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Scottish Infected Blood Support Scheme (SIBBS) - further questions: FOI release

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Directorate: Population Health Directorate

Part of: Health and social care, Public sector



Information request and response under the Freedom of Information (Scotland) Act 2002.

Date received: 15 Aug 2019
Date responded: 5 Sep 2019
Information requested

- 1. Details of the numbers of beneficiaries of the Scottish Infected Blood Support Scheme (SIBSS) who were in receipt of specific one off grants or any other available fundings such as: Income Top up support, application for living cost supplements or support and assistance grants used towards the cost of social care and the care of infected victims such as additional funding to support respite care, additional care support? Or specific financial support accessible to stage 2 beneficiaries (with cancers or stage 2 classed diseases).
- 2. Can the Scottish Government please clarify which staff and or which groups devised and informed the criteria for the Scottish Infected Blood Support Scheme, and which officer(s) wrote the guidance and documents published about the scheme from conception to the launch of the scheme? Should the Scottish Government not wish to provide names, the job titles or names of groups would be sufficient.
- 3. Could you confirm which groups make up the advisory board of the Infected Blood Support Scheme. For example how many NHS practitioners, Beneficiaries, their families members, government official or politicians or any other type of group? For example if the advisory board comprised of ten people, how would this ten be divided into representing each group of stakeholder? Could you also identify and provide documents which stipulate the numbers allowed to be members of the advisory board, and the definition of its make up.
- 4. Could the Scottish Government please confirm how much it has spent since the Scheme was introduced and where this money originates from? For example does the government in Westminster provided additional funding for this scheme or is this funded from Scottish budgets? Could you please clarify the amounts and source of the funding for each calendar year since 2017

Infected Blood Inquiry began in September 2018?

6. Could the Scottish Government please in full provide a copy of the Financial Review document used to inform the Scottish Infected blood Support scheme in 2015?

Response

Question 1. Based on the data provided to the Scottish Government by NHS National Services Scotland (NSS), the number of Scottish Infected Blood Support Scheme (SIBSS) beneficiaries who have received Support and Assistance grants from SIBSS is:

Category	Number of beneficiaries given grants
Income Top-Up support	50
Living Costs Supplement	213
One-Off Grant	10

(Note that the £1,000 living costs supplement is included within annual payments paid to beneficiaries and so all those beneficiaries receiving annual payments do receive the supplement, but it has only been included in the above where it has been applied for separately.) In addition, 117 beneficiaries currently receive advanced hepatitis c (HCV) annual payments (Stage 2) of £27,000 per year.

We do not hold information on whether any of the grants listed above were used towards the cost of social care and the care of infected victims, such as additional funding to support respite care or additional care support. It is worth clarifying that NSS, as managers of SIBSS, process all applications for grants. They would not have information on how beneficiaries spend the money they receive in relation to their annual payments, income top-up support or the living costs supplement as they do not collect that information. However, you may wish to contact them if you would like more information on the types of one-off grants funded by SIBSS. For more information on how to contact NSS see https://nhsnss.org/how-nss-works/freedom-of-information/

This is a formal notice under section 17(1) of FOISA that the Scottish Government does not have the information you have requested in relation to this sub question.

Question 2. The guidance and documents covering SIBSS scheme criteria were primarily drafted by the Organ Donation and Blood Policy team within the Scottish Government, both by the team leader and the Policy Manager for Blood Policy in discussion with NSS staff. The overarching Scottish Infected Blood Support Scheme 2017 and subsequent amending scheme documents were developed with Scottish Government legal advisers. The SIBSS Advisory Group members were also given the opportunity to comment on a number of the guidance documents so some stakeholders represented on the Advisory Group, such as Haemophilia Scotland, had input into the wording of the guidance.

Haemophilia Scotland

The Hepatitis C Trust

Hepatitis Scotland

NSS Health Protection Scotland

Scottish Government (as observers)

There is no document which specifies the number of people allowed to attend the Advisory Group or sets out a specific definition of its make up, although more information about the Group's terms of reference, which includes some information on the proposed mix of members and the skills and qualities required of Group members, is available on the NSS website at https://nhsnss.org/media/2363/sibss-advisory-group-tor-v10-final.pdf . The Advisory Group itself has sometimes discussed points about membership of the Group; minutes of the Group's meetings are available on the NSS website at

https://nhsnss.org/services/practitioner/medical/scottish-infected-blood-support-scheme/advisory-group/ .

Question 4. The funding provided to SIBSS by the Scottish Government since its establishment on 1 April 2017 is as follows:

2017-18 - £6,967,561 2018-19 - £8,392,939 2019-20 - £8,750,000 Total since April 2017: £24,110,500

The great majority of this funding comes from the Scottish Government budget, although the UK Department of Health and Social Care provided £519,171.32 in 2017-18 and £786,113.30 in 2018-19 to the Scottish Government towards costs in relation to SIBSS beneficiaries with HIV and their widows, widowers, civil partners or long-term partners.

Question 5. Based on the information we have received from NHS National Services Scotland (NSS), 33 infected beneficiaries of SIBSS have died between 1 April 2017 and 30 June 2019. Of those 33 deaths, 7 have died since the Infected Blood Inquiry hearings began on 24 September 2018.

Please note that we only hold information regarding SIBSS beneficiaries so do not hold information regarding numbers of deaths of those infected via infected blood who may be beneficiaries of other UK infected blood support schemes or those who were infected outside the UK.

Question 6. The final report of the Financial Review Group is available on the Haemophilia Scotland website at https://haemophiliascotland.files.wordpress.com/2015/11/contaminated-blood-financial-support-conclusions-and-recommendations.pdf
. Under section 25(1) of FOISA, we do not have to give you information which is already reasonably accessible to you. If, however, you do not have internet access to obtain this information from the website listed, then please contact me again and I will send you a paper copy

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