

Sexual Health and Blood Borne Virus Framework

2015-2020 Update

SEXUAL HEALTH AND BLOOD BORNE VIRUS FRAMEWORK

2015-2020 UPDATE

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MINISTERIAL FOREWORD



It has been four years since we brought together our separate policies on sexual health, hepatitis C and HIV into the *Sexual Health and BBV Framework*. A great deal has happened over that period, and we have made significant progress in some areas, as this update to the Framework sets out. But the job is in no way complete, and we were clear four years ago that the high-level outcomes we identified would not be delivered quickly – this was always a much longer journey. We remain ambitious about continuing that journey, about setting ourselves testing targets and about trying to tackle difficult problems in this important area.

However we must acknowledge that there are challenging times ahead. With increasing pressure on the NHS and public sector, with welfare cuts exacerbating problems for many vulnerable people, and with changes in society and culture it is not enough for us simply to do 'more of the same'. We have to think differently and react and adapt to emerging issues and opportunities. This updated document seeks to do that, in our commitment to research, in our commitment to tackling viral hepatitis, and in the way we will respond to key developments in the world of HIV and sexual health. We will build on our successes and continue trying to find solutions to those problems we haven't yet solved.

I am proud of what we have achieved over the last four years. I am proud of the original Framework and its ambition to improve services, to better support people who are affected or at risk, and to support the NHS and other service-providers in the work they do. I am particularly proud of our bold commitment to challenge stigma in all its forms. I believe that over the next five years, through this updated Framework and by building on the excellent foundations that have been laid, we can continue to make real progress towards a society whereby attitudes towards sexual health, HIV and hepatitis are supportive and non-stigmatising, and towards healthy relationships based on choice and free from coercion or harm.

Scotland is leading the way on a number of issues covered by this Framework, and I am keen that we can achieve a similar level of success across the piece. I look forward to working closely with those involved over the coming years to make that a reality.

A handwritten signature in black ink that reads "Maureen Watt".

Maureen Watt MSP
Minister for Public Health

INTRODUCTION

The first *Sexual Health and Blood Borne Virus Framework* was published by the Scottish Government in 2011. The Framework brought together policy on sexual health and wellbeing, HIV and viral hepatitis for the first time. It set out five high-level outcomes which the Government wished to see delivered, and it sought to strengthen and improve the way in which the NHS, the Third Sector and Local Authorities supported and worked with individuals at risk of poor sexual health or blood borne viruses.

Four years have passed since the Framework was published and much work has been undertaken. In some areas good progress has been made, in others it is still early days. When the Framework was published it was clearly recognised that the five high level outcomes would not be delivered within the lifetime of that policy document. The Framework was intended to be the first steps upon a longer journey.

This document is an update to the 2011 Framework. This is not intended to present a significant change in direction, nor to replace the original Framework. As well as reporting on progress, this update seeks to reflect on experience over the last four years to refine main messages. It will identify key emerging issues where more focus is now needed and set out where a different approach is now possible. This document also recognises that teenage pregnancy, which was addressed in the original Framework document, will now have its own separate strategy document, to be published by the Scottish Government in early 2016. There will continue to be links between the two policy areas, as reflected throughout this document.

The original *Sexual Health and Blood Borne Virus Framework* remains an important underpinning policy document, and this update should be read alongside it. In an effort to keep this document as concise as possible no attempt is made to re-state or reiterate the main points from the original Framework.

This updated document outlines the specific areas of focus for 2015-2020.

THE OUTCOMES: PROGRESS AND UPDATE

The *Sexual Health and Blood Borne Virus Framework* set out five high-level Outcomes that were relevant across the topic areas. These have guided activity over the last four years and although progress has been made the Outcomes remain relevant. The Outcomes are re-stated here, with a brief summary on progress over the last four years and an outline of on-going issues and priorities. More detail is provided within the following subject chapters.

Outcome 1: Fewer newly acquired blood borne virus and sexually transmitted infections; fewer unintended pregnancies¹.

Good progress has been made in reducing new hepatitis C infections, but this progress is fragile and needs to be maintained by a continued commitment to prevention. We continue to face challenges in preventing new HIV infections and sexually transmitted infections (STIs). Over the first four years of the Framework the Scottish Government has invested in research undertaken by NHS Greater Glasgow and Clyde and NHS Lothian to inform HIV prevention strategies for men who have sex with men (MSM), and we need to translate that research and other emerging evidence into practice. Work has also been carried out to improve access to longer acting reversible contraception (LARC) and to sexual health services. At least in part because of these efforts the rate of abortions has fallen annually since the launch of the Framework and the number of live births has also fallen. However we need to continue our work to prevent STIs and to provide good quality contraceptive options to further reduce unintended pregnancies.

Outcome 2: A reduction in the health inequalities gap in sexual health and blood borne viruses.

The Framework stated the importance of health inequalities to the subjects of sexual health and blood borne viruses, and much work has been done locally and nationally to reduce such inequalities. However, the greatest impact of poor sexual health and blood borne viruses (BBVs) continues to be on those who are most vulnerable in our society. The broad financial context and welfare and benefits changes are major drivers and influencers of health inequalities.

In order to make progress we have to understand the population groups in which we wish to see change. More work needs to be done to define this robustly, to ensure we can target resources and monitor impact. In 2014 the Scottish Government surveyed a representative sample of 1,500 adults who had been in a sexual relationship in the past year.² Amongst other findings this survey identified that those with a disability or illness were more likely to have experienced a sexual health and wellbeing issue with a potentially negative impact, as were respondents who were lesbian, gay or bisexual. Only 48% of people with a disability claimed to be happy in their sex life compared to 67% of those without a disability.

¹ Outcome 1 originally also reflected issues in relation to teenage pregnancy. The Scottish Government's new *Teenage Pregnancy and Young Parent Strategy*, will be published in early 2016, and this will address this high level outcome, however unintended pregnancies in older women remains an issue relevant to the Framework, and so this has been retained within this Outcome.

² Sexual Health and Wellbeing Survey: Main findings <http://www.gov.scot/Publications/2014/11/1876/0>

Outcome 3: People affected by blood borne viruses lead longer, healthier lives, with a good quality of life.

This outcome is about ensuring that people affected by blood borne viruses can access the best treatment and care and can lead a healthy life in all senses of the word. In Scotland we have a National Health Service free at the point of need and therefore anyone who needs care and/or support for HIV, hepatitis C or hepatitis B should be able to access it without financial barriers. We have increased the number of people accessing hepatitis C therapies over the life of the Framework and many more people have been cured of their infection. The smaller number of people infected with hepatitis B are well-supported and have opportunities to access the best care. The overwhelming majority of people diagnosed with HIV continue to have access to treatment.

The next five years will present greater challenges – principally concerning the cost of new hepatitis C therapies and the increasing costs of HIV treatment and care (particularly in the context of emerging evidence about the benefits of commencing treatment for HIV at an earlier stage). To ensure individuals can access treatment at a time that will lead to improved health outcomes we also need to do more to test for and diagnose all blood borne viruses as early as possible. We need to continue to work to promote testing in all services which engage with those at risk and not restrict testing to traditional NHS settings.

Critically, we also need to reflect that a healthy life is not purely about medical interventions – quality of life is also vital and this relates to much broader issues such as mental health, employment, relationships and wellbeing in the broadest sense. These are less tangible quality-of-life measures which are more subjective and difficult to define and measure. However, consideration will be given to whether or how these aspects can be captured within Framework indicators.

Outcome 4. Sexual relationships are free from coercion and harm.

All sexual relationships, whatever life stage, gender, gender identity or sexual orientation, should be free from coercion and harm. We continue to educate and raise awareness around positive sexual health, through Relationships, Sexual Health and Parenthood (RSHP) Education, and through Government, NHS and Third Sector awareness and information campaigns. Sexual health services in Scotland are adept at dealing with these issues and discussing sexual relationships with clients, but in other services there is more work that can be done. Good sexual health and wellbeing is about the promotion of healthy fulfilling relationships – not just preventing STIs or unintended pregnancy. This means that this outcome cannot be met purely by sexual health services and there is a leadership role for the promotion of good healthy relationships by other organisations and service providers. There are particular issues with young people, the influence of pornography and the perception of ‘normal’ healthy relationships amongst peers, but challenges also remain around coercion and harm in other relationships, notably within LGBT relationships and also in relation to online safety. Violence against women and girls damages health and wellbeing, and sexual health services have a role in early intervention. Practitioners in these services have daily contact with women and girls, and it is essential that

they are able to identify those most at risk and are able to offer an appropriate, safe and consistent response. Sexual exploitation, including child sexual exploitation, is a particularly important issue that is relevant to this outcome and more work is needed to establish how best to measure our impact on this.

Outcome 5: A society where the attitudes of individuals, the public, professionals and the media in Scotland towards sexual health and blood borne viruses are positive, non-stigmatising and supportive.

Outcome 5 remains the most ambitious of the Framework outcomes. It is a statement about how we want Scotland to be. The success or failure of each of the other outcomes are predicated – to a greater or lesser extent – on the successful delivery of this outcome. We know there continue to be challenges around stigma and negative attitudes towards those affected by poor sexual health and blood borne viruses, and no strategy will resolve this in five years. What is needed is consistent, on-going efforts to raise awareness, to educate and to inform. Great efforts have been made over the last five years, through professional awareness-raising and public information and awareness campaigns such as the *Always Hear* campaign. This work must continue, but we also need to give further consideration to how we can measure the impact of this work, and how we can improve the attitudes of individuals and professionals towards those with poor sexual health or BBVs.

In the original Framework document we stated that there is a need to normalise attitudes towards the provision of HIV, viral hepatitis and sexual healthcare in Scotland, moving away from an exceptional approach and towards a more transparent and mainstream one. This continues to be the case, and continues to be a challenge as stigma and prejudice exist despite recent progress.

CROSS-CUTTING ISSUES

Multi-agency Approach

The original Framework made clear the importance of a multi-agency approach to sexual health and blood borne viruses. To truly deliver on the Framework Outcomes in the long term will require the involvement of patients and service users, NHS Boards, Local Authorities, the Third Sector, academics, the media and the general public. The following chapters highlight where particular links are important but these comments do not reflect the entirety of the multi-agency engagement which is necessary for progress.

In particular, the **integration of health and social care**, the Scottish Government's ambitious programme of reform to improve services for people who use health and social care services, will present opportunities for tackling the priorities within the Framework. It is intended that integration will ensure that health and social care provision across Scotland is joined-up and seamless, especially for people with long term conditions and disabilities. For example, Health and Social Care Partnerships should support a patient-centred approach around hepatitis C that includes psychosocial interventions and should support work across health and social care including towards supporting the ageing HIV cohort.

Third Sector

The Public Bodies (Joint Working) (Scotland) Act 2014 places a statutory responsibility upon Health Boards, Local Authorities and Integration Authorities to actively involve the Third Sector in the planning and design of integrated health and social care services. The Third Sector is as key to success of this Framework as are the NHS and Local Authorities, both in terms of operational delivery and informing policy and practice. Third Sector organisations can also play an important role in the training and education of staff across organisations, in accessing very vulnerable and hard to reach people, linking them to local authorities and NHS, and in tackling stigma and in raising awareness. There are several good examples from across Scotland of partnership working with the Third Sector, but to ensure a consistent level of best practice more work will need to be done. **The Third Sector remains a critical partner supporting the implementation of the Framework, working with people on broader, holistic prevention and support issues beyond clinical care.**

Third Sector organisations can also work with clinical services to support patients before, during and after clinical treatment and may be commissioned to provide clinical services. In many cases Third Sector support is vital to individuals remaining on, and adhering to, treatment. Unless there are particular reasons not to involve Third Sector organisations they should be involved in local multi-disciplinary discussions about individual patients, assuming the necessary information governance approvals are in place. This is in line with the multi-agency approach articulated above. However it is clear that Third Sector organisations will vary, and NHS Boards may find it difficult to adopt a consistent approach. For this reason there could be value in considering whether more can be done to promote consistency and quality in the relationship between Third Sector organisations working in the field

of sexual health and blood borne viruses and commissioners. **The Scottish Government will host a meeting with the Third Sector and NHS representatives to consider further what more can be done to ensure appropriate information sharing between the NHS and the Third Sector in the best interests of integrated patient care.**

The Scottish Government funds Hepatitis Scotland and HIV Scotland as national Third Sector organisations with the role of supporting policy and practice. **The Government will continue to fund both organisations for three years from 2015-16, but during this period will conduct a due diligence review on the operation and funding of these organisations beyond 2017-18.**

Vulnerable Groups

The Framework recognises that many people affected by poor sexual health and blood borne viruses are vulnerable and will have multiple needs. The social inequality of these vulnerable groups will be particularly pronounced in a time of recession, welfare reform and poverty. Community Planning Partnerships (as well as Health and Social Care Partnerships/Integration Authorities) have an important role and issues of poor sexual health and blood borne virus infections should be part of local plans. The main issues are well understood, including but not limited to: homelessness, addiction, alcohol use and offending, contact with the criminal justice system, violence against women and girls and sexual exploitation. But more recent issues such as new psychoactive substances, the influence of social media and technology, and the sexual health of older people and those with long-term disabilities also need to be addressed.

NHS Boards, Local Authorities and Third Sector organisations should ensure interventions continue to be targeted towards particularly vulnerable groups, improving awareness of those with multiple vulnerabilities and in recognition of the risk of increased inequalities emerging as a result of wider financial challenges. Local planning structures across the NHS and Local Authorities should recognise the importance of these groups in structured responses to the needs of local populations.

Patient and Service User Involvement

The Framework recognises the importance of engaging patients and service users in the design of sexual health and BBV services at local and national level. Patient involvement is core to good practice and should not be considered optional. Direct patient involvement is important but can be challenging. Third Sector organisations can act as facilitators or proxies where it is not possible to secure direct patient involvement, but it should be recognised that people who engage with Third Sector organisations may be different from those who would engage directly.

Both Hepatitis Scotland and HIV Scotland as national patient and policy organisations undertake patient involvement activities which provide a mechanism for individuals living with hepatitis C and HIV to feed into national policy. **The Scottish Government will work with both organisations, NHS Boards and other Third Sector organisations to formalise national patient involvement groups as**

part of the Framework network structure. Both Hepatitis Scotland and HIV Scotland are able to provide tools and support to NHS Boards, Local Authorities, and Third Sector organisations wishing to improve their local involvement strategies. This work should contribute to, and not replace the duty of NHS Boards and Local Authorities to continue their local engagement.

Drug and Alcohol use

There is no doubt that addiction and substance misuse – including alcohol – continue to be drivers of behaviour which can put people at risk of poor sexual health and BBV infections. Young people and other vulnerable groups may be particularly affected. It is also true that living for a long time with a BBV can have a psychological impact, in particular when there have been problems with treatment or where treatment has failed, and this can lead to addictive behaviours. As well as potentially being a result of addiction, BBV infection can lead to people being more vulnerable to alcohol and/or drugs misuse.

Emerging issues in the field of substance misuse, including new psychoactive substances (NPS) and ‘chemsex’, reflect the fact that this is a continually evolving field. The Scottish Government has clear national policies on alcohol³ and problem drug use⁴ and Alcohol and Drugs Partnerships should plan interventions and services in line with these documents, supporting recovery from addiction. There are however opportunities for addiction services and other service providers to support the Framework Outcomes and vice versa. For example Injecting Equipment Provision (IEP) services have been established and funded to minimise the risk of transmission of BBVs through sharing of needles, but such services also provide an excellent gateway for information for people who inject drugs (PWID) and a route into care and support as part of a stepped pathway to recovery.

A related, important issue is the use of **injectable performance and image enhancing drugs** (PIEDs). There is a clear BBV risk related to the injecting behaviour associated with PIEDs, but anecdotal reporting from services in Scotland suggests that sexual behaviour of people who use PIEDs may also be higher risk. Services working with people who inject PIEDs therefore need to work in a holistic manner ensuring condoms and sexual health advice are available and offered at every transaction, as well as providing injecting equipment.

A similar important emerging issue is that of **new psychoactive substances**. Recent statistics⁵ reflect the significance of NPS. Whilst NPS use in Scotland, and the number of deaths where NPS is the only substance present in a drug-related death, is relatively low, 98.5 per cent of NPS-related deaths recorded between 2009 and 2013 involved polydrug consumption, typically combinations of NPS, opioids, alcohol and benzodiazepines. There are recognised issues in some parts of Scotland relating to the injecting of NPS, and the use of NPS is recognised as a potential driver of risky behaviours, both in relation to injecting and sexual behaviour. It is also important to recognise that NPS users may present different usage patterns and different cohorts to those traditionally dealt with by drug services. Services must

³ *Changing Scotland's Relationship With Alcohol*, <http://www.gov.scot/Publications/2009/03/04144703/0>

⁴ *The Road to Recovery*, <http://www.gov.scot/Publications/2008/05/22161610/0>

⁵ National Drug Related Deaths Database Report 2013

evolve to meet new and changing needs and NHS Boards should develop clear pathways managing the interface between substance use and sexual health.

Welfare Reform

There has been significant reform to the welfare system by the UK Government since the publication of the first *Sexual Health and Blood Borne Virus Framework* document. Anecdotal evidence is clear that changes to benefits and welfare have had an impact on people in Scotland infected with HIV and hepatitis C. It can also have a detrimental impact on service users' families and children. In some cases benefit changes have made it more difficult for individuals to access or continue treatment, thereby further impacting on their ability to work and contribute to society.

HIV Scotland and Hepatitis Scotland have published a report on the impact of welfare reform on people living with HIV and hepatitis in Scotland⁶. The report concluded: *"the welfare reforms being implemented at a UK level are not appropriate in a Scottish context, and not at all suitable for people with blood borne viruses. The reforms are causing significant uncertainty and anxiety, worsening the mental and physical health of people in grave need, and adding to the burden carried by specialist services that are already stretched and oversubscribed."* These impacts of welfare reform are unlikely to be limited to those affected by BBVs – they may also have an impact on those affected by poor sexual health.

The Smith Commission report on the further devolution of powers to the Scottish Parliament made recommendations about the further devolution of powers relating to welfare and benefits. The Scottish Government will give careful consideration as to how best to ensure that new powers are appropriate for the Scottish context, tailored to the needs of individuals and will do what it can to make the system fairer and simpler. **Until these powers are devolved the Scottish Government will oppose all further cuts to the welfare budget and reforms which undermine the provision of care and support for vulnerable people.**

Research

The first Framework document said little about research. Scotland's size and the data systems used in the NHS, as well as the high quality clinical and academic sectors within Scotland, mean that there are significant opportunities for Scotland to contribute to national and international literature on sexual health and blood borne virus issues. Scotland already has an impressive record of research and publication in some areas but there is the potential to do more, and to make use of existing data sources such as the National Sexual Health system (NaSH). While there have been recent improvements made to NaSH, there is still more that can be done to see the system deliver to its full potential.

The challenge, for clinicians, managers and academics is finding the time and capacity to make positive steps towards research, and to bid for grants and funding. Over the last five years the Scottish Government has provided funding for specific projects, including the MSM Prevention Needs Assessment by NHS Greater

⁶<http://www.hivscotland.com/downloads/1406034566-impact%20of%20welfare%20reform%20on%20people%20with%20HIV%20and%20hepatitis%20in%20Scotland%202014.pdf>

Glasgow and Clyde and NHS Lothian, research by the MRC/CSO Social and Public Health Sciences Unit, University of Glasgow on later and repeat termination of pregnancy, and on media reporting on sexual health and BBVs. The Scottish Government will continue to fund particular research projects when able to do so, but there is also a need to build capacity to enable other sources of funding to be accessed and for existing research to be shared across Scotland and more widely. **The Scottish Government will therefore fund a Framework research manager post to co-ordinate research across the Framework, to support the NHS and other partners in accessing funding and grants, and to work with networks to identify research priorities, to collate and share evidence of what works, and to develop a research strategy for the Framework.** This will complement work being done to develop and support a national drug research strategy due to be published in the autumn.

In addition to this new post, the existing National Monitoring and Assurance Group will extend its remit into research and the chair, membership and name of the group will change to reflect this new role. Representatives of all networks will have membership of the group and will contribute to the generation of the Framework research strategy, focusing particularly on sexual and reproductive health and HIV (while maintaining the world-leading standard of research on viral hepatitis). Meetings of national networks for lead clinicians in sexual health, HIV and viral hepatitis will have research and audit as permanent agenda items, to provide a forum for engagement for the research manager.

Indicators and Monitoring

Some stakeholders involved in the work of the Framework have reported that some of the Framework Indicators are too clinically focused and do not reflect the reality of people's lives, nor the range of factors relevant to sexual health and BBVs. This has led to many aspects of the Framework's implementation being perceived as being the sole responsibility of the NHS.

While health services are very important, finding work, attaining education and living in a community without prejudice are just as important to the health and wellbeing of people – health in the broadest sense. This is very much recognised within this update to the Framework, and it is also recognised that more work is needed to further update and refine the Outcome Indicators, not only to reflect newly emerging and important issues, but also to better reflect the non-medical aspects of supporting the delivery of the Outcomes. There will undoubtedly be challenges here, as some of the things we wish to capture and monitor may not be easily measured. However this will be considered in detail by the National Monitoring and Assurance Group. Furthermore the Framework Indicators should not be seen as fixed for the life of this update. The expectation is that Indicators will be reviewed and updated regularly, in consultation with the networks in place.

Supporting the Framework

The implementation of the first Framework was supported by a range of national networks. These networks will continue to mature as forums for debate and discussion, and as a mechanism to exchange best practice. The Scottish

Government and Health Protection Scotland will continue to oversee and input into these networks as appropriate. The National Monitoring and Assurance Group will continue, with a new additional focus on research as discussed above.

The Scottish Government employed two National Coordinators to support the first Framework – a National Coordinator for HIV and Sexual Health and National Coordinator for Viral Hepatitis. Now that the Framework approach is well-established, these roles are no longer needed and the resources associated with the National Coordinators will be released to be reinvested in other Framework activity.

The Framework as a whole will continue to be a priority for Scottish Ministers, and the National Sexual Health and Blood Borne Virus Advisory Committee, chaired by the Minister for Public Health, will continue to meet at least twice a year.

Over the past four years National Coordinators based in Scottish Government carried out local areas visits to all Boards on an annual basis. There has been significant progress over this period and these routine annual visits are no longer required. **Instead the role of the national network of Executive Leads will be strengthened to include a responsibility for monitoring progress and reporting on the national indicators for the Framework. The Executive Leads will work with Scottish Government to ensure that all parts of Scotland are continuing to deliver the Framework Outcomes. The remit of the Executive Leads will be updated to reflect this change of role. The Scottish Government will also retain the option of undertaking local visits to Boards to monitor progress or in response to any specific concerns.**

SEXUAL HEALTH AND WELLBEING

Introduction

As reflected in the original Framework document sexual health and wellbeing is a broader subject than the other topics within the Framework, and there are areas where progress is needed across all age groups and risk groups. We need to continue work to minimise risk-taking behaviours and consequences, and to promote positive sexual relationships and wellbeing. There are significant emerging issues around coercion and harm and the influence of new technology and social media. Awareness of and reduction of sexual exploitation and harm should be core priorities for all organisations and agencies.

Key Progress

- In November 2011 Healthcare Improvement Scotland (HIS) published an overview report on its review of sexual health services in Scotland against the HIS sexual health standards⁷. This report found that Boards had made significant progress in raising the profile of sexual health services; in improving the individual patient experience; and in providing more suitable accommodation for clinics.
- There is a differing pattern emerging regarding acute STIs in Scotland during the past four years; diagnoses of some sexually transmitted infections have increased while those of others have declined or stabilised. Evidence suggests that the incidence of STIs among young heterosexuals and MSM through unprotected sexual intercourse remains a problem in Scotland; challenges for control and prevention of STIs continue.
- There have been increases in the use of longer-acting reversible methods of contraception (LARC) across Scotland. The uptake of very long acting methods (the contraceptive implant, IUDs (the coil) and Mirena® (IUS)) in Scotland increased from 56.7 per 1,000 women aged 15-49 in 2009/10⁸ to 62.1 per 1,000 women in 2013/14⁹. However, there is still variation in provision across Scotland which must be improved.
- The rate of teenage pregnancies in Scotland have been in decline since 2007 and are the lowest they have been since at least 1994¹⁰.
- A modelling study on the cost effectiveness of chlamydia screening in Scotland, funded by the Scottish Government, was published in January 2015¹¹. The study concluded that the current chlamydia testing strategy in Scotland is not cost-effective under the conservative model assumptions applied. However, with better data enabling some of these assumptions to be relaxed, current coverage could be cost-effective.
- The Scottish Government national awareness raising campaign on sexual health (*'Sex: It's Healthy To Talk About It'*) led to an increase in numbers of people

⁷ http://www.healthcareimprovementscotland.org/our_work/reproductive_maternal_child/sexual_health/national_overview.aspx

⁸ <https://isdscotland.scot.nhs.uk/Health-Topics/Sexual-Health/Publications/2011-07-26/2011-07-26-LARC-Report.pdf?66788882018>

⁹ <https://isdscotland.scot.nhs.uk/Health-Topics/Sexual-Health/Publications/2014-09-30/2014-09-30-LARC-Report.pdf?66788882018>

¹⁰ <https://isdscotland.scot.nhs.uk/Health-Topics/Sexual-Health/Publications/2015-07-07/2015-07-07-TeenPreg-Report.pdf?71546572447>

¹¹ <http://www.ncbi.nlm.nih.gov/pubmed/25588390>

accessing online information about sexual health. There have been over 168,000 unique visitors and over 192,000 visits a year to the website.

- Over the past five years there has been a reduction in the number and rate of terminations of pregnancy carried out in Scotland, with 11,777 carried out in 2013 compared to 13,904 in 2008. In addition the proportion of early terminations has been rising steadily in recent years, with 69.2% of all terminations performed at less than 9 weeks in 2013, in line with HIS Clinical Indicators, compared to 62.2% in 2009¹².
- The Scottish Government has funded the establishment of a Sexual and Reproductive Health post within Scottish Drugs Forum to provide training to staff working in sexual health services and drugs services on the links between sexual behaviours and drug and alcohol use.
- The Scottish Government funded the MRC/CSO Social and Public Health Sciences Unit, University of Glasgow to undertake research on how sexual health and BBV issues are reported in the media.^{13,14,15}
- The Scottish Government commissioned and published the findings from a sexual health and wellbeing survey in 2014.¹⁶ This provides a baseline for future monitoring of change in the general population on specific topics and identified some sexual wellbeing themes as needing closer consideration.
- The Scottish Government funded Brook to develop the “*Sexual Behaviours Traffic Light Tool*”¹⁷ to assist those working with young people to have an awareness of normal childhood sexual behaviour.
- The Scottish Government funded NHS Lothian to undertake research comparing the delivery of abortion care in hospital settings versus the community¹⁸.
- The Scottish Government funded researchers at the MRC/CSO Social and Public Health Sciences Unit, University of Glasgow to undertake research into people who present very late (after 19 weeks 6 days) for terminations in order to improve care for these individuals¹⁹.

Key Developments

- The Smith Commission on the devolution of further powers to Scotland recommended that a process be established to consider the devolution of powers relating to abortion (amongst others).
- In December 2014 the Scottish Government published updated statutory guidance on the conduct of Relationships, Sexual Health and Parenthood (RSHP) Education in Schools. This revised guidance reflected the need for discussion of all types of relationships as part of RSHP education to acknowledge that, as a result of the Marriage and Civil Partnership (Scotland) Act 2014, both

¹² <https://isdscotland.scot.nhs.uk/Health-Topics/Sexual-Health/Publications/2014-05-27/2014-05-27-Abortions2013-Report.pdf?22182863951>

¹³ Martin S, Hilton S, McDaid LM. United Kingdom newsprint media reporting on sexual health and blood-borne viruses in 2010. *Sexual Health* 2013;10:546-552

¹⁴ Purcell C, Hilton S, McDaid LM. The stigmatisation of abortion: a qualitative analysis of print media in Great Britain in 2010. *Culture, Health & Sexuality* 2014;16:1141-55

¹⁵ Martin S, McDaid LM, Hilton S. Double-standards in reporting of risk and responsibility for sexual health: a qualitative content analysis of negatively toned UK newsprint articles. *BMC Public Health* 2014;14:792/

¹⁶ *Sexual Health and Wellbeing Survey: Main findings*, <http://www.gov.scot/Publications/2014/11/1876/0>

¹⁷ <http://www.brook.org.uk/old/index.php/traffic-light-tool-0-to-5>

¹⁸ Cameron S, Glasier A, Johnstone A. Shifting abortion care from hospital to a community sexual and reproductive health care setting. *Journal of Family Planning and Reproductive Health Care* (submitted March 2015)

¹⁹ Access to and Experience of Later Abortion: Accounts from Women in Scotland by Carrie Purcell, Sharon Cameron, Lucy Caird, Gillian Flett, George Laird, Catriona Melville and Lisa M. McDaid <http://www.guttmacher.org/pubs/journals/46e1214.html>

opposite sex and same sex couples can marry. The guidance also made explicit links to the *Sexual Health and Blood Borne Virus Framework*.

- The Scottish Government's Children and Young People (Scotland) Act 2014 was passed, setting out a number of new duties on public authorities in Scotland. The Act, which is at various stages of implementation, is central to the Scottish Government's aim of making Scotland the best place in the world to grow up by putting children and young people and their wellbeing at the heart of the planning and delivery of services and ensuring their rights are taken into account across the public sector. In particular Part 3 of the Act – Children's Services Planning - emphasises the importance of prevention and early intervention, which is relevant to work with young people in relation to sexual health.
- Findings from the third National Survey of Sexual Attitudes and Lifestyles (NATSAL-3) were published during 2014²⁰ with findings from Scotland published in March 2015.²¹
- Significant public and media interest has occurred in relation to child sexual exploitation and historic sexual abuse resulting in an increased need for clear information and messages for young people, parents and those supporting them.
- The emergence of new psychoactive substances in recent years gives rise to a number of issues relevant to the Framework, including the work of IEP services and the risks associated with injecting of NPS, but also the increased potential for risk-taking behaviours amongst individuals while using NPS.

Key Priorities

Prevention

Prevention remains a fundamental principle for all parts of the framework. In the context of sexual health this means: supporting good relationships and sexual health, and preventing poor sexual health and resultant sexually transmitted infections and/or unintended pregnancies. The implementation of Relationships, Sexual Health and Parenting (RSHP) education is key to ensuring all young people across Scotland have the information and skills to make healthy choices regarding their sexual health. Given the disproportionate and rising burden of HIV and STIs in MSM, especially young MSM, it is important that all RSHP is inclusive.

The implementation of RSHP education in schools is the responsibility of Directors of Education, and the Scottish Government issued updated statutory guidance in December 2014. NHS Boards and Third Sector organisations can support the delivery of education by building links with schools and local education departments. A strategy in supporting this work is to emphasise the important issues of child sexual exploitation²², coercion, gender-based violence and healthy relationships. All schools should recognise the importance of informing and educating children on these important topics, particularly in relation to younger and vulnerable children (including looked-after children).

²⁰ <http://www.natsal.ac.uk/natsal-3/findings.aspx>

²¹ <http://www.gov.scot/Topics/Health/Services/Sexual-Health/Natsal3>

²² An important document is the Scottish Government's Action Plan on Child Sexual Exploitation: <http://www.gov.scot/Resource/0046/00463120.pdf>

RSHP education is important in making progress on issues relating to teenage pregnancy and young parenting, and the Scottish Government's new Teenage Pregnancy and Young Parent strategy will provide more detail on these issues. However the development of the strategy has already involved significant consultation with young people across Scotland. This has highlighted that young people are looking for more information on relationships and more comprehensive RSHP education in schools. Young people have also said they would like more input into the curriculum on these subjects. There remains a challenge in ensuring that young people are able to access sexual health information and advice in schools and public buildings (libraries etc.) and that these are not subject to restrictions/filters.

Local Authorities/Directors of Education, NHS Boards and Third Sector partners should continue to work together to support high quality, consistent and inclusive RSHP education in all schools across Scotland. RSHP education should continue to be provided to all young people in all schools and wherever learning takes place, with delivery in line with equality and diversity legal obligations.

Teaching staff delivering RSHP education should be trained to ensure they have the necessary skills, attitudes and confidence. NHS Boards and Third Sector partners can support such training and can make links to services for young people.

Local Authorities, supported by NHS Boards and Third Sector organisations, should ensure they provide support to parents and carers on improving communication between them and their children on RSHP issues.

Young people should be involved in the design of local approaches to teaching of RSHP.

These issues will be articulated through the new Pregnancy and Young Parents Strategy, and that Strategy will also set out responsibilities on monitoring and reporting on progress of these actions.

The Scottish Government's sexual health campaign: *Sex: It's Healthy To Talk About It* encourages adults to have conversations with their partners about all aspects of sex and relationships. This aimed to increase confidence, reinforce the importance of negotiation and boundaries as well as empowering people to have healthy and fulfilling relationships.

Given the importance of continuing to have reliable, accurate information available **the Scottish Government will continue to fund the 'SexualHealthScotland' website**, which remains the go-to place for sexual health and relationship information in Scotland. We will give consideration to whether *Sex: It's Healthy To Talk About It* should be strengthened or refreshed or whether a higher profile campaign approach would bring benefits in reaching specific audiences such as young people. Services also need to consider how they can increase the number and quality of conversations about relationships and good sexual health in response to the needs of the public.

Contraception

In 2013 NHS Lothian established a pilot project to look at the viability of providing post-partum contraception universally. The 'APPLES' (Accessing Postpartum LARC in Edinburgh South East) project looked at improving access to contraception for postpartum women, with particular emphasis on the most effective (longer acting reversible or 'LARC') methods. The study integrated contraceptive advice and supplies of women's chosen contraceptive method into maternity care, envisaging that this might prevent future unintended pregnancies for women and give women more control over inter-pregnancy intervals. Inter-pregnancy intervals of less than a year have been proven to increase risk of stillbirth and neonatal death, and it has been shown that a significant number of women have a repeat pregnancy within one year of giving birth. Therefore it is important that services recognise that all women are entitled to access contraception, not just those judged to have specific risk factors for repeat pregnancy.

The pilot is on-going, but initial positive findings were presented to the Ministerial Advisory Committee in late 2014. In light of this, and the potential benefits of an approach of integrating the provision of post-partum contraception into perinatal care, **NHS Boards should roll-out this approach, ensuring that all women have the opportunity to be counselled antenatally regarding postnatal contraception and to be provided with their preferred choice of contraception, or a bridging method, in maternity services across Scotland prior to discharge following delivery or immediately after where feasible – the six week check-up can be too late for some women.** This will make it easier for women to access contraception in a patient-centred way. The potential challenge to implementation of this project relates primarily to the training of maternity staff. Therefore **the Scottish Government will support training costs for maternity staff including community midwives and health visitors for the purposes of implementing this approach.**

The provision of contraception directly after termination of pregnancy is also an important approach to preventing repeat unintended pregnancies and increasing ease of access to contraception for those women who wish it. **NHS Boards and services providing termination of pregnancy services should include information on contraception, and the opportunity for women to be provided with contraception if they wish it, as soon as possible post termination as a core part of abortion care.**

While the provision of longer acting reversible contraception has led to reductions in unintended pregnancies and terminations, the same impact has not been seen in relation to sexually transmitted infections, and condom promotion and distribution continues to be important.

Emergency Hormonal Contraception will continue to be available free of charge through community pharmacies in Scotland.

Abortion

The Smith Commission on the further devolution of powers to the Scottish Parliament recommended the establishment of a process to consider the devolution of legislative powers on abortion. The Scottish Government is in discussion with the UK Government on this issue.

In order to improve health outcomes the majority of abortions should be carried out before 9 weeks gestation.²³ NHS Boards should continue to develop pathways so that as many abortions as possible are carried out early in pregnancy and that unnecessary delays at all stages are minimised. Boards should however ensure the appropriate support and services are available for the small number of women who present very late (after 19 weeks 6 days) for abortions.

The number of repeat terminations in Scotland still remains high with around a third (30.7% in 2013) having had at least one previous termination in their lifetime (but not necessarily in quick succession). Research is being carried out by the MRC/CSO Social and Public Health Sciences Unit, University of Glasgow into the reasons why women seek multiple terminations. **The results of this study will inform future work.**

Inequalities

Inequalities are relevant to all aspects of sexual health work, and approaches discussed in the original Framework, and elsewhere in this chapter, will contribute to tackling inequalities specifically (e.g. access to contraception) and more generally (education and awareness raising).

There are a number of groups who may be particularly disadvantaged in respect of sexual health, including looked-after and accommodated children and young people; prisoners; MSM and individuals involved in commercial sexual exploitation. Often these people will have multiple needs and risks, including alcohol use and poly-drug misuse. The Scottish Government funded a Sexual and Reproductive Health post within Scottish Drugs Forum (SDF) to support the further development of links between sexual health and addictions services, focussing on the needs of vulnerable groups. This has been an important capacity-building post so **the Scottish Government will continue to fund this post until at least 2017 to allow this important work to continue and develop.**

In addition to this specific post there are opportunities for greater links between Alcohol and Drug Partnerships and sexual health services. The SDF post has started to address this in some local areas and the Scottish Government will support work to continue to build on this, complimenting the Scottish Government's work to increase the capacity and effectiveness of alcohol and drug partnerships. A range of local and national interventions will be used to embed work in this area into the core business of local partnerships.

²³ The KCI was introduced in March 2008 by NHS Healthcare Improvement Scotland and states that 70% of women seeking a termination should undergo the procedure at less than 9 weeks (under 63 days) gestation

Chlamydia

Scotland's Chief Medical Officer (CMO) previously established an expert group to examine the evidence for chlamydia testing policy in Scotland, and that group reported to the CMO in 2014. The group's report recognised the significant uncertainty that exists around the clinical implications of chlamydia infection and the cost effectiveness of different screening or testing approaches, and therefore recommended that a cost effectiveness study be undertaken on chlamydia testing policy in Scotland. The Scottish Government commissioned this work via Health Protection Scotland and the results were published in January 2015²⁴.

Scotland does not have a national chlamydia screening programme; rather NHS Boards are responsible for testing for chlamydia in line with existing clinical guidelines.²⁵ In light of the cost effectiveness study findings, the **Scottish Government will work with the Scottish Intercollegiate Guidelines Network to make any necessary updates to existing guidelines on the management of chlamydia**. NHS Boards will continue to be responsible for delivering chlamydia testing in their own areas, in line with National Guidelines and local needs and priorities.

Treatment/services

NHS Boards should continue to ensure that sexual health services are provided in line with Healthcare Improvement Scotland sexual health standards. Sexual health services should be high quality and designed to meet the needs of patients, including young people and vulnerable groups.

It is important that sexual health services do not operate in isolation. The links between poor sexual health, addictions, alcohol use and other vulnerabilities are apparent. Sexual health services should have good quality links with addictions, mental health and other services, and service planners should be mindful of the need to provide holistic services to patients. For example, Scottish Drugs Forum work with addictions services highlighted that very little sexual and reproductive health work was being undertaken by these services. In most cases, questions were not even being asked of clients regarding issues of sexual and reproductive health. This led to the Scottish Government-funded work with SDF to train staff on the links between addictions and sexual health. This work will continue to be funded by the Scottish Government, but local planners should also consider these issues as part of their core responsibilities.

Emerging evidence (including from NATSAL and the recent MSM HIV Prevention Needs Assessment) is telling us that staff in services beyond core sexual health services may not be comfortable with or confident in discussing important sexual health risks and issues, including with young people. This requires us to increase efforts to enable a wide range of staff to have frank discussions with anyone who is or may be sexually active about sexuality (including young people and older people), all forms of sexual behaviour, consent, pleasure, rights and safety in a sexual

²⁴ <http://www.ncbi.nlm.nih.gov/pubmed/25588390>

²⁵ <http://www.sign.ac.uk/pdf/arg109.pdf>

context. **The Scottish Government will work with the NHS Executive Leads to determine whether there is work that could be done nationally to develop core educational materials or information resources for staff in specialist and non-specialist services.**

Coercion and harm

Coercion and harm related to sexual relationships is a particularly important issue of which all health staff should be aware. This issue is relevant to sexual relationships at all ages, and to the issue of violence against women and girls.

NATSAL 3²⁶ data reported an increase in reports of anal sex in young heterosexual men and women, and subsequent research illustrated the coercive circumstances in which this often occurs²⁷. There were also reports of non-volitional sex in the same research and in the Scottish Government's 2014 survey on sexual health and wellbeing. Education and awareness-raising are part of the solution to these issues, but will never be the entire solution. Services, parents, teachers and carers need to be able to provide support and advice to service users and to those who do not access services (including understanding of why services are not being fully utilised)

At the extreme end of coercion and harm, childhood sexual exploitation is a subject where there has been much public and media debate in the last few years. The links to sexual health and other NHS services in Scotland are important, and again the role of education and awareness-raising of healthy relationships is vital.

There has also been much concern expressed across Scotland regarding the impact of social media and the facility for sexual expression through communication technology. This has transformed the lives of young people and the context in which they explore and express their sexuality and form relationships. Many sexual contacts are now managed on-line and there is increased use of pornography, especially by boys and young men. This is likely to have an impact on expectations around sex and relationships and their links to gender-based violence. There is the potential for harm and exploitation through the use of such technology and services need to be aware of these issues.

There are no simple solutions to these issues, but **the NHS Executive Leads will continue to give consideration to the role of NHS services in helping to tackle coercion and harm.** As a minimum, sexual health specialists should be involved in local multi-agency groups addressing child sexual exploitation to ensure that effective pathways and information sharing protocols are created. The Scottish Government will also ensure the necessary links are made to other policy areas within Government, and **the National Monitoring and Assurance Group will consider what more can be done to improve the identification and interpretation of appropriate outcome indicator data as a first step to informing action.**

²⁶ <http://www.natsal.ac.uk/natsal-3.aspx>

²⁷ Marston C, Lewis R. Anal heterosex among young people and implications for health promotion: a qualitative study in the UK. BMJ Open 2014

Stigma

Longer term challenges remain in addressing stigma and homophobia, the impact of which may increase sexual risk behaviour and act as a barrier to sexual health and other service use.

A sexual health and blood borne virus media group is already in existence, chaired by Health Scotland. This group aims to support accurate reporting around the topic areas of the Framework. The group is working to develop a bank of expert speakers from the NHS, who can be available to support reporting and media activity. This activity is intended to be a mechanism to provide positive contributions to media reporting. This work will continue. In addition, NHS Boards and local partners should consider how to challenge stigma and prejudice locally through their local action plans.

Sexual dysfunction

Surveys and research conducted during the first four years of the Framework have shown that sexual dysfunction can have a significant impact on their quality of life for many people. The Scottish Government's 2014 survey found that 23% of respondents had a health condition that had affected their sexual activity in the previous year and that 22% of men and 19% of women had avoided sex in the previous year because of sexual difficulties. (This was considerably more than the NATSAL sample which was 11% of men and 13% of women). This is an issue for people of all ages, however many services focus on younger people only and do not fully consider the needs of an ageing population who are sexually active into older age.

Good sexual health is not only about reducing disease but also about improving sexual wellbeing. Services need to be aware and willing to have discussions with people about their sexual wellbeing and referral into treatment for sexual dysfunction where appropriate should be provided. In addition it is vital that 'normal' healthy relationships are promoted to reduce inaccurate perception of dysfunction.

HIV

Introduction

HIV is a serious chronic infection that can be managed throughout life with highly effective current therapies. This is demonstrated in the increasing numbers of people living with HIV to older ages. In Scotland there is very good access to treatment for HIV, and it is vital that we test and diagnose all of those who have been infected but remain undiagnosed. Normalising testing and expanding provision of testing is key to this. While treatment is highly effective, public and individual health in Scotland is best improved by preventing infections, and this must also continue to be a priority.

Key Progress since 2011

- As MSM continue to be most at risk of HIV infection in Scotland, the Scottish Government funded NHS Lothian and NHS Greater Glasgow and Clyde to undertake an HIV prevention needs assessment amongst MSM. This work was published in June 2014²⁸ and will inform the development of prevention services with MSM in Scotland. Main findings included the importance of vulnerable men (mental health, esteem) and specific populations such as younger men; challenges around the knowledge, skills and interest of staff; the importance of HIV testing and knowledge/discussion of HIV status, and the emotional importance attached to anal sex for some MSM.
- NHS Lanarkshire and Glasgow Caledonian University undertook research in relation to MSM, social media and sexual health which was published in 2013 which should also inform the development of services across Scotland.²⁹
- Over the period 2011 to 2015 the MRC/CSO Social and Public Health Science Unit at the University of Glasgow has published a number of papers relating to HIV and MSM issues relevant to the work of the Framework³⁰. In particular valuable research was undertaken by the Unit and Health Protection Scotland on HIV prevalence and undiagnosed infection amongst MSM in Scotland³¹.
- The *Always Hear* awareness raising campaign, delivered by Waverley Care and funded by Scottish Government has provided materials and information through targeted groups (schools and churches/faith groups) as part of our work to inform, educate and to challenge stigma.
- The Scottish Government has updated legislation previously preventing the sale and marketing of HIV self-tests. The HIV Testing Kits And Services Revocation (Scotland) Regulations 2014 has revoked the HIV Testing Kits and Services Regulations 1992, lifting the ban on the sale of instant result testing kits in Scotland, from 6 April 2014 as long as kits meet European quality standards. In light of this change, and following leadership on this issue by HIV Scotland, a subgroup of the Executive Leads Group published a questions and good practice

²⁸ <http://www.gov.scot/Topics/Health/Services/Sexual-Health/HIVMSMNeeds>

²⁹ <http://www.sexualhealthnetwork.org.uk/wp-content/uploads/2014/05/2014-05-23-01.38.46-PM-Lanarkshire-SMMaSH-Survey-Report-2013-For-Circulation.pdf> and <http://www.sexualhealthnetwork.org.uk/wp-content/uploads/2014/05/SMMaSH-Qualitative-Report-Final-For-Circulation1.pdf>

³⁰ See <http://www.sphsu.mrc.ac.uk/research-programmes/sh/hivvp/>

³¹ Wallace LA, Li J, McDaid LM (2014) HIV Prevalence and Undiagnosed Infection among a Community Sample of Gay and Bisexual Men in Scotland, 2005–2011: Implications for HIV Testing Policy and Prevention. PLoS ONE 9(3): e90805. doi:10.1371/journal.pone.0090805

document on instant result self-testing in March 2014³². The good practice document was the first of its kind in the world, and has since been used internationally as an example of good practice by the World Health Organization

- As of December 2014, 91% of persons attending HIV services for monitoring were receiving antiretroviral therapy across Scotland with high levels of viral suppression being achieved. Scotland is therefore meeting UNAIDS 2020 target of 90% of all people diagnosed with HIV infection receiving sustained antiretroviral therapy. These data suggest continuing high levels of care and treatment are being provided for the increasing number of people living with HIV in Scotland. However, Scotland still does not meet the target of 90% of infected individuals being diagnosed – this remains an area for improvement.
- NHS Education for Scotland, in partnership with the HIV Clinical Leads Group, has developed a CPD programme ‘Recognition and diagnosis of HIV infection’ which targets registered healthcare practitioners in non-HIV specialist settings. These resources discuss opportunities for diagnosis of HIV using case studies and clinical information.³³
- All NHS Boards in Scotland now have protocols in place in relation to HIV post-exposure prophylaxis (PEP) for sexual and non-sexual exposures.
- In July 2011 Healthcare Improvement Scotland published a self-evaluation tool for standards in HIV prevention, treatment and care and supported Boards in developing Integrated Care Pathways (ICPs). The HIV Clinical leads network continues to monitor progress on the standards, but all Scottish NHS Boards now have ICPs in place for the initial three months after HIV diagnosis.
- In 2013 the Crown Office and Procurator Fiscal Service in Scotland published a new prosecution policy on intentional or reckless transmission or exposure to sexually transmitted infections. The policy was drawn up in partnership with public health and Third Sector organisations such as HIV Scotland, the National AIDS Trust and the Terrence Higgins Trust. The Crown Office is one of the few prosecution services worldwide to have published its prosecution guidance on this issue³⁴.
- HIV Scotland have developed a campaign around World AIDS Day to encourage a range of businesses to raise awareness of HIV/AIDS.
- An increased number of NHS Boards have worked with migrant communities at risk of HIV infection, especially those from sub-Saharan Africa, making use of resources provided by Waverley Care.

Key Developments

- Since 2011 the technology and regulatory landscape in relation to instant result self-testing kits has advanced. In 2011, a House of Lords Select Committee stated that the ban on home testing had become unnecessary and unsustainable, and should be repealed.³⁵ In July 2012 the first device specifically designed for

³² <http://www.hivscotland.com/downloads/1396272272-04467%20HIV%20Scot%20Report%202%20WEB.pdf>

³³ <http://www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/public-health/health-protection/blood-borne-viruses/recognition-diagnosis-of-hiv-infection.aspx>

³⁴ <http://www.copfs.gov.uk/media-site/media-releases/178-new-prosecution-policy-on-international-or-reckless-transmission-of-or-exposure-to-sexually-transmitted-infections>

³⁵ House of Lords Select Committee on HIV and AIDS, 1st Report of Session 2010–12: No vaccine, no cure: HIV and AIDS in the United Kingdom

home testing was approved by the US Food and Drug Administration³⁶. The first HIV home tests became licenced and available for use in Scotland in April 2015.

- In 2014 avidity tests became available in Scotland allowing clinicians to ascertain the likelihood that HIV infection had been recently acquired. Knowing whether infections are recent or not provides a more accurate picture of who in the population is at increased risk of HIV infection; can help target resources to the populations in greatest need; contributes to the monitoring and evaluation of HIV prevention initiatives and HIV testing strategies; and helps describe changes in the epidemiology of HIV infection, and therefore the future human and economic costs of HIV. Avidity testing is also a key tool in accurate contact-tracing.
- In January 2014 the UK Advisory Panel on Healthcare Workers infected with Blood Borne Viruses (UKAP) published updated guidance on the management of HIV-infected healthcare workers who perform exposure prone procedures.³⁷ As a result of this updated guidance HIV-infected health care workers who previously were prevented from undertaking exposure-prone procedures – and who therefore may have had limitations placed upon their career – could now undertake such procedures where they meet certain monitoring and/or treatment requirements.
- On 24 February 2015 the ‘PROUD’ study on the impact on gay men of using pre-exposure prophylaxis (PrEP) was presented. The PROUD study reported that PrEP reduced the risk of HIV infection by 86% for gay and other men who have sex with men when delivered in sexual health clinics in England³⁸.
- Almost one in three people living with diagnosed HIV infection is now aged 50 years and over. This is due to improved survival and continued transmission amongst older people and signals a need to develop services appropriate to an ageing population³⁹.
- The emergence of new psychoactive substances in recent years gives rise to a number of issues relevant to the Framework, including the work of IEP services and the risks associated with injecting of NPS, but also the increased potential for risk-taking behaviours amongst individuals while using NPS.

Key Priorities

Prevention

Prevention of HIV infection continues to remain a priority. It is clear that while core prevention strategies – including condom provision by services, provision of sterile injecting equipment, and advice and information – are important, there has been no significant reduction in the transmission of HIV over the last five years. Men who have sex with men (MSM) remain a key risk group for the transmission of HIV and this is why the Scottish Government funded the MSM prevention needs assessment referred to above. This report provides important lessons to inform service delivery and engagement with MSM. As set out in the original Framework document, multi-

³⁶ <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm310542.htm>

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https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/333018/Management_of_HIV_infected_Healthcare_Workers_guidance_January_2014.pdf

³⁸ http://www.proud.mrc.ac.uk/news/study_results.aspx

³⁹ HIV infection and AIDS: Quarterly report to 31 December 2014
<http://www.hps.scot.nhs.uk/ewr/subjectsummary.aspx?subjectid=27>

agency partners should make use of the most up to date evidence to inform prevention approaches. Likewise, the research by the MRC/CSO Social and Public Health Science Unit at the University of Glasgow and Health Protection Scotland, on HIV prevalence and undiagnosed infection amongst MSM in Scotland,⁴⁰ is important in relation to HIV testing and prevention policy. **NHS Boards and other partners should ensure that future prevention and testing strategies in this at-risk group are informed by up-to-date research and evidence such as these publications.**

Prevention work should also reflect the needs of other groups, including heterosexual populations: people who have come from areas of higher prevalence, particularly sub-Saharan African countries; young people; and older heterosexuals. The age distribution of people newly diagnosed with HIV is changing, with diagnoses among older age-groups showing an increase both in number and proportion. Almost one in five newly diagnosed heterosexual people was aged 50 years or above in 2014 compared to one in ten in 2004. Sexual health services should be able to meet the needs of all populations, but NHS Boards should also be aware of the potential that not all populations will access sexual health services. The needs of other populations should inform service design, **and the Scottish Government and Executive Leads will continue to assess what further research or prevention needs assessments are required in light of current epidemiology.**

Transmission of HIV among other populations in Scotland occurs infrequently and, generally, the comprehensive provision of injection equipment and opiate substitution therapy has led to long-term control of HIV infection among PWID; the impact of this combination of interventions in saving lives and healthcare costs should not be underestimated. Nevertheless, evidence generated in late 2014/early 2015 indicates that HIV infection is being transmitted among a small, but appreciable, population of highly chaotic, vulnerable, and often homeless PWID. Such transmissions reinforce the importance of prevention work with such populations.

PrEP has emerged as a potentially effective prevention strategy, particularly for high risk MSM. In Scotland market access arrangements for new medicines are through recommendations from the Scottish Medicines Consortium (SMC). The SMC will only consider new treatments within their licensed indication once they have been granted a marketing authorisation. Manufacturers seek marketing authorisations (licences) for the new drugs/indications from either the European Medicines Agency (EMA) or Medicines and Healthcare products Regulatory Agency (MHRA). As yet relevant pharmaceutical manufacturers of PrEP candidates have not made an application for such approval. **The Scottish Government will continue to monitor the regulatory position in respect of Pre-Exposure Prophylaxis in Scotland but in anticipation of developments in this area the Scottish Government will work with HIV Clinical Leads, the Executive Leads and HIV Scotland to consider policy implications and to understand attitudes and knowledge of professionals and the public.** The MRC/CSO Social and Public Health Sciences

⁴⁰ Wallace LA, Li J, McDaid LM (2014) HIV Prevalence and Undiagnosed Infection among a Community Sample of Gay and Bisexual Men in Scotland, 2005–2011: Implications for HIV Testing Policy and Prevention. PLoS ONE 9(3): e90805. doi:10.1371/journal.pone.0090805

Unit at the University of Glasgow has published work on the attitudes towards PrEP amongst those at risk of HIV⁴¹, and this will inform future work.

Testing and Diagnosis

The testing of individuals at risk of HIV infection, and the diagnosis of those who have been infected continue to be priorities. People living with HIV can expect far better clinical outcomes if they are diagnosed promptly, and yet in 2014, 49% of those newly diagnosed with HIV in Scotland were already at a late or very late stage of infection. A person diagnosed very late can have a life expectancy at least ten years shorter than somebody who starts treatment earlier in the course of infection, and late diagnosis is also associated with increased morbidity, impaired response to treatments and increased cost to healthcare services.

NHS Boards and multi-agency partners should continue work to offer HIV testing to all those who may be at risk of HIV infection. Consideration should be given to innovative approaches to increasing testing, such as community and self-testing, and testing in other healthcare settings; working with Third Sector organisations to deliver testing in the community; and supporting Primary Care and other clinical specialities to be aware of the risks of HIV and to consider testing when appropriate. The Scottish Government will do all it can to support such innovative approaches or pilot studies, including supporting work to improve local-level data on HIV prevalence.

Normalisation of testing for HIV continues to be a challenge. **HIV should be treated like any serious condition.** Consideration of traditional risk factors are no longer enough in terms of testing, and services should think beyond groups such as MSM, sub-Saharan Africans and young people. Key to this is the education and awareness-raising of professionals and the public, and securing the support of regulatory bodies to efforts to normalise testing. **The Scottish Government and the Scottish HIV Clinical Leads are of the view that testing for HIV should not be exceptionalised. HIV tests should be regarded as a routine investigation in all healthcare settings comparable to other clinical investigations. Such testing is likely to be cost effective in terms of early entry into treatment of HIV positive patients and reduced transmission of infection.**

Inequalities

In 2014 the World Health Organization (WHO) published Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care⁴². These Guidelines clearly define groups who, due to specific higher-risk behaviours, are at increased risk of HIV irrespective of local epidemiology. These populations are: men who have sex with men; people who inject drugs; people in prisons and other closed settings; people involved in commercial sexual exploitation; and transgender people. Although there is a need not to limit testing and responses to those most at risk, these groups must be reflected in the priorities of the Framework, and targeted efforts must be made to

⁴¹ For example, see: Young I, Flowers P, McDaid L. Barriers to uptake and use of Pre-Exposure Prophylaxis (PrEP) amongst communities most affected by HIV in the UK: findings from a qualitative study in Scotland. *BMJ Open* 2014; 4:e005717.

⁴² <http://www.who.int/hiv/pub/guidelines/keypopulations/en/>

ensure services meet the needs of these groups, and that populations are partners in service design and HIV response.

In line with the WHO Guidelines, and reflecting the priority given to HIV testing, **the Scottish Government will work with NHS Boards and the Scottish Prison Service to introduce opt-out BBV testing (hepatitis B and C and HIV) for all new prisoners in Scotland during their induction period.** This will provide an important opportunity to test and support a population who may otherwise not engage with health services.

Treatment and Care

Individuals living with HIV in Scotland have access to high quality clinical care and the overwhelming majority of individuals diagnosed are engaged with specialist services and are on antiviral therapy. NHS Boards meet the costs of HIV antiviral therapy and as those who are infected live longer lives, and while new infections continue to occur, the overall cost of treatment of HIV for the NHS will continue to rise. **The Scottish Government will continue to work with patient groups, NHS Boards and NHS National Procurement to look at innovative ways of reducing the costs of HIV therapy for those infected, including the use of generic antiretrovirals and national procurement of medicines.**

One in three people living with a diagnosed HIV infection is now aged 50 years or over. This is due to improved survival and continued transmission amongst older people and signals a need to develop services appropriate to an ageing population. Over the next five years this population will continue to grow and services should consider the needs of those aged 50 and over in the design of services, and when undertaking needs assessments. Those in this age group will also need access to information about their rights and what to expect from services. **The Scottish Government will therefore support the development of materials for care services and patients in this group to help raise awareness and promote effective support. This relates not only to NHS services, but also to residential and domiciliary services provided by Local Authorities.**

Over the last five years the Scottish HIV Clinical Leads have taken forward work to ensure delivery of the Healthcare Improvement Scotland Standards for HIV Services⁴³. This has contributed to the development and use of Integrated Care Pathways across the NHS in Scotland. Given the need for additional focus on testing and preventing late diagnosis in particular **the Scottish Government will work with the HIV Clinical Leads to ensure delivery of the HIS HIV standards in relation to reducing/preventing late diagnosis, (Standards 6 and 7) and with the Scottish Sexual Health Promotion Specialists on promoting HIV testing with key population groups.**

Awareness Raising and Stigma

The Scottish Government is committed to raising awareness around HIV as a public health issue, both in relation to important health messages (prevention, testing and

⁴³ http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/hiv_treatment_and_care/hiv_standards.aspx

diagnosis) but also as a means of tackling and reducing stigma. In the course of the last Framework the Government undertook work towards developing a new national awareness-raising campaign on HIV. However initial research with the public on potential approaches to such a campaign led to an unexpected finding: that any high level public awareness campaign led by Scottish Government is likely to have a negative effect. The very fact that there is a Government campaign about HIV raises concerns rather than awareness, and does little to reduce stigma.

On this basis the Government took a different approach and invested in targeted awareness raising. The *HIV Always Hear* campaign,⁴⁴ which was designed and implemented by Waverley Care, has made use of personal stories and case studies of those infected with HIV to develop a suite of resources. The campaign has so far provided information and raised awareness amongst schools and faith organisations, and has been evaluated positively. **The Scottish Government will continue to fund the delivery and on-going development of *Always Hear* as a targeted awareness-raising campaign over the period 2015/16 and 2016/17, after which further research will be undertaken on the potential benefits of a national campaign, or on the continued/wider use of *Always Hear*.** This work does not obviate the need for local awareness-raising activities by NHS Boards and other partners, and such work should continue.

For young people, HIV (and STIs) should be part of Relationships, Sexual Health and Parenthood (RSHP) education **which should continue to be provided to all young people, in all schools and wherever learning takes place, with delivery in line with equality and diversity legal obligations.**

Some progress has been made over the last five years in raising awareness and tackling stigma in professional organisations. In particular the publication by the Crown Office of their updated prosecution policy on transmission of sexually transmitted infections is something of which Scotland can be proud. However, more work is needed in the criminal justice field to tackle stigma. The formation of Police Scotland as a national police force has provided an opportunity for a more streamlined approach. Police Scotland has worked with HIV Scotland and the National AIDS Trust to produce and publish guidance to officers on how to treat someone who is living with HIV, (including confidentiality, rights and access to treatment while in police custody), but **the Scottish Government will continue to work with Police Scotland, either directly or through NHS Boards and Third Sector organisations, to support them in their engagement with individuals who may be infected with HIV.**

The views and behaviours of NHS staff are also important. Stigma from those working in healthcare professions has been shown to be particularly high amongst people living with HIV⁴⁵, therefore targeted work is needed with a range of non-specialist staff to provide up-to-date factual information and resources. **On-going development of *HIV Always Hear* to target health care staff will help address this, but NHS Boards should also seek to assess the views of employees on HIV to inform professional development and training.**

⁴⁴ <http://www.hivalwayshear.org/>

⁴⁵ *Give Stigma the Index Finger –Scotland report 2009*, International Planned Parenthood Federation 2009.

Workforce education development

NHS Education for Scotland (NES) has been funded to work with the HIV Clinical Leads to develop a CPD programme promoting the recognition and diagnosis of HIV infection by staff in non-HIV specialist areas⁴⁶. NES, working with partners, will continue to develop and support HIV national resources. Education and training of non-specialist staff is relevant to the above discussion in relation to stigma.

⁴⁶ <http://www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/public-health/health-protection/blood-borne-viruses/recognition-diagnosis-of-hiv-infection.aspx>

VIRAL HEPATITIS

Introduction

The original Framework set out separate sections on hepatitis B and hepatitis C. For the purposes of this update both hepatitis B and hepatitis C are addressed in this chapter on viral hepatitis.

Since the first Framework document much work has been done to better understand the epidemiology of hepatitis B in Scotland. That work has now been completed and we know that there is little transmission of hepatitis B in Scotland and the total number of infected individuals is low in comparison to hepatitis C, although the prevalence is much higher in populations from endemic areas. Hepatitis B remains an important infection and clinical care in Scotland is of the highest standard. Testing and diagnosis is vital in relation to both hepatitis B and hepatitis C, to ensure that individuals can access treatment and care as quickly as possible.

The introduction of new effective therapies for hepatitis C is a watershed moment and we can now look forward to a Scotland where hepatitis C is no longer a public health concern. Despite these new therapies, prevention of new blood borne virus infections remains key and it is vital that we do not reduce our prevention resources and infrastructure.

Key Progress since 2011

- As a result of investment in prevention strategies there has been a reduction in the annual number of new hepatitis C infections in Scotland – from 1,500 new infections in 2007 to 700 new infections in 2013.
- Testing/diagnosis: Significant increases in testing for hepatitis C have been observed, particularly in GP practices, addictions services and prisons. More than 55% of the estimated hepatitis C infected population in Scotland was diagnosed in 2013, compared with only 38% in 2007.
- A report on the prevalence and incidence of hepatitis C amongst Scottish prisoners was published in May 2012.⁴⁷ This study found that incidence of hepatitis C is very low among Scottish prisoners, including prisoners with a history of injecting.
- The number of people commenced on antiviral therapy for hepatitis C has increased significantly, from 470 in 2007/08 to 1,270 in 2014/15.
- With the development of new monitoring systems our understanding of the incidence, prevalence, and characteristics of, and thus public health challenges associated with, hepatitis B infection is very much greater than before.
- A great deal of activity takes place around World Hepatitis Day, co-ordinated by Hepatitis Scotland and the Hepatitis C Trust, with a particular focus on testing and awareness-raising.
- NHS Boards across Scotland have taken forward work with populations particularly vulnerable to viral hepatitis, including engaging directly with Mosques and employing Chinese-speaking staff for outreach.

⁴⁷ Taylor et al, *Hepatitis C Prevalence and Incidence among Scottish Prisoners and Staff Views of its Management: Final Report*, University of West of Scotland & University of Bristol & NHS Health Scotland, May 2012

- NHS Education for Scotland has developed educational resources ‘Hepatitis B and C detection, diagnosis and management’. These resources have been developed for those who deliver programmes of CPD in relation to BBV and are aimed at primary care staff. The resources have been piloted and courses run with approximately 120 people attending, and a ‘train the trainer’ day for NHS Board staff has also been held.

Key Developments since 2011

- Prevention: during the first phase of the Framework the UK Government made changes to the list of items under the Misuse of Drugs Act which can be provided to injecting equipment provision service users such that it is now possible for IEP services to include foil within equipment provided to people who inject drugs. The provision of foil is an important harm reduction measure which advises/advocates smoking rather than the injecting of drugs.
- Treatment: the most significant development towards the end of the first phase of the Framework has been the emergence of highly effective new therapies (directly acting antivirals) for hepatitis C. The first such new therapy was approved for restricted use by the Scottish Medicines Consortium in late 2014, with approvals of other therapies occurring during the course of 2015. These new therapies mark an important moment in the treatment of hepatitis C, offering much more tolerable therapies which can achieve very high levels of viral clearance (which is considered a cure).
- The Penrose Inquiry into the transmission of hepatitis C and HIV via infected NHS blood and blood products was published on 25 March 2015. The report highlighted the importance of case-finding by the NHS and diagnosis of individuals who may have been infected for a number of years.
- The emergence of new psychoactive substances in recent years gives rise to a number of issues relevant to the Framework, including the work of IEP services and the risks associated with injecting of NPS, but also the increased potential for risk-taking behaviours amongst individuals while using NPS.
- The UK National Screening Committee has published a review of screening for hepatitis B and C among ethnic minorities born outside UK. This document was last updated in 2011⁴⁸.

Key Priorities to 2020

Prevention

Significant developments have occurred in the field of treatment for hepatitis C in recent years, and this will have an impact on the next five years as set out below, but prevention must remain our priority. This update to the Framework restates the importance of prevention of viral hepatitis, particularly because it is vital that the developments in treatment do not distract us from this work. An effective vaccination against hepatitis C is not yet available but other effective prevention strategies are available. **Prevention remains a priority for all blood borne viruses and all NHS Boards and partners should ensure efforts continue to prevent infections.**

⁴⁸ <http://legacy.screening.nhs.uk/hepatitis-ethnic>

As a result of the Hepatitis C Action Plan, the Scottish Government published Guidelines for Services Providing Injecting Equipment⁴⁹ in 2010. This document set out best practice for injecting equipment service providers and has been recognised internationally as a model of best practice. Since 2010 there have been a number of important developments – such as the provision of foil, the emergence of new psychoactive substances, the publication of guidance on needle and syringe programmes by NICE in March 2014⁵⁰, and emerging evidence around performance and image enhancing drugs. Research, for example, from Public Health England in 2013 showed that men who inject PIEDS are at a much higher risk of hepatitis C.⁵¹ There is limited but growing scientific and anecdotal evidence of very risky injecting practices amongst small pockets of the MSM community, including in Scotland, and recent outbreaks of infections amongst injectors demonstrate that despite recent efforts there continues to be sharing of injecting equipment in Scotland. MSM living with HIV, particularly those using recreational drugs, are at risk of hepatitis C transmission through sex, as well as through injecting. The IEP guidelines should provide an evidence-informed approach taking into account new and emerging drug trends to ensure services are based on need, and with the twin aims of reducing infection risks and addressing the health needs of the user. **The Scottish Government will provide funding to support a review and update of the IEP Guidelines, working with the Scottish Prevention Leads network.** The review should take account of the NICE guidance in relation to young people to reflect any issues in relation to those under-16 who may be particularly vulnerable.

Hepatitis B vaccination is recommended for and available on the NHS in Scotland to those who are at particular risk of infection. Although there are very low levels of transmission of hepatitis B in Scotland, those at greater risk include people who inject drugs, those who change sexual partners frequently (including sex-workers) and prisoners. Provision of hepatitis B vaccination on the NHS for individuals at risk is available in sexual health and GUM clinics, via some addictions services and in prisons. Availability of hepatitis B vaccination via GP practices varies across Scotland. **The Scottish Government's view is that, as with all vaccinations recommended for clinical reasons where there is no national vaccination programme, GPs are expected to apply General Medical Council's guidance on Good Medical Practice by protecting people at risk from hepatitis B in the same way that they would provide treatments for other conditions and infectious diseases.**

Vaccination against hepatitis B will be offered to all prisoners during the induction period in prison. Any course of treatment will continue throughout their sentence and upon release, and across NHS Health Boards. Those prisoners who are hepatitis C antibody positive will also be offered immunisation against hepatitis A.

Testing, Case-Finding and Diagnosis

Detecting those who have been infected with hepatitis C and diagnosing them as early as possible enables individuals to receive treatment as early as is possible, and

⁴⁹ <http://www.gov.scot/Publications/2010/03/29165055/0>

⁵⁰ <https://www.nice.org.uk/guidance/ph52/resources/guidance-needle-and-syringe-programmes-pdf>

⁵¹ Hope et al, *Prevalence of, and risk factors for, HIV, hepatitis B and C infections among men who inject image and performance enhancing drugs: a cross sectional study*, BMJ Open, 2013

can improve long term health outcomes. In the era of highly effective therapies it is more important than ever that everyone who has been infected is diagnosed and in contact with specialist services so that general and liver health can be monitored, and treatment can be provided when appropriate. The Penrose Inquiry also identified the possibility of there being a number of individuals who were infected with hepatitis C as a result of receiving NHS blood and blood products before 1991 remaining undiagnosed.

NHS Boards and Third Sector organisations should continue work to test high-risk groups and case-find those who may have been lost to follow-up (which may include individuals who were infected via blood or blood products). Hepatitis C Managed Care Networks should identify and prioritise initiatives to diagnose or re-diagnose those most likely to (i) have moderate to severe disease, or (ii) progress rapidly to severe disease. This includes those who may have been exposed to NHS blood and blood products pre-1999. Different parts of Scotland have trialled various approaches to this over the last five years and Boards should learn from good practice.

To make it easier for people with a drug problem to access testing, treatment and care, **NHS Boards should consider innovative approaches to delivering services including peer support and buddying schemes, and/or integration with harm reduction/recovery services.**

It is particularly important that efforts are made to target testing at groups which may be a higher risk of being exposed to infection. In the case of hepatitis C, prisoners are a particular risk group. A study funded by the Scottish Prison Service and published in 2012 showed that most prisoners who were also injecting drug users had been tested for hepatitis C and most received their last test while in prison. However the study also concluded that the hepatitis C prevalence rate among prisoners is estimated at 19%. As a result of this, coupled with the particular health inequalities of those likely to be incarcerated and the very good treatment outcomes for those who access treatment while in prison, **the Scottish Government will work with NHS Boards and the Scottish Prison Service to introduce opt-out BBV testing (hepatitis B and C and HIV) for all new prisoners in Scotland during their induction period.**

There are clear and unambiguous links between hepatitis C and factors related to health inequalities. These have been well articulated in the last Framework and in the Scottish Government's Hepatitis C Action Plan. Those who are infected with hepatitis C are more likely to live in the most deprived areas of Scotland and may not access healthcare routinely. In order to increase diagnoses amongst those most at risk the **Scottish Government will work with Health Protection Scotland and representatives of the NHS Managed Clinical Networks to evaluate the potential and cost-effectiveness of a population-based case-finding approach (age-cohort or living in higher HCV prevalence areas). Such an approach would complement existing initiatives involving a targeted, risk factor based approach.**

Treatment

Background

Ever since the publication of the *Hepatitis C Action Plan* in 2008, the Scottish Government has been recognised as a world-leader in its response to hepatitis C. We continue to be ambitious and in light of the emergence of highly-effective new therapies, the **Scottish Government is committed to the elimination of hepatitis C as a public health concern in Scotland.**

The Minister for Public Health established a Treatment and Therapies Group in late 2013 to consider the implications of new therapies on the Scottish Government's hepatitis C policy. This group included clinical leads from across the NHS, patient representatives and public health experts. The conclusions of this group were submitted to the Scottish Government in May 2015, and the group's report has been published in parallel with this document. The conclusions of this work inform the following comments and commitments.

Although new, highly effective therapies are now available, very considerable challenges still exist:

- Over the period 2008-2013 the annual number of new presentations of hepatitis C related liver failure or cancer increased from 125 to 194; approximately 50% occurred in people who had been diagnosed with hepatitis C within five years of presentation.
- 16,800 infected people, a high proportion of whom are older, former PWID with moderate or severe liver disease, remain undiagnosed.
- Most (75%) diagnosed hepatitis C-infected people are not, or have never been, in specialist care.
- Nearly 11,000 infected with hepatitis C people have either cirrhosis of the liver or are in the pre-cirrhotic stage and, thus, are in urgent need of therapy; most are undiagnosed or are not in specialist care.

Reducing Morbidity and Mortality

The aim of investing in hepatitis C services in Scotland is to reduce severe morbidity and mortality caused by infection. With the availability of highly effective direct acting antiviral therapies which can prevent liver disease progression even in those who already have advanced disease, there is the potential to see a dramatic reduction in the incidence of such severe morbidity and mortality in a similar way to that achieved with AIDS cases and deaths following the introduction of HIV combination antiviral therapy in 1996. **Scotland should seek to reduce the number of people who develop HCV related liver failure, hepatocellular carcinoma (HCC) and the number of people who die from HCV related disease.**

Decision-Making

It is essential that principles regarding decision-making around the administration of hepatitis C antiviral therapy should be equitable, made by both patient and attending clinician, and be driven principally by the patient's need and the effectiveness and

safety of available drugs. How a patient acquired hepatitis C infection should never influence therapy decision-making.

Compelling evidence, based on Scottish and international data, indicates that the liver disease stage of the hepatitis C-infected patient strongly determines the short to medium term risk of developing severe hepatitis C-related liver disease; those with no or mild disease, for example, are very unlikely to progress to severe disease for many years. Nevertheless there is also compelling evidence that hepatitis C can cause serious non-liver related conditions and can have major psycho-social effects even in the presence of mild, or absence of, liver disease.

In the context of this evidence and the current high cost of the optimal therapies, prioritisation of such treatment – in terms of its timing – should be given to people at risk (imminently or in the next few years) of developing severe life threatening or seriously debilitating liver and/or non-liver hepatitis C related disease. This approach, coupled with the rigorous clinical monitoring of people not being offered therapy, is consistent with European Association for the Study of Liver (EASL) 2015 guidelines on the management of hepatitis C⁵².

The ultimate goal should be the offer, as soon as practically possible, of therapy to all people with chronic hepatitis C. Early treatment is likely to convey population benefits in terms of the prevention of onward transmission of infection (particularly among active PWID) and reduces the risk of infected people – lost to clinical monitoring (a common occurrence among those who have ever injected drugs) – presenting years later with end-stage liver disease. Early treatment also reduces the risk of people living for many years with debilitating symptoms and associated psycho-social consequences.

Hepatitis C infected patients should be offered optimal SMC-approved therapies (as judged by effectiveness and adverse effect profile): thereafter, the cost of therapy becomes an important consideration.

All hepatitis C infected individuals are eligible for treatment with optimal SMC accepted regimens. However, in view of the current high cost of these regimens and the high number of individuals infected in Scotland,⁵³ priority, in terms of the timing of treatment, should be initially given to those patients with the highest need. This means, as a minimum:

- **patients with F3/F4 hepatic fibrosis;**
- **and/or patients with severe extra-hepatic manifestations of hepatitis C;**
- **and/or patients with significant psychosocial morbidity as a consequence of hepatitis C.**

Because the availability of new treatments and their pricing is changing rapidly, the above recommendations will be reviewed on an on-going basis. The Treatment and Therapies Group established by the Minister for Public Health, will continue to meet at least annually to do this.

⁵² <http://www.easl.eu/medias/cpg/HEPC-2015/Full-report.pdf>

⁵³ Est. 37,000 (20,000 diagnosed and 17,000 undiagnosed)

Delivering Treatment

Scotland's Hepatitis C Action Plan achieved a rapid scale-up of therapy from 450 to approximately 1,050 initiates between 2007 and 2010; thereafter the numbers plateaued. The principal barriers to getting people treated have been sub-optimal effectiveness, adverse effects and the duration of Interferon-based therapeutic regimens. A further barrier has been the practice, in most instances for logistical reasons, of administering Interferon-containing therapy in the hospital setting. With the availability of easy-to-administer, safe, highly-effective, short-duration therapies, it is now practical to deliver treatment in community settings.

Scotland should aim to deliver hepatitis C therapy for most infected people in community settings (including prisons); such an approach must be overseen by the NHS Board Managed Care Network responsible for hepatitis C. This strategic change in service delivery should not preclude certain people receiving all or some of their management in a secondary care setting if their clinical status merits this.

Targets

The principal goal of the Scottish Government's commitment to Hepatitis C service development is the prevention of serious morbidity and mortality. Modelling work, undertaken by Health Protection Scotland and Glasgow Caledonian University, estimates that a minimum of 1,500 treatment initiates per year during 2015-2020 is required to stand a chance of reducing the number of new liver failure/cancer presentations from the current level of around 200 to 50 by 2020⁵⁴.

As such, during 2015-2020 at least 1,500 people per year will be initiated onto antiviral therapy in Scotland. This represents a near 20% increase on the number of people treated in 2014⁵⁵.

Assuming this treatment target is met, the Scottish Government is aiming for a 75% reduction in the annual number of people developing hepatitis C-related liver failure and/or liver cancer by 2020. This equates to a reduction from around 200 in 2013 to 50 in 2020.

Monitoring

The success of Scotland's Hepatitis C Action Plan has been achieved in part through the ability of service providers to monitor performance through a range of outcome indicators including numbers of people diagnosed, getting into specialist care, undergoing treatment and eliminating their infection. Accordingly, it is essential that outcome indicator data continue to be collected and made available. **Scotland should continue to assess the impact of its investment in HCV infection and disease prevention through the monitoring of outcome indicators.**

⁵⁴ Innes H, Goldberg D, Dillon J, Hutchinson SJ. Strategies for the treatment of Hepatitis C in an era of interferon-free therapies: what public health outcomes do we value most? Gut. 2014 Nov 6.

⁵⁵ These are all-Scotland targets; for NHS Boards targets will be set according to population based criteria.

Research

This document recognises the importance of investment in research across the sexual health and blood borne virus field. The research dividend of Scotland's *Hepatitis C Action Plan* has been spectacular⁵⁶. Reports published in the world's leading liver disease journals have not only informed and evaluated policy and practice in Scotland, but internationally. **Scotland should continue to lead the world in this way over the next five years, with a continued focus on research.**

Three priority areas of research for hepatitis C have been identified:

- The cost, effectiveness and cost-effectiveness of different models of diagnosing, assessing and delivering of therapy to hepatitis C infected people
- Assessing the drivers and impact of alcohol consumption on hepatitis C case management and evaluating interventions to address the adverse impact of such consumption
- Evaluating the concept of the administration of antiviral treatment to people who actively inject drugs to prevent onward transmission of infection.

⁵⁶ Hutchinson SJ, Dillon JF, Fox R, McDonald SA, Innes HA, Weir A, McLeod A, Aspinall EJ, Palmateer NE, Taylor A, Munro A, Valerio H, Brown G, Goldberg DJ. Expansion of HCV treatment access to people who have injected drugs through effective translation of research into public health policy: Scotland's experience. *Int J Drug Policy*. 2015 Jun 6



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