

Witness Name: Martin Bell
Statement No: WITN4728001
Exhibits: WITN4728002-039
Dated: 28 April 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARTIN BELL

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 18 August 2020.

I, Martin Bell, will say as follows: -

Section 1: Introduction

- 1. Please set out your name, address, date of birth and any relevant professional qualifications relevant to your work at SIBSS.**

1.1 Martin Stalker Bell (DoB: GRO-C1966) MSc, BSc(Hons), Fellow of the Institute of Healthcare Managers (FIHM)
Director Primary Care & Counter Fraud Services
NHS National Services Scotland
Area 1.67c, Gyle Square
1 South Gyle Crescent
Edinburgh, EH12 9EB
T: GRO-C
E: [GRO-C">martin.bell@GRO-C](mailto:martin.bell@<span style=)

- 2. Please describe your employment history including the various roles and responsibilities that you have held throughout your career, as well as the dates. In particular, please set out whether you had any role in the Alliance¹ House Organisations (“AHOs”) and, if so, please describe that role and your responsibilities within it.**

¹ i.e. the Macfarlane Trust, the Eileen Trust, the Macfarlane and Eileen Trust Limited, the Caxton Foundation and the Skipton Fund. Provide details of your involvement and copies of any statements or reports which you provided.

2.1 Director Primary Care & Counter Fraud Services - 1 Feb 2019 to date.

As a Director, I am a member of the Executive Management Team inputting to strategic discussions and operational delivery across NHS National Services Scotland. I also have executive lead for Primary Care activity across NSS and I am the champion and executive sponsor of the NSS Armed Forces and Veterans and (dis)ability networks.

2.2 As Director for Primary Care and Counter Fraud Services, I am responsible for the strategic direction and operational delivery of the strategic business unit (SBU). My SBU is one of five within NSS. The business unit has c500 staff made up of professionally qualified dentists, accountants and a variety of administrative staff. The business unit is divided into two elements: Practitioner Services and Counter Fraud Services.

2.3 Practitioner Services provides services on behalf of Scottish Government and Health Boards to support General Practitioners, Dentists, Opticians, Community Pharmacies and Dispensing Contractors delivering primary care across Scotland. This support includes payment, maintaining an up-to-date patient registration database, medical record transfers and clinical governance for dental services.

2.4 Our Counter Fraud team seeks to protect NHS Scotland's resources from financial crime. As well as SIBSS, the business unit also administers the Scheme to support Mesh Claims in Scotland and the NHS Scotland Health Boards' Clinical Negligence and Other Risk Indemnity Scheme (CNORIS).

2.5. Associate Director Planning, Performance & Service Delivery, Strategy & Governance Directorate, NHS NSS - 30 Oct 2013 to 31 Jan 2019.

This period included brief spells as Interim Director for Strategy & Governance bridging gaps during departure and arrival of different incumbents. The role was predominantly to support the Chief Executive by owning and running the organisation's strategic development process and associated business performance management processes. I also provided leadership and management to the Planning, Performance and Service Delivery team, including Corporate Risk Management, Business Intelligence, Sustainability and Resilience/Business Continuity, and to lead the development, implementation and ongoing management and improvement of these areas across NHS NSS. My aim was to provide a comprehensive range of

strategic planning and performance, business support and business development services to the Strategy and Governance Function and ensure delivery of effective internal control and corporate governance.

2.6 *British Army Officer – 1992-2013.* A summary of appointments is:

- **Jan to Oct 2013** – Assistant Head Plans & Resources, Defence Primary Healthcare – Grade Colonel – As the first incumbent in the new post, my role was transformational. I designed the new Defence Primary Healthcare organisation's concept of operations and the transition plan that allowed the new headquarters to take on responsibility for military primary care, globally, from the three single service organisations preceding it.
- **Jan 2012 to Jan 2013** – Staff Officer Grade 1 (Lieutenant Colonel) Army Personnel Centre – HR and career management for officers and soldiers of the Army Medical Services.
- **Jun 2011 to Dec 2011** – Deputy Medical Director (Lieutenant Colonel) 2nd US Marine Expeditionary Force, Afghanistan – Operational planning to ensure multi-national, coalition forces had medical cover when performing their military operations across Helmand and Nimroz provinces. I was also the lead for designing and delivery of an ambulance service for Afghan Police and Army units across the same area; part of the capacity building effort for indigenous forces.
- **Jul 2010 to Jun 2011** – Student Advanced Command & Staff College, Defence Academy of the UK – Masters student on a multi-national leadership course.
- **Jul 2007 to Jul 2010** – Commanding Officer (Lieutenant Colonel) 1 Medical Regiment, British Forces Germany – Commanded 650 personnel from across the Army Medical Services and supporting services. I deployed the Regiment to Iraq in 2007 to support all coalition forces in Basrah Province, including the hospital, patrol medics and evacuation across the Province. I also deployed the Regiment to Kenya in 2009 for six weeks on medical outreach clinics; working with the Kenyan Ministry of Health and World Health Organisation polio campaign. Delivering primary care and vaccinations to remote and rural populations.
- **Jul 2006 to Jul 2007** – Chief Instructor (Lieutenant Colonel) Army Medical Services Training Centre, 2nd Medical Brigade, Strensall, York. – Designing and delivering military and clinical training for all Army Medical Services Territorial Army personnel and simulated hospital exercises for all regular medical hospital units prior to deploying to Iraq or Afghanistan.
- **Aug 1992 to Jul 2006** – Various operational and planning roles in Army regimental units and divisional headquarters (2nd Lieutenant to Major) globally.

These roles have included running general practice medical centres, ambulance services and hospital departments.

2.7 I have never had a role with the Alliance House Organisations.

3. Please set out the positions you have held at SIBSS, including with any committees, working parties or groups relevant to the Inquiry's Terms of Reference, and describe how you came to be appointed to those positions.

3.1 Due to my role as Director Primary Care & Counter Fraud Services, I am by appointment SIBSS Director. I chair the SIBSS Advisory Group which is made up of representatives from the NHS, Hepatitis Scotland, Haemophilia Scotland, the Scottish Infected Blood Forum and Members.

3.2 The SIBSS Advisory Group was set up to ensure that the Scottish Scheme takes account of members' concerns and views on areas for operational scheme improvement, in light of the budget available. It provides advice on positive action to ensure that lessons are learned, trust in the Scheme is maintained and that respect and courtesy between members and Scheme administrators and others involved in contributing to the Scheme, such as medical professionals, is maintained. The Group is independent and seeks to sustain the confidence of the public, members and the NHS through demonstrable communication and impartial cooperation. The Advisory Group's Terms of Reference [WITN4728002] are available on the SIBSS webpage.

3.3 As Advisory Group Chair, I seek to ensure all on the Group have a voice and are listened to, the agenda is co-produced with Group members and that reporting from SIBSS is as transparent as possible. I also oversee any actions arising from discussions to ensure these are completed in a timely manner.

4. Please describe your role and responsibilities in the above positions.

4.1 As SIBSS Director, my principal responsibility is to ensure the team administering the Scheme is resourced properly and that they deliver the Scheme's outcomes in as effective and efficient a way possible. I also have formal responsibility to approve or not, applications to the Scheme. This necessitates a review of all application evidence and I communicate closely with the SIBSS Manager to ensure that, where

required, appropriate evidence is secured either from the applicant or an appropriate clinical specialist.

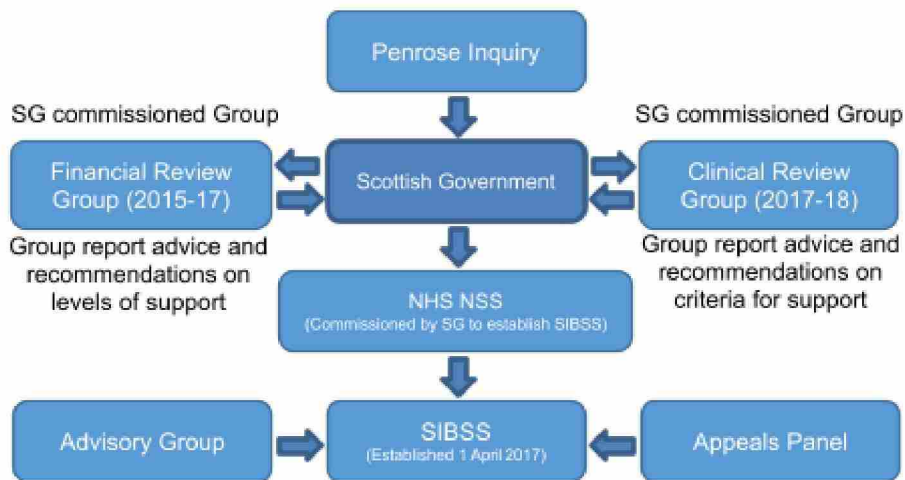
4.2 The Scheme is funded directly by Scottish Government via annual allocation and I report progress monthly to my Chief Executive, quarterly to the Scottish Government and bi-annually to the Advisory Group.

4.3 As chair of the Advisory Group, I believe I have built a good working relationship with the membership. I actively seek advice and opinion on all matters arising and ensure all have a voice in the selection and design of questions for our membership survey and input into the action plan following our collective analysis of said survey results.

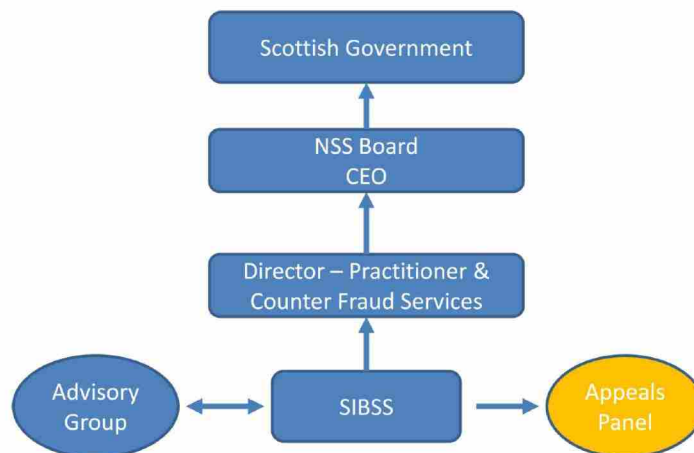
5. What induction, training and information did you receive from SIBSS as to its functions, aims and objectives?

5.1 On taking up appointment, my predecessor briefed me on the Scheme's development and its then current operation and objectives. I followed this initial briefing with personal reading of the Scheme's 'Terms of Reference'; Scottish Infected Blood Support Scheme 2017: A Scheme of support and assistance for those infected with Hepatitis C, HIV, or both, as a result of NHS treatment [WITN4728003] and the minutes of recent Advisory Group meetings and action notes from the quarterly meetings with Scottish Government. This reading was essential to expand my understanding of the Scheme, its membership, objectives and the challenges faced. The SIBSS Manager has also given continuous support to me across all operational aspects of the Scheme.

5.2 My understanding is that the Scheme came about as an outcome of the Scottish Financial Review Group, commissioned by the Scottish Government. The Scottish Government then commissioned NHS NSS to establish and run the Scottish Scheme. SIBSS was then established to take over from the existing UK schemes (Eileen Trust, Macfarlane Trust, MFET Ltd, Skipton Fund and Caxton Foundation) in providing financial support for Scottish members, i.e. those infected with Hepatitis C, HIV, or both, as a result of NHS treatment. I have given a pictorial account of my understanding of the relationships between the core elements and the part they played in the establishment of the SIBSS:



5.3 My personal relationship and accountability with the Advisory Group, the Independent Appeals Panel, our host organisation (NHS NSS) and Scottish Government is explained pictorially as:



5.4 As explained in answer to question 4 above, as SIBSS Director I engage with Advisory Group members and Chair the bi-annual meetings. I report to the Chief Executive Officer of NHS NSS and up to Scottish Government. I have no role in the Appeals Panel as that is wholly independent. The SIBSS manager supports the Appeals Panel with its administrative needs only.

5.5 SIBSS also supported David Goldberg, the chair of the Scottish Government's Clinical Review Group. This support was in the form of administration in the arranging of interviews and meetings between David Goldberg and members to support the Clinical Group's research.

6. Please set out your membership, past or present, of any other committees, associations, parties, societies or groups relevant to the Inquiry's Terms of Reference, including the dates of your membership and the nature of your involvement.

6.1 I was a member of the Institute of Healthcare Managers between 2006 and 2017, then the Scottish Institute of Healthcare Managers 2017-18. Between 2006 and 2009, I completed my continuous professional development requirements to achieve fellow status (FIHM) in 2009. I have never been a member of a trade union or political party.

7. Please confirm whether you have provided evidence to, or have been involved in, any other inquiries, investigations or criminal or civil litigation in relation to human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products.

7.1 I have had no previous involvement in any other inquiries, investigations or criminal or civil litigation in relation to human immunodeficiency virus (HIV) and / or hepatitis B virus (HBV) and / or hepatitis C virus (HCV) infections and / or variant Creutzfeldt-Jakob disease ("vCJD") in blood and / or blood products.

Section 2: Establishment of the Devolved Schemes

8. Further to SIBSS Manager Sally Richard's first witness statement dated 16 November 2018 (especially in answer to question 2), please provide additional details of the involvement (to your knowledge) the Scottish Government had in the setting up of SIBSS.

8.1 My understanding is that following the Penrose Inquiry Report, the Scottish Government established a Contaminated Blood Financial Review Group in 2015. The Financial Review Group's recommendations [WITN4508014] led to the establishment of SIBSS. In 2017, a separate Clinical Review Group was established. The Clinical Review Group's work [GGCL0000168] supported Scottish Government in designing the eligibility criteria for the HCV Stage 1 group [WITN4728004].

8.2 Scottish Government established SIBSS to take on the financial support to those already benefiting from the AHOs, as described in response to question 5 above, as well as provision of support to new members. NHS NSS was commissioned by Scottish Government to establish and administer the Scheme.

9. Were you personally involved in the consultation by the Scottish Government's Financial Review Group about the establishment of SIBSS, its functions, aims and objectives? If so, please:

- a. If possible, describe that process further to the details provided in your first rule 9 response.**
- b. Set out the contribution you made to the consultation.**

9.1 No, I was not personally involved in the consultation by the Scottish Government's Financial Review Group about the establishment of SIBSS, its functions, aims and objectives.

9.2 NHS NSS set up a project board to establish SIBSS. The final project board report on the establishment of the Scheme is attached [WITN4728005].

9.3 It is my understanding that Norma Shippin and Susan Murray, representatives of Central Legal Office, a separate business unit within NHS NSS, were involved on the Financial Review Group consultation.

10. Further to your answer to question 4 in the second witness statement dated 23 January 2019, please provide details of any informal accountability mechanisms in relation to the management of SIBSS by NHS National Services Scotland ("NSS") in the absence of an operational agreement.

10.1 There is a Memorandum of Agreement between Scottish Government and NHS NSS setting out the commission for NHS NSS to run the new Scottish Scheme, SIBSS. See [WITN4728006].

10.2 The SIBSS Manager and Director meet directly (with the Scottish Government on the performance and overall management of the Scheme in quarterly meetings. These quarterly meetings have a standing agenda [WITN4728025] and ensure Scottish Government are kept updated in real-time on the number and type of

applications received, how many of these applications have been approved or not, including where additional information or evidence has been sought before a decision can be made. Financial management of the Scheme is also discussed. This ensures the Scottish Government are sighted on progress against our annual allocated budget and whether or not a possible 'top-up' to said budget is required.

10.3 There is also a biannual meeting of the SIBSS Advisory Group. As stated above, in response to question 3, the Advisory Group is made up of representatives from Scottish Government, the NHS, Hepatitis Scotland, Haemophilia Scotland, the Scottish Infected Blood Forum and Scheme members.

10.4 The Advisory Group are also briefed on the number and type of applications received, how many of these applications have been approved or not, including where additional information or evidence has been sought before a decision can be made. The financial position of SIBSS is discussed and the Advisory Group are able to question and challenge the SIBSS administrators from the perspective of Scheme members. This helps maintain a focus on the membership's needs and challenges and allows areas for improvement to be identified. The Scottish Government attend the Advisory Group as observers and this ensures the membership's perspective is also taken into account by it during its own involvement with the Scheme.

11. What did you understand the aims and objectives of SIBSS to be? What principles or philosophy underpin, or are intended to underpin, it?

11.1 As described in response to question 5 above, SIBSS was established to take over from the existing UK schemes (Eileen Trust, Macfarlane Trust, MFET Ltd, Skipton Fund and Caxton Foundation) in providing financial support for Scottish members, i.e. those infected with Hepatitis C, HIV, or both, as a result of NHS treatment. SIBSS also supports the immediate family in cases where the infected person has died or where an infected member has passed on the infection to them unknowingly.

11.2 In its administration of the Scheme, the SIBSS staff seek to help and support applicants and existing members through our processes. Where online applications cannot be undertaken, we provide paper copies of application forms to ensure full access. Help with applications is also offered via phone or email.

11.3 Applications are assessed on the basis of 'balance of probability' when we look at the evidence to establish how we can accept the claim. Where insufficient evidence is submitted further investigations are undertaken. We ask the applicant if there is any other evidence known to them. We follow up with hospital clinics and GP practices where applicable, to establish if there is any further evidence exists in a patient's file. Finally, in many cases there is a lack of historical medical records to prove a transfusion took place. We therefore seek clinical expert opinion on the probability of a procedure, as described in the application, needing a transfusion.

11.4 SIBSS also provides administrative support to the Independent Appeals Panel, chaired by Professor Alison Britton. This is administrative support to facilitate panels where unsuccessful applicants can seek an independent review of their applications.

Section 3: Transitional arrangements from AHOs to Devolved Schemes

12. Please describe the extent of your personal involvement in the transitional arrangements from the AHOs to SIBSS.

12.1 I was not personally involved in the transitional arrangements from the AHOs to SIBSS.

12.2 My understanding is that Robert Girven (Scottish Government) and the following representatives from NSS, Sally Richards, (SIBSS Manager) and Steven Fenton (Project Manager), had one meeting, in London, with AHO representatives, Jan Barlow (Caxton Foundation), Nick Fish (Skipton Fund) and Victoria Prouse (Macfarlane Trust), on 1st February 2017. The aim was to discuss the transfer of Scottish members to the new Scottish Scheme. A note of the meeting has been provided to the Inquiry [SIBS0000032]. All other communication was completed by email/phone.

13. Are you aware of the criteria the AHOs applied to identifying whether a beneficiary was for referral to SIBSS – in particular, was it based on place of infection or place of residence?

13.1 I am not personally aware of the criteria the AHOs applied to identify whether a beneficiary was for referral to SIBSS - this may be a matter on which the Scottish Government can respond.

14. Further to the answer to question 2(d) in your first witness statement dated 16 November 2018, please explain the following in respect of data and policy sharing between the AHOs and SIBSS. Specifically:

a. Were any attempts made by SIBSS to obtain more detailed information about beneficiaries from the AHOs so as to avoid beneficiaries having to submit information to SIBSS that had already been provided to the AHOs? If so, please give details. If not, why not?

14.1 I was not involved personally in obtaining more detailed information about beneficiaries from the AHOs as this was before my arrival. I understand from my SIBSS Manager that Scottish Government did try to persuade AHOs to transfer all documentation relating to Scottish members. This included liaison with the Scottish Information Commissioner and the AHOs. While the majority of AHO members consented to their data being passed to SIBSS, at least 12 that SIBSS is aware of, did not. Therefore, AHOs could not pass all information due to Data Protection reasons.

b. Did the AHOs share any of their policy documentation or eligibility criteria with SIBSS and if so what were they?

14.2 I understand that SIBSS did seek policy documentation or eligibility criteria from AHOs. These were required to assist SIBSS understand the schemes our members had been dealing with and to establish comparison between the various scheme criteria, to ensure members received the correct level of payments within the new Scottish Scheme. The Skipton Fund, MFET, the Caxton Foundation and the Macfarlane Trust shared the following documents with SIBSS:

- [SKIP0000033_057]
- [WITN4728007]
- [WITN4728008]
- [WITN4728009]
- [WITN4728010]
- [WITN4728011]
- [WITN4728012]

14.3 No changes to SIBSS criteria arose following receipt of these documents. Members already had a 'built-in' guarantee that their award level within SIBSS would be equal to or better than the existing AHO criteria, assuming in the case of income top-up that their income had not increased significantly. SIBSS administrators sought the documentation to ensure that members were given the correct awards in relation to their previous experience with the AHOs.

c. Has SIBSS been disadvantaged in any way as a result of a lack of information provided to it by the AHOs? If so, please provide details.

14.4 SIBSS did find gaining access to information from AHOs a challenge at the outset due to data protection. This meant not all background information was available on AHO beneficiaries eligible to transfer to the Scottish Scheme. Without this information SIBSS was unable to write to all appropriate beneficiaries of the AHO schemes. This might have meant some beneficiaries had to then start again by re-applying to SIBSS rather than simply transferring. SIBSS believes at least 12 beneficiaries from the AHO schemes had to reapply to the SIBSS. This has required SIBSS to engage with Russell Cook LLP to gain consent for the applicant's personal information to be transferred to SIBSS. Russell Cook LLP were appointed by the AHOs to hold personal data of the AHO beneficiaries. SIBSS had to engage them to gain access to any personal data. Russell Cook LLP remain our point of contact should SIBSS need to check if a new applicant had been a previous beneficiary of the AHOs.

14.5 When receiving a new application, SIBSS check whether or not the applicant has been a member of one of the previous schemes. SIBSS undertakes these enquiries to ensure payments made already were correct and any additional entitlement is calculated. This does add time to our process but it is not SIBSS that is disadvantaged but applicants who had to apply rather than transferring automatically.

d. What, if any, additional attempts were made by SIBSS to acquire background information on beneficiaries to ensure that those beneficiaries did not have to reapply to SIBSS?

14.6 The SIBSS team were not engaged directly in discussions with AHOs as the Scottish Government (SG) led the action to persuade AHOs to transfer all data without the need for written consent from the beneficiary (Per 14.1 above). Advice

from the Information Commissioner was sought and this confirmed that consent was not required; however, the AHOs refused to provide any contact information on beneficiaries who did not provide written consent to transfer data. Therefore, unfortunately, there was no way of contacting them directly. SIBSS did publicise the Scheme through our GP Practice Newsletters to make GPs aware of the service and get them to engage possible beneficiaries; signposting them to us.

15. Is it your understanding that all the Scottish beneficiaries registered with the AHO transferred to SIBSS? If not, what steps were taken by SIBSS to ensure that any past beneficiaries of the AHOs were either registered with SIBSS or informed about potential eligibility for support from SIBSS?

15.1 It is my understanding that the Scottish Government wrote in January 2017 to the AHOs seeking the personal information, i.e. names and addresses, of existing Scottish beneficiaries. I believe the AHOs did write to all their beneficiaries including wording that was co-produced with the Scottish Government, see [SIBS0000040] attached.

15.2 It is also my understanding that 453 Scottish beneficiaries registered with the AHOs transferred to SIBSS on inception. Once information was passed to SIBSS, by the AHOs, regarding beneficiaries, SIBSS wrote to each one advising them of the establishment of SIBSS and inviting them to transfer automatically to the new Scottish Scheme. SIBSS received an anonymised list of 12 AHO beneficiaries who had not consented to their information being passed. This meant that SIBSS could not write directly to these potential members.

a. Are you aware of any steps taken by SIBSS, once formed, to locate additional beneficiaries who were not included in the initial transfer? If so, please provide details.

15.3 SIBSS had no indication of who any additional beneficiaries might be and so the Scheme sought to engage our GP community to both alert them of our new service and to encourage GPs to signpost potential beneficiaries to the Scheme.

15.4 As mentioned, SIBSS did get a list of Skipton Fund, four-digit reference numbers for beneficiaries who had not given consent. No names or contact details were provided so there was no way of knowing how we could contact these people. Since the

Scheme was set up, all but 5 of these beneficiaries have contacted us, cross referenced with their Skipton reference number, and given their consent.

15.5 For the remaining five, we continue to engage the GP community and our Advisory Group to get knowledge out via their patient support group websites and communications. We also have details on our own website.

16. What steps (to your knowledge), were taken by the AHOs and SIBSS to publicise each of the following:

a. the establishment of SIBSS?

16.1 I believe AHO's wrote to all Scottish beneficiaries advising them of the establishment of SIBSS and asking for their consent to transfer their details. SIBSS sent a welcome letter to all transferring members who had given consent for their data to be shared with us. SIBSS set up a website at the end of March 2017 and all Scottish GP practices were advised of the establishment of the Scheme via the monthly newsletter issued by NSS Practitioner Services (<https://archive.nhsnss.org/services/practitioner/medical/good-practice-newsletter/>). The Scottish Government agreed to announce the establishment of SIBSS via a press release (<https://www.wired-gov.net/wg/news.nsf/articles/Support+for+those+affected+by+infected+blood+04042017080500>) following a request for this from the Advisory Group in February 2017.

16.2 NSS website migrated to a new beta site on 31 March 2021. This is at:

<https://www.nss.nhs.scot/browse/patient-support-schemes/scottish-infected-blood-support-scheme-sibss>

16.3 The original site and content can still be found at:

<https://archive.nhsnss.org/services/practitioner/medical/scottish-infected-blood-support-scheme/>

b. the date on which the respective AHOs would cease operations?

16.4 I believe AHOs ceased operations at the end of October 2017.

c. methods of contacting or applying to SIBSS?

16.5 As described in response to question 16.a. above, SIBSS wrote welcome letters to all beneficiaries identified to us by the AHOs. This welcome letter explained that members were automatically transferred to SIBSS and no additional paperwork was required. A dedicated website was established and SIBSS issued information on the new Scheme to all general practitioners across Scotland. The Scottish Government also issued a press release.

16.6 The application process for new potential members is available from the website. If applicants call the SIBSS phone number, paper copies can also be posted to them.

b. the general scope of support and other forms of assistance available from SIBSS, including (i) types of support and (ii) eligibility criteria?

16.7 As described in response to question 16.a. above, welcome letters were sent to transferring members, newsletters were sent to GP practices across Scotland and a website was established to advertise SIBSS. The welcome letters and website highlight that the Scheme provides support to people who were infected, as well as members of their immediate family affected following treatment with NHS blood, blood products or tissue prior to September 1991. The information explained that the Scheme provided financial support to members, including recurring annual payments and where agreed, one off grants and credits for bespoke support, e.g. mental health counselling. Full details of the Schemes eligibility criteria is attached [WITN4728004].

17. You stated in paragraph 4(d) in your first witness statement that steps were taken to trace those who received a blood transfusion before September 1991 in order to investigate whether they had been infected with Hepatitis C. Was any information given about SIBSS in that awareness raising campaign? If not, how was it anticipated that potential applicants would become aware of SIBSS?

17.1 SIBSS did not exist at the time of the awareness raising campaign following the Penrose Inquiry. That campaign was led by Scottish Government who can give the detail on its aims and objectives.

17.2 My understanding is that the tracing of potentially infected Scottish citizens was an outcome of the Penrose Inquiry and conducted by the Scottish National Blood Transfusion Service (SNBTS); a separate business unit within NHS NSS.

17.3 How potential applicants would become aware of SIBSS is covered in my response to question 16 above. SIBSS expected AHOs to write to all applicable beneficiaries advertising the new Scheme and the opportunity to transfer automatically. SIBSS wrote to all beneficiaries where AHOs passed details on to us. SIBSS also wrote monthly newsletters to general practices across Scotland to ensure clinicians knew about the Scheme and how it could benefit their patients, both those transferring from AHOs or potential new applicants who, for whatever reason, had not yet applied to a legacy scheme. The Scottish Government also issued a press release on the launch of the Scheme.

18. What if any steps were taken to ensure that unsuccessful applicants to the AHOs were contacted about potential eligibility for support from SIBSS? In particular – did SIBSS take any steps to obtain the names and contact details of the unsuccessful applicants from the AHOs? Please give details.

18.1 I believe the Scottish Government only sought information from AHO's relating to Scottish beneficiaries; not unsuccessful applicants. However, Data Protection prevented a comprehensive list of beneficiaries being received by SIBSS. I don't believe that Scottish government received any additional data.

19. Further to the answer to question 2(d) in your first rule 9 response, please explain how (a) past beneficiaries of the AHOs and (b) family² of beneficiaries, registered with SIBSS. Your response seems to suggest that only those registered with Caxton to receive income top up payments had to fill out a further application form. To your knowledge, why was this procedure adopted or considered necessary?

19.1 As described in response to questions 15 and 16, SIBSS wrote to all beneficiaries notified to us by the AHOs, not just Caxton. Those AHO beneficiaries we had been notified of were transferred automatically and no application form was needed. The only applications required to be submitted, on transfer into the Scottish Scheme were

² The term 'family' in this rule 9 includes spouses, widows, widowers, long-term partners, children and adult dependents.

those for the income top up grants. This impacted 26 members at that time and paper application forms were sent to these members.

19.2 SIBSS applies different payment rates and eligibility criteria compared to the AHO schemes it was taking over from. We therefore needed to process all current recipients of discretionary income top-up payments, not just Caxton members, under the new set of criteria. This was to ensure a full evaluation was undertaken and that all members received the awards they were entitled to on transfer into SIBSS. There was also a commitment built in that regardless of the result of said evaluation, no member would receive an award that was less favourable than their current level of payment - unless their financial circumstances had improved significantly, i.e. their income had increased. This was a policy decision by Scottish Government following a recommendation by the Financial Review Group [WITN4508014].

20. Do you consider that more could and/or should have been done (and, if so, what and by whom) to reach people who might be eligible for support or assistance? Are there plans to take these steps now?

20.1 It is my understanding that, at the time, a comprehensive effort was made to make the whole community of interest aware of the establishment of the new Scottish Scheme; SIBSS, i.e. NHS staff, the Hepatitis Trust, Hepatitis Scotland, Haemophilia Scotland, the Scottish Infected Blood Forum, Waverley Care and Members. The Scottish Government also engaged with third sector organisations, represented on the Financial Review Group, to spread the word as far as possible to their constituents. The Scottish Government also ran a press release. I am also aware that there was TV coverage highlighting the issues around infected blood and the fact of the Scheme's establishment as part of the Scottish Government's response.

20.2 Having reviewed much of the information available to me, I am reflective that more might have been done at the time but I am not sure what. Possibly continuing the high profile TV coverage might have allowed friends and relatives of those infected more information and awareness and the opportunity to influence potential members to apply.

20.3 SIBSS continues to engage all GP practices across Scotland to remind them of the Scheme's existence and how we can support their patients. This is reinforced with input into monthly newsletters to all GP practices across Scotland. Existing members

are encouraged to pass on the Schemes existence to friends and colleagues and we continue to work with third sector organisations, through the Advisory Group, to optimise our reach.

20.4 The membership surveys of 2018 and 2020 have given additional insight in regard to how we might communicate better with our members. The 2020 survey in particular, sought to identify the level of awareness amongst members of the mental health support available through the Scheme. This additional insight has led to a specific action in our post survey action plan [WITN4728013] around awareness raising. Said action plan, agreed at the Advisory Group, seeks to raise awareness to all eligible citizens of the Scheme's existence and purpose.

21. In relation to new beneficiaries of SIBSS did you consider implementing (other than in relation to the new annual payments described in your second witness statement dated 23 January 2019), backdating payments for first time registrants to (i) the date of diagnosis, (ii) the date of first eligibility for support or (iii) the date on which SIBSS was established? If not, why not?

21.1 SIBSS did not consider backdating payments for first time registrants to (i) the date of diagnosis, (ii) the date of first eligibility for support or (iii) the date on which SIBSS was established. The policy, set by Scottish Government, is to backdate payments to the date an application is received by SIBSS.

22. Please describe the extent to which SIBSS had a digital presence when it was set up. What was the key information on its website?

22.1 SIBSS website went live in March 2017 and has been available from the Scheme's commencement. The website is managed by the SIBSS administrators and hosts all information relating to the establishment of the Scheme, eligibility for payment, how to make an application to SIBSS and other forms of support available. The site can be found at:

<https://www.nss.nhs.scot/browse/patient-support-schemes/scottish-infected-blood-support-scheme-sibss>

Section 4: Relationship with Government

23. Further to the details provided in answer to question 4 in the second rule 9 response, please describe the decisions SIBSS (administered by NSS) is able to take, and those decisions that are and/or must be taken by the Scottish Government. In particular:

a. Which organisation set the eligibility requirements?

23.1 Scottish Government set the eligibility requirements for SIBSS.

b. Which organisation set the procedural requirements?

23.2 All procedural requirements are co-designed between SIBSS, the Scottish Government and Advisory Group. This is an ongoing process to ensure the Scheme continues to develop and ensures appropriate help and support is available to members and applicants.

c. Which organisation makes the decisions as to whether or not an applicant meets the eligibility requirements?

23.3 SIBSS makes the decisions as to whether or not an applicant meets the eligibility requirements. As explained in response to question 11 above, it does so during the course of processing applications, where the evidence that the applicant submits is considered and a 'balance of probability' standard is used to establish if the application will be granted. Where insufficient evidence is submitted initially further investigations are undertaken. We ask the applicant if there is any other evidence known to them. With applicant's consent, we also assist them by making enquiries of hospital clinics and GP practices (where applicable), to establish if any further evidence exists. In many cases there is a lack of historical medical records to prove, for example, that a transfusion took place. We therefore seek clinical expert opinion on the probability of a procedure, as described in the application, needing a transfusion. Where the evidence gained is not sufficient to get to the threshold for 'balance of probability', i.e. 51%, but is in the balance, i.e. around 50%, then we would give the applicant the benefit of the doubt and award in favour of them.

d. Which organisation sets the payment levels?

23.4 Scottish Government sets the payment levels. My understanding is that these levels were set at the outset of the Scheme based on recommendations from the Financial Review Group. The Scottish Government also decided in April 2020 that levels were to be reviewed annually and inflationary effect included from 2020 onwards.

e. Are any applications for assistance either determined by or referred to the Scottish Government?

23.5 No applications for assistance are determined by or referred to Scottish Government. SIBSS reviews applications in line with Scottish Government criteria and guidance. However, SIBSS does maintain regular contact with Scottish Government colleagues to keep them aware of applications that are in process.

24. Please describe any matters upon which SIBSS provides advice to the Scottish Government to assist the latter's decision making. Please include:

a. An explanation of the process by which advice passes (i.e. is it sought out or is it offered, or a combination of both, and by whom?).

24.1 There are few matters upon which SIBSS provides advice to the Scottish Government in relation to the latter's decision making. Most discussion relates to SIBSS administrators explaining the lived experience of applicants, from an administrators' perspective, so that the impact of decisions can be thought through by Scottish Government colleagues. One example was where the SIBSS Advisory Group discussed the makeup of the Clinical Review Group with Scottish Government colleagues at a meeting in May 2017 [WITN4728014]. Members expressed concern over the participants all being from an NHS / clinical / scientific background. Suggestions of potential membership were welcomed and representation from Haemophilia Scotland, Hepatitis C Trust and the Scottish Infected Blood Forum were confirmed as participants in the Clinical Review Group. Additionally, contributions from wider support groups were also welcomed by Scottish Government colleagues. A further example of this would be the case in 2017 where a cohabitee of a deceased member was transferred to SIBSS from an AHO. The cohabitee was ineligible for the

widow's regular payment under the Scheme criteria and SIBSS administrators felt this was unfair. The case was raised with Scottish Government and following discussions, subsequently led to a change in the criteria. This change gave the member eligibility in these circumstances.

b. Some examples of when advice has been given and accepted.

24.2 The SIBSS Administrators give Scottish Government examples of where current policy and / or guidance has created challenge or confusion for some applicants. By ensuring Scottish Government colleagues are aware of the impact of decisions, or even how these decisions are worded in the documentation, Scottish Government colleagues can take the impact into account before making their decisions. An example of where eligibility criteria wording has been revised came in 2017. Then, following a complaint from an applicant, the wording around what could be claimed in relation to an estate application was clarified by Scottish Government in the revised criteria.

24.3 In 2017, the previous SIBSS Director suggested an internal audit on the SIBSS Scheme be carried out to provide assurance given the number of processes and value of payments involved. This was agreed by both Scottish Government and the Advisory Group. The Internal Audit report [WITN4728015] was carried out by KPMG LLP, resulting in a positive outcome. The report was discussed at the NSS Audit and Risk Committee as well as Scottish government quarterly meeting and Advisory Group bi-annual meeting.

c. Some examples of when advice has been given and rejected.

24.4 There have been no occasions where advice offered by SIBSS has been rejected by Scottish Government colleagues.

d. Whether the advice is usually taken.

24.5 My experience is that Scottish Government colleagues do ask for SIBSS thoughts, advice and guidance during routine quarterly meetings, and that these discussions help them understand any challenges SIBSS experiences when engaging with applicants or existing Scheme members

e. Whether reasons are given for rejecting the advice.

24.6 To date, there has been no occurrence where SIBSS advice or guidance, given during routine discussions, has been rejected by Scottish Government colleagues.

25. Have you, or others within SIBSS, raised any concerns and/or issues with the Scottish Government about the funding, structure, organisation or running of SIBSS, or about the involvement of the Scottish Government, or about any other matter? If so, please explain what concerns and issues were raised. What was the response of the Scottish Government to those matters being raised?

25.1 SIBSS has no concerns and/or issues with the Scottish Government about the funding, structure, organisation or running of SIBSS, or about the involvement of the Scottish Government, or about any other matter. For example, any requirement for an increase in funding to meet new applications has been found and supported by Scottish Government colleagues. Indeed, said colleagues have been proactive in supporting the Scheme.

25.2 The Scottish Government also attend the SIBSS Advisory Group as observers. The Advisory Group meets twice a year and as Scottish Government colleagues are present there is an opportunity for Advisory Group members to raise any concerns or points they might have. Key is that the Advisory group can share some of the life stories and challenges their constituents are facing, so improving awareness for Scottish Government colleagues. I believe this allows any decision making to be fully informed. For information, the Advisory Group's Terms of Reference and minutes of meetings can be found on the SIBSS website.

26. Please describe the working relationship between SIBSS and the Scottish Government. Is there a particular point of contact? If so, who is that? Are you aware of any difficulties? If so, what are they, how do they impact on the running of SIBSS and how, if at all, have they been resolved?

26.1 In my experience, SIBSS and Scottish Government have a very good working relationship. Points of contact in the Scottish Government are Sam Baker (Donation and Abortion Policy) and Michelle Kivlin (Blood Policy Officer). Sally Richards (SIBSS Manager) and I meet Sam and Michelle formally on a quarterly basis and also at

Advisory Group meetings twice a year; so at least 6 formal meetings per year. There is also regular, informal contact with both Sam and Michelle via email and phone. Overall, I have found the proactive approach from both Sam Baker and Michelle Kivlin very supportive.

Section 5: Funding/finances of the Devolved Schemes

27. Please provide an update as to the additional resources that were under consideration by the Scottish Government as a response to the Clinical Review Group's recommendations, at the time of your first witness statement.

27.1 The Clinical Review Group was commissioned by Scottish Government to conduct a clinical review and report on the impacts of hepatitis C. This was led by Professor David Goldberg of Health Protection Scotland. The review looked at data concerning the mental and physical impacts of chronic hepatitis C (HCV) alongside information from interviews with SIBSS members.

27.2 The review found evidence that HCV has a negative impact on mental health, and recommended that SIBSS members should qualify for an annual payment based on their own assessment of the impact of HCV on their life.

27.3 The review also found evidence that those with chronic HCV are at increased risk of renal disease due to Membranoproliferative Glomerulonephritis (MPGN), and recommended that any SIBSS members affected by this should in future qualify for advanced HCV payments.

27.4 The full report is on the Scottish Government website (<https://www.gov.scot/publications/clinical-review-impacts-hepatitis-c-short-life-working-group-report/>). As a result of the Clinical Review Group's recommendations [**GGCL0000168**] the Scottish Government increased the budget allocated to SIBSS. This increase was to accommodate the introduction of a new payment for Stage 1 HCV from September 2018. Funding of SIBSS has been increased as follows and is in line with increased demand and latterly, inflationary effects:

- 2017-18 - £6,967,561.00
- 2018-19 - £8,393,436.41

- 2019-20 - £9,491,747.00
- 2020-21 - £9,861,617.73 (forecast £10m)

28. Please explain what funding SIBSS receives from the English Government. Is this limited to HIV allocation? Please explain what the HIV allocation is and how much it is.

28.1 All direct funding for SIBSS comes from the Scottish Government. I am unaware of the funding arrangements between the UK Government and Scottish Government.

29. What do you know about how the Scottish Government sets the budget for SIBSS, other than that funding is considered in each annual spending review? Please describe any particular formula or methodology for calculation.

29.1 Initially, I believe the Scottish Government set the initial budget based on what they were already giving the AHOs plus estimates based on the recommendations from the Financial Review Group. Currently, the budget setting process involves the Scottish Government allocating an annual budget at the start of the year and SIBSS reporting on actual spend against this budget and routinely notifying Scottish Government of additional demand, both actual and anticipated, within the financial year. If during that year it is clear that additional funding is required, then a 'top-up' allocation is sought and given by Scottish Government.

29.2 SIBSS also supports the Scottish Government's budget planning by providing detailed information about changes to membership numbers, new applications and changes of member status from Stage 1 to Stage 2. Also, an inflationary element has been added for the first time in 2020.

30. What input did you or SIBSS have (or continue to have) in the budget process? What input do you consider you should have in this process? Does the Scottish Government take account of any representations made by SIBSS?

30.1 As detailed in response to question 29 above, while I have no authority on budget setting, I do feel fully engaged by Scottish Government in the budget setting for SIBSS. Our continuous dialogue and formal quarterly meetings ensure we can support estimation of future budget requirements. I have always found Scottish Government colleagues to be receptive to our input and discussions and feel there is

a collaborative approach with both SIBSS and involving the Advisory Group. The year on year rise in budgetary allocation, from £6.9m actual spend in 2017-18 to this year's forecast of £10m, highlights the Scottish Government's commitment to fully fund demand on the Scheme.

31. How much funding (to your knowledge) has been provided to SIBSS each year since it was established?

31.1 As detailed in response to questions 27 and 29 above, funding has expanded to match demand for financial support. While a single allocation is made at the start of the year, we have been reimbursed via a 'top-up,' if necessary, to ensure financial resource meets the demand. The actual spend over the Scheme's existence is:

- 2017-18 - £6,967,561.00
- 2018-19 - £8,393,436.41
- 2019-20 - £9,491,747.00
- 2020-21 - £9,861,617.73 (forecast £10m)

32. Do you consider that the funding provided to SIBSS by the Scottish Government has been adequate? Please explain your reasoning.

32.1 Yes, as explained in response to question 31 above. Scottish Government allocate funding for the Scheme at the start of the year and have, to date, 'topped-up' any difference at year end to ensure all demand is met.

32.2 The Scottish Government include a small element of funding, within the budget, to pay for the three members of staff employed by NHS NSS to run the Scheme, i.e. the Scheme Manager and two administrators. The Appeals Panel expenses are also charged to the Scheme. To date, the Appeals Panel has cost:

- 2017 - £1588.81
 - 2018 - £ 715.00
 - 2019 - £1559.60
 - 2020 - £4500.00
- Total - £8363.41**

32.3 The Scheme Director's time is not charged to this budget and neither is the teams logistic support, e.g. office space, travel, or equipment. These latter items are all provided for out of the NHS NSS budget.

33. What mechanisms, if any, are in place to deal with budget overspends by and/or additional and/or top-up funding for SIBSS? In particular, if applicable:

a. Has SIBSS experienced a budget overspend (annual or quarterly)? If so, in what frequency?

33.1 As explained in response to question 32 above, Scottish Government allocates the expected budget at the start of the year. If routine reporting identifies the possibility for an overspend against the original figure, Scottish Government have given SIBSS a 'top-up' allocation to ensure resource meets demand. In effect, we cannot overspend and so there are no overspends carried forward into future years.

b. Is there any mechanism for transferring an overspend into the next financial period? If so, what is the practical effect of transferring an overspend?

33.2 As explained in response to question 32 above, there are no overspends carried forward into future years.

c. Is there any other procedure for SIBSS to seek additional and/or top-up funding from the Scottish Government in the course of a financial year? If so, what is the procedure?

33.3 Other than as already described, there is no requirement for another procedure to seek additional and/or top-up funding from the Scottish Government in the course of a financial year.

d. If available, to what extent has SIBSS used any such mechanisms?

33.4 As described above, SIBSS already has a 'top-up' mechanism so no others are required.

e. Is there an absolute maximum amount in respect of any budget overspend, additional funding request and/or top-up funding request?

33.5 No, as explained there is flexibility in our operation so there is no absolute maximum amount in respect of any budget set.

34. Are there annual or other regular reviews between SIBSS and the Scottish Government? Do the reviews take the form of meetings? If so, please provide details including the following:

a. Who sets the agenda for the meeting?

34.1 Yes, as explained in answer to question 4 and 5, SIBSS meets Scottish Government formally quarterly. The agenda is agreed, in advance, collaboratively.

b. Who attends these meetings?

34.2 Meetings are attended by Sam Baker (Donation and Abortion Policy) and Michelle Kivlin (Blood Policy Officer), Martin Bell (SIBSS Director) Lee Flannigan, (Practitioner Services National Finance Manager with oversight of SIBSS) and Sally Richards (SIBSS Manager).

34.3 These meetings have been held as physical meetings up to March 2020. Due to Covid we have met virtually on two occasions since then, in May and August 2020.

c. What is usually discussed at these meetings?

34.4 The meetings have standing agenda items covering: Actions from previous meetings, Scheme update - covering numbers of members, applications received for various elements / grants, numbers approved or non-approved. Scottish Government colleagues update on any policy points that might occur and the budgetary forecast is also covered. Outputs from the meetings are shared with the Advisory Group and, going forward, progress against the 2020 Membership Survey Action Plan will also be discussed.

d. Are formal minutes, or any other written record, taken at these meetings? If so, by whom and who would be provided with copies? Please provide copies.

34.5 There are no full formal minutes. Action notes are taken by the Scheme Manager and distributed to all attendees. These have been provided to the Inquiry, please see **[SIBS0000010, SIBS0000011 and SIBS0000012]**.

35. Does SIBSS have ad hoc meetings with the Scottish Government? If so:

a. How are these meetings arranged? Can SIBSS call for such meetings?

35.1 No, we meet formally on a quarterly basis. Scottish Government also observe the Advisory Group twice yearly so there is an opportunity to engage formally then also.

35.2 If there was a requirement for an additional meeting either party can call this and the agenda would be co-produced. This would only be expected if there was a specific policy change or serious challenge being made on the Scheme, such as unexpected financial pressure if a surge in applications appeared.

b. Who sets the agenda for these meetings?

35.3 We do not normally have 'ad-hoc' meetings. As described above, if such a meeting was required the agenda would be co-produced between SIBSS and Scottish Government.

c. Please describe any such meetings you know took place or which are planned, including dates where possible.

35.4 No 'ad-hoc' meetings have taken place.

d. Who attends these meetings?

35.5 If there was a need for such a meeting, attendees would be the same as at the quarterly meetings.

e. Are formal minutes, or any other written record, taken at these meetings? If so, by whom and who would be provided with copies?

35.6 If there was a need for such a meeting, the same arrangements for action points would be observed as per quarterly meetings.

f. If the reviews are conducted without meetings taking place, please provide full details of the process.

35.7 No, all reviews are conducted within the meetings.

36. To your knowledge, does SIBSS have any other streams or sources of funding/income other than that provided by the Scottish Government? If so, from what source, how much funding/income was (or is) provided, and how are those funds managed/spent by SIBSS?

36.1 No, I am not aware of any other streams or sources of funding/income other than that provided by the Scottish Government.

37. The Inquiry understands from your previous witness statement that SIBSS was informed about the needs of the beneficiary population following the Financial Review Group Report. Please explain, further to the answer to question 3(b) in your first witness statement, how the needs of the beneficiary population are forecast for the purposes of the Scottish Government's annual budget for SIBSS, in particular expected variations from the previous year.

37.1 As explained at question 29 above, SIBSS supports the Scottish Government's future budgeting by providing changes to member numbers, new applications and changes of member status from Stage 1 to Stage 2. Finally, an inflationary element was included for the first time in 2020.

38. In your view, has SIBSS been underfunded at any point since it was established? If so, what was the impact on SIBSS? If so, was this due to (a) spikes in the number of applications, (b) an increase in the amounts applied for and/or (c) any other reason?

38.1 No. SIBSS has not been underfunded at any point since it was established. As described previously, there is an arrangement in place that allows Scottish Government to 'top-up' the budget to ensure demand is matched with funding.

39. Does SIBSS maintain reserves? Who decides on the level of reserves SIBSS should maintain? Do/did you have involvement in those decisions? What was/is the justification for the level of reserves? Have reserve levels had any impact on discussions with the Scottish Government about increased or maintained levels of funding?

39.1 No. Given the flexibility of our arrangement with Scottish Government, i.e. for a 'top-up' to the budget if required, a reserve is not required.

40. In answer to question 3(b) in the first rule 9 response, it is explained that “[t]he Scottish Government’s annual budgets are subject to the agreement of the Scottish Parliament and therefore funding levels for future years cannot be guaranteed by the Scottish Government.” What, if any, steps has SIBSS taken to ensure continuity of payments and existing payment levels to beneficiaries at SIBSS, both vis-à-vis (a) the Scottish Government and (b) the UK Government?

40.1 The statement quoted is from a section of the response that was provided by the Scottish Government to SIBSS. The original email could not be found however. The SIBSS manager, in order to be as helpful as possible, had sought this input from Scottish Government colleagues.

40.2 SIBSS has taken no action to secure continuity of payments and maintaining existing payment levels is a matter for Scottish Government.

41. As to SIBSS’s operational costs:

a. Do these operational costs have to be met entirely from the money provided by the Scottish Government? In particular, is there any cost-sharing with other services provided by the NSS (e.g. as to premises or staff)?

41.1 Scottish Government agreed with NHS NSS at the outset that the SIBSS funding would only accommodate the three staff directly administering the Scheme and the Appeals Panel expenses. NSS absorbs all other operational costs including the SIBSS Director, accommodation, travel and equipment.

b. What, if any, steps has SIBSS taken to manage its operational costs so as to maximise the monies available for beneficiaries?

41.2 NSS absorbs SIBSS operational costs by utilising its scale to find efficiencies across wider areas of the business unit. This means funds allocated for members is, in effect, not impacted by wider operational cost pressures.

c. What, if any, steps has SIBSS taken to ensure that staff salaries are proportionate and/or commensurate with the NHS or public sector?

41.3 Staff job descriptions were graded in line with NHS Agenda for Change policy. Costs are therefore in line with the NHS Agenda for Change pay scales and role grading.

Section 6: Communication and engagement with the beneficiary community

42. What steps, if any, has SIBSS taken to ensure that staff communicate appropriately with beneficiaries, applicants for support or assistance, and their families? Please include a description of any training or internal know-how practices, including mentorship or other networks.

42.1 The SIBSS is administered by a small team of three. The SIBSS Manager's role is primarily to manage and control the resources, budget and staffing required for the delivery of SIBSS; ensuring payments are made to members in accordance with the Infected Blood Scheme. In essence, the SIBSS Manager ensures the Scheme payments are in line with eligibility criteria and paid accurately and in a timely manner. She also ensures members and applicants are supported through the process.

42.2 Current staff were chosen for their roles at the Schemes inception due to the extensive experience they had dealing with the public and our professional contractors across general practice, dentistry, pharmacy and ophthalmology. These interactions can be complex and need to be managed with empathy, so having staff who communicated effectively was essential.

42.3 Current staff also have experience and understanding of the wider organisation - 'internal know-how' which adds further value throughout their practice. Examples of this include the team's ability to support applicants by trying to find more evidence if needed, including liaison with the Scottish National Blood Transfusion Service (SNBTS) and Information Services Division (ISD), now part of Public Health Scotland.

These latter organisations can often support whether or not blood or blood products have been used or whether or not an operation had been carried out on the applicant. This investigatory practice can often bring the additional evidence needed in a case where hospital records might not be available; improving the potential to pass the 'balance of probability' threshold.

42.4 At the Scheme's inception, all SIBSS staff were taken through the Scheme Procedure for Staff (see [WITN4728016]) eligibility criteria and all documentation required. Thereafter any updates or amendments are briefed to staff as they occur.

42.5 Staff also undertake annual education on information governance, including data protection and management of quality. Staff also maintain their knowledge and skills through formalised personal development programmes. These are discussed and agreed annually as part of our formal appraisal process and recorded within the NHS Appraisal system, TURAS. The NHS is keen for staff to develop transferrable skills in order to improve capability but also to ensure a culture of continuous learning. Education can include on-line learning modules and or physical trailing events or meetings.

42.6 The 2020 SIBSS survey results highlighted high satisfaction in how our staff run the Scheme and interact with members on a daily basis. We asked Scheme members to comment on the quality of the advice received and the overall service provided by SIBSS. The outcome was that 82% of respondents scored our staff's engagement as good or very good. Full details are at question 3 in our 2020 survey of members [WITN4728013].

42.7 SIBSS utilises a number of forms of communication to reach its members, including: formal reports, the Advisory Group, newsletters, our website, the membership surveys as well as helpdesk calls and emails.

42.8 SIBSS also sends out two newsletters per annum to all members that have consented to receive these, i.e. c340 of our 542 members. These are sent in hard copy and also included on our website.

42.9 Copies of the SIBSS Newsletters are attached [WITN4728026 - WITN4728032].

43. To what extent, if at all, has SIBSS responded to, and acted on, any complaints in relation to its working methods or in relation to the way in which it communicates with beneficiaries, applicants and their families? Please give details of any cases within your knowledge, in particular as to:

a. Complaints about lack of empathy from staff.

43.1 SIBSS follows the NHS Scotland Modern Complaints Handling process. This places, *“greater emphasis on early resolution of complaints where possible, valuing the feedback we receive, accurately recording it and learning from the experience to drive improvements in care.”*

43.2 The new NSS Beta website went live on 31 March 2021. The NHS Scotland Modern Complaints Handling process policy is not yet on there, although a link to complain or give feedback is. The policy sits on the old website which is archived at: <https://archive.nhsnss.org/contact-us/complaints/>. The policy is attached at [WITN4728033] and [WITN4728034] for completeness.

43.3 No complaints have been made to SIBSS in relation to a lack of empathy from staff.

b. The wording of application forms.

43.4 We have had one complaint regarding the wording of the guidance for applicants where the infected person was previously a member of one of the UK Schemes or SIBSS, but has since died. The complaint was received in 2017 and related to a Father making a claim on behalf of his deceased Son. The complaint related to a lack of clarity in the guidance, which was upheld by the Appeals Panel. Clarification of this part of SIBSS guidance was implemented immediately. The revised guidance is on our website. The key change was the addition of the following:

Wording lifted from guidance - “Support available where the infected person was previously a member of one of the UK Schemes or SIBSS, but has since died

In a small number of cases where a person did previously receive money from either SIBSS or one of the UK schemes, you can apply to the scheme if you are the executor of the person’s estate or are acting on behalf of or with the consent of the executor. Apart from the support available to widows, widowers and partners of those who have died (see separate guidance on that support), the estate may be eligible for an additional lump sum payment in

cases where the infected person received payments in relation to their chronic Hepatitis C, but had actually progressed to advanced Hepatitis C before they died.

If your application is successful, the estate will receive a lump sum of £20,000 if the person (or their estate) had already received both the initial £20,000 lump sum payment and the £30,000 additional lump sum in relation to their chronic Hepatitis C. If the person (or their estate) had not received the £30,000 additional lump sum, then the estate will instead receive an additional £50,000. However, if the infected person or their estate had received £70,000 before then you would not be able to claim any additional lump sums. In addition, if the infected person or their estate previously received a lump sum in relation to their HIV infection (either from the then Scottish Office or from the Macfarlane or Eileen Trusts), then you are not eligible to receive any further lump sums from SIBSS in relation to HIV.”

c. The wording of information provided on SIBSS’s website.

43.5 I am not aware of any complaints relating to the wording of information provided on SIBSS’s website.

44. Please provide a detailed account of the steps taken by SIBSS to engage with and understand the beneficiary community. In particular, what is the role of the Advisory Group in taking into account beneficiaries’ views about operational improvement. Please elaborate on the description in your second witness statement (especially at question 2), including details of:

44.1 The Project Team that was established to deliver the Scottish Government’s commission for the new, National scheme engaged with a range of stakeholders including: Scottish Government, AHOs, Patient Interest Groups and AHO Beneficiaries. This included a stakeholder event aimed at raising awareness of the Scottish support Scheme, providing an outline of how the Scheme would work and seeking to build confidence and trust amongst all stakeholders. The SIBSS website was created as a single focal point for information. AHOs were engaged to write to all Scottish beneficiaries in order to raise awareness of the Scheme. These AHO letters were followed up by SIBSS, which wrote out to Scottish beneficiaries advising of the Scheme and how it would work for them. Details of these engagements are included in the Project Report and associated Communication Plan [WITN4728005].

44.2 An Advisory Group was also established. As mentioned in question 3 above, the SIBSS Advisory Group was set up to assist SIBSS in taking account of members’ views on areas for operational scheme improvement. It provides independent advice to SIBSS and its role is defined in its Terms of Reference, which are available on the SIBSS webpage. They are also provided at [WITN4728002].

44.3 SIBSS has also engaged all members through surveys in 2018 and 2020. The aim of these surveys is to gain feedback on what is working well and where SIBSS could continue to improve. The reports for each survey are published on our website here.

a. the past and current composition of the Advisory Group;

44.4 Current Membership is made up from representatives of:

- Scheme Member
- Haemophilia Scotland
- Haemophilia Scotland – Deputies for Dan Farthing-Sykes
- Health Protection Scotland
- Scottish Infected Blood Forum
- Hepatitis Scotland

44.5 Former Members came from:

- Scottish Infected Blood Forum
- NHS Greater Glasgow & Clyde
- Waverley Care
- Hepatitis C Trust

b. the proportion of beneficiary community members;

44.6 There are two Scheme members on the Advisory Group, i.e. a third of the Panel are Scheme Members.

c. common items of discussion or consultation; and

44.7 The standing agenda items include an Update on Scheme membership, number of deceased, payments made, declined applications and appeals made and upheld. The 2020 Survey of Membership questions and results have also been discussed. The Advisory Group has also been involved in contributing to and agreeing an action plan [WITN4728013] to address the areas identified for improvement.

d. decisions by SIBSS following guidance from the Advisory Group and declining to follow such guidance respectively.

44.8 I am not aware of any points or advice raised by the Advisory Group that have not been taken into account when SIBSS has made decisions. There are numerous examples of where the advice received from the Group has helped improve our service, i.e. amending reports to include more detailed information; amending communications to ensure full accessibility for members and support in the co-production of the 2020 survey questions and subsequent action plan.

45. What is the relationship between the senior management of SIBSS and the beneficiary community? Could this be improved, in your view? What steps have been taken to improve this relationship? What further steps could be taken in your view, and why?

45.1 By SIBSS senior management I assume this to mean the SIBSS Manager, Sally Richards and myself, as SIBSS Director. I believe Sally Richards has a very good relationship with the wider membership. She engages members on the phone and through electronic communications. She deals with all enquiries and questions with empathy and has received numerous thank you cards for her support. Ms Richards also briefs the Advisory Group on the Scheme performance bi-annually and ensures all present have the proper preparation and papers, if required, prior to meetings.

45.2 My direct engagement with the member community is primarily through the Advisory Group as the representatives of our membership. Since taking up the post, I have chaired the Group three times and feel my relationship with members strengthens through that interaction. I believe I am open and fair, ensuring everyone has time and space to have their voice, and that of their constituents' heard.

45.3 Since October 2020 I have chaired the Advisory Group two more times. Minutes are attached at [WITN4728035] and [WITN4728036].

45.4 In terms of engaging the wider membership, I wrote the forward to the most recent newsletter thanking everyone for contributing to the 2020 survey and assuring them that I will see the improvement action plan resulting from it through to conclusion.

Section 7: Eligibility requirements for SIBSS

46. As to substantive eligibility requirements:

- a. Please explain why the cut-off date for treatment for a person suffering from Hepatitis C is 1 September 1991. In particular, did SIBSS make any enquiries (and if so what) as to whether all blood/plasma/blood products collected prior to this date and so not subject to HCV screening, were taken out of circulation and destroyed?**

46.1 I am not aware of why the cut-off date for eligibility for treatment for a person suffering from Hepatitis C is 1 September 1991. I understand that this date was set by Scottish Government.

46.2 SIBSS did not make any enquiries as to whether all blood/plasma/blood products collected prior to this date and so not subject to HCV screening, were taken out of circulation and destroyed. That would be within the remit of the Scottish National Blood Transfusion Service (SNBTS). SNBTS manage all blood stocks and blood products across Scotland.

- b. Confirm whether it is correct that a person must be resident in Scotland to receive support from SIBSS, even if they were infected in another part of the UK.**

46.3 A person, or relative of a deceased person, can apply to SIBSS for support providing the person was resident in Scotland, or was resident outside the United Kingdom but, immediately before that residence, was resident in Scotland. This element of eligibility is repeated throughout the Scheme document [WITN4728004].

- c. To what extent were the policies provided to the Inquiry in response to question 5(c) in your first witness statement prepared by SIBSS or the Scottish Government? If by SIBSS, what oversight or decision making role did the Scottish Government have in them?**

46.4 The policies sent in response to question 5(c) in SIBSS first witness statement were prepared by the Scottish Government [WITN4508001].

d. Are the policies provided still in use? Please provide any revised versions to the Inquiry, indicating changes and explaining them where appropriate.

46.5 The Assessment Guide for New HCV Applications has been revised in 2020 to include some additional guidance on Scottish Civil Courts Proceedings. The revised guidance is attached [WITN4728017].

46.6 A new Assessment Guide for New HIV Applications has been written to support SIBSS staff managing these cases. This was completed in 2020 following receipt of our first HIV applications. This document is attached [WITN4728018].

e. How is the information within these policies publicised?

46.7 Our primary methods of publicising policies is via our Newsletter and website.

The Newsletter is sent to all members who have consented to receiving it. We have had a website since the Schemes initiation and publish all documentation there. We also include any policy changes within the Practitioner Services' monthly newsletter, which is sent to all Scottish GP practices. The Hepatitis C Trust, the Scottish Infected Blood Forum and Haemophilia Society also share our guidance on their web platforms to ensure the information is publicised as widely as possible across their communities.

f. To the extent that these requirements are only available with internet access, what adjustments exist to provide them in other formats?

46.8 SIBSS posts hard copies of its newsletter to members who have consented to receive it. These include all policy amendments or updates. In instances where a significant Scheme change occurs, e.g. the introduction of Stage 1 HCV payments, we post this update to all members to ensure that they are made aware of it.

g. Has the Scottish Government expressed a view to your knowledge as to the publication of policies about the eligibility criteria? If so, what is it?

46.9 Scottish Government openly publishes policies about eligibility criteria on its website. SIBSS also publishes or links to this data on its website.

47. Were you, in your role, consulted about the substantive eligibility requirements or otherwise involved in formulating them? If so, please provide details.

47.1 I assumed this role on 1 March 2019, two years after the Scheme was set up.

My understanding is that eligibility requirements were set at the outset of the Scheme by the Scottish Government.

48. Further to your fourth witness statement dated 7 October 2019 in relation to the 12-month time limit from diagnosis for applications to SIBSS, please explain what other circumstances might be treated as falling within the exception where there was “a good reason why that was not possible”.

48.1 Other circumstances which might be treated as falling within the exception where there is “a good reason why that was not possible” would include:

- Applicants who had previously been rejected by legacy / AHO schemes.
- An applicant who had been infected for years but had lived very remotely in the Outer Hebrides and was genuinely unaware of the Scheme.
- Applicants who have either been ill or suffering bereavement and so unable to concentrate on making an application.

49. The policy ‘Assessment of Chronic Hepatitis C Infection Applications’, Item D5c1, provided to the Inquiry with your first witness statement refers to giving applicants the “benefit of the doubt” (page 2). Does that approach to the balance of probabilities standard and burden of proof on the applicant apply only to Stage 1 HCV support applications?

49.1 Giving applicants the “benefit of the doubt”. applies to both Stage 1 HCV and HIV applications where the evidence is borderline. At Stage 2 HCV, a clinical decision is made in regard to criteria being met. Again, if the evidence / clinical diagnosis is borderline, benefit of the doubt is given.

50. Please explain (a) the extent of any difference arising from and (b) the reason for the different phrasing of the proof requirement for different infections and applicants to SIBSS. In particular, please address the following:

- a. Those infected with HCV from treatment “should be able to confirm” that they meet the eligibility criteria.
- b. Those infected from treatment with HIV “would need to show that” they meet the criteria.
- c. **Secondarily infected parties with either HCV or HIV “will need to confirm” that they meet the criteria.**

50.1 The policies were drafted by Scottish Government and I do not know the reason for the different terminology. In our practical application of these policies there is no difference as we interpret these phrases as having equivalent meaning.

- 51. Have applicants been accepted as eligible despite not having medical records showing the treatment they alleged to have caused the infection? If not, please explain why.**

51.1 Yes. Our experience is that it is common to receive applications where there are few or no medical records showing the treatment alleged to have caused the infection. Where the applicant can evidence an injury or operation, e.g. from GP notes, we seek expert clinical advice to ascertain if it is likely that treatment associated with the injury could have caused infection. For consistency, we instruct the same consultant, Professor Peter Hayes (Consultant Hepatologist) in each case. If he considers that it is more likely than not that treatment caused the infection, then the application is approved. If the likelihood is in the balance, the applicant is given the benefit of the doubt and the application is approved.

- 52. To what extent is the reason for lack of medical records relevant, i.e. does it matter whether an NHS body is responsible for destruction or loss of or failure to document relevant information or the applicant personally?**

52.1 The reason for lack of medical records is not relevant and makes no difference to the application.

- 53. Having regard to the policy ‘Chronic Hepatitis C (Stage 1) Widows, Widowers and Civil Partners – Cause of Death Assessment Guidance’, Item D5c2, provided with your first rule 9 response, please address the following:**

- a. Where an application by a widow, widower or civil partner is made, to what extent is it a requirement to have evidence in a death certificate that HCV infection and related treatments “directly contributed to the person’s death” (page 5)?**

53.1 This is a policy decision made by Scottish Government.

53.2 In practice, if there is no clear evidence in a death certificate that HCV infection and related treatments “directly contributed to the person’s death”, SIBSS would write to the clinician related to the applicant’s or deceased case to confirm whether or not HCV or associated treatments was a contributing factor to the death. If this was the case, then the application would be accepted. I believe this has happened in one case.

- b. If required, what is the rationale?**

53.3 This is a policy decision made by Scottish Government.

- c. How easy or difficult in practice do applicants find it to comply with this provision?**

53.4 Death certificates often do not include HCV treatment as the cause of death. Where that is the case SIBSS will ask the former GP of the deceased to confirm if HCV was a cause of death. SIBSS has not had any practical problems getting such information from GP practices.

53.5 SIBSS has not had any specific feedback or comment from members regarding this being a difficult issue for them and it did not feature in responses to the 2020 survey of members.

- 54. Other than in relation to the 12-month time limit, are you aware of any concerns about or dissatisfaction with either the substantive or the procedural eligibility requirements for SIBSS? If so, which concerns have been identified and what did you/SIBSS do in response?**

54.1 Initially, in 2017, there was concern expressed about eligibility requirements by a

partner of a deceased member who was cohabiting but not married or in a civil partnership. Therefore, she was at that time not entitled to a widow's regular payment. In response to this case, the Scottish Government changed the Scheme eligibility criteria to include cohabiting partners.

Section 8: Decisions on support applications within SIBSS

The Process

55. In your first witness statement dated 16 November 2018 (question 5(a)) you specify the decision-makers for SIBSS applications. Please (a) confirm whether the table remains up to date (indicating any changes) and (b) specify relevant training and experience or qualifications of each decision-maker.

55.1 The table submitted on 16 November 2018 requires one change. The SIBSS Director changed from David Knowles to myself on 1 March 2019. A revised table is below.

Application Type	Role of Decision Maker	Name
New applications/ High value grants	Director / Scheme Manager	Martin Bell / Sally Richards
Income Top Up/Low value grants	Payment Manager Assistant Payment Manager	Carol O'Connor Lisa Scammell

55.2 Training and experience:

Name	Relevant training, experience, qualifications
Martin Bell	See section 1 and specifically responses to questions 2 and 5. As well as utilising experience from a long career in healthcare management, I ensured I reviewed the Scheme's aims and objectives, our

	<p>guidance documents and the formal criteria utilised. I also familiarised myself with the activities of the Advisory Group and previous meetings with Scottish Government colleagues.</p>
Sally Richards	<ul style="list-style-type: none"> <input type="checkbox"/> 12 years' experience in NHS dealing with patients, Boards, GPs and Practices. <input type="checkbox"/> Over 20 years' experience dealing with student finance in a higher education setting <input type="checkbox"/> Degree in Business Studies <input type="checkbox"/> Post Grad Degree in Quality Management <input type="checkbox"/> Three years in SIBSS <input type="checkbox"/> Induction, familiarisation with scheme criteria, and guidance documents
Carol O'Connor	<ul style="list-style-type: none"> <input type="checkbox"/> 25 years' experience in NHS dealing with patient, Boards, GPs and Practices <input type="checkbox"/> Three years in SIBSS <input type="checkbox"/> Induction, familiarisation with scheme criteria, and guidance documents
Lisa Scammell	<ul style="list-style-type: none"> <input type="checkbox"/> 20 years' experience in NHS dealing with patient, Boards, GPs and Practices. <input type="checkbox"/> Three years in SIBSS <input type="checkbox"/> Induction, familiarisation with scheme criteria, and guidance documents

56. In what circumstances, if at all, are committees formed for the determination of applications and, if so, how are they formed, who has been chosen (and why) to sit on them, how often do they met, who do they report to and what process do they adopt for the determination of applications?

56.1 Committees are not formed to make decisions on applications. Applications are reviewed and checked by the Scheme administrators and manager. Once all evidence is checked and completed the application is submitted to the Director for

final decision. This could lead to approval, non-approval or the Director might ask further questions and seek clarifications prior to decision.

- a. Please describe in more detail the role of the Scheme administrators and manager. Do the scheme administrators and the manager therefore have total discretion regarding applications? Are there any additional staff that review applications?**

56.2 New applications are reviewed by the two scheme administrators and where there is a lack of evidence to support the claim the team contact GP practices, hospitals and SNBTS in an effort to find medical records to support the claim. Applications are then passed to the Scheme Manager for an initial decision and if there is a need for medical opinion, this is sought from and provided by our medical advisor, Professor Hayes. Applications are then passed to the Director for final review and decision / authorisation. This process is described in the 'in-house' guidance to staff, given at [WITN4728018].

- 57. To the extent not already addressed above or in previous rule 9 responses, please provide details of any written or unwritten policies for the determination of SIBSS applications. Please include the following:**

- a. Who has developed these? Are they publicly available and, if so, where?**

57.1 All policies for the determination of SIBSS applications are written and published by Scottish Government on their website (<https://www.gov.scot/policies/illnesses-and-long-term-conditions/infected-blood/>).

- b. Was any expert (medical, psychosocial or other) advice sought when developing such policies? If so, what advice? Please give examples.**

57.2 As I was not party to the consultations related to the development of policy I cannot comment directly. The Scottish Government will be in a better position to respond to this question.

- c. Were or are the views of the beneficiary community taken into account when setting the policies? If so, how was this achieved? Please give examples.**

57.3 The Scottish Government can respond to this question in relation to establishment of the Scheme. What SIBSS has done is to ensure any updates, amendments or additions to the Government's policies are communicated to all members by post and also via our website.

d. Please describe the respective policies.

57.4 Policies can be found on the Scottish Government website (<https://www.gov.scot/policies/illnesses-and-long-term-conditions/infected-blood>).

58. Are you aware of beneficiaries who were unable to satisfy the procedural requirements for payments from SIBSS after successful registration? Please comment in particular on requirements to produce the following and, where they are required, why this is necessary:

58.1 Applicants are not members until their application is approved. By definition, a member cannot have been unable to satisfy the procedural requirements for payments from SIBSS after successful registration.

a. historic medical records, particularly on blood transfusions;

58.2 We always prefer to see historic medical records as these hold the best evidence for blood transfusion or treatment with a blood product.

b. supporting letters, notes and other documentation from GPs and/or specialist consultants;

58.3 Supporting letters, notes and other documentation from GPs and/or specialist consultants would be supplementary to historic medical records, if available. If historic medical records are not available these letters, notes and other documents become more important in providing evidence of NHS treatment with a blood transfusion and / or blood products.

58.4 Supporting evidence can also highlight the impact of infection on a member which is important as this can influence the level of award.

c. details of household income (past and present);

58.5 Details of household income (past and present) are required to assess eligibility for means tested discretionary grants
(<https://archive.nhsnss.org/services/practitioner/medical/scottish-infected-blood-support-scheme/existing-members-of-the-scheme>).

d. full itemised details of monthly income and expenditure;

58.6 Itemised details of monthly income and expenditure are required to assess eligibility for means tested discretionary grants.

e. multiple quotes for a particular product or service;

58.7 Multiple quotes for a particular product or service are required, for means tested discretionary grants to ensure best value is achieved.

f. proof of marital status, cohabitation or dependency of a child, including through historic bank statements.

58.8 Proof of marital status, cohabitation or dependency of a child, including through historic bank statements, is required to ensure that an applicant meets the Scheme's eligibility criteria in terms of applicant status, so allowing them to benefit from the Scheme.

**59. How long from the receipt of an application is a decision typically made?
Please distinguish between different types of application where necessary and specify the basis for reported timescales.**

59.1 SIBSS are committed to making a decision in respect of all applications within 25 days of receipt of the application and typically do so. This timeframe is agreed within our key performance indicators with Scottish Government and is within our guidance published on our website. On occasion, we may take longer where we have to search for medical records or refer to our Clinical Advisor for expert medical opinion. Average decision making timeframes, in days, for each category are:

Applications between: 01/04/2017 and 31/08/2020

Application Type	Average Days
Payment Scheme - Advanced HCV (Stage 2)	8
Payment Scheme - Chronic HCV (Stage 1)	22
Payment Scheme - Chronic HCV (Stage 1) - Moderately Affected	1
Payment Scheme - Chronic HCV (Stage 1) - Severely Affected	0
Payment Scheme - Chronic HCV (Stage 1) with Widows Annual Payments	7
Payment Scheme – Co-infected	5
Payment Scheme - HIV	12
Support Grants - Income Top-Up	7
Support Grants - Living Costs Supplement	1
Support Grants - One Off Grant	9
Overall	3

60. What proportion of applications have been granted (wholly or in part) and what proportion have been refused? Please provide up to date statistics as to:

a. How many applications in total SIBSS has received since its inception?

60.1 The total number of applications to SIBSS, since inception, has been 765, of which 370 were for support grants.

b. How many applicants have been refused because they do not meet the eligibility criteria? Of those, how many claim to have been infected via a transfusion?

60.2 43 applications to SIBSS have not been approved. The reasons for non-approval were:

- Blood transfusion in 1993, post 1991 (1)
- Confirmed intravenous drug user (6)
- HCV did not cause death (3)
- Infected with Hep B, not Hep C (1)
- Infected elsewhere, not in the UK (2)
- Means tested (13)
- No evidence of a blood transfusion (4)
- Self-cleared (7)
- Applicants making an estate claim ineligible due to separation (2)
- Deferred Stage 2 (4)

60.3 All applications mentioned in 60.2 above, less those not accepted due to means testing, claim to have had a blood transfusion, i.e. 30.

c. How many applications have been granted?

60.4 721 applications have been approved since SIBSS inception, 177 of these were for supporting grants. One application to SIBSS remains 'pending appeal.'

60.5 A fuller summary of this data is attached [WITN4728019].

61. Has SIBSS received general expert advice which it applies when determining applications? If so, please provide details of the author of that advice, the date it was provided to SIBSS, how frequently it is relied upon, and whether or not the advice is referred to in decision letters. Please provide copies of the advice(s) or, if the advice was provided other than in writing, please describe the contents of the advice and how and when it was provided.

61.1 SIBSS does not seek general expert advice which it applies when determining applications. However, as described in question 51 above, there are occasionally applications that require medical expert advice. We seek this from Professor Hayes on a case by case basis and it is always relied upon. This has happened on 13

occasions since the Scheme's inception. Copies of Professor Hayes' written advice are attached [WITN4728020].

61.2 In its decision letters SIBSS does include the fact that expert medical advice, from Professor Hayes has been sought in cases where an application is not accepted. We have not included this information within successful applicant letters as it was felt to have less relevance to the successful member.

62. Is there a procedure in place to consider applications made on an urgent basis? If so, when does that procedure apply and how does it operate? If not, why not?

62.1 All applications to become Scheme members are treated as urgent, hence the 25-day target for decision. Once a decision is made benefits will typically be paid in a matter of days.

62.2 If a Scheme member approached the Scheme Manager or administrators articulating an urgent need for an additional grant, we would review this immediately. Typically, applications take 8 days for decision and again payment is typically within days.

63. To the extent not already explained, what practical support or assistance is available to applicants and what has been given to applicants to help them in making applications?

63.1 Most applicants make first contact to the Scheme administrators via phone call, having reviewed the information on the website. Most are seeking support around their application.

63.2 Scheme administrators give verbal advice and guidance particularly around the need for supporting documents to support their applications. SIBSS administrators also explain how to ensure their application is directed to the appropriate clinical lead, normally their consultant hepatologist. We also direct to the website if appropriate. For those who have not used the website, guides and application forms can and are sent by post.

63.3 Once applications are received, the administrators check all evidence for

completeness and if required seek confirmation from the applicant on any information that might be missing. If necessary the Scheme administrators can also contact the applicant's GP, lead consultant or seek further hospital records to establish if further evidence can be gained in support of the application.

General approach to different types of support:

64. Further to Item E6a provided to the Inquiry with your first rule 9 response, please provide an updated table of lump sum and regular annual payment levels, as well as income top up thresholds.

64.1 See below:

Category	Lump Sum	Regular Annual Payment	Note
Chronic HCV (Stage 1)	£50,000		
Chronic HCV (Stage 1) with Widows Annual Payments		£20,594	1.7% Increase
Chronic HCV (Stage 1) - Severely affected		£19,221	1.7% Increase
Widow/Partner Chronic HCV (Stage 1) - Severely affected		£14,416	1.7% Increase
Chronic HCV (Stage 1) - Moderately affected		£6,407	1.7% Increase
Widow/Partner Chronic HCV (Stage 1) - Moderately affected		£4,805	1.7% Increase
Chronic HCV (Stage 1)- Not noticeably affected		£1,000	
Widow/Partner Chronic HCV (Stage 1) - Not noticeably affected		£1,000	
Chronic HCV (Stage 1) -Support Grants - Living Costs Supplement		£1,000	
Advanced HCV (Stage 2)	£70,000	£27,459	1.7% Increase
Widow/Partner - Advanced HCV (Stage 2)		£20,594	1.7% Increase
Co-infected		£37,629	1.7% Increase
Widow/Partner – Co-infected		£28,222	1.7% Increase
HIV	£70,000	£27,459	1.7% Increase
Widow/Partner - HIV		£20,594	1.7% Increase
Support Grants - Income Top-Up		Means tested	
Support Grants - One Off Grant		Means tested	

Income Top Up Thresholds			
(1) A single person with no children under 21 years old	£11,500.00	No change	
(2) A single parent with one child under 21 years old	£17,000.00	No change	
(3) A single parent with two or more children under 21 years old	£22,000.00	No change	
(4) A couple with no children under 21 years old	£17,500.00	No change	
(5) A couple with one child under 21 years old	£22,500.00	No change	
(6) A couple with two or more children under 21 years old	£28,000.00	No change	
(7) A three adult household	£23,000.00	No change	
(8) A four adult household	£29,000.00	No change	

65. Further to your answers to questions 4(b) and 4(c) in your first rule 9 response, please provide the current number of:

a. SIBSS beneficiaries who receive annual payments (i.e. first tier payments).

65.1 Note the following tables are the same as those used to brief Scottish Government quarterly and the Advisory Group bi-annually.

Category	Primary Infectee	Secondary Infectee	Widow, widower, or civil partner	Grand Total
Chronic HCV (Stage 1) - Severely Affected	149	7	11	167
Chronic HCV (Stage 1) - Moderately Affected	77	5	7	89
Advanced HCV (Stage 2)	95		46	141
Co-infected	18		7	25
Chronic HCV (Stage 1) with Widows Annual Payments			1	1

HIV	2	1	3	6
Grand Total	341	13	75	429

b. SIBSS beneficiaries who receive second tier payments, specifically:

- i. income top up payments;**
- ii. non-means tested living cost supplements; and**
- iii. discretionary grants.**

65.2 See below:

Category	Primary Infectee	Widow, widower, or civil partner	Grand Total
Support Grants - Income Top-Up		1	1
Support Grants - Living Costs Supplement	32	2	34
Support Grants - One Off Grant	1		1
Grand Total	33	3	36

66. Please explain the rationale for the self-assessment of the impact of HCV on the life of SIBSS beneficiaries (or, in case of death, by their widows, widowers or civil partners) following the Clinical Review commissioned by the Scottish Government.

66.1 I do not have any personal knowledge of the rationale for the self-assessment of the impact of HCV on the life of SIBSS members (or, in case of death, by their widows, widowers or civil partners) following the Clinical Review commissioned by the Scottish Government. My understanding is this was a policy decision by Scottish Government.

67. To the extent possible, please explain what consideration was given to adopting the EIBSS Special Category Mechanism or the WIBSS Enhanced Hepatitis 1+ Payment Scheme, and why they were not considered suitable in Scotland.

67.1 I do not have any personal knowledge regarding what consideration was given

to adopting the EIBSS Special Category Mechanism or the WIBSS Enhanced Hepatitis 1+ Payment Scheme, and why they were not considered suitable in Scotland. My understanding is this was a policy decision by Scottish Government.

68. What, if any, issues or concerns have arisen since the introduction of the three self-assessment categories of (a) severely affected, (b) moderately affected and (c) no noticeable impact on day to day to life? How have they been resolved or addressed by SIBSS (or the Scottish Government)?

68.1 The 3 self-assessment categories were introduced following a recommendation by the Clinical Review Group in June 2018. The payments associated with these categories were made in December 2018 and backdated to September 2018.

68.2 All Scheme members in the Chronic HCV stage were written to following the outcome from the Clinical Review Group. They were invited to apply / self-assess via a hard-copy application process.

68.3 SIBSS monitor members who re-categorise to try and gauge the effectiveness of the self-assessment process. The Advisory Group have also commented on members finding the self-assessment difficult. The key concern was that the self-assessment is very open and reliant on the member's interpretation of impact on their life. This is particularly around potential borderline decisions, e.g. where the member has a job currently but they had to give up their preferred, previous occupation due to the effect of HCV on their life. There is however, an option to re-assess themselves. Due to this concern, SIBSS is investigating the production of either a video and / or a written guide, to add to our website in order to aid members' self-assessment.

69. As to payments or grants for specific expenses/items:

a. To what extent and why is prior authorisation for an expense needed (by reference to quotes)?

69.1 It is Scottish Government criteria that prior to authorisation of an expense, three quotes are required. This is to ensure that best value is achieved and Scheme funds are managed appropriately.

- b. Is there a policy or practice to always grant the application in the sum of the lowest quote provided? If so, why?**

69.2 Yes. This relates to ensuring best value is achieved.

- 70. Further to your second witness statement dated 23 January 2019 (which explained that annual payments recommended by the Financial Review Group were backdated to 1 April 2016 and those recommended by the Clinical Review to September 2018), please explain to what extent, if at all, SIBSS allows other types of payments to be backdated (such as to cover a period prior to first registration with SIBSS or the specific application date).**

70.1 All payments made following successful applications or other types of payments, e.g. additional support grants and income top-ups, are backdated to the date of receipt of the application. This is in line with Scottish Government policy.

- 71. How is consistent decision-making in respect of applications for discretionary grants ensured under SIBSS?**

71.1 Since introducing the Self-Assessment for Hepatitis C Regular payments, we have had very few, i.e. five applications for discretionary grants **[SIBS0000052]**.

71.2 SIBSS is administered on a day to day basis by a small team of three, all of whom have been with the Scheme since its inception. We continually refer to the guidance to ensure that decision making is consistent. We also seek the same level of evidence, i.e. similar supporting documents to support applications. The advice offered is also consistent as it is the same three staff who engage with members and applicants on a daily basis. Formal decisions on membership applications come to the SIBSS Director and so consistency is maintained there also.

- 72. Does the success or otherwise of an application depend on the number of applications made per year or is each application considered on its merits, irrespective of the overall demand on the relevant fund? If the latter, please explain any safeguards in place to ensure individual consideration.**

72.1 Each application made to SIBSS, of whatever nature, is considered on its merits irrespective of the demand on the budget.

72.2 In respect of each individual applicant, their applications will be considered with reference to their particular history of applications, e.g. if they had been on a legacy scheme and had received an initial payment, SIBSS would ensure any additional payment they were entitled to was calculated and awarded accordingly.

73. Other than in relation to income top-up payments which are stated to take into account DWP benefits (see ‘Assessor’s Guidance – Support and Assistance Grant Application’, Item D5c3, page 2, provided with your first rule 9 response), does SIBSS consider the amount of money previously given to an applicant from (a) SIBSS and/or (b) the previous AHOs, and/or (c) income from benefits when determining each application? If so, why?

73.1 The various categories of support SIBSS can award are given at question 64 above.

73.2 SIBSS, having taken over from the legacy schemes, was designed to provide follow on support to existing members. This necessitates consideration of awards already received by former AHO beneficiaries so that SIBSS can ensure any additional entitlement under the new scheme is appropriately calculated and awarded.

73.3 All discretionary grants are means tested, except for where the grant is for the cost of counselling. For clarity, the annual living cost supplement, to cover winter heating and / or insurance costs, is not means tested.

73.4 Each application for a discretionary grant is considered taking into account all other household income, including the SIBSS regular payment. This process is in line with Scottish Government eligibility criteria.

74. In relation to means-testing for support:

a. Having regard to the ‘Assessor’s Guidance – Support and Assistance Grant Application’, WITN4508008, provided with your first rule 9 response, please explain the rationale for each of the following thresholds (including details of any consultation processes and relevant results):

i. One-off high-value grants are generally available only up to a household income of £50,000.

ii. For one-off high-value grants, a contribution towards costs of the item or service is normally expected for a household income of above £27,000.

iii. One-off low-value grants are generally available only up to a household income of £27,000.

b. Please explain why it is considered appropriate to take into account household income, rather than the applicant's, in setting such thresholds.

74.1 The rationale for current thresholds in relation to the grants mentioned is linked to the policy of means testing against household income. This is a policy decision and for Scottish Government to answer.

c. Are relevant income brackets published? If so, where and how can beneficiaries or applicants access this information?

74.2 Yes, SIBSS publishes relevant income brackets and details of household income within our guidance [WITN4728037] to applicants on our website <https://archive.nhsnss.org/services/practitioner/medical/scottish-infected-blood-support-scheme/existing-members-of-the-scheme/> If applicants contact the Scheme via phone this guidance can also be posted to them.

d. Are income brackets kept under review? If so, how and at what intervals?

74.3 Since the Scheme's inception, the income brackets were not reviewed until April 2020. Going forward, Scottish Government have stated they will conduct an annual review, each April, and this would include an inflationary element.

74.4 See comments below at paragraph 106.1 in relation to revised parity statement.

75. Please provide your view on the consistency and fairness of decision-making by SIBSS when assessing applications. Please include details as to:

a. any improvements during your time at SIBSS

75.1 As mentioned in my responses to questions 51 and 71, all applications are

determined on their own merits. Decision making is conducted by the same small team and the same decision makers, using the same criteria and internal guidance.

75.2 If input from a medical expert is required, this is given by Professor Hayes, as described earlier, so we maintain a consistent view.

75.3 In my tenure, we have updated guidance around support and assistance grants. We have expanded the guidance to show all the grants available, including mobility and psychological support. Internally, we have also produced formal guidance for HIV applications and we have updated guidance for the Appeals Panel. The latter guidance document is attached at [WITN4728021] and the HIV guide is at [WITN4728018].

b. the extent to which new applications are compared with applications with similar fact patterns or claims.

75.4 Every application is different. They are therefore assessed on individual merit using the same criteria and guidance but taking into account any specific supplementary supporting information.

Relationship with other sources of support

76. To what extent is the availability of other sources of support, including benefits and charitable support, taken into account when determining (a) eligibility for and (b) levels of support from SIBSS? Is this relationship explained in any written guidance? If so, where and how can beneficiaries or applicants access this information, if at all?

76.1 The support available from SIBSS is set out in answer to question 64 above.

76.2 Of those awards available, one-off grants and income top-up grants are means tested. To-date, we have not dealt with a situation where the applicant has been in receipt of a routine payment from a charity. If that were the case, this routine payment would be taken into consideration as part of the household income. Non-financial charitable support would not be considered within the means testing process.

76.3 The guidance for applicants in relation to awards that are means tested is available on the SIBSS website and can be posted to applicants if they call the helpdesk.

- a. Please clarify whether other sources of support for beneficiaries, separate from SIBSS, are taken into account when determining the level of support given to a beneficiary.**

76.4 All income sources are taken into account except the benefits listed below:

- Independent Living Fund Scotland
- Personal Independence Payments (PIP)
- Attendance Allowance
- Disability Living Allowance

- b. Does household income also include Government benefits payments if the beneficiary is in receipt of them?**

76.5 Yes, except the benefits listed above.

- c. Does the Scheme require beneficiaries to apply for Government funding first before assessing eligibility for one off grants?**

76.6 Yes, this would be the case for high value grants related to home adaptations for which other Government funding is available.

- 77. To the extent not addressed in your second witness statement (question 2, sub-heading 'Operation of the scheme – proposals'), are there any particular arrangements between SIBSS and the Department of Work and Pensions and/or Social Security Scotland as to entitlements to benefits? Please describe any issues and steps taken.**

77.1 There is no formal arrangement between SIBSS and DWP and/or Social Security Scotland as to entitlement to benefits. We do not advise DWP / SSS of awards made but we do inform members that it is their responsibility to declare any awards to DWP. SIBSS were directed to give this advice by Scottish Government from the inception of the Scheme - see [SIBS0000054].

77.2 It is Government policy that any payments or awards by SIBSS should not be taken into consideration in the DWP's assessments (<https://www.legislation.gov.uk/uksi/2017/329/contents/made>).

77.3 SIBSS has contacted DWP directly to raise awareness of the Scheme and that SIBSS awards should not be considered within their calculations.

77.4 Government guidance is linked here for ease of reference:

- HMRC:
<http://www.legislation.gov.uk/uksi/2017/446/contents/made>
- DWP:
<http://www.legislation.gov.uk/uksi/2017/329/contents/made>
- Universal Credit:
<http://www.legislation.gov.uk/uksi/2013/376/contents/made>
- Council Tax:
<http://www.legislation.gov.uk/ssi/2017/41/contents/made>

78. To your knowledge, to what extent are payments from SIBSS exempt from tax (not limited to income tax)? How is this ensured in practice?

78.1 In line with the guidance linked at 77.4 above, i.e. under The Scottish Infected Blood Support Scheme (Application of Sections 731, 733 and 734 of the Income Tax (Trading and Other Income) Act 2005) Order 2017, all regular SIBSS payments are exempt from tax. In practice, SIBSS has no responsibility in respect to individual members' tax position. In relation to lump sum payments, it is up to members to check if any tax is due (depending on their financial circumstances).

79. Are you aware of any beneficiaries having had problems with the DWP and/or Social Security Scotland as a result of payments made to them by SIBSS?

79.1 A small number of members, less than ten, have reported problems with the DWP as a result of payments made to them by SIBSS.

79.2 These problems were in relation to benefits being affected when DWP erroneously took SIBSS payments into account.

79.3 These instances were discussed with the Advisory Group and Scottish Government colleagues and SIBSS supporting actions explained. Both the Advisory Group and Scottish Government colleagues were happy with the SIBSS actions.

80. If so, what assistance, if any, does SIBSS provide to beneficiaries who face benefits or tax issues as a result of payments received from the scheme?

80.1 In some individual cases, SIBSS has contacted the DWP on behalf of members to explain SIBSS payments. This has followed an instance where the member has informed SIBSS that their benefits have been impacted due to SIBSS payments being included in their calculations. We also provide letters for members to share with the DWP. See [WITN4728022].

Non-financial Support

81. What, if any, non-financial support is available to eligible beneficiaries of SIBSS? Please comment on coverage of therapy, counselling and other psychological support, including reimbursement of travel expenses.

81.1 SIBSS only provides payments. However, we do signpost members to other support services such as our third sector colleagues in the Hepatitis C Trust, Hepatitis Scotland, Haemophilia Scotland, the Scottish Infected Blood Forum and Waverley Care.

81.2 SIBSS also fund and signpost to mental health and psychological support which is not means tested. This includes a link to local counsellors if requested.

81.3 There is free psychological support available for haemophiliac members from the Haemophilia Psychological Support Group. This is a service paid for by Scottish Government and NHS National Services Division and operates out of NHS Lothian.

82. Is the availability of any such non-financial support made known to the potential beneficiaries, and if so how?

82.1 In the 2020 membership survey [WITN4728013], specific questions were asked to gauge the membership's use and awareness of the availability of psychological support and whether or not there was a demand for it. The questions were:

- Do you currently receive or have you recently received any psychological, counselling or other mental health support?
- If you don't currently receive support, would you or any of your family want to access some form of counselling, psychological therapy or other support linked to your infection or your partner's infection?
- Are you aware one-off grants are available to help with the cost of counselling or other health services, where you find it difficult to access it through the NHS?

82.2 In response, 11% of members stated that they did want to access such support and a further 21% were unsure. As a result of the survey, the following actions were agreed:

- We will include a feature in the next newsletter highlighting the support organisations available who members may wish to seek support from.
- We will review how easy it is for members to obtain information on mental health support from the SIBSS website.
- The Scottish Government will look at how best to provide bespoke psychological or counselling support for those members and their families who have indicated that they do not receive support, but would or may want to do so. This is expected to build on the existing psychological support service for patients with bleeding disorders and their families by ensuring equivalent support is also available for those who were infected via a blood transfusion or tissue transplant.
- We will include further information on eligibility and applying for grants as well as clear signposts to our website information in the next newsletter.
- We will review the application process to make it as straightforward as possible. We have already ensured that applications for counselling or psychological support are not means-tested, so members don't need to provide income details, and we also don't require members to have tried to access support through the NHS first. However, we will do more to make members aware of this.

82.3 We publicise support available on our website and in our newsletters to members.

83. To the extent not addressed in the ‘Assessor’s Guidance – Support and Assistance Grant Application’, Item D5c3, what is the role of SIBSS in arranging or facilitating psychological support? Please specify in what circumstances SIBSS would consider it “necessary” to assist in searching for a counsellor locally.

83.1 As per question 81 above, SIBSS only delivers financial support in the way of payments.

83.2 There is currently a special arrangement for haemophiliacs using a national service based out of NHS Lothian. That service is provided by NHS Lothian and is commissioned and paid for by Scottish Government.

83.3 In respect of all other applicants who seek psychological support, SIBSS sign-posts them to a list of local counsellors. The list itself is created and owned by COSCA (<https://www.cosca.org.uk/our-services/find-counsellor/find-a-counsellor>) and SIBSS has no say in who is included or not. SIBSS would expect the counsellor utilised to be on the list before payment is made. This is an assurance measure.

83.4 We routinely remind members of the services available through the Newsletter and on our website. New applicants are given information on support available and the website link on successful application.

84. Please provide an update in relation to work with Haemophilia Scotland, the Scottish Infected Blood Forum and the Scottish Government in relation to access to insurance products for SIBSS beneficiaries.

84.1 SIBSS has not undertaken work with Haemophilia Scotland, the Scottish Infected Blood Forum and the Scottish Government in relation to access to insurance products for SIBSS members. SIBSS focus is on administering the Scheme.

Section 9: Disparities between support under the Devolved Schemes

85. From your first witness statement the Inquiry understands that you do not consider it necessary or appropriate to seek parity with the English, Welsh and Northern Irish scheme. Is that correct? Does that mean that no steps have been taken to end the disparities?

85.1 The SIBSS response on this point contained in the witness statement dated 16 November 2020 recounted Scottish Government policy and follow-up questions would be better responded to by the Scottish Government.

86. Are you aware of any mechanism by which information is exchanged between any of the Devolved Schemes? If so, how are these coordinated and at what intervals? Have such exchanges led to any particular changes within SIBSS? In answering this question, please have regard to:

a. The answer to question 2(b) in your first rule 9 response.

86.1 Other than the initial information exchange on setting up the Scheme, SIBSS has no formal exchange with the Devolved Schemes.

Section 10: Appeals and complaints process

87. Further to your first witness statement (at question 5(f)), providing a link to the SIBSS 'Guidance on Appeals', and your fourth witness statement (at section A):

a. Who was responsible for designing the appeal procedure?

87.1 The Scottish Government commissioned NHS NSS to set up a Project Board to deliver on their commitment to creating the new Scottish scheme. The Board engaged widely and took input from the following stakeholders:

- Scottish Government
- Department of Health
- Caxton Foundation
- Eileen Trust
- Skipton Fund
- Macfarlane Trust
- MFET Limited
- Haemophilia Scotland
- Hepatitis C Trust
- Hepatitis Scotland
- Scottish Infected Blood Forum (SIBF)

- NHS National Services Scotland (NSS)

87.2 The Project Board's objectives are given in full within the Project Board Report [WITN4728005] and are summarised below. A key objective included considering how complaints and appeals to the Scheme would be processed:

- By April 2017, design, develop and document processes and guidelines for:
 - Scheme eligibility criteria and authority levels
 - Making applications to the scheme
 - Assessing applications to the scheme
 - Processing one-off and regular payments
 - Considering complaints and appeals made to the scheme
 - Any other administrative tasks necessary in the running of the scheme
- To transfer the required data and records from existing payment schemes in England allowing National Services Scotland (NSS) to assume responsibility for ongoing payments from April 2017
- To develop and implement an appeals process for applicants who wish to challenge the outcome of their application to the scheme, by April 2017.
- To develop and implement an effective Communication Strategy throughout the creation and launch of the new scheme, including the development of a scheme website.

87.3 One objective stated in the original Project Initiation Document (PID) was subsequently removed as it was out of scope and was an action on the Scottish Government. This was the objective to, *“ensure that the necessary legislative changes and agreements [were] in place to allow the new scheme to begin making payments from April 2017.”*

b. Has the appeal procedure been modified since SIBSS was first established? If so, why? If not, how is it kept under review, if at all?

87.4 There have been no major changes to the appeal procedure since SIBSS was first established. The Appeals Panel met on 19th June 2020 to discuss improvements suggested by Panel members based on their growing experience. This resulted in a minor change to the guidance in the form of redrafted guidance for the Appeals Panel, prepared by Scottish Government, which provides that paperwork be issued to all participants well in advance of an appeal, that hearings can be deferred if additional information is required, clarifying the role of the applicant's representative and noting that a majority decision of the Appeals Panel is acceptable. This year SIBSS has also conducted Appeal hearings using Microsoft Teams due to Covid-19.

c. Please explain the rationale for the three-month time limit for bringing an appeal. What would normally qualify as a "good reason" for a late appeal?

87.5 The rationale for the three-month time limit for bringing an appeal is a policy question for Scottish Government to answer. In practice, SIBSS has not received any late appeals. Likely reasons for allowing a late appeal to be processed would include an appellant having been hospitalised or otherwise incapacitated due to illness.

d. Please confirm that the annex with details of appeals panel members, provided as Item A4 with your fourth rule 9 response, remains accurate. If not, please identify any changes.

87.6 We have a new Appeals Panel Chair, Professor Alison Britton, in replacement of Graeme Laurie. We have also recruited an additional panel member, Professor Clifford Leen, a HIV specialist. See [WITN47280023].

e. Please explain why it is considered appropriate to apply the same appeals procedure, including choice of panel members, for non-medically based applications (see fourth rule 9 response, question A(v)).

87.7 Non-medically based applications include discretionary grants for counselling, respite care, additional carer needs, home adaptation and mobility car deposits. SIBSS has received very few appeals relating to discretionary grants. It is considered

appropriate to utilise the same appeals procedure, including choice of panel members, for non-medically based applications as this offers both consistency of decision making and allows the clinicians on the Panel to apply their clinical knowledge to consideration of the required linkage between the applicants' infection and the discretionary grant sought.

f. What standard of appeal or review is applied to appeals on the ground that the decision “regarding a Support and Assistance grant application is not justified when taking account of the guidance provided on this website” (emphasis added)? Why and by whom was this standard chosen?

87.8 A Support and Assistance grant application can be made by both HCV and HIV members. The guidance for application is on the SIBSS [website](#). As described earlier, if the initial application is not granted by the Scheme administrators, applicants are informed of the reasons for this and the appeals process.

87.9 The Appeals Panel will apply the same standards, as described in response to question 23 earlier, in that the Panel would apply the 'balance of probability' to the criteria being met and if the case was in their opinion borderline, they would give the 'benefit of the doubt' to the appellant.

g. What criteria are used when selecting the “lay person” for the panel?

87.10 SIBSS has no formal written process for recruitment to the Appeals Panel. At the Scheme's inception, it was deemed a requirement of the Scheme Managers (NSS) to seek and appoint suitable lay membership. The incumbent SIBSS Director sought advice from the Advisory Group members and possible candidates were approached by the SIBSS Director and Manager.

h. What is the typical timeframe for determining an appeal? Please describe the steps or stages involved in the process, including time periods for each.

87.11 Where an application is unsuccessful Applicants are informed of the appeals process within the decision letter sent to them. Once the appellant requests an appeal, within three months of the decision being notified, the Appeals Panel are contacted immediately to check availability and a date is set for the hearing, usually

within a 4 to 6-week period. Papers are sent out within 1-2 weeks of the date being set.

87.12 At the hearing, the appellant and their representative may wish to be in attendance. The representative is there to give the appellant support. The appellant is invited to make a submission in support of their appeal. The Panel will usually pose questions to the appellant. This process is included in the guidance [WITN4728021] and is on our website. Following all statements and questions the appellant leaves and the panel deliberate in private. The whole process can typically take 2-3 hours.

87.13 The Panel decision may be deferred if further information is required but that has not happened in and appeal to date. Once the Panel decision is made, it is communicated in writing to the appellant within a week. During the Covid-19 emergency early in 2020, the decision was emailed to the appellant to ensure a timely communication, as the postage mail system was experiencing delays.

87.14 Also during the Covid-19 emergency the Panel has convened twice using MS Teams to ensure timely process. On one of these occasions, the appellant came into an office within NSS to utilise our software and the Panel members participated online.

i. Is there any mechanism for the appeal panel to seek any further representations from the applicant, in writing or in person, if required?

87.15 Yes, if the Panel require more information after reading the papers they can request it and SIBSS will contact the appellant in writing or by phone prior to the hearing. The appellant attends the hearing so the Panel can question him or her directly. While this is optional, all appellants have so far chosen to attend.

88. Further to your second witness statement (question 2), please explain whether SIBSS has considered a right of further (or ultimate) appeal to a body other than the Cabinet Secretary for Health and Sport. If so, please provide details, If not, why not?

88.1 SIBSS has not considered a right of further (or ultimate) appeal to a body other than the Cabinet Secretary for Health and Sport. If the appellant remains unhappy with the Appeals Panel decision, the recourse is to judicial review.

89. How common is it for decisions to be appealed? Please provide up to date statistics on the number of appeals launched since SIBSS was established.

89.1 It is not very common. As at 30 September 2020, there have been: nine appeals.

a. Can you provide further details of the nine applications that were appealed? Can you provide an example of an instance where the appeal was unsuccessful despite the applicant undergoing a blood transfusion?

89.2 We have not had an instance where the appeal was unsuccessful despite the applicant receiving a blood transfusion. We have had an instance where the appellant claimed that they had received a blood transfusion but had no evidence to support this but there was clear evidence of intravenous drug use.

90. How frequently do appeals succeed? Please provide up to date statistics on success and failure since SIBSS was established. To your knowledge, what are typical grounds for (a) allowing and (b) refusing an appeal?

90.1 Appeal Panels sat in the undernoted months and the decisions made are also given:

- August 2017 1 successful, 1 unsuccessful
- December 2018 1 successful
- October 2019 2 unsuccessful
- February 2020 1 successful
- June 2020 2 successful

90.2 These cases are being provided to the Inquiry.

90.3 The majority of appeals have related to applications involving blood transfusions. In those appeals that have succeeded, typically the appellant has persuaded the Panel that, on balance of probability, a blood transfusion was required in conjunction with the medical procedure undertaken. In unsuccessful appeals, the appellants have been unable to meet this standard.

91. Has there been a sufficient number of appeal decisions for informal guidelines

or precedent to emerge? Is there any other mechanism used to ensure consistency across appeals?

91.1 See response to question 87 b. We ensure consistency by utilising the same Panel members. Improvements have emerged and guidelines have been amended. There are no informal guidelines in place.

92. Further to your first witness statement (at question 5(f)), providing a link to the NSS complaints process, please provide any further details relevant to SIBSS complaints. In particular:

a. Within what time period, if any, do complaints need to be made?

92.1 As described in response to question 43, SIBSS follows the NHS Scotland Modern Complaints Handling Process.

92.2 The Modern Complaints Handling Process states that normally, complaints are expected to be received within six months of the event being complained about occurring or finding out that you have a reason to complain, but no longer than 12 months after the event itself. In exceptional circumstances, SIBSS may process a complaint after the time limit. Such an exceptional circumstance might be where a complainant has been hospitalised or otherwise incapacitated and unable to meet the timeframe for making a complaint.

b. What are typical complaints (as distinct from appeals) relating to SIBSS?

92.3 Only two formal complaints have been received by SIBSS since its inception in 2017. The first, received in February 2018, related to the wording of a response that a member received from Scheme administrators, in which the member was asked to provide further details as to the financial effect on housing benefits of his change of residential address. The second, received in November 2019, in the context of an unapproved application, related to an alleged failure of the Appeal Panel to provide a fair and impartial hearing. In this latter case, the appellant referred the Appeal Panel decision to the Scottish Public Services Ombudsman (SPSO). The SPSO did not uphold the complaint. For clarity, the SPSO's role is fully described in our Complaints Handling process [WITN4728023]. In essence, this is the body to which the citizens

can escalate their complaints should they be unhappy with the public sector body's handling or ruling of their complaint.

c. How often were such complaints (i) upheld or (ii) investigated further?

92.4 Neither complaint was upheld. As described, one complainant escalated the complaint to the Ombudsman but it was not upheld.

d. What, if any, redress is offered to successful complainants?

92.5 If a complaint was upheld, either by the SIBSS Director or the SPSO, the SIBSS Director would write formally to apologise to the complainant and set out what actions would be taken in response to the complaint. This could cover areas such as training and development for staff through to formal action under an HR policy. All would depend on the nature of the complaint.

93. How common is it for SIBSS to receive complaints (as distinct from appeals)? To your knowledge, how many complaints have been made during your tenure?

93.1 We have only had two complaints since the Scheme's inception in 2017, as described above in question 92 a to c. One of these has been in my tenure.

94. What information is provided to beneficiaries about (a) the SIBSS appeals procedure and (b) the above complaints procedure? How is this provided to potential appellants or complainants?

94.1 Details of how to appeal are contained in the decision letter advising the applicant of the unsuccessful application. Our complaints and appeals policies are also available on our website as described at question 92. If we receive correspondence from an unsuccessful applicant that is potentially a complaint, even if not specified as such, we would respond to the individual asking if they want to make a formal complaint and advise them of how we would process it.

Section 11: Mechanisms for ongoing review and improvement

95. Please describe any mechanisms for ongoing review and improvement of

SIBSS, including through the NHS, the Scottish Government and/or the UK Government.

95.1 We have just held our second survey of SIBSS membership. The 2020 survey included questions relating to a 3-year review of our service as recommended by the Financial Review Group and our Advisory Group. The response was very positive, as described in response to question 42 above, i.e. 82% of respondents scored our staff's engagement as good or very good. Learning from the survey report has enabled us to draw up an improvement action plan. Both the 2018 [WITN4728024] and 2020 [WITN4728023] membership survey results are on the SIBSS website.

95.2 The key themes for improvement include: Communication, Payments, Criteria, Mental health and Future Services. Progress against our improvement action plan will be reported quarterly to Scottish Government and twice a year to the Advisory Group.

95.3 There are currently no other formal mechanisms for ongoing review and improvement of SIBSS, whether through the NHS, the Scottish Government and/or the UK Government.

96. Please comment on any reviews and/or reforms, other than by the Financial Review Group and the Clinical Review, that have been conducted within SIBSS to your knowledge, including timescales, outcomes and costs involved.

96.1 We have run membership surveys in 2018 and 2020 as described in question 95 above. NSS also commissioned an Internal Audit on SIBSS in 2018 as this fitted into the overall organisational audit framework. This was at the cost of NSS and had no impact on the Scheme's budget. The Internal Audit on Financial Performance, performed by KPMG gave, '*significant assurance with minor improvements.*' The 5 recommendations made were all completed within timeframes agreed. Reports on the two surveys and the Internal Audit can be found on the SIBSS website. The Internal Audit report is attached at [WITN4728038]. The two surveys are covered at [WITN4728024] and [WITN4728023] respectively.

Section 12: Relationships with other organisations

97. What involvement or interactions does SIBSS have with the Haemophilia

Society and/or Haemophilia Scotland?

97.1 SIBSS meet formally with representatives of the Haemophilia Society and Haemophilia Scotland as they are members of our Advisory Group. We also communicate informally by phone and email as required.

98. Please describe the working relationship between SIBSS and the Haemophilia Society and/or Haemophilia Scotland. Are you aware of any difficulties? If so, what were (or are) they, what has been their impact on the running of SIBSS and how if at all, were they (or are they being) resolved?

98.1 I believe SIBSS has a good working relationship with the Haemophilia Society and Haemophilia Scotland. There is positive engagement and a constructive relationship between Haemophilia Society, Haemophilia Scotland and SIBSS, which is evidenced during the biannual meetings of SIBSS Advisory Group. Members of these organisations have regularly expressed to SIBSS their satisfaction with the Scheme itself, how it is administered and the relationship between scheme members and the SIBSS payments team. The previous SIBSS Director and current Scheme Manager were invited to attend the joint meeting between Haemophilia Scotland and the Scottish Infected Blood Forum at which positive feedback was given regarding how the transfer to SIBSS had been undertaken.

99. What involvement or interactions does SIBSS have with the UK Haemophilia Centre Directors Organisation?

99.1 SIBSS has no involvement or interactions with the UK Haemophilia Centre Directors Organisation.

100. Please describe the working relationship between SIBSS and the UK Haemophilia Centre Directors Organisation. Are you aware of any difficulties? If so, what were (or are) they, what has been their impact on the running of SIBSS and how if at all, were they (or are they being) resolved?

100.1 SIBSS has no relationship with the UK Haemophilia Centre Directors Organisation.

101. Please list any particular clinicians you have been in regular contact with during your work with SIBSS.

101.1 Professor Peter Hayes is the primary Medical Advisor for SIBSS and has been since the Scheme's inception. There are also clinical experts within the Appeals Panel. See [WITN47280023].

102. Please describe the working relationship between SIBSS and the Hepatitis C Trust. Are you aware of any difficulties? If so, what were (or are) they, what has been their impact on the running of SIBSS and how if at all, were they (or are they being) resolved?

102.1 As with the Haemophilia Society and Haemophilia Scotland, I believe that SIBSS has a good working relationship with the Hepatitis C Trust, which is also a member of the Advisory Group. Currently SIBSS is awaiting a further nomination from the Trust for a replacement representative to attend the regular meetings.

Section 13: Criticisms or observations

103. The following criticisms or observations have been made to the Inquiry by witnesses:

a. Some potential beneficiaries were not aware SIBSS existed, i.e. there is insufficient publicity/proactive contact and dependence on word of mouth.

103.1 As described earlier in this statement, at the inception of the Scheme, considerable effort was made to ensure that all existing Scottish beneficiaries were informed of the transfer to the new Scheme. The initial responsibility for that effort was with the legacy AHOs, as only they had the personal details of all beneficiaries at that point.

103.2 The Financial Review Group contained extensive representation from the infected and affected communities and it also publicised the new Scheme through their own communication channels.

103.3 The Scottish Government also issued a press release at the time of the Scheme's inception, to publicly announce the Schemes' existence and its aims and objectives which are to support those infected through NHS treatment.

103.4 On inception, SIBSS wrote to all of the AHO beneficiaries for which the AHOs provided contact details. These letters explained what benefits were available and how the new Scheme would work in Scotland. SIBSS website went live in March 2017 and it also publicised the Scheme to all General Practitioners across Scotland, to ensure they knew about this new form of support for their patients. This communication to practitioners continues via a monthly newsletter, issued by Practitioner Services, which covers all updates to primary care.

b. While levels of support provided to SIBSS beneficiaries are favourable compared to the other Devolved Schemes, payment levels are still below those found in the Republic of Ireland support scheme.

103.5 The Scottish Government set the level of support as part of their policies around the Scheme.

c. Payments by SIBSS are not backdated to the date when the scheme was first established.

103.6 The Scottish Government set the policy that annual payments would only be backdated to the date the application was received by SIBSS. Lump sum awards are paid regardless of timeframe, if not already paid by one of the AHOs.

d. One-off payments and ongoing support for family members are too limited. Beneficiaries cannot make more flexible applications for specific support (e.g. for loans) which could previously be made to the Skipton Fund.

103.7 The Scottish Government policy set the content of types of support for which applicants and members may apply. Regular payments have been set up by Scottish Government to mitigate the need for members to have to apply for these alternative support mechanisms. This policy decision was in line with recommendations from the Financial Review Group, which included future potential members and their representatives. Our experience and our customer survey results support the contention that regular payments do provide levels of support that make it less necessary for members to apply for the discretionary grants that are available.

e. Letters issued by SIBSS are not sufficiently clear about the exemption of SIBSS

payments for pension credit purposes.

103.8 All successful applications to SIBSS are responded to in the way of a payment letters. Every payment letter issued by SIBSS contains the following message:

“Any payments you receive from the Scottish Infected Blood Support Scheme do not need to be taken into account when calculating your income tax bill, or any entitlement to means-tested benefits from the Department for Work and Pensions (DWP); however, you are required to declare to them that you are a member of the Scheme. They will ignore this payment when working out entitlement to benefit but if you do not tell the DWP about this money, they will not be able to determine what money they should ignore and any benefits that depend on the amount of money you have could be affected. Further details are available on our website at

<https://nhsnss.org/media/2585/sibss-guidance-on-tax-and-benefits-exemptions-v12-final.pdf>” (Guidance is now at <https://www.nss.nhs.scot/publications/sibss-guidance-on-tax-and-benefits-exemptions/>).

f. How do you respond to each of these criticisms or observations?

103.9 SIBSS welcomes members’ feedback, comments, concerns and complaints, as we recognise these to be important ways in which challenges can be identified and improvement supported. We actively seek feedback, hence the close working relationship with SIBSS Advisory Group and the regular surveys sent out to the membership, with action plan follow up.

104. Do you consider that SIBSS is well run? Do you consider that it achieves its aims and objectives? To the extent not commented on above, were or are there particular difficulties or shortcomings in the way in which SIBSS:

- a. conducts its operations?**
- b. interacts with beneficiaries and/or applicants for support or assistance?**

104.1 Yes, I believe that SIBSS is well run and the results of our surveys in 2018 and 2020 indicate that the great majority of our members agree. The SIBSS administration team also receives many compliments and thank you cards from members.

104.2 All aspects of SIBSS operation were audited by KPMG in late 2017, giving formal independent assurance on the set-up and running of the Scheme.

104.3 I believe SIBSS has good processes which are followed consistently. Our main aim is to support applicants to ensure that they have the best chance of success when applying to the Scheme. We work hard to ensure that payments are accurate and delivered in a timely way. We also support applicants by trying to find more evidence to support their application, if needed. This includes SIBSS liaising with, for example, the Scottish National Blood Transfusion Service and NSS Information Services Division.

104.4 Although there are a few applicants who have been disappointed when their grant applications were unsuccessful, and there have been a small number of complaints and appeals, on the whole our day to day interactions with applicants and members and membership survey results demonstrate that members are generally happy with the service we provide.

104.5 We have good engagement with our Advisory Group and our Scottish Government sponsors, with whom SIBSS has open dialogue, leading to improved satisfaction rates between the 2018 and 2020 survey results.

104.6 However, we are not complacent and the action plan following the 2020 survey analysis highlights how we continue to develop the Scheme by introducing improvements.

104.7 In summary, SIBSS does not see itself as simply a payments operation, but rather as the means by which members and applicants obtain the best levels of support for which they are eligible.

104.8 SIBSS also believes that it is important for its staff to demonstrate empathy by listening to members' accounts and to support family members, for example when a member dies.

Section 14: Other

105. Please provide any other information you may have that is relevant to our Terms of Reference.

105.1 I would like to thank the Inquiry for the opportunity to give feedback on the operation of the Scottish Scheme, SIBSS. I believe we are a service that cares for our constituents and that we approach our work with empathy and consistency. We have a small but dedicated team, delivering consistent support since the Schemes inception. This is particularly important as it ensures policy and guidance is delivered by the same people in the same way, day after day.

105.2 Relationships with all our stakeholders and government sponsors is good and all strive to make sure we continue to improve the delivery of our support where at all possible. We actively engage with our members, the Advisory Group and Scottish Government colleagues to seek feedback on how we might improve. The 2020 survey of membership highlights the positive perspective the vast majority of our members have on how we deliver support to them. We are not complacent however, and so an action plan has been co-produced with the Advisory Group to address areas highlighted in the survey as potential improvements.

105.3 Financially, we are well supported by our Scottish Government colleagues. Budgets are allocated early in the year and regular reviews help ascertain whether or not any additional funding might be required towards the financial year-end. NHS NSS, our host health board, also supports us fully by covering all logistical costs to put least possible pressure on the Schemes funding.

Update – April 2021

106. Since my original submission in October 2020 the following additions are worthy of note:

106.1 **Changes to SIBSS payments.** Following an announcement by the UK Government on 25th March 2021, SIBSS issued details of parity payment to be made for all SIBSS beneficiaries. This, along with detail on CPI increases were included in our Newsletter Number 7, attached at [WITN4728032].

106.2 **Advisory Group.** The SIBSS Advisory group has sat twice in the intervening period; 10th December 2020 and 8th April 2021. Minutes are attached at [WITN4728035] and [WITN4728036]. Sadly, Leon Wylie has resigned from the Group as he is no longer involved with Hepatitis Scotland. A new member is being sought.

Table of exhibits:

Date	Notes/ Description	Exhibit number
Undated	BACKGROUND FOR POTENTIAL MEMBERS	WITN4728002
01/01/2017	A Scheme of support and assistance for those infected with Hepatitis C, HIV, or both, as a result of NHS treatment	WITN4728003
Undated	Contaminated Blood: Financial Support: Conclusions and Recommendations	WITN4508014
01/05/2018	Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government	GGCL0000168
Undated	Payments for People Infected With Hepatitis C or HIV or both from Infected Blood	WITN4728004
17/05/2017	End Project Report	WITN4728005
09/03/2017	SIBSS Memorandum of Agreement	WITN4728006
23/02/2021	Standing agenda for quarterly meetings between SIBSS and Scottish Government	WITN4728025
02/02/2017	Note of meeting on 1st February 2017	SIBS0000032
09/11/2016	Agency and Services Agreement between the Secretary of State for Health and Skipton Fund	SKIP0000033_057
01/01/2016	Secretary of State Directions to	WITN4728007

	Skipton Fund Limited	
14/11/2016	MFET SLA	WITN4728008
01/01/2016	Secretary of State Directions to MFET Limited	WITN4728009
05/03/2010	MFET Articles of Association	WITN4728010
Undated	Caxton Foundation Payments Scheme	WITN4728011
Undated	MFT Discretionary Payments 2016/17	WITN4728012
18/01/2017	Email chain from Sam Baker to Jan Barlow re: the establishment of the new Scottish Infected Blood Support Scheme	SIBS0000040
01/01/2020	SIBSS 2020 Customer Satisfaction Survey and 3-year Review of Service	WITN4728013
05/05/2017	Minutes of Scottish Infected Blood Support Scheme – Advisory Group	WITN4728014
08/11/2017	NHS National Services Scotland Internal Audit 2017-18	WITN4728015
21/02/2020	Actions and notes of SIBSS Quarterly Review with Scottish Government	SIBS0000010
15/05/2020	Actions and notes of SIBSS Quarterly Review with Scottish Government	SIBS0000011
14/08/2020	Actions and notes of SIBSS Quarterly Review with Scottish Government	SIBS0000012
17/09/2019	SIBSS Staff Procedure Guide	WITN4728016
21/04/2021	First Written Statement of Sally	WITN4508001

	Richards	
Undated	ASSESSMENT OF CHRONIC HEPATITIS C INFECTION APPLICATIONS	WITN4728017
Undated	ASSESSMENT OF HIV INFECTION APPLICATIONS	WITN4728018
Undated	SIBSS Applications received between: 01/04/2017 and 03/09/2020	WITN4728019
12/06/2017	Email from Vanessa Campbell to Sally Richards	WITN4728020
Undated	Table	SIBS0000052
Undated	SIBSS Guidance on Appeals	WITN4728021
27/09/2017	Email from Robert Towers, DWP, to Sally Richards	SIBS0000054
Undated	Template letter for members to share with the DWP	WITN4728022
Undated	NHS National Services Scotland Complaints Handling Procedure	WITN4728023
01/01/2018	SIBSS 2018 Customer Satisfaction Survey Final Report	WITN4728024
23/02/2021	Standing agenda for quarterly meetings between SIBSS and Scottish Government	WITN4728025
April 2017	Newsletter Issue 1	WITN4728026
April 2018	Newsletter Issue 2	WITN4728027
Undated	Newsletter Issue 3	WITN4728028
Undated	Newsletter Issue 4	WITN4728029

April 2020	Newsletter Issue 5	WITN4728030
Undated	Newsletter Issue 6	WITN4728031
Undated	Newsletter Issue 7	WITN4728032
Undated	NHS National Services Scotland Complaints Handling Procedure	WITN4728033
Undated	National Services Scotland The NHS Scotland Public Facing Model Complaints Handling Procedure	WITN4728034
10/12/2020	Minutes of Advisory Group	WITN4728035
08/04/2021	Minutes of Advisory Group	WITN4728036
Undated	Scottish Infected Blood Support Scheme Guidance on Support and Assistance Grants	WITN4728037
08/11/2017	Infected blood scheme payment process Plan reference 2018.12: NHS National Services Scotland Internal Audit 2017-18 8 November 2017	WITN4728038
Undated	Scottish Infected Blood Support Scheme Appeal Panel Member Person Specification	WITN4728039