

EQUALITY IMPACT ASSESSMENT - RESULTS

Title of Policy	Implementation of the key Financial Review Group recommendations in relation to support available to those affected by infected NHS blood, tissue and blood products (hepatitis c and HIV)
Summary of aims and desired outcomes of Policy	In light of the Scottish Financial Review Group Recommendations (December 2015), the purpose of this policy is to improve the approach to support available to those affected via a new Scottish scheme to be administered by NHS National Services Scotland (NSS).
Directorate: Division: team	Population Health Directorate Health Protection Division SNBTS and Organ Donation branch

Executive summary

This equalities analysis accompanies the Scottish Government’s proposals to provide new Scottish arrangements to replace the current UK-wide payment schemes for those affected by HIV/hepatitis C infection via NHS treatment. The existing schemes were set up by the UK Government from 1988 onwards for people infected with, or affected by, HIV and/or hepatitis C as a consequence of treatment with NHS-supplied blood or blood products before September 1991. While the UK Government and devolved administrations have steadily increased the support available as a result of past reviews, over time the support

system has become complex, and has attracted significant criticisms from those it is intended to help.

Those primarily affected by the reforms will be infected individuals and affected family members of infected individuals, particularly those who are/were financially dependent on support given by the schemes. This includes spouses or partners who do not work full-time because of caring responsibilities; bereaved spouses or partners and any dependent children.

We are proposing to improve the financial support available for all those affected, who will include many of the equality groups. There are no negative impacts on any equalities groups. All those infected and their families should be better off (or at least receive the same support) under the new scheme as compared to the current arrangements.

Background

On March 18 2016 the Scottish Government accepted all the key financial support recommendations in the Final Report of the independent Financial Review Group, established in Scotland to undertake a review of the existing UK-wide financial support schemes for individuals infected with Hepatitis C and HIV through NHS blood and blood products. This considered what support should be available for individuals and families receiving payments from the Scottish Government via the UK schemes.

The Review Group which was established to make recommendations on the proposals featured a majority of infected patients (or their representatives). The proposals were therefore directly shaped by patients through that process, and in response to the consultation exercise that was distributed via the schemes to all beneficiaries infected in Scotland.

Scottish Ministers have asked NHS National Services Scotland (NSS) to administer a new Scottish Infected Blood Support scheme - the scheme will act as the single scheme providing targeted support for those infected and their direct families, which is expected to operate from April 2017. An advisory group involving beneficiaries and other independent stakeholders is being set up to provide advice on operational aspects of the new scheme.

The Scope of the EQIA

The financial review was taken forward in partnership with beneficiaries at all stages. The EQIA focuses on past Scottish beneficiaries of the existing UK support schemes, and future beneficiaries of the new Scottish scheme. This includes some equalities groups who may have experienced stigma, health impact and financial impact as a result of the infection. Some beneficiaries will be classified as disabled, either as a result of their infection or otherwise. Some will be on low incomes and accessing benefits in addition to the support provided by the scheme. In addition, tackling inequalities should be considered as a cross-cutting theme as beneficiaries and the scheme administrator will give due consideration to access to other support services (local authority/NHS/third sector) and funding streams available.

Key Findings

The existing schemes already offer some positive discrimination in that those most likely to be disabled as a result of their infection receive the most financial support. This will not change under the new schemes - the payments will just be more generous. We have committed to review the current assessment thresholds for the scheme to ensure payments reflect actual, causal health impact as far as possible.

AGE

The overwhelming majority of individuals were infected before 1991, with the exception of a small number of people who have been secondarily infected. The age ranges of all beneficiaries are from 20 – 100, with the majority in the 50-70 age group.

DISABILITY

HIV is considered a disability under the Equality Act 2010. Hepatitis C is not, although some of those with hepatitis C are or may in future become disabled within the meaning of the Act. Some people who have been treated may be disabled as a result of the treatment they received causing residual health problems - short-term or long-term. Additionally, some scheme members may be disabled as a result of other conditions unrelated to hepatitis c, such as haemophilia, or the effects of ageing. Others received treatment with infected blood in connection with treatment for existing serious conditions, such as cancer, or serious injuries. At present all those with HIV automatically receive regular annual payments, as do those with advanced hepatitis C. All those who experienced chronic infection with HCV receive lump sum payments and also access to additional discretionary payments, which are primarily targeted on the basis of financial need.

There is a wide range of other disability-related financial support, including benefits, tax credits, payments, grants and concessions. The infected blood support scheme payments are exempt from consideration with regard to key benefits, so those affected can still claim them. The intention is to preserve those exemptions for the new scheme.

A key difference between HIV and HCV infection is that HCV can be successfully treated to achieve a Sustained Viral Response (viral clearance). In that sense, the continuing medical treatment required to control HIV infection creates a temporary improvement to the impairment rather than a permanent

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improvement. With the new medications now available and widely deployed, the chances of successful HCV treatment are much higher (more than 90%), with far fewer side effects than previous treatments. Clearing the viral infection is associated with improved long-term clinical outcomes and improved health-related quality of life. With HIV treatment, you will take a combination of drugs for the rest of your life. HIV is also generally associated with greater stigma than HCV.

SEX

The biggest single patient group infected are people with inherited bleeding disorders, nearly 90% of whom are male. As such, the majority of direct beneficiaries of the schemes are male, and the majority of bereaved spouses/partners are likely to be female.

Recommendations and Conclusion

We conclude that the proposals will significantly benefit all beneficiaries and that they are as proportionate to the specific impact of the infections as they can be, without instigating an additional programme of individual medical assessment, which beneficiaries generally object to. We are proposing to improve the financial support available for all those affected and deliver it in a more flexible, simple and accessible way. There will in particular be more generous funding for those with more advanced hepatitis C and those with HIV, which recognises the additional health impacts caused by these conditions and the fact that many in these categories are unable to work due to their illness. This approach was recommended following a UK scientific and clinical review in 2011 and the current assessment criteria are all based on past reviews of international evidence. The HCV-related conditions that trigger the higher annual payments have been identified as having a clear causal link to infection, resulting in serious deterioration in quality of life and life expectancy. On the balance of probabilities, the most severely disabled beneficiaries will be those who are co-infected

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with HCV and HIV, those with advanced (Stage 2) HCV and those with HIV, with the coinfecting experiencing the worst outcomes. They are also the beneficiaries who will receive the highest levels of financial support under the Scottish Government's proposals.

It is possible that a small group of infected people with a disability as a direct result of infection or treatment are treated differently from others with a similar level of impairment. However, we propose to conduct a further evidence-based clinical and scientific review of the current assessment criteria to mitigate this as far as possible. In some cases the disability will not have been caused by hepatitis c infection or treatment. It is often difficult to be sure about the specific cause of the symptoms or impairment, which may include the effects of ageing and the interplay of other health conditions and lifestyle factors.

There are no negative impacts on any equalities groups. All those infected and their families should be better off (or at least receive the same support) under the new scheme as under the current arrangements. However, we recommend the latest international evidence and beneficiary data be kept under review to ensure the new scheme remains reactive to any changing needs. The new Scottish scheme will also create an independent advisory group to advise on operational matters, good practice and any changing features of the beneficiary group.