Department of Health
An Roinn Sláinte
Männystrie O Poustie
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Public Health Agency

Northern Ireland Hepatitis C Elimination Plan

Phase 1, 2021-2025

Introduction

The opportunity of eliminating hepatitis C as a public health threat is truly an extraordinary one. This serious health condition can lead to liver failure, cancer and death. Hepatitis C can now be tested for, treated, and cured. Testing can be done on just a few drops of blood. The mainstay of treatment is now oral tablets, taken once daily, for 2 to 3 months. Even in this era of modern medicine, there are few chronic diseases that can actually be cured.

Furthermore, there is evidence that being treated for hepatitis C can be life changing for individuals in terms of their own self-esteem, and can be a pivotal moment for people in ‘turning their lives around’ and making positive changes to lifestyles. Hepatitis C treatment has proven to be a very positive way of engaging with people who feel marginalised by society, of rebuilding trust with healthcare professionals, and therefore acting as a gateway to healthcare services.

Significant progress has been made with tackling hepatitis C in Northern Ireland over recent years, and since the 2006-2008 Hepatitis C action plan for Northern Ireland. This has largely been driven by the efforts of the Northern Ireland Hepatitis B and C Managed Clinical Network. A key milestone was the roll-out of new oral treatments which have cured over 97% of people treated here.

Hepatitis C elimination is, however, a complex issue. Some people find it more challenging to access treatment than others, and we must ensure that those who need treatment the most are supported to access it. Over 3,000 people in Northern Ireland have tested positive for hepatitis C since 1996; approximately half of these have been referred for treatment; and just over 1,000 have been treated to date.

Prevention and case finding are as important and necessary as treatment and care. There is little point in investing heavily in treatment services if people are not enabled to protect themselves from becoming infected and re-infected. We need to ensure that harm reduction services are optimised. The previous backlog of those waiting for hepatitis C treatment has been cleared following the roll out of new medications, and to achieve elimination there needs to be a step change in testing of priority populations to find remaining cases, particularly in people who inject drugs, and those in prison.

To achieve maximum impact, the collective action and support of all key stakeholders will be required, underpinned by the Health and Social Care values of working together, compassion, honesty, and providing excellence in care. Working in collaboration across different sectors, sharing insight and best practice, will help to drive improvements in the care of those at risk of, or with hepatitis C infection.

Strategic context

The World Health Organisation (WHO) has set out a commitment to eliminate hepatitis B and hepatitis C as major public health threats by 2030. The United Kingdom has signed up to achieve this goal, and England and Scotland have set earlier elimination dates of 2025 and 2024 respectively. This action plan focuses on hepatitis C elimination in Northern Ireland over the next 4 year period, from 2021 to 2025. A further plan will follow to cover 2025 to 2030.

Hepatitis C infection remains disproportionately prevalent in several marginalised groups. Making Life Better, the strategic framework for public health in Northern Ireland, sets out the overriding approach of a need for greater intensity of action for those with greater disadvantage. Our elimination efforts must therefore ensure that response is proportionate to need, with a particular focus on engaging with marginalised groups to raise awareness that this is a curable condition, encouraging people to get tested, and helping more people to access treatment.

Vision and aims

Our vision is to eliminate hepatitis C as a public health threat in Northern Ireland by 2025.

Beyond 2025, we will seek to reduce hepatitis C infection to an absolute minimum, relegating it to a rare disease of the past, similar to polio.

The overall aims of the action plan are:

1. To galvanise commitment and co-ordinate action to tackle hepatitis C across a large number of individuals, groups and organisations across Northern Ireland;

2. To build on existing activities to prevent and pick up cases of hepatitis C;

3. To provide professionals and service users with the information and support needed;

4. To gather robust data to inform the development and evaluation of services, and monitor progress towards achieving hepatitis C elimination targets;

5. To ensure services are designed to be truly accessible for service users.

The action plan will be a living document responsive to emerging threats or challenges, developments or changes to our understanding, and progression of services or guidance over time. It is recommended that all action points are reviewed annually for progress and updated if necessary. By 2025, any major concerns that relate to achieving 2030 targets for hepatitis C elimination as set by the WHO and in keeping the Northern Ireland context should be highlighted, and attempts to rectify this should be addressed through amendments or additions to the recommended actions going forwards.

COVID-19 is a challenge that has emerged during 2020. Reprioritisation of staff and resources led to a delay in publishing this action plan, and services have reported reduced testing and treatment initiations for hepatitis C. It is important that we are agile in our ways of working in order to respond to these challenges in order to move towards hepatitis C elimination.

A multi-agency hepatitis C elimination oversight group, chaired by the Chief Medical Officer (CMO) for Northern Ireland, has been established. This group has responsibility for approval of the action plan, monitoring progress towards elimination, and delivery on the targets set out within the plan. The Health Protection branch will provide progress updates to the CMO every 6 months.

The PHA and Hepatitis B and C Northern Ireland Managed Clinical Network will be responsible for the implementation of the action plan, and will report to the chair of the hepatitis C elimination oversight group.

Development of plan

The hepatitis C elimination action plan for Northern Ireland has been informed by:

1. Evaluation of the 2006-2008 hepatitis C action plan for Northern Ireland;
2. Stocktake of progress with tackling hepatitis C in Northern Ireland since the last action plan, including a forward look at remaining gaps, challenges, and barriers;
3. A series of engagement exercises with stakeholders (listed in appendix 1), including experts by experience;
4. Review of the epidemiology of hepatitis C in Northern Ireland, with the understanding that, globally, epidemiological data is limited;
5. Review of evidence to identify effective interventions in hepatitis C prevention, case-finding and linkage to care;
6. Engagement with those leading hepatitis C elimination efforts across the UK and Ireland, and shared learning from their experience;
7. Publication of findings to date in the stocktake paper in January 2020, including draft recommendations;
8. Consultation with stakeholders.

A stakeholder engagement event was arranged for March 2020, however, this was cancelled due to COVID-19 and the associated lockdown restrictions. In place of the workshop, a targeted online consultation for those who were invited to attend the event was conducted, and the plan revised to take into account the responses received.

Targets

Northern Ireland is a low prevalence country for hepatitis C, and hepatitis C related mortality is already in single figures. This puts us in an excellent position to achieve hepatitis C elimination as a public health threat by 2025.

The proposed impact targets for Northern Ireland are:

- Reducing the number of new chronic infections diagnosed and maintaining hepatitis C chronic cases at ≤5 per 100, 000 of the population;
- Maintain hepatitis C viraemia related mortality in single figures, or lower.

The proposed service coverage targets include prevention, testing and treatment targets.

Prevention targets:

- Adequacy of needle and syringe exchange availability, as self-reported by service users; and
- Minimum of 300 sterile needle and syringe sets distributed per person per year.

Testing targets:

- 90% of people who inject drugs attending addiction services tested for hepatitis C within previous year (Commissioning plan direction, monitored by HSCB);
- Every person is offered a test upon arrival to the prison, with a minimum of 95% being tested by 2023; and
- Interim minimum testing threshold of 50% to be achieved by end of 2021.

Treatment targets:

- 100% of those eligible and willing for treatment being treated;
- Treatment available after one PCR positive test result;
- Accelerated access to treatment for those who are at high risk of infecting others;
- Micro-elimination of hepatitis C in the Northern Ireland prison estate by 2023;[1]
- Pathway for prisoners for treatment of hepatitis C on release to the community;
- Out-reach treatment available for all those unwilling or unable to attend conventional services.

[1] To achieve 'micro-elimination' within a prison, there are several key factors:

- Every person is offered a test upon arrival to the prison, with a minimum of 95% being tested;
- A minimum of 90% positive patients are commenced on treatment;
- Prisons have regular, quarterly reviews of uptake of screening, and need for assertive outreach;
- A whole prison testing programme is being delivered.

Priority populations

Why:

Certain populations experience a disproportionate burden of hepatitis C infection, and challenges in accessing care. Barriers to accessing care include stigma, perceived attitudes of healthcare workers, low regard for own health, challenges in keeping fixed appointments, and practical barriers such as lack of transport, finance or a companion to help them attend appointments.

Over two thirds of those treated for hepatitis C infection in Northern Ireland have a history of injecting drug use, for example: heroin, cocaine, or image or performance enhancing drugs. Surveys would suggest that around 29% of people who are injecting drugs in Northern Ireland have been infected with hepatitis C at some stage. This population is a priority in terms of the clear burden of experiencing hepatitis C infection. Within this population, priority risk factors include homelessness, addictions, and admission to prison. Other populations include: people who were infected with blood/blood products, healthcare staff with needle stick injuries, those with experience of the custodial system and people from countries when hepatitis C is common.

What:

We will ensure that harm reduction, testing and treatment services are accessible, and acceptable to people who are members of these groups.

How:

- *'Nothing for me without me'* - Co-design of services, ensuring experts by experience are meaningfully involved in the design and evaluation of hepatitis C prevention, testing and treatment services;
- Identifying and addressing barriers to harm reduction, testing and treatment;
- Peer support;
- Education of those in priority groups;
- Education of health and social care staff and others supporting these groups;
- Micro-elimination of hepatitis C in the Northern Ireland prison population[2];
- Pathway for prisoners for treatment of hepatitis C on release to the community;
- Having an addiction centre willing to act as a treatment hub within each trust;
- Testing targets being achieved within all addiction centres in Northern Ireland.

With:

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[2] To achieve 'micro-elimination' within a prison, there are several key factors:

- Every person is offered a test upon arrival to the prison, with a minimum of 95% being tested;
- A minimum of 90% positive patients are commenced on treatment;
- Prisons have regular, quarterly reviews of uptake of screening, and need for assertive outreach;
- A whole prison testing programme is being delivered.

Service user groups, PHA, Hepatitis B and C Managed Clinical Network, Health and Social Care Board (HSCB), prisons, network, community and voluntary sector, Northern Ireland New Entrants service (NINES)

Stigma and misinformation

Why:

Service users report that hepatitis C is still a heavily stigmatised condition. Patients encounter stigma in their daily life, including from peers, the general public, and health care workers.

Quotes from focus groups:

'I can tell you why there is stigma. It is related to dirty needles and dirty sex'

'It turns into AIDS'

'No-one would tell you they had it'

'I would be suicidal if I found out I had it'

What:

We will seek to address stigma and improve understanding.

How:

- Baseline survey of knowledge and attitudes towards hepatitis C in priority groups, and for those working with these groups including: community and voluntary sectors, prisons, custody suites, and healthcare providers;
- Education and awareness raising in priority groups, and in those working with these groups;
- Peer advocates and educators, particularly in those at risk of injecting drugs and in prisons;
- Develop and implement curricula and training to increase knowledge and tackle stigma among all healthcare staff, those working in prisons, custody suites and police services.

With

PHA, Hepatitis B and C Managed Clinical Network, Community and voluntary sector, Experts by experience

Prevention

Why:

Hepatitis C is a preventable infection. In order to eliminate hepatitis C, it is essential to optimise prevention efforts.

What:

We will ensure that evidence based methods of prevention including needle and syringe exchange services, and treatment services for addiction including opiate substitution therapy, are easily accessible and available to those in need. This may require prioritisation of certain services for those who are known to be infected with hepatitis C in order to reduce the risk of onward transmission and new infections.

How:

- Make every encounter matter: ensure all relevant interactions include sign posting to advice and support for harm reduction by providing all relevant services with access to up-to-date information resources including advice and services in the local area;
- Peer education and support in harm reduction services;
- Ensure adequacy of provision of needle and syringe exchange services, including establishing mechanisms for accurate measurement of packs distributed per person, and through patient feedback;
- Maximise access to needle and syringe exchange services by ensuring all services who are involved in caring for people who inject drugs are able to provide needle and syringe exchange services;
- Implement the recommendations of the 2019 review of addiction services; in particular, reduce the waiting time to 3 weeks;
- Increase the proportion of people who inject drugs who are accessing opioid substitution therapy by improving access and referral via outreach services;
- Ensure people who inject drugs diagnosed with hepatitis C infection are considered for prioritisation for opioid substitution therapy to reduce risk of onwards transmission.

With:

Hepatitis B and C Managed Clinical Network, PHA, Drug and alcohol treatment services, Prisons, Community and voluntary sector

Testing and diagnosis

Increase diagnosis of existing cases of hepatitis C

Why:

It is estimated that 2 out of 3 people who are infected with hepatitis C do not know they have it. This puts their own health is at risk, and hepatitis C is curable - if you know you have it. These people are also risk of passing it on to others unwittingly. NICE guidance (PH43) on testing for hepatitis B and C recommends that all people who are at risk should be tested at least annually. Given the common risk factors for hepatitis B, hepatitis C, and HIV, it is advised that when a test is indicated for one of these infections, all are tested for.

We have limited information on how complete our testing of high risk populations is. We do know that approximately 13% of prison committals are tested annually, and this has remained stable over the last 5 years. The target for testing of committals in England is now 75%. We do not know what the testing rates are in addiction services, however, some small audits have shown this is suboptimal.

What:

We will seek to increase testing and diagnosis of hepatitis B, C and HIV by using innovative and proactive, outreach approaches that are acceptable to service users. Key settings for case finding include: addiction services, community pharmacies, custody suites, prisons, primary care, emergency departments, migrant, and outreach homeless services. There is significant potential for building on existing needle and syringe exchange services to provide early diagnosis through rapid testing in the community pharmacy setting.

How:

- Consider streamlining testing pathways, in particular, consider moving away from existing the two stage testing pathway (initial test, followed by repeat test in 3 months) to a single test and rapid treatment model for certain priority groups;
- Peer education and sign posting for testing;
- Increase access to testing for at-risk groups;
- Opt-out testing for all at high risk, particularly for all prison committals, those using addiction services, and commencing on opioid substitution therapy;
- Making testing an integral part of the committal process in prison;
- Minimum of annual testing for those who continue to be at risk;
- High intensity testing events;
- Ensure dried blood spot testing (or capillary blood testing) is available in all services caring for those at increased risk, including homeless, addiction and prison health services;
- Improve governance and surveillance of dried blood spot (or capillary testing) testing in Northern Ireland;

- Consider use of point of care testing in prison healthcare;
- BBV testing champions in key settings, with an over-arching testing coordinator;
- Better recording and monitoring of offer and uptake of test, particularly in addiction services and prisons;
- Design a testing protocol for Emergency Departments to include hepatitis B and C, building on the existing HIV testing protocol;
- Building on existing needle and syringe exchange services to provide early diagnosis through rapid testing in the community pharmacy setting.

With:
Hepatitis B and C Managed Clinical Network, PHA, HSCB, Trusts, Prisons, Community Pharmacies, Community and Voluntary Sector

Linkage to treatment and care

Why:
Hepatitis C can be cured in the majority of cases, with a 2 to 3 month course of oral medication. Once cured, people are no longer at risk of passing it on. However, many people who have been diagnosed with hepatitis C have not been treated for a number of reasons. They may have been diagnosed at a time when the treatments were less effective, and are unaware of the new treatments.

Key barriers identified to completing treatment included: delay from testing to treatment, stigma, difficulty in travelling to regional centre in Belfast, and treatment not locally available, lack of trust in healthcare professionals, chaotic lifestyles making fixed appointments inaccessible, lack of support to attend appointments, and continuing to inject drugs. There is currently no policy regarding treatment of people who are continuing to inject, and also for treatment of those who are re-infected. These two groups are likely to be at the highest risk of transmitting hepatitis C, and therefore should also be prioritised for treatment where possible.

What:
We will seek to increase the number of people with hepatitis C who complete treatment, by designing patient centred treatment pathways and removing barriers to treatment.

How:
- Ensure treatment is readily accessible to service users in each Trust area, ideally delivered within services already used by priority groups, for example nested in addiction services, GUM, homeless services, prisons and community pharmacies;
- Expand the pool of those able to treat hepatitis C, with supervision and oversight of the hepatology team;
- Promote the message that hepatitis C is now curable with public messaging;
- Identify and address barriers for individual patients;
- Ensure patients are aware of options for assistance with transport costs;
- Additional support to attend appointments, for example, peer support or key worker support;
- Remove barriers to treatment for those who continue to inject, and those who are re-infected and ensure adequate support through the treatment process, availing of peer services;
- Consider a multi-disciplinary approach for those who continue to inject, and those who are re-infected, to ensure adequate support is given for successful treatment and long term cure;
- Minimise delays between test and treatment, similar to the test and treat model in English prisons;

- Streamline the prison testing and treatment pathway in order to treat as many people as possible during a custodial sentence;
- Re-engage those who have tested positive for hepatitis C, but have not been treated;
- HSCB Regional Group for Specialist Medicines to review dispensing arrangements for direct acting antivirals for Hepatitis C, with consideration given to dispensing in community pharmacies;
- Each trust having an addiction centre as a ‘treatment hub’.

With:
Clinical hepatology team, Hepatitis B and C Managed Clinical Network, PHA, HSCB, Trusts, Prisons, Community Pharmacies, Community and Voluntary Sector

Peer support

Why:

There is evidence that peer support can be effective in harm reduction services, encouraging people to get tested, and helping people to complete hepatitis C treatment.

What:

We will seek to have peer support embedded in education, harm reduction, testing and treatment services

How:

- Learn from existing hepatitis C peer support programmes in UK and Ireland;
- Explore linkages with existing peer support programmes;
- Explore linkages with peer support programmes under consideration by PHA for harm reduction services;
- Work with prisoner engagement lead to develop peer support in prison setting, for example, using the health champion, or listeners;
- Consider establishing a role for a hepatitis C peer worker within the Hepatitis B and C clinical network.

With:

PHA, Trusts, Hepatitis B and C Managed Clinical Network, Community and Voluntary Sector

Systems for monitoring progress

To ensure we are working towards elimination of infection

Why:

There are significant gaps in knowledge about hepatitis C in Northern Ireland. We need better information about the number of people living with chronic hepatitis, and those with new infections.

Data on uptake of testing in priority populations is incomplete, particularly in addiction services. We don't currently have good estimates of the size of the population of people who inject drugs in Northern Ireland. Our participation in the UK-wide Unlinked Anonymous Monitoring Survey, which gives information on risk behaviours and population prevalence of infection, is relatively small. We are not currently able to obtain individual level data on adequacy of needle and syringe exchange.

What:

We will obtain better information on the population at risk of hepatitis C, improve monitoring of testing activity, and enhance surveillance arrangements.

How:

- A review of surveillance arrangements for hepatitis C;
- Recommend to the NI Assembly that hepatitis C is designated a notifiable condition;
- Monitor adequacy of coverage of harm reduction services through a harm reduction database;
- Monitor and increase testing activity within priority populations;
- Consider carrying out an anonymous prevalence sero-survey, on routine biochemistry samples and on antenatal screening samples;
- Increase participation in the Unlinked Anonymous Monitoring Survey;
- Consider a pilot of antenatal screening for hepatitis C.

With: PHA, HSCB, Trusts, GPs, Prisons, Hepatitis B and C Managed Clinical Network

Enablers

1. People:

- Identify gaps in existing services;
- Develop confidence and competencies with offering hepatitis C testing for those working with priority populations;
- Use the experience of service users to inform the development of services, and embedded in prevention, testing, care and support;
- Consider how to tap in to the resource of the community and voluntary sector, many of whom are already engaged with the priority groups.

2. Ways of working:

- Facilitate communication and build upon collaborative working within and between teams, particularly between addiction, prison and hepatology, to increase support and engagement with treatment;
- Streamline care pathways, for example, by embedding testing and treatment in addiction and prison services;
- Avail of new opportunities to work in partnership with the pharmaceutical industry via a new collaboration between the Association of the British Pharmaceutical Industry (ABPI) and the Medicines Optimisation Innovation Centre (MOIC);
- Ensure healthcare workers are aware of services in their area for support.

3. Technologies:

- Invest in dried blood spot (or capillary testing) and point of care testing;
- Develop a web-based system for needle and syringe providers, including a unique identifier to track risk factors and usage of services;
- Improving access to fibro-scanners in each Trust area, including portable fibro-scanners as required.

4. Knowledge and evidence:

- Actively share insights, knowledge and evidence across the five nations, perhaps by setting up a 5 Nations hepatitis C elimination group.

Appendix A

List of stakeholders who contributed to the development of this elimination plan

- Addiction and Opioid Substitution Treatment Services
- Antenatal Infection Screening Programme
- BeBe - Belfast Experts By Experience
- BHSCT Homeless Nursing Team
- Clinical Lead for the NHS England Hepatitis C Elimination Programme
- Council for the Homeless NI
- Drug Outreach Team (DOT)
- Emergency Department
- Extern
- Genitourinary Medicine
- General Practice
- Health and Social Care Board (HSCB)
- Hepatology B and C Managed Clinical Network
- People in prison custody
- Prison health services (SEHSCT)
- Public Health Agency (PHA)
- Regional Service User Network
- Virology Specialists