocates for those infected with HCV have nevertheless shown that greater awareness of the problem and public pressure can in some cases produce rapid responses from governments. While the scale of the problem and the potential solutions differ from one country to another, a number of conclusions can be drawn from recent developments.



Surveillance needs to improve and be integrated with national strategies.

Better data on infection rates and the groups most affected are crucial to formulating a national policy on HCV. National governments should continue to use the advice and resources available from both multinational institutions, such as the WHO, and grassroots organisations to tailor health systems so that they establish standards that are appropriate for local conditions and circumstances, and integrated care models that are effective in terms of both patient uptake and outcome.



Screening and diagnosis are key components of prevention and must reach vulnerable groups.

With the newest treatments potentially able to eradicate the virus in a significant proportion of cases, screening and early diagnostic options will allow for earlier treatment and more simplified forms of care, ultimately reducing transmission among marginalised populations.



Better outreach can help mobilise support for co-ordinated initiatives.

Activists and patient groups have found a number of successful ways to target messages at both high-risk groups and the general population. Increasing awareness will be key to mobilising healthcare stakeholders and educating patients as the disease reaches peak levels in the next decade.

While every effort has been taken to verify the accuracy of this information, The Economist Intelligence Unit Ltd. cannot accept any responsibility or liability for reliance by any person on this report or any of the information, opinions or conclusions set out in this report.

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