

Health and Community Care



The Scottish
Government

An External Review of HIV Scotland



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An External Review of HIV Scotland

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EXECUTIVE SUMMARY

Introduction

1. The Review of HIV Scotland is part of a rolling programme of external reviews of organisations which are required under the Scottish Compact of Good Practice Guide “Advice on Scottish Executive relations with the voluntary sector”¹. HIV Scotland has welcomed the Review and has cooperated fully throughout the process.

2. The Review of HIV Scotland was commissioned to:

- Examine HIV Scotland's aims, objectives and organisational focus.
- Assess HIV Scotland's short and long-term strategic planning processes, management and organisational systems and its dissemination and communication strategy.
- Assess the organisation's contribution to developing and delivering the Scottish Government's forthcoming HIV Action Plan, and more generally to relevant Scottish Government policy.
- Determine the effectiveness of HIV Scotland's interventions and work in terms of reducing the number of people in Scotland with HIV and more generally health outcomes of the target group.
- Identify key organisation strengths which can be built upon, and propose solutions to any weaknesses which need to be addressed.
- Explore HIV Scotland's performance in providing value for money in relation to the funding made available by the Scottish Government.

Methodology

3. The Review team engaged with HIV Scotland Board and staff using face-to-face and group interviews. Stakeholders were drawn from two groups: professionals representing the views of their agencies *and* professionals and non-professionals who wished to contribute personal views informed by participation in events, projects or consultations facilitated by HIV Scotland. These stakeholders were engaged using face-to-face interviews, telephone interviews and on-line questionnaires. All participants received an information leaflet about the Review which explained the approach and how reporting and anonymity would work.

HIV in Scotland

4. In 2006, 2,416 HIV infected persons were receiving HIV specialist care in Scotland; the majority of the cases in specialist care attended for treatment in Lothian (986), Greater Glasgow & Clyde (778), Tayside (188) and Grampian (160) NHS Boards.² HIV also disproportionately affects key groups of people, notably in

¹ Scottish Compact of Good Practice Guide “Advice on Scottish Executive relations with the voluntary sector” at <http://www.scotland.gov.uk/library2/doc16/cgpg-00.asp>

² Sexually Transmitted Infections and Other Sexual Health Information for Scotland Year of publication – 2007
http://www.isdscotland.org/isd/4906.html#Sexually_transmitted_infections

men who have sex with men (MSM) and in African communities. As the HIV Action plan states, in recent years we have seen a substantial rise in the number of cases of HIV. While part of this rise can be attributed to an increase in testing, we know that there is also a true rise in the number of new transmissions in Scotland.

5. Recent statistics³ about HIV Infection and HIV testing tell us that:

- In 2008, 412 new cases of HIV were identified in Scotland; this represents a 9% decrease on the 452 cases reported in 2007.
- In terms of most affected groups or communities: There were 155 new diagnoses amongst gay, bisexual or men who have sex with men (MSM), 204 new diagnoses amongst heterosexual men and women who are not injecting drug users and 19 new diagnoses amongst injecting drug users.
- There is an increased uptake of HIV testing; between 2004 and 2008 there was a 71% increase in the numbers of persons taking an HIV test.

About HIV Scotland

6. HIV Scotland, a registered charity, is an independent voluntary sector agency located in Scotland. HIV Scotland's **aims** are:

- To provide effective leadership in policy and strategic development and interventions within the HIV sector in Scotland.
- To ensure HIV prevention priority is focused on communities most at risk and that support is prioritised for groups disproportionately affected by HIV.
- To represent the views, benefits and values of the voluntary sector's response to the epidemic.
- To ensure the development within Scotland of capacity, activity and resources that respond to current evidence, policy and epidemiology around HIV.

7. The agency states these aims are met by delivering these **activities**:

- Advocating for HIV issues in Scotland and building strategic partnerships.
- Being active in the development of evidence-informed government policy.
- Building capacity and coordinating networks within the Scottish HIV sector.
- Resourcing the HIV sector with training, information, promotional material, websites and campaigns.

8. The Scottish Government is HIV Scotland's main funder and provides funding under Section 16b of the NHS (Scotland) Act.

9. The Board meets quarterly and the agency hosts an annual general meeting. As a company HIV Scotland has provision for two classes of members: ordinary members (who must be voluntary or self help bodies working in the field of HIV and who can vote at an AGM) and associate members (who can be other individuals but who do not have a vote). Those agencies represented on the Board are ordinary members. There are currently no other ordinary members and no associate members.

10. HIV Scotland activities are described as focusing on partnership working and resourcing the HIV sector, particularly the voluntary sector, to respond to the

³ 'Scotland's Sexual Health Information Report: 2009 Statistical Publication Notice (24 November 2009)' Available at <http://www.isdscotland.org/isd/6062.html>

epidemic. The agency has established two national health improvement projects to support delivery of these commitments. *Healthy Gay Scotland* (HGS) has delivered several important projects but activity on several current initiatives has stalled. The *African Minority Ethnic HIV Project* (AMEHP) has successfully supported African communities in Scotland to engage with HIV issues; clarity is now required about how its work interfaces with that of Waverley Care.

11. HIV Scotland also identifies other key areas of activity including national policy work, training and responding to requests for views on a range of HIV related issues. While successfully delivering in terms of support for the development of the HIV Action Plan for Scotland⁴ capacity to deliver other areas of work has been impacted upon by staff vacancies and poor partnership working.

An examination of aims, objectives and organisational focus

Agency focus

12. Stakeholders identify the need for HIV Scotland to remain flexible and responsive to emerging issues and challenges. There is agreement that HIV Scotland should retain its clear organisational focus on HIV. To maximise effectiveness HIV Scotland needs a set of aims and statements about activities which are negotiated and agreed with a membership base as well as with Scottish Government as funders.

Providing effective leadership

13. While Government and statutory sector agencies value HIV Scotland's role as a representative voice of the voluntary sector agencies from that sector question how this can be achieved in the context of relationships which some describe as poor. There are concerns that HIV Scotland seeks to *lead* the sector but does not adequately *represent* its views. HIV Scotland Board and staff recognise difficulties and are committed to addressing them.

Ensuring a focus on communities most at risk

14. The agency has successfully focused attention on communities most at risk with the work of HGS and AMEHP; however the needs of other groups and communities should also be considered more explicitly.

Partnership working and advocacy

15. The agency recognises that it has been involved in *collaborations* but has not created *strategic partnerships*. Stakeholders identify a need for the agency to rebuild a membership base, and improve relationships with voluntary sector stakeholders. Stakeholders want outreach and community development to be part of HIV Scotland's remit. Developing and supporting models for advocacy and

⁴ HIV Action Plan in Scotland: December 2009 to March 2014' Available at: <http://www.scotland.gov.uk/Publications/2009/11/24105426/0>

representation with and on behalf of people living with HIV should be included in their remit.

Engagement with policy

16. The knowledge and experience of HIV Scotland gained over the many years during which it has monitored and understood the impact of the epidemic on Scotland is recognised as a key strength. From this strong knowledge base HIV Scotland has informed national policy, particularly the HIV Action Plan for Scotland. The agency's relationship with Scottish Government is strong. While this is welcome stakeholders also want the independence of HIV Scotland to be clarified.

17. The agency has evidenced its understanding and influence on policy relating to HIV prevention, treatment and care but external stakeholders identify that it should extend its policy reach and influence to a fuller range of policy concerns which also impact on the lives and wellbeing of individuals and communities affected by HIV.

Supporting and resourcing the HIV sector

18. Historically HIV Scotland's focus has been to inform and support the voluntary sector's response to HIV issues. However, contributors identify there is now a more broad-based cross-sectoral service landscape within which HIV Scotland must operate.

19. HIV Scotland Board and staff agree that some projects in the HGS work stream need to be reviewed, HIV Scotland's role renegotiated and trust re-invested back in partners.

20. Stakeholders suggest that HIV Scotland could provide training and be more proactive in terms of supporting others in the development of information provision, promotional materials, websites and campaigns.

Planning, management and organisation

21. The Review considers HIV Scotland's approach to management, planning and organisation systems and issues around dissemination and communication about the agency's role and activity. A number of problematic issues have been identified.

22. The relationship between the Board and the Chief Executive is difficult and deteriorating. There is a mutual lack of trust in each other's capacity to fulfil the roles required. The Board is engaged in, and feels overwhelmed by, day to day problems and does not focus on strategic issues and partnerships. There are no formal staff support and supervision structures in place nor annual appraisals.

23. Working groups established to steer HIV Scotland's projects HGS and AMEHP no longer meet. This is viewed by stakeholders as indicative of a lack of commitment by HIV Scotland to engage with partner agencies. Stakeholders and the agency itself recognise that work done in silos can mean that opportunities for work across populations might be lost.

24. External stakeholders express concerns about a lack of communication about HIV Scotland's work. HIV Scotland Board and staff recognise the need for improved communication.

25. Prior to this Review a temporary member of HIV Scotland staff conducted work which explored issues around communication and partnership working. A report was produced in April 2009 however this work has not been progressed. Board members report that they have been poorly informed of its purpose or progress. Some staff members appear to have found the process and product unsettling. The Review team find the work to be insightful and positive and has a role to play in considerations of the agency's communication and work-planning.

Contribution to Scottish Government policy

26. The resourcing by Government of a national HIV organisation is seen by external stakeholders and HIV Scotland Board and staff as a strong commitment to continuously improving policy and supporting the HIV sector. Stakeholders also recognise that HIV Scotland's work over many years has contributed to raising knowledge and awareness amongst many agencies about HIV and its impact in Scotland; thus informing current debates and developments.

27. Agency contributions to the recently published HIV Action Plan for Scotland have been a significant area of work. HIV Scotland's Chief Executive is identified by contributors as being particularly well informed, measured and, where appropriate, challenging. Some voluntary sector stakeholders however, report dissatisfaction with the efforts HIV Scotland has made to engage them and communicate their concerns.

28. HIV Scotland, via the Chief Executive, has been integral to the Scottish Public Health Network treatment and care needs assessment for people living with HIV. The findings of the process include an identification of the role of the voluntary sector in these key areas. HIV Scotland has also undertaken a Needs Assessment project on behalf of NHS Forth Valley, reporting in 2009⁵. HIV Scotland Board and staff view this work as a model for further agency activity in support of NHS Board's responses to the HIV Action Plan for Scotland.

29. The agency was involved in the development of Scotland's sexual health strategy 'Respect and Responsibility'. HIV Scotland's Chief Executive played a role in both the main Reference Group for developments and in two sub groups looking at the needs of gay and bisexual men and men who have sex with men (MSM) and at HIV health promotion issues.

Reducing the number of people with HIV and improving health outcomes

30. In terms of HIV Scotland's contribution to reducing the number of people in Scotland with HIV and improving health outcomes stakeholders stress the importance of a co-ordinated response to addressing HIV issues in Scotland and

⁵ 'NHS Forth Valley Needs Assessment report' Available at:
<http://www.hivscotland.com/index.php?controller=Default&action=NewsDetails&id=30>

acknowledge the difficulties in quantifying the effectiveness of a single organisation such as HIV Scotland.

31. However stakeholders identify specific aspects of HIV Scotland's work, often in partnership with others, that they consider of value. This includes resources developed within the Healthy Gay Scotland work stream, the agency's engagement with targeted social marketing campaigns for gay and bisexual men, and work to connect and inform Africans living in Scotland with groups and relevant information.

32. HIV Scotland and stakeholders also identify a number of areas where the agency could do more; this is focused on improving partnerships and creating opportunities for dialogue between agencies, continuing a focus on prevention and supporting voluntary sector providers to evaluate practice, disseminate findings and promote learning.

Strengths and weaknesses

33. The agency has a number of strengths which have been identified in the course of the review.

34. HIV Scotland has strengths in relation to knowledge, awareness and understanding of HIV issues in Scotland spanning the areas of prevention, treatment and care. The agency is strong on accessing and utilising research and evidence from a range of sources.

35. The agency has also established a constant presence on the HIV scene in Scotland; particularly in relation to its work with communities most at risk and disproportionately affected by HIV and its interest and commitment to action on prevention. It is hoped that HIV Scotland, particularly in the context of the HIV Action Plan will be active *nationally*.

36. The agency is well positioned to influence the policy making process. Recent work on needs assessment for NHS Forth Valley models an approach to an area of work that will be beneficial to partner agencies.

37. The agency also needs to address a number of areas of weakness.

38. There are concerns about HIV Scotland's current level of activity and profile. It is accepted that part of the problem may be staff changes and vacancies but there are concerns that the agency has lost direction in terms of looking to its constituency and communicating effectively with it. In broad terms the agency needs to re-build the staff team and increase capacity to respond to the interests and demands of the HIV sector.

39. HIV Scotland needs to widen its policy reach or areas of interest. The agency should be proactive and seek to be *the* policy hub for HIV in Scotland. Whilst fulfilling such a role, and being funded by Government, the agency also needs to clarify and maintain its independence.

40. In terms of Healthy Gay Scotland projects HIV Scotland needs to address which initiatives have lost purpose or momentum and which are best done by other partner agencies more connected to service delivery. Whilst continuing to respond to the epidemiology of HIV the agency should re-focus some attention and resource beyond gay/bisexual men and African communities to other at risk groups and communities.

41. Voluntary sector stakeholders identify a crucial role for a national representative HIV agency in monitoring and engaging with the delivery of the HIV Action Plan in Scotland; but worry that if HIV Scotland does not have vibrant and positive relationships with voluntary sector agencies it cannot fulfil such a role effectively.

42. The Review team proposed in the course of the Review that HIV Scotland consider appointing an interim *Change Manager* from within existing resources to begin to support Board and staff to address weaknesses and build on strengths identified in the course of the Review. HIV Scotland began this process toward the end of the Review.

Value for money

43. The Board and staff team have struggled in the past year to 18 months to deliver on aims and activities. Both Board and staff team have been coping with a number of vacancies, the agency has been less successful at delivering innovative work and relationships with some partners have deteriorated. One staff member identified early in the Review process that “This Review needs to help the organisation find its place of maximum value: we haven’t got there yet”.

44. A key strength of HIV Scotland is in its depth of knowledge and connection to the history of Scotland’s policy and service response to HIV. The agency has shown its value and importance in the context of the development of the HIV Action Plan for Scotland.

45. The Review team concludes that it would be unfair and unhelpful to judge HIV Scotland’s work based solely on the current difficulties it is experiencing, although they undoubtedly require to be addressed. HIV Scotland Board and staff are aware of the problems and understand that in order to reclaim and retain the confidence of partners and funders they must build on strengths and address the weaknesses identified here. In short, the agency must ensure that following acceptance of the recommendations of this Review, the quality of their relationships must improve, good governance must be assured and work programmes must clearly evidence a continued role and significance for the agency in informing, supporting and representing the HIV sector.

Recommendations on the future of HIV Scotland

46. In recent times the agency has struggled to maintain momentum and partnerships. In order to re-invigorate the agency’s work there are a range of issues which must be addressed. Recommendations are made which aim to support the agency fulfil its aspiration to be the independent voice for HIV in Scotland; the main thrust of these recommendations is summarised below.

Recommendation 1: Maintain a focus on HIV

47. To ensure its relevance and clarity of purpose HIV Scotland must maintain its focus on HIV.

Recommendation 2: Ensure a national perspective

48. HIV is present across Scotland. In this context HIV Scotland must respond by ensuring it has, is seen to have, and maintains a national perspective.

Recommendation 3: Help create policy and services which reflect the human rights and promote the human dignity of people living with HIV

49. HIV Scotland's work should be based on an explicit commitment to the rights and entitlements of people living with HIV. Whilst this sits comfortably alongside common notions of social justice and fairness which underpin much Scottish Government policy and the ethos of the voluntary sector, it is nevertheless important to place values and principles at the heart of what the agency does, to articulate and express these clearly and often, and to use these as a basis for all activity.

Recommendation 4: Ensure effective governance

50. A priority for the agency is to address issues of governance. The Review recommends that changes are made to current arrangements to allow the Board to be more reflective of the HIV sector as well as increase its capacity to fulfil necessary functions. The Board needs to be made up of 14 people who bring knowledge, experience and a commitment to re-shape and genuinely steer the agency. A number of these Board members should come from partner agencies working in the HIV sector. In addition to the 14 member Board it is recommended that the position of Chair should be advertised as a 2 day per month, unpaid commitment, seeking an individual who brings expertise in organisational management.

Recommendation 5: Re-build the staff team

51. The skills, expertise and commitment of existing HIV Scotland staff must be considered alongside the needs of the agency as it seeks to reconnect with the HIV sector and make the most of the new context which the HIV Action Plan brings. There is a job to be done in bringing new staff members on board to increase capacity but also to re-build confidence in, and the confidence of, the current staff team. This will be supported by improving staff management systems.

Recommendation 6: Re-build HIV Scotland as a membership organisation

52. A new HIV Scotland Board should be clear that there is an urgent need to re-build a membership base. Once established the membership needs to be nurtured and managed. This will require staff time and commitment but also creative approaches to engagement whether they be face-to-face or virtual. Board and staff

should take some time to explore how other networks and membership systems work and find best practice which can be adopted.

Recommendation 7: Communicate effectively with the membership

53. Having rebuilt a membership base and trust with its constituents HIV Scotland must communicate effectively with them. A key means will be via the HIV Scotland web site. HIV Scotland needs to look at what would be unique and relevant for it to engage in on-line. Other national bodies and initiatives have developed on-line networks which produce and disseminate regular e-updates with a mix of news, events and developments in the field. As HIV Scotland rebuilds its membership it needs to commit time and resource to this area of work.

Recommendation 8: Focus on policy, knowledge and advocacy/representation

54. Policy, knowledge and advocacy/representation should form the core of agency activity. The agency should not be involved in service delivery. One area of activity, the *Condoms by Post* scheme, needs to be looked at and decisions made by the new Board about whether its provision is a relevant, perhaps unique example of what HIV Scotland can do for a vulnerable or marginalised group, or whether it should be seen as service provision and managed elsewhere.

Recommendation 9: Support and help rebuild the HIV sector

55. While HIV Scotland cannot create new community provision it needs to commit some resource to fostering and supporting it where it exists. HIV Scotland should therefore consider its community development role and work with service delivery partners (both voluntary and statutory sector) to support them to respond to the needs which the agency identifies.

Recommendation 10: Support the HIV sector on-line

56. Several HIV Scotland supported projects have on-line elements which have been problematic. Improved IT competence within HIV Scotland has meant that these difficulties are being addressed. While it is expected HIV Scotland will draw back from day-to-day management of some of these projects it would be useful and relevant for the agency to consider how it might retain an IT capacity so that support can be given to partners/members to support their on-line work.

Recommendation 11: Maintain a focus on prevention

57. Whilst being interested in a more integrated and holistic policy and service response to HIV covering prevention, treatment and care, HIV Scotland should ensure a Scotland-wide focus on prevention.

Recommendation 12: Maintain an interest in the voluntary sector

58. The HIV sector is now a mix of both voluntary and statutory sector elements, often integrated through shared work and contractual arrangements. HIV Scotland should continue to work across the HIV sector in the best interests of people living

with HIV, but retain a particular interest in the voluntary sector's response to the epidemic, ensuring that in its activities HIV Scotland supports the voluntary sector and builds capacity to respond effectively and creatively to HIV in Scotland.

Recommendation 13: Recognise those most at risk but avoid work in silos

59. Scotland's response to HIV must continue to follow the epidemiology and it is right for HIV Scotland to continue to put efforts into responding to the impact of HIV on gay/bisexual/MSM and African communities. In its emerging work plan HIV Scotland should make explicit commitments to at risk groups and communities but recognise that work will also be undertaken with others impacted upon by HIV. The Review recommends that the agency no longer structures its work with gay/bisexual/MSM and African communities as the HGS and AMEHP projects, each with fixed budgets and staff but instead integrates work with and for these communities into a full HIV Scotland work plan.

Recommendation 14: Represent and advocate on behalf of the HIV sector

60. The Review recommends that HIV Scotland does not use the language of *leadership* (currently used in aim 1) but instead discusses with partners what they would expect from a broad-based national membership organisation in terms of *representation* and *advocacy*. HIV Scotland should also work with partner agencies to help them improve *their* efforts at user involvement, representation and advocacy. Representation and advocacy are built on trust. It is hoped that HIV Scotland *and* other agencies are willing to make a commitment to re-building relationships and collectively addressing these issues.

Recommendation 15: Support delivery of the HIV Action Plan

61. HIV Scotland is identified in the HIV Action Plan for Scotland as a key partner and specifically as a link to the voluntary sector and the contributions the sector makes. With a full complement of Board members and staff team in place HIV Scotland needs to work on the detail of its support for implementation and delivery of the Plan.

Recommendation 16: Write a business plan

62. HIV Scotland should produce a business plan which sets objectives for the agency (in detail for 2009/10 but also looking to 2010/11 and 2011/12) which should be specific, measurable, achievable, realistic and linked to a timeline/date for delivery. New funding arrangements with the Scottish Government and newly re-energised partnerships with the HIV sector require the clarity which a plan will bring. In turn, the Board and staff team of HIV Scotland will then have no doubts as to what is expected of them and what criteria will then be used to monitor and evaluate the effectiveness of the agency.

1. INTRODUCTION

1.1 This study, commissioned by Scottish Government Social Research, on behalf of The Chief Medical Officer and Public Health Directorate, reviewed HIV Scotland in the context of the funding support it receives from the Scottish Government. It was undertaken by the TASC Agency between April and November 2009.

Context

1.2 In 2006, 2,416 HIV infected persons were receiving HIV specialist care in Scotland; the majority of the cases in specialist care attended for treatment in Lothian (986), Greater Glasgow & Clyde (778), Tayside (188) and Grampian (160) NHS Boards.⁶ HIV disproportionately affects key groups of people, notably in men who have sex with men (MSM) and in African communities.

1.3 Rates of transmission of HIV in Scotland require Government and partner agencies to reflect on how they might renew efforts on prevention, particularly amongst communities most affected by those increases. Alongside prevention, with a growing population of people living with HIV, there is also recognition that there are improvements required in treatment and care. In line with commitments to joined-up policy and practice across public services this demands an integrated approach across voluntary and statutory sectors.

1.4 Recent statistics⁷ about HIV Infection and HIV testing tell us that:

- In 2008, 412 new cases of HIV were identified in Scotland; this represents a 9% decrease on the 452 cases reported in 2007.
- In terms of most affected groups or communities: There were 155 new diagnoses amongst gay, bisexual or men who have sex with men (MSM), 204 new diagnoses amongst heterosexual men and women who are not injecting drug users and 19 new diagnoses amongst injecting drug users.
- There is an increased uptake of HIV testing; between 2004 and 2008 there was a 71% increase in the numbers of persons taking an HIV test.

1.5 Living with HIV in Scotland remains a challenge for individuals. People fear the stigma that is still associated with HIV positive status. A positive diagnosis has both social and psychological consequences. Managing drug regimens is difficult and those living with HIV/AIDS know better than others that it is too simplistic to think of HIV/AIDS as just a chronic but manageable condition. In Scotland today HIV positive status remains linked to poverty⁸. Beyond the individual it is also important to recognise that communities most affected by HIV may need different responses.

⁶ Sexually Transmitted Infections and Other Sexual Health Information for Scotland Year of publication – 2007

http://www.isdscotland.org/isd/4906.html#Sexually_transmitted_infections

⁷ 'Scotland's Sexual Health Information Report: 2009 Statistical Publication Notice (24 November 2009)' Available at <http://www.isdscotland.org/isd/6062.html>

⁸ 'Poverty and HIV: Findings from the Crusaid Hardship Fund in Scotland' available at: <http://www.waverleycare.org/userfiles/file/publications/Poverty%20&%20HIV%202007%20for%20web.pdf>

1.6 The context is complex and in response the Scottish Government has been coordinating efforts to produce an HIV Action Plan in Scotland⁹. Now published (November 2009) its development has run in parallel with the Review of HIV Scotland. The Action Plan intends to clarify Government and partner agencies roles and contributions towards commitments to ensuring that Scotland reduces HIV transmission and levels of undiagnosed HIV alongside developing more effective co-ordination of prevention, treatment and care.

1.7 The HIV Action Plan further intends to build on commitments made to promoting sexual health and wellbeing in 'Respect and Responsibility: Strategy and Action Plan for Improving Sexual Health'¹⁰ and 'Respect and Responsibility Sexual Health Outcomes: 2008 – 2011'¹¹.

Aim

1.8 The Review of HIV Scotland is part of a rolling programme of external reviews of organisations in receipt of major recurring grants of £100k or more at six year intervals which are required under the Scottish Compact of Good Practice Guide 'Advice on Scottish Executive relations with the voluntary sector'¹². HIV Scotland has welcomed the Review and has cooperated fully throughout the process.

1.9 The Review of HIV Scotland was commissioned to do a number of things. Each of these is listed below and sections of the report which address each are highlighted:

Review aims	Report reference
Examine HIV Scotland's aims, objectives and organisation focus.	Chapter 4
Assess HIV Scotland's short and long-term strategic planning processes, management and organisation systems and its dissemination and communication strategy	Chapter 5
Assess the organisation's contribution to developing and delivering the Scottish Government's forthcoming HIV Action Plan, and more generally to relevant Scottish Government policy	Chapter 6
Determine the effectiveness of HIV Scotland's interventions and work in terms of reducing the number of people in Scotland with HIV and more generally health outcomes of the target group	Sections 6.15 – 6.22

⁹ 'HIV Action Plan in Scotland: December 2009 to March 2014' Available at: <http://www.scotland.gov.uk/Publications/2009/11/24105426/0>

¹⁰ Respect and Responsibility: Strategy and Action Plan for Improving Sexual Health 2005 at <http://www.scotland.gov.uk/Publications/2005/01/20603/content>

¹¹ Respect and Respect and Responsibility Sexual Health Outcomes: 2008 – 2011 at <http://www.scotland.gov.uk/Resource/Doc/924/0079236.pdf>

¹² Scottish Compact of Good Practice Guide "Advice on Scottish Executive relations with the voluntary sector" at <http://www.scotland.gov.uk/library2/doc16/cgpg-00.asp>

Review aims	Report reference
Identify key organisation strengths which can be built upon, and propose solutions to any weaknesses which need to be addressed	Chapter 7
Explore HIV Scotland's performance in providing value for money in relation to the funding made available by the Scottish Government	Sections 7.48 – 7.51

1.10 Finally, before presenting findings from the Review and offering recommendations for the future it is important to recognise that across stakeholder contributions there has been recognition of the work and commitment of Board members and many members of staff who have been part of HIV Scotland and the Scottish Voluntary HIV and AIDS Forum before it. HIV Scotland's constant presence is a reminder about the impact of HIV in Scotland. This Review will highlight that the agency appears to have struggled in the last couple of years to connect positively to the many and diverse partners which make up the HIV sector but at the same time it has continued to bring a focused and impressively well-informed view to national policy development. It is hoped that this Review process and final report will help the agency and others across the HIV sector to look toward the next phase of action to tackle the epidemic in Scotland.

Report Structure

1.11 Chapter Two describes the methods used to carry out the research. The subsequent chapters present further findings. Chapter Three describes the agency and current activities. Chapter Four examines the aims, objectives and organisation focus. Chapter Five considers planning, management and organisation of HIV Scotland. Chapter Six discusses HIV Scotland's contribution to Scottish Government policy. Chapter Seven presents an analysis of the strengths and weaknesses of the agency. Recommendations for future development of the agency are found in Chapter Eight.

2. METHODOLOGY

Key point summary

- The Review team engaged with HIV Scotland Board and staff using face-to-face and group interviews.
- Stakeholders were drawn from two groups: professionals representing the views of their agencies *and* professionals and members of non-professionals who wished to contribute personal views.
- Stakeholders were engaged using face-to-face interviews, telephone interviews and on-line questionnaires.
- Participants received an information leaflet about the Review which explained the approach and how reporting and anonymity would work.

Introduction

2.1 The Review team has engaged with HIV Scotland Board members and staff, with external professionals representing the views of their agencies and with individuals (both professionals and members of the public) who have engaged with HIV Scotland, perhaps through events, projects or consultations.

2.2 Individual interview schedules and tools are provided in the following appendices.

- **Appendix 2** Group interview schedule for initial workshop with senior manager and Board
- **Appendix 3** Group interview schedule for initial workshop with staff team
- **Appendix 4** Group interview schedule for joint Board/Staff workshop
- **Appendix 5** Individual interview schedule for Board members
- **Appendix 6** Individual interview schedule: staff team
- **Appendix 7** Format of individual interview schedule for stakeholder face-to-face and telephone interviews
- **Appendix 8** Individual and group interviews: guide questions for individuals who engage with HIV Scotland services/projects/initiatives.
- **Appendix 9** On-line survey for stakeholders who are professional colleagues speaking on behalf of the agency/organisation
- **Appendix 10** On-line survey for stakeholders who are individuals who engage with HIV Scotland services/projects/initiatives

2.3 Information about those professional participants who represented the views of their agencies is provided in **appendix 11**.

Stage 1: Gathering views from HIV Scotland

HIV Scotland Board

2.4 The HIV Scotland Board engaged with the Review process as follows:

- An initial meeting with the Board to discuss the purpose of the Review and to describe the approach to the work.
- Individual interviews with Board members.
- A joint session with Board and staff.
- A session with the Board midway in the process to report back on progress.
- Regular contact with Board members regarding progress and emerging findings.

HIV Scotland staff

2.5 The HIV Scotland staff team engaged with the Review process as follows:

- An initial meeting with the Chief Executive officer followed by a meeting with the staff team to discuss the purpose of the Review and to describe the approach to the work. This initial session also provided an opportunity to begin to map out the work of the agency.
- Individual interviews with staff members.
- A session with the staff team toward the end of the process to report back on progress.
- Contact with staff members regarding any specific questions about their work in the course of the Review.
- Regular meetings, telephone and email contact with the Chief Executive.

Documentary analysis

2.6 HIV Scotland provided a range of documentary information which was reviewed (more in **appendix 12**).

Stage 2: Gathering external stakeholder views

2.7 External stakeholders were considered in two groups; professional stakeholders representing the views of their agencies and individuals contributing personal perspectives.

Professional stakeholders representing the views of their agencies

2.8 This group of stakeholders were identified by Scottish Government (as commissioners) and HIV Scotland. Potential participants who had good knowledge of HIV Scotland's work and who could speak about their agency's connections to HIV Scotland were identified. From a contact list of 149 people 53 were identified as having strong connections to HIV Scotland and were offered the opportunity to participate via a face-to-face or telephone interview.

- 36 people took up this offer and participated in an interview: 21 face-to-face interviews and 15 telephone interviews were conducted
- The remainder of this group (17) plus the further 96 contacts were invited to respond to an on-line questionnaire; 44 responded, a response rate of 38.93%.

Individuals contributing personal perspectives

2.9 HIV Scotland used its own contacts and also sought the help of partner agencies to identify a second group of individuals all of whom have attended HIV Scotland events, conferences or consultations or perhaps have contributed to the development of resources or materials or projects facilitated by HIV Scotland alone or in partnership with others. These individuals were asked to contribute their personal views or experiences of engagement with HIV Scotland; some were members of the public, some were workers in agencies. These contacts were sent a link to an on-line questionnaire.

2.10 The following sources were used to identify this second group of potential contributors:

- 88 were identified from the database of HIV Scotland's African Ethnic Minority HIV Project.
- 59 people were identified from the database of HIV Scotland Condoms by Post scheme (individuals who had used the scheme in the past 3 months)
- 177 delegates to the *GayCon 2008* conference
- 16 professional colleagues and 8 individuals who had contributed to HIV Scotland projects or initiatives
- 12 individuals who had been part of the HIV Scotland scrutiny panel in relation to the Scottish Public Health Network project on needs assessment.
- 89 delegates to the *Sisters Are Doing it for Themselves* conference in 2007
- 7 individuals who had participated in the HIV stigma index training and consultation
- 17 contacts at Student Unions
- 448 individuals registered for the HIV Scotland *Update* newsletter.

2.11 The total number of possible contributors was 921, with each person emailed an invitation with a link to the on-line questionnaire.

- 96 responses were received to this questionnaire.
- Although a response rate of only 10.42% it should be remembered that the offer of engagement was intended to be broad and inclusive and was made to many individuals whose connection to HIV Scotland may have been minimal.

2.12 From within this group of stakeholders HIV Scotland were also able to identify 6 individual members of the public who had contributed to HIV Scotland consultations or projects and who were willing to be interviewed on the telephone by a member of the Review team. A partner agency also brought together a group of 5 people who met and were interviewed as a group. It was agreed with these participants that they would not be named in the report or appendices. TASC normally reimburse research

participants if their participation has incurred costs, for example transport or childcare. The small number of participants who attended a focus group discussion received a £20 payment.

Obtaining informed consent

2.13 In order to ensure informed consent to participation HIV Scotland Board and staff and all potential stakeholder participants were provided with an information leaflet which described the review process (see **appendix 1**). Interviewees were asked if they had read the information sheet and if they had any questions before proceeding. On-line contributors could access the information leaflet via their questionnaire. All contributors were informed that contributions would be anonymised. Professional stakeholders representing the views of their agencies were informed they would be named as contributors in an appendix to the report; those contributing as individuals were informed they would not be named.

Ethics and codes of practice

2.14 While research ethics approval was not required for the Review, ethical practice remains important to TASC's practice. The TASC Agency is a registered body with Disclosure Scotland and all members of the team have Enhanced Disclosures. This typifies our concern to work appropriately with children and vulnerable adults. We are also committed to research practice within which we work at all times with kindness, honesty, truth, openness and clarity. TASC staff are members of the Social Research Association and follow the SRA code of practice for social research.

Timeline

2.15 The review was commissioned in April 2009 with an inception meeting on 29th April 2009. First drafts of the Review report were shared in early November 2009. The timeline for the key elements of the review were as follows:

<i>Key approach</i>	<i>Undertaken:</i>
Desk-based analysis of key documentation	From May 2009 and ongoing
Team meeting and individual interviews with the staff team and HIV Scotland Board	Initially in May 2009, with follow up throughout the process
Individual interviews with external stakeholders (group 1)	June to September 2009
On-line questionnaire for external stakeholders (group 1)	August – September 2009
On-line questionnaire and interviews with group 2 stakeholders	September – October 2009

Conclusion

2.16 The following chapters are based on evidence collected from these sources.

3. A DESCRIPTION OF HIV SCOTLAND

Key point summary

- HIV Scotland aims describe an agency whose focus is on informing and influencing policy and interventions on HIV issues; particularly in relation to communities most at risk.
- HIV Scotland activities are described as focusing on partnership working and resourcing the HIV sector, particularly the voluntary sector, to respond to the epidemic.
- The agency has established two national health improvement projects to deliver these commitments. *Healthy Gay Scotland* (HGS) has delivered several important projects since its launch in 1997 but activity on several current initiatives is stalled. The *African Minority Ethnic HIV Project* (AMEHP) has successfully supported African communities in Scotland to engage with HIV issues; clarity is required about how its work interfaces with that of Waverley Care.
- While successfully delivering in terms of support for the development of an HIV Action Plan in Scotland, capacity to deliver other areas of work has been impacted upon by staff vacancies and poor partnership working.
- Constituted as a membership organisation the agency does not currently have a membership base.
- The Scottish Government is the agency's major funder.
- Interim findings from the Review have led the agency to appoint a Change Manager to address current difficulties and support ongoing actions.

Introduction

3.1 This chapter provides an overview of HIV Scotland's aims and main activities. This includes a description of HIV Scotland's national health improvement projects, Healthy Gay Scotland and The African Minority Ethnic HIV Project which are designed to meet the needs and raise the profile of the two target groups most affected by HIV in Scotland. The chapter also describes management and staff structures and relationships. Key sources of funding are identified.

History and purpose

3.2 The Scottish Voluntary HIV and AIDS Forum was established in 1995 to provide effective leadership with regard to the HIV voluntary sector in Scotland. The Forum was established as part of the UK wide National AIDS Trust and hosted by the Scottish Council for Voluntary Organisations (SCVO). The Forum was reconstituted as an independent Scottish charity **HIV Scotland** in 2003 with the intent of establishing a national, identifiably Scottish agency working in the new context of a Scotland with devolved government.

3.3 HIV Scotland's **aims** are:

1. To provide effective leadership in policy and strategic development and interventions within the HIV sector in Scotland.

2. To ensure HIV prevention priority is focused on communities most at risk and that support is prioritised for groups disproportionately affected by HIV.
3. To represent the views, benefits and values of the voluntary sector's response to the epidemic.
4. To ensure the development within Scotland of capacity, activity and resources that respond to current evidence, policy and epidemiology around HIV.

3.4 The agency states these aims are met by delivering these **activities**:

1. Advocating for HIV issues in Scotland and building strategic partnerships.
2. Being active in the development of evidence-informed government policy.
3. Building capacity and coordinating networks within the Scottish HIV sector.
4. Resourcing the HIV sector with training, information, promotional material, websites and campaigns.

3.5 In addition to the wider leadership and advocacy role of HIV Scotland, the organisation has two national health improvement projects designed to meet the needs, and raise the profile, of the two target groups most affected by HIV in Scotland: **Healthy Gay Scotland** (HGS) responds to the needs of gay, bisexual and men who have sex with men (MSM) and the **African Minority Ethnic HIV Project** (AMEHP) works with African communities in Scotland.

Organisational management

3.6 HIV Scotland is a registered Scottish Charity (No: SCO 33951) and a Registered Company Limited by Guarantee (No: 242242). Accounts list Company Directors, Accountants, Advisors, Auditors, Bankers and Solicitors. The last Annual Report to be published was for 2007/08 and reports on main agency activities.

3.7 HIV Scotland, as a company, has provision for two classes of members: ordinary members (who must be voluntary or self help bodies working in the field of HIV and who can vote at an AGM) and associate members (who can be other individuals but who do not have a vote). The agency reports that at the moment the only ordinary members are those agencies represented on the Board. There are no other ordinary members and currently no associate members.

3.8 Staff and Board worked together in February 2007 on days identified as *strategic planning days*. In 2007 HIV Scotland was also involved in some discussion with senior staff from voluntary sector providers including Gay Men's Health, Waverley Care and PHACE Scotland to explore existing and future relationships. This included some exploration of creating a more integrated national organisation and closer working relationships however this was not progressed.

3.9 HIV Scotland Board and staff have expressed a hope that this Review brings some clarity and describes a constructive way forward when it comes to management and governance issues.

The Board

3.10 The HIV Scotland Board meets quarterly; minutes from 2006 to 2009 have been shared as part of the Review. The agency hosts an annual general meeting, usually

in November/December of each year. Board minutes reflect an interest at Board meetings in key areas such as financial management, staffing issues and discussion of project work but a lack of discussion of strategic issues and forward planning.

3.11 The HIV Scotland Board is small. When the Review started the Board had 5 members (Directors) but at that point 2 members had indicated their retirement was imminent; leaving a Board of 3 people. Three further Board members have been identified as willing to join the Board but have not yet done so.

3.12 As is normal in such organisations Board members are not paid. Formally the role of the Board is to manage the business of the company. Currently there are up to 14 places on the Board; one is allocated to a representative of National AIDS Trust and a further place to the Scottish Network of HIV Self Help Groups however this no longer exists. Directors elect a Chair.

The Chief Executive

3.13 The Chief Executive role is described in a job description which has not changed since the post holder took up post when HIV Scotland was previously constituted as the Scottish Voluntary HIV and AIDS Forum.

3.14 The Chief Executive is responsible to the Board (still described as the Management Committee in the job description) for a range of duties which include developing and coordinating activities, establishing and maintaining the agency's relationships with partners and generally planning and implementing strategies to achieve the organisations objectives. The job description also includes responsibilities in relation to the agencies activities in policy work and research and for management of project streams such as Healthy Gay Scotland and for day to day financial management. A further key task is in terms of management, support and supervision of staff.

Current staffing structures and issues

3.15 HIV Scotland currently employs team members in the following posts:

- Chief Executive
- Office Administrator
- Resources administrator and cleaner (8 Hours per week)
- Black and Minority Ethnic Information and Development Officer
- Web Development and ICT Support Officer (21 hours per week and funded by a grant from the Monument Trust for an initial period of 18 months)

3.16 In terms of the current staffing structure 2 posts are currently vacant: Healthy Gay Scotland project worker and Information and Development worker.

3.17 In 2008 HIV Scotland created a new post of Operations and Development Manager which was filled by a member of the existing team; that staff member left post in April 2009 and the post remains vacant.

3.18 Within the agency there is a lack of established support and supervision and appraisal systems. Lines of communication between Board and staff are unclear.

Interim post of Change Manager

3.19 In months prior to the review HIV Scotland Board were exploring options regarding filling staff team vacancies. At the outset of the Review the posts of Operations and Development Manager and HGS project worker were vacant. In regular feedback about progress of the Review the Review team proposed to the Board that findings were indicating that the agency should address fundamental internal issues of governance, staff management, agency purpose and communication *before* making permanent appointments. Secondly, it was suggested to the Board that they take time to consider the role of HGS project work before appointing a worker whose role might need to change significantly, depending on final recommendations and the agency's response to those.

3.20 Whilst recognising the Board and staff of HIV Scotland were keen to increase capacity within the agency to deliver on aims and objectives the Review team proposed that HIV Scotland consider appointing an interim Change Manager from within existing resources to begin to support both Board and staff to address weaknesses and build on strengths. This proposal to use a short term post was agreed by Scottish Government. The Review team drafted a number of key tasks which a Change Manager might usefully undertake on behalf of the Board and the post was advertised and recruited in October/November 2009.

Funding

3.21 The Scottish Government is HIV Scotland's main funder and provides funding under Section 16b of the NHS (Scotland) Act. Funding has been provided in three linked awards for HIV Scotland core costs and for the projects managed by HIV Scotland: Healthy Gay Scotland and the African Minority Ethnic HIV Project.

3.22 In the course of the Review Scottish Government has made the decision to change the way in which HIV Scotland is funded. Whilst still funded under the powers of 16b, the money is now sourced from programme monies (which are annual and recurring) rather than project monies which follow a 3 year funding/application cycle. The funding continues to be allocated to the same criteria and will be linked to agreed objectives but will be made as one agency grant rather than different streams of core costs plus project costs. The same reporting arrangements also remain.

3.23 While this decision provides financial security to the agency, HIV Scotland Board and staff are keen to explore how this altered funding relationship will work in practice and how it will be perceived in the HIV sector. While Board and staff recognise that this does not shift HIV Scotland's dependency on Scottish Government as its main funding source there are some concerns about the need to reaffirm and guarantee the independence of the agency. The Scottish Government has clarified that this arrangement is common in a number of national agencies of similar size and nature in Scotland, and that HIV Scotland's independent stand is welcome and secure under the arrangement

3.24 The agency receives other funding from grant-making bodies and from pharmaceutical companies, usually for the purposes of events or resources. HIV

Scotland will, on occasion, act as a facilitator of partnership work and in doing so hold and manage a budget on behalf of a group of agencies.

3.25 Financial management of HIV Scotland has not been part of the Review. However in order to give an overall picture of the agency it is helpful to identify funding sources and amounts received. In the past 5 Years HIV Scotland has received a total of £1,445,000.00 from the Scottish Government. In the financial year 2007-2008 funding sources and amounts received were as follows:

- Scottish Government HIV Scotland core funding: £85,000
- Scottish Government Healthy Gay Scotland funding: £150,000
- Scottish Government African Minority Ethnic HIV Project funding: £54,500
- Scottish Government grants for conferences relating to HGS and AMEHP work: £15,000

Donations (including funding from Monument Trust for a staff post and private sector donations for national partnership events/conferences) a total of: £78,253.

Agency activity: broad context

3.26 In their engagement with the Review team the Board and staff of HIV Scotland have shown a comprehensive understanding of HIV issues in Scotland. Individually and collectively participants have discussed the need to frame Scotland's commitment to prevention, treatment and care in the wider context of gender, sexuality, culture, the law, and personal experience, including issues of stigma and discrimination.

3.27 HIV Scotland Board and staff identify that specific issues which the agency is required to engage with (for example blood donations, access to testing, education for young people, decisions about funding for HIV services) can all touch on complex personal and political views and values about human sexuality, human behaviour and health belief systems. While the agency is committed to the best possible policy and service response to HIV it is clear that Board and staff members have a strong commitment to locating their work in the experience of people living with HIV, their human rights and dignity.

3.28 HIV Scotland Board and staff report that the opportunities which are presented by the new HIV Action Plan in Scotland are seen as a key moment in Scotland's collective response to HIV.

3.29 In discussing the purpose and activities of the agency Board and staff identify a broad range of individuals and agencies with whom HIV Scotland is connected. These include colleagues in voluntary and statutory sectors and in the private sector and academia.

3.30 Voluntary sector contacts include large service providers, often with a history of engaging with gay and bisexual men and men who have sex with men (MSM). The voluntary sector is also characterised by emerging work with and alongside African communities in Scotland and with agencies and communities affected by issues around intravenous drug use. HIV Scotland also has a history of engagement with faith groups and communities. The agency recognises that the voluntary sector has

contracted in recent years; in particular self-organised and representative groups of HIV positive people have been lost with only one remaining Body Positive group remaining in Scotland in Tayside.

3.31 HIV Scotland reports strong connections to Government and the statutory sector. From the development work around 'Respect and Responsibility: Strategy and Action Plan for Improving Sexual Health' published in 2005 to current engagement with the HIV Action Plan to be published late 2009 HIV Scotland reports it is actively engaged in informing Government responses to sexual health and wellbeing and to HIV. In terms of other statutory partners Board and staff report a commitment to engaging with NHS Boards and a range of Government funded non-departmental public bodies.

3.32 Staff and Board report a commitment to engaging with both evidence and the epidemiology of HIV. With this in mind the agency is connected to academics in Scotland, the UK and internationally.

3.33 HIV Scotland also reports connections to the private sector pharmaceutical companies whose products are used in HIV treatment. These companies provide financial support for some of HIV Scotland's activities and on occasion seek input from the agency with regard to emerging treatments.

3.34 The agency reports an active engagement with the media, ensuring accuracy of reporting and challenging of inaccuracy of information about HIV.

Agency activity: projects and initiatives

3.35 HIV Scotland staff were asked to identify key areas of activity. The team have discussed the following items with the Review team. These will be outlined further in the sub-sections which follow:

- National policy work
- Treatment and care needs assessment for people living with HIV
- HIV Scotland on-line
- Newsletters and communication
- Healthy Gay Scotland (HGS)
- Condoms by post
- African Minority Ethnic HIV Project (AMEHP)
- Training
- Stigma
- Representing the sector

National policy work

3.36 Contributions to Respect and Responsibility the national sexual health and wellbeing strategy and the HIV Action Plan development process have been significant and are detailed in chapter 6.

Treatment and care needs assessment for people living with HIV

3.37 HIV Scotland's Chief Executive Officer was a member of the 10 member Project Group which facilitated this process managed by the Scottish Public Health Network. Contributions and outcomes are detailed in chapter 6. HIV Scotland has also undertaken a Needs Assessment project on behalf of NHS Forth Valley, reporting in 2009. HIV Scotland Board and staff view this work as a model for further agency activity in support of NHS Board's responses to the HIV Action Plan in Scotland.

HIV Scotland on-line

3.38 There is a website at www.hivscotland.com The agency uses the site as a means of communication with a largely professional audience. With support from a grant from the Monument Trust HIV Scotland's web development staff member has updated the site with new features and content management systems. There is a facility for partner agencies to use an events calendar. A news update facility has been added. As yet HIV Scotland staff have not taken on opportunities to manage content on the site; updates are completed by the web development officer.

3.39 As with other on-line elements of HIV Scotland's work and identity, the agency reports that progress is being made in terms of in-house site management, the relevance and management of content and consideration of the potential which the medium presents, but that work is ongoing.

Newsletters and communication

3.40 The agency has produced 2 newsletters a year in hard copy and monthly e-newsletters called 'Update'; however these are now produced irregularly with only 1 issue in 2009 (October). The purpose of these newsletters has been to inform subscribers about relevant policy development, evidence and epidemiology and related issues in prevention, treatment and care. The staff team know the importance and value of this communication with stakeholders and see it as a priority to re-establish these elements of work. It is the intention of staff to make these newsletters monthly in the months that follow.

3.41 HIV Scotland also places advertisements and articles in a range of publications. In 2009 full page inserts of HIV information has been put in copies of Big Issue and Holyrood Magazine. In addition, HIV Scotland has provided regular news and issue-based copy to magazines such as Plus Ve (for people living with HIV) highlighting developments specific to Scotland.

Healthy Gay Scotland (HGS)

3.42 HGS was established in 1997 as part of the Scottish Voluntary HIV and AIDS Forum and has remained a project within the reconstituted HIV Scotland. The agency describes HGS as having an interest and focus on issues such as stigma, HIV testing, community action and improving services. In 2005 the agency consulted with stakeholders about the role and remit of HGS. The following work has been undertaken within the HGS work stream.

- *Changing the Focus (2006) and GayCon (2007)*: These national conferences focused on the sexual health of gay and bisexual men. HIV Scotland was central to development and successful delivery of the events.
- *Research*: HIV Scotland has supported UK wide and Scottish research including the SIGMA Gay Men's Sex Survey, contributing questions for the MRC bar survey, and support for work undertaken by Glasgow Caledonia University
- There has also been HIV Scotland staff involvement in: The development of the *Essential Guide to Coming Out DVD and Resource pack*; involvement in *Worlds AIDS Conference Toronto 2006*; involvement in social marketing campaigns in both NHS Lothian (The HIV Comeback Tour) and NHS Greater Glasgow and Clyde (Equal); involvement in *Pride Scotia* events; participation in conferences such as those facilitated by the British HIV and AIDS Association; participation and support for residential events for men living with HIV in partnership with other agencies.

3.43 The following projects also lie within the remit of HGS. Each has an online element established before HIV Scotland had its current web development staff member in post. There are technical difficulties with each which are being addressed. Commenting on each project external stakeholders and HIV Scotland staff highlight that while each started as vibrant, relevant projects current working relationships between partners are poor and project activity is minimal. A lack of activity in relation to HGS projects in 2008/09 means there is an under spend on current HGS grant funding.

- *Connected*: This is a hard copy and on-line resource for men who have been recently diagnosed as HIV positive. The resource is on-line at: www.connectedscotland.co.uk
- *Cocktales*: This initiative presents a series of stories targeting young gay men with information about sexual health and relationships. The project is an initiative between HIV Scotland and other key voluntary sector agencies.
- *Scottish Network Netreach*: This partnership project coordinates a range of health information/health promotion inputs to on-line chat rooms where gay/bisexual/MSM meet. The purpose is to promote awareness of sexual health including HIV issues.

Condoms by post

3.44 This service is located within HGS project work and is part of the agency's focus on HIV prevention. It provides free condoms and lubricant to individuals who register via a dedicated website hosted and managed by HIV Scotland. HIV Scotland views the service as particularly important to men who are unable to access condoms on a commercial gay scene, unable to afford to buy condoms or are concerned about the visibility of buying condoms from a shop or pharmacy.

3.45 There are problems with functionality and management of the site to date. Now that HIV Scotland has a web development officer work to bring management in-house has been undertaken and a new dedicated condoms by post website has been developed. To date statistics for usage have been difficult to ascertain but in the last Annual Report (2007/08) the agency reports that in a 12 month period 3,750 condom and lubricant packs were distributed via the scheme. The major change for the site is a re-design and rebranding which identifies the service as 'condoms by post' on a stand-alone site, but with links from the Healthy Gay Scotland site. Hosting and managing in-house will give improved functionality and access to statistics about users nationally and by Health Board area.

African Minority Ethnic HIV Project (AMEHP)

3.46 This project focuses on the needs of specific populations within Scotland. It aims to build awareness of HIV and to influence policy and service delivery for these communities.

3.47 Project successes include the development of a network of interested individuals and agencies, support for the development of *Kanais* an email group for Africans living in Scotland and support for the African Country Association Health Forum which is made up of representatives from 23 different African countries who participate in events, some social and cultural, which address common needs including HIV. In 2007 AMEHP also co-facilitated a conference entitled 'Sisters Are Doing it for Themselves' to look at women, sexual health and HIV. A conference report is available via the HIV Scotland web site.

3.48 In order to understand the experiences of Africans living with HIV in Scotland the project worker is engaged in limited international work. The AMEHP worker provided support to ex Zambian President Kenneth Kaunda on his recent visit to Scotland to talk on HIV issues. AMEHP has supported a conference on microbicides (a new product being developed that could be used vaginally or rectally to reduce a person's risk of HIV infection).

3.49 In addition to funding AMEHP the Scottish Government funds work with African communities undertaken by voluntary sector agency Waverley Care via its African Health Project. Stakeholders and HIV Scotland staff have identified an overlap in the work of both agencies. At the behest of Scottish Government, HIV Scotland and Waverley Care have met recently to discuss roles and activities. The agencies have drafted a paper which establishes roles in relation to areas where there is a shared interest. This remains a discussion paper and awaits further clarification and implementation.

Training

3.50 In 2008/09 the agency explored the potential in developing and delivering a training programme which would address a range of HIV issues. Consideration was given to offering training at different levels which would include *Foundation*, *Intermediate* and *Advanced* level training. Some work was done to identify a small number of individuals who could be commissioned to deliver HIV Scotland branded

training and early consideration given to accreditation. With the departure of a member of staff this work has not been progressed further.

Stigma

3.51 A long-term area of interest for the agency, recent work has been done in 2009 to support the People Living with HIV index work on stigma. HIV Scotland recruited people to participate in training to work on promoting the project amongst the HIV sector and conducting interviews with individuals. The agency identifies that its work in relation to recognising and addressing stigma should continue within the context of the new HIV Action Plan.

Representing the sector

3.52 Staff and Board identified this activity as central to HIV Scotland's purpose. Recent efforts have been in terms of HIV Action Plan developments but the agency also responds to many requests for views on a range of HIV related issues. As examples of this activity the agency has input to work on a range of issues

- **HIV testing:** The agency continues to inform and influence debate and policy on this key area; this has included a response to the BASHH/BHIVA/BIS draft Testing Guidelines. The agency has also been involved in debate and informing discussion about mandatory testing.
- **Blood donor policy:** The agency has had an ongoing interest in this issue and current policy which excludes MSM from donating blood. Engagement has included reviewing and reporting on evidence, facilitation of a seminar on the issue and regular meetings and updates with agencies across the UK.
- **HIV and the law:** With the support of a leading academic in the field HIV Scotland produced a summary document about the law and has provided a range of links and information via the HIV Scotland website. Work has also involved press coverage and advising other agencies (including Crown Office and Police) and individuals.
- **Poverty and HIV:** Along with partners the agency supported and produced a report on this issue.
- **Children and HIV:** Work has been undertaken with partners to highlight issues both in Scotland and globally. This has included involvement in the report 'I want to be like the others'¹³ (Cree and Sidvha 2009). The HIV Scotland site is used to promote access to information and current research.
- **Confidentiality:** Recognising this as an important issue for people living with HIV, the agency has contributed recently to development of the GMC Confidentiality Guidelines.

¹³ 'I want to be like the others: A cross sector needs assessment of children infected and affected by HIV in Scotland' Cree and Sidvha 2009
Available at: <http://www.waverleycare.org/userfiles/HIV%20Report.pdf>

Summary

3.53 This chapter has described HIV Scotland's aims and main activities; including the work of the national health improvement projects Healthy Gay Scotland and The African Minority Ethnic HIV Project. Work in other areas has also been identified including the agency's contribution to the HIV Action Plan in Scotland. In discussing management and staffing it has been possible to identify that while there are difficulties HIV Scotland Board and staff have expressed a hope that this Review brings some clarity and describes a constructive way forward when it comes to management and governance issues. In the course of the Review the post of *Change Manager* has been introduced to help Board and staff implement change.

4. AN EXAMINATION OF HIV SCOTLAND'S AIMS, OBJECTIVES AND ORGANISATION FOCUS

Key points summary

- Historically HIV Scotland's focus has been to inform and support the voluntary sector's response to HIV issues. Contributors identify the 'HIV sector' is now more broad-based and inclusive of both voluntary and statutory sectors.
- The knowledge and experience of HIV Scotland over many years during which it has monitored and understood the impact of the epidemic on Scotland is recognised as a key strength.
- HIV Scotland has informed national policy, particularly the HIV Action Plan in Scotland. The relationship with Scottish Government is strong. While this is welcome stakeholders also want to clarify the independence of HIV Scotland.
- The agency would benefit from extending its policy reach and influence to a fuller range of policy concerns which also impact on the lives and wellbeing of individuals and communities most affected by HIV.
- The agency needs to be more pro-active in identifying issues and more inclusive and creative in establishing the partnership-based responses which are required.
- While Government and statutory sector agencies value HIV Scotland's role as a representative voice of the voluntary sector agencies from that sector question how this is achieved in the context of relationships which some describe as poor. There are concerns that HIV Scotland seeks to *lead* the sector but does not adequately *represent* its views. HIV Scotland Board and staff recognise difficulties and are committed to addressing them.
- The agency has successfully focused attention on communities most at risk with the work of HGS and AMEHP; however the needs of other groups and communities should also be considered more explicitly.
- HIV Scotland Board and staff agree that some projects in the HGS work stream need to be reviewed and HIV Scotland's role renegotiated and trust re-invested back in partners.
- The agency recognises that it has been involved in *collaborations* but has not considered and created *strategic partnerships*.
- Stakeholders want outreach and community development to be part of HIV Scotland's remit. Developing and supporting models for advocacy and representation with and on behalf of people living with HIV should be included.
- Stakeholders suggest that HIV Scotland could provide training and be more proactive in terms of supporting others in the development of information provision, promotional materials, websites and campaigns.
- Stakeholders identify the need for HIV Scotland to remain flexible and responsive to emerging issues and challenges. There is agreement that HIV Scotland should retain its clear organisational focus on HIV.
- HIV Scotland needs a set of aims and statements about activities which are described in terms of specific, measurable, achievable, realistic, time-specific objectives which are negotiated and agreed with a membership base as well as with Scottish Government as funders.

Introduction

4.1 This chapter reflects on the delivery of HIV Scotland's main aims and organisational activities. Contributors comment on the degree to which HIV Scotland prioritises and successfully delivers in each area. The chapter also identifies what is missing from HIV Scotland's aims, objectives and organisation focus.

The HIV sector

4.2 Several of the aims and means of delivery considered below use the term 'the HIV sector'. In discussion, external stakeholders and HIV Scotland Board and staff have posed the question: *What is the HIV sector?*

4.3 HIV Scotland identifies that historically the primary focus of the agency was to inform and support the voluntary sector's response to the epidemic. However recent times have seen changes. Many smaller community-based voluntary sector HIV agencies have closed and a small number of larger voluntary organisations are increasingly being commissioned to deliver services for statutory sector agencies. The statutory sector itself has also worked to improve policy and service provision to those living with HIV. It seems to many contributors to the Review that an 'HIV sector' should now be more broad-based and inclusive of both voluntary and statutory sectors.

4.4 HIV Scotland staff report that the agency's own projects, activities and events reflect the changing nature of the sector by attracting a mix of partners, contributors and participants. Both Board and staff conclude that HIV Scotland now has a role to play in serving a sector which is made up of both voluntary and statutory sector agencies. One staff member has identified that HIV Scotland now needs to play a role in "re-shaping the HIV sector in Scotland".

4.5 However, contributors from voluntary sector agencies, and from within HIV Scotland itself, support the idea that HIV Scotland should retain a *particular or special* focus on the voluntary sector's response to the epidemic. Whilst contributors identify existing relationships between the agency and the sector need to be improved there is a hope that HIV Scotland can continue to ensure that the voluntary sector's response, its values, perspectives and benefits, can be supported and promoted.

AIM 1: HIV Scotland aims to provide effective leadership in policy and strategic development and interventions within the HIV sector in Scotland.

4.6 Stakeholders who were interviewed identify that relationships and close collaboration with the Scottish Government are given a high priority by the agency.

4.7 Stakeholders identify that as the epidemic evolves there is a need for an agency which can make representation on behalf of the voluntary sector in forums where policy and strategy are discussed and developed. While the growth in capacity of a number of voluntary sector service providers is recognised by statutory sector stakeholders there is a view that HIV Scotland is best placed to present a *national* and *independent* perspective.

4.8 There is concern across contributions from stakeholders, and within HIV Scotland itself, about the capacity of the organisation in the past year to two years to inform and respond to all possible or relevant policy areas due to staff vacancies and staff changes. One stakeholder identified:

- “I think that at times they have difficulty in meeting deadlines and responding to policy requests. I think this is a capacity issue and reflects the size of the organisation.” (Stakeholder)

4.9 With a full staffing complement in place it is suggested by external stakeholders that the organisation will benefit from expanding its policy focus from matters explicitly related to HIV (for example drugs treatments, criminalisation and HIV transmission, stigma) to give more attention to a fuller range of policy concerns which also impact on the lives and wellbeing of individuals and communities most affected by HIV; for example this might include housing, mental health and wellbeing, benefits, older people’s services. One stakeholder identified:

- “At present I think that they cover specific policy areas exhaustively. I would like to see them cover more areas well but in less depth. If HIV Scotland is the trusted policy hub in Scotland then they need to be on top of this and cover all relevant policy issues”. (Stakeholder)

4.10 Beyond policy and looking to best practice in prevention, treatment and care stakeholders also identify that HIV Scotland could do more to identify learning from responses to other chronic conditions to inform responses to HIV. Again with capacity to do so, HIV Scotland Board and staff agree.

4.11 Some stakeholders from the voluntary sector express concerns about HIV Scotland’s interest and commitment to challenging positions and provoking debate about Government and broader HIV sector thinking or activity on HIV issues. For some stakeholders HIV Scotland feels somewhat conservative in its approach to issues which are deemed to be too controversial; this might include creating or leading debate for example on matters such as individual sexual behaviour, homophobia or racism in service provision or stigma within the gay community.

4.12 Voluntary sector stakeholder’s expressed disagreement with the position taken by HIV Scotland on the issue of blood donation by gay/bisexual/MSM; where support for the current SNBTS ban is seen as an example of HIV Scotland not representing the views of the voluntary sector. In this instance HIV Scotland is keen to stress that it must adopt a view based on analysis of evidence and argues that it has advocated for review of the evidence at UK level, improved communications on this issue and for research into gay/bisexual/MSM attitudes and actions regarding the policy.

4.13 Voluntary sector stakeholders express a desire to see HIV Scotland create a dialogue with the sector about what *representation* of the sectors views or activities might mean; but there is a reticence to accept HIV Scotland in the role of *leadership* of the sector. One stakeholder expressed concerns as follows:

- “The emphasis on leadership detracts from the organisations role as a representative agency. This means that HIV Scotland frequently focuses on progressing its own agenda and raising its profile rather than bringing the sector together and acting in a consultative capacity.” (Stakeholder)

4.14 It is suggested by some stakeholders that the organisation should build stronger partnership with other Scottish and UK based HIV/AIDS policy organisations to improve its ability to inform and respond to the policy process in Scotland and the UK context.

4.15 The professional stakeholders who represented the views of their agencies and who responded to an online questionnaire confirm the views of those interviewed that HIV Scotland gives a *high priority* to this stated aim (69.8% agree n=30). Further, 34.9% of respondents think HIV Scotland is *highly successful* at this work, and 48.8% (n=21) *moderately successful*. Finally the respondents confirm that this aim *should* receive a *high priority* from the agency with 83.7% (n=36) agreeing. More detail in **appendix 13**.

AIM 2: HIV Scotland aims to ensure HIV prevention priority is focused on communities most at risk and that support is prioritised for groups disproportionately affected by HIV.

4.16 Stakeholders who were interviewed identify that the priority given to this aim is evident in the agency’s work delivered through its projects Healthy Gay Scotland (HGS) and the African Minority Ethnic HIV Project (AMEHP). The agency is perceived to be good at using epidemiological data to support the need for this emphasis and related activity.

4.17 There is support amongst stakeholders for maintaining a focus on groups and communities most affected but it is also identified that the focus on gay/bisexual/MSM and to a lesser extent on African communities can be perceived of as work done to the exclusion of others. Contributors with such concerns would like to see HIV Scotland re-focus attention on other communities and support for agencies who work with them. Specifically stakeholders identify the need to refocus work with individuals and communities where HIV is an issue as a result of intravenous drug use and heterosexual transmission (out with African communities). There is support from both HIV Board and staff for a re-examination of HIV Scotland’s work with these communities. One stakeholder commented:

- “I also think that in targeting groups most at risk they need to be careful that there is not a cohort of people who are missed and fall through the net”. (Stakeholder)

4.18 Stakeholders identify a role for HIV Scotland in ensuring that through implementation of the HIV Action Plan, in both policy and service delivery, agencies in *all* parts of Scotland maintain a focus on communities and groups most at risk and disproportionately affected. There are concerns that where at risk populations have low visibility, for example gay/bisexual/MSM in rural communities, some statutory sector providers may be resistant to identifying and focusing responses on those ‘harder to reach’.

4.19 In discussing this aim voluntary sector stakeholders raise concerns about a lack of dialogue with HIV Scotland and question HIV Scotland's ability to deliver this aim without strengthening these relationships.

4.20 Across contributions, stakeholders identify a role for HIV Scotland in relation to broader based awareness raising, education and prevention work with the general population, but particularly with young people.

4.21 The professional stakeholders who represented the views of their agencies and responded to an on-line questionnaire recognise the high priority given by the agency to this aim; with 63.4% (n=26) agreeing HIV Scotland give this aim a *high priority*. In terms of successfully achieving this aim 48.8% (n=20) think HIV Scotland is *highly successful*, and 36.6% (n=15) think *moderately successful*. When asked to consider the priority which *should* be given to this organisational aim 82.5% (n=33) of respondents agreed it should be given a *high priority*. More detail in **appendix 13**.

AIM 3: HIV Scotland aims to represent the views, benefits and values of the voluntary sector's response to the epidemic.

4.21 Statutory sector stakeholders who were interviewed report that HIV Scotland is strong on representing the views and values of the voluntary sector. They have seen this work in practice in the development of the HIV Action Plan in Scotland as well as the Scottish Public Health Network Project Group which has worked on the project 'Treatment and Care Needs Assessment: People Living with HIV'; interviewees pointed to the fact that with the support given by HIV Scotland, this publication makes important statements about the voluntary sector with 3 of its 24 recommendations specifically addressing the sector's role.

4.23 Stakeholders from voluntary sector agencies recognise that there can be a diversity of views on any given issue. However, some stakeholders feel that HIV Scotland develops and progresses its own agenda and cannot claim to be representative. There are concerns that what is presented as the view of the agency can be perceived of as the view of a particular staff member, leaving staff and the agency vulnerable to criticism.

4.24 Stakeholders in the statutory sector question whether HIV Scotland is representing the *benefits* of the sector because the sector itself requires to do more work to articulate and evidence what these benefits are. Stakeholders hope that HIV Scotland might be able to do more work in this area and support agencies to demonstrate effectiveness.

4.25 HIV Scotland Board and staff recognise the challenge inherent in *representing* the sector, particularly in the context of relationships which are currently at a low point. They suggest that the agency needs to discuss and clarify what this *representation* might mean, and that while the benefits and values of the sector might be promoted that it is important to recognise the diversity of views which might be held on a given issue.

4.26 Agencies whose base is Scotland and whose educational or campaigning activities are delivered outside Scotland would like to see their activities more reflected in the ways in which HIV Scotland's represents the sector.

4.27 Several stakeholders from across sectors asked for further information about the status of HIV Scotland itself and whether it is constituted as a voluntary sector organisation with or without charitable status, or whether it operates as a non-departmental government agency. Those interviewees who are unclear as to HIV Scotland's status suggest this causes confusion and questions HIV Scotland's autonomy and independence from Government.

4.28 In their online questionnaire the professional stakeholders report that in terms of priority given by the agency, while 43.9% (n=18) of respondents agree that HIV Scotland currently gives this aim a *high priority* 80.5% (n=33) say it *should have a high priority*. Views are mixed on the success of HIV Scotland in this area: with 34.1% (n=14) stating that HIV Scotland is *highly successful*, 22% (n=9) *moderately successful* and 26.8% (n=11) *not successful*, while 17.1% (n=7) *don't know*. More detail in **appendix 13**.

AIM 4: HIV Scotland aims to ensure the development within Scotland of capacity, activity and resources that respond to current evidence, policy and epidemiology around HIV.

4.29 HIV Scotland staff interviewees are keen to emphasise the importance placed by the agency on sourcing, sharing and utilising evidence and epidemiology in their work. Agency knowledge of evidence and epidemiology is considered to be strong by stakeholders.

4.30 HIV Scotland Board and staff recognise that in recent times HIV Scotland activity on delivering this aim has been focused mainly on work on statutory sector-led initiatives, particularly in relation to the development of the HIV Action Plan and Scottish Public Health Network Project Group.

4.31 There are concerns amongst HIV Scotland Board members that the agency, whilst knowledgeable and capable, is largely reactive in this work and is not helping to create the agenda. One Board member put this concern as follows:

- "We need to be more rigorous - ahead of the game. I worry we are behind the curve not ahead". (Board member)

4.32 Stakeholders in the voluntary sector identify the need for HIV Scotland to re-focus some activity from work on national policy to more work with at risk communities *at the community level* by building relationships with small community based groups and with individuals living with HIV who are interested in self-organisation. Stakeholders want to see outreach and community development as an explicit part of HIV Scotland's remit and delivery.

4.33 In their on-line questionnaire 46.3% (n=19) of professional stakeholders who responded agree that HIV Scotland gives this aim a *high priority*, 29.3% (n=12) a *medium priority* but 26.8% (n=11) a *low priority*. Respondents were more agreed on

whether HIV Scotland *should* give priority to this aim with 70% (n=28) stating they *should* give it a *high priority*. When it comes to the extent to which HIV Scotland *achieves* this aim only 19.5% (n=8) said HIV Scotland was *highly successful*, 48.8% (n=20) *moderately successful* and 12.2% (n=5) said *not successful*. 19.5% (n=8) *don't know*. More detail in **appendix 13**.

ACTIVITY 1: HIV Scotland advocates for HIV issues in Scotland and builds strategic partnerships.

4.34 Stakeholders from the voluntary sector and those who have contributed as individuals are concerned about the loss in Scotland of independent advocacy provision for individuals living with HIV. While they recognise the complexity of effectively advocating on behalf of people with HIV they identify that a national organisation such as HIV Scotland, *if* it had strong partnerships in place with service providers, and *if* it considers best ways to engage with HIV positive people, might be well placed to address how this advocacy and representation *with and behalf of* people living with HIV could be done creatively, inclusively and in a *national* context.

4.35 Stakeholders in both statutory and voluntary sectors recognise the difficulties and challenges in engaging service users with consultations and research. They highlight consultation/research fatigue amongst people asked to participate too often, the fact that people living with HIV can be wary of losing anonymity, and that some people just want to receive the best information or treatment and care without any additional responsibility to contribute to feedback or research.

4.36 Stakeholders from the statutory sector would like to see HIV Scotland take up an explicit role in advocacy in relation to people living with HIV. They indicate this could provide both national and local perspectives which agencies could draw on to inform both policy and service delivery.

4.37 Within HIV Scotland there is an interest in improving delivery on the claim to be 'the independent voice for HIV in Scotland'. Staff members recognise that this is different from simply having a view on HIV issues and that it requires the agency to have positive and broad based partnerships which include people living with HIV, their partners, friends and families.

4.38 HIV Scotland Board and staff recognise that HIV Scotland has, in some partnership work, become too involved in operational aspects of delivery after a resource or initiative has been established. In their view this results from a lack of clarity within the agency about roles and occasionally a lack of confidence in partners to maintain the quality of work. Staff identify that they find it hard to let go of projects once initiated. Board and staff agree that some projects in the HGS work stream need to be reviewed and HIV Scotland's role renegotiated, trust re-invested back in partners and an exit strategy agreed.

4.39 Board members identify the need to refocus efforts on building and nurturing partnerships with both voluntary and statutory sector agencies. Both Board and staff recognised that rather than engaging in *strategic partnerships* HIV Scotland had been involved in a series of collaborations and as such has been poor at identifying which are more important, long-term or significant for the agency.

4.40 Board and staff identify that the agency should be better at identifying what areas of joint work are *strategic*. In the course of individual and group discussion they identify that strategic partnerships should involve clarity and agreement with partner agencies on purpose, ways of working, timescales, decision-making, deliverables and outcomes. They might also involve written agreements and should certainly involve monitoring and review. Board members stressed that strategic partnerships should be understood and agreed by the Board.

4.41 In their online questionnaire professional stakeholders agree that the agency gives this activity *high priority*: 73.2% (n=30) agree. A similar number (73.8% n=31) agree this activity *should* have this high level of priority. Most contributors agree that the agency has some level of success with delivery: 43.9% (n=18) say *highly successful* and 41.5% (n=17) *moderately successful*. More detail in **appendix 13**.

4.42 In the second on-line questionnaire stakeholders who responded as individuals (some of whom are professional staff, some members of the public engaged in HIV Scotland consultations or projects) were asked to comment on the success of HIV Scotland in terms of delivery on a number of given areas linked to activity 1. More detail in **appendix 14**.

- The majority of the 78 respondents to this question agreed that the agency is either *highly* (25.6% n=20) or *moderately* (47.4% n=37) successful at **promoting better understanding about HIV issues**. While only 7.7% (n=6) of respondents thought HIV Scotland is unsuccessful at this activity a further 19.2% (n=15) *do not know if it delivers this activity*.
- Most of the 78 respondents to the question about success at **speaking on behalf of people and communities most affected by HIV** agreed that the agency has some degree of success: 30.8% (n=24) see the agency's work as *highly successful* and 28.2% (n=22) as *moderately successful*. However, 16.7% (n=13) of respondents thought HIV Scotland is unsuccessful at this activity and a further 24.4% (n=19) *do not know if it delivers this activity*.
- There were similar rates of success identified for the agency's work to **build partnerships and good relationships between groups interested in HIV**. Again with 78 respondents 32.1% (n=25) see the agency's work as *highly successful* and 34.6% (n=27) as *moderately successful*. However, 15.4% (n=12) of respondents thought HIV Scotland is unsuccessful at this activity and a further 17.9% (n=14) *do not know if it delivers this activity*.

ACTIVITY 2: HIV Scotland is active in the development of evidence-informed government policy.

4.43 Stakeholders who were interviewed recognise the priority which HIV Scotland gives in its work to delivering this aim and many identified the quality of HIV Scotland's work in this area. However, it is suggested that the organisation should broaden and develop the range of research and evidence it utilises when engaged in policy work; concerns are related to issues identified earlier about a lack of

connection and dialogue with voluntary sector agencies delivering services on the ground and the need to engage more strategically with people living with HIV.

4.44 In their online questionnaire a majority of the professional stakeholders (74.4% n=32) recognise the *high priority* HIV Scotland gives to this activity; more (83.7% n=36) agree that it is an activity which *should* be given *high priority*. In terms of successfully delivering this work most agree the agency is successful: with 42.9% (n=18) recognising that the agency is *highly successful* and the same number agreeing *moderately successful*. More detail in **appendix 13**.

4.45 In the second on-line questionnaire stakeholders who responded as individuals were asked to comment on the success of HIV Scotland in terms of **ensuring the Government's response to HIV is based on good information and facts about living with HIV**. The majority of the 77 respondents to this question agreed that the agency is either *highly* (31.2% n=24) or *moderately* (32.5% n=25) successful. More detail in **appendix 14**.

ACTIVITY 3: HIV Scotland builds capacity and coordinates networks within the Scottish HIV sector.

4.46 The knowledge and experience of HIV Scotland over many years during which it has monitored and understood the impact of the epidemic on Scotland is recognised as a key strength by stakeholders. There is also confidence within the agency about its knowledge base. With much to be done in the realms of prevention, treatment and care efforts to build capacity and to connect workers and agencies to each other are identified as a key task for HIV Scotland and an area within which improvements must be made. Stakeholders commented as follows:

- "I think HIV Scotland is a Government focused organisation which is reflected in their advocacy and policy work. I would like to see more emphasis and focus on the HIV sector". (Stakeholder)
- "They have a track record of working in this field over a long period of time and need to use that experience to bring more coherence to the voluntary sector". (Stakeholder)

4.47 HIV Scotland Board and staff discussed their understanding of the term *networks* in the course of the Review. The agency has built contacts with many individuals and agencies and uses this *network* of contacts to disseminate information, promote events or consult. In the past there has also been support provided for groups who have met face-to-face to discuss HIV related issues. The AMEHP project in particular sees a major part of its work in building and co-ordinating with community partners a series of networks which bring people together by email and in social, cultural and health-related events.

4.48 HIV Scotland Board and staff now realise that there is a need to review what kinds of connections, what kinds of *networks*, professional colleagues and people living with HIV want HIV Scotland to coordinate.

4.49 A concern for some voluntary sector stakeholders is the emphasis and effort HIV Scotland puts into work with and for Scottish Government. This detracts from what stakeholders identify is the need for HIV Scotland to increase efforts and activity on creating, supporting and facilitating opportunities for the sharing of knowledge and expertise across the voluntary sector.

4.50 Stakeholders recognise that building capacity in the voluntary sector means recognising that agencies can be in competition with each other for resources, service contracts or grants. It is viewed as important then that HIV Scotland is not viewed as a competitor but as a fair and honest broker when it comes to identifying sector needs and encouraging agencies to see and create opportunities to support each other in the best interests of the communities and individuals affected by HIV in Scotland.

4.51 While 39% (n=16) of the professional stakeholder respondents report HIV Scotland gives this activity a *high priority* 73.8% (n=31) say it *should be given a high priority*. In terms of success to date in delivering this activity only 20% (n=8) agree HIV Scotland is *highly successful* and 35% (n=14) *moderately successful*. More detail in **appendix 13**.

4.52 In the second on-line questionnaire stakeholders who responded as individuals were asked to comment on the success of HIV Scotland in terms of **successfully helping community and voluntary groups in the work they do in HIV issues**. Most of the 75 respondents to this question agree some degree of success: 24% (n=18) agreed that the agency is *highly successful* and 38.7% (n=29) *moderately successful* at this work. However 26.7% (n=20) *do not know if HIV Scotland delivers this activity*. More detail in **appendix 14**.

ACTIVITY 4: HIV Scotland resources the HIV sector with training, information, promotional material, websites and campaigns.

4.53 Related to commitments to build capacity, identified above, these specific commitments to training, information provision, promotional materials, websites and campaigns are seen by stakeholders and HIV Scotland Board and staff as essential elements of a capable and strong HIV sector.

4.54 Stakeholders suggest that HIV Scotland could be more proactive in terms of this area of work, in particular through the provision of high quality training. It is also suggested by stakeholders that HIV Scotland could use efforts to build the capacity of other agencies to develop materials, websites and campaigns rather than engage in development of its own.

4.55 The larger voluntary sector service providers working with gay/bisexual/MSM and African communities have concerns about communication, about HIV Scotland maintaining control and decision making over projects or initiatives that were thought to be based on partnership working, and a concern that there is a risk of duplication in this area of work.

4.56 From within HIV Scotland the view is that through its work, and particularly through the work of HGS and AMEHP, HIV Scotland seeks to mobilise, support and

work in partnership on resourcing the sector. The agency's view is that this has been successful in terms of initiatives such as conferences (for example *Changing the Focus/GayCon* events on gay/bisexual/MSM sexual health and *Sisters are Doing it for Themselves* in terms of AMEHP work) and materials, some of whom have related products or websites (for example the *Connected* resource and *Cocktales* materials).

4.57 Stakeholders recognise the success of many of these initiatives, but in terms of ongoing projects, particularly those related to the work of the HGS project, there is a sense that HIV Scotland has sought to keep control when their role might have more usefully been as an instigator, creator and motivator who, in time, stands back and allows the sector itself to manage a project or product.

4.58 Stakeholders and HIV Scotland staff also report problems with design, management and delivery of several web-based initiatives which in their inception were poorly thought through and have left a legacy of problems in terms of management and functionality. While these issues are being addressed by improved knowledge and capacity within HIV Scotland and partners they indicate a need for more considered approaches to the development of web-based resources.

4.59 Just over half of the professional stakeholder respondents (51.2% n=21) agreed in their on-line questionnaire that the agency gives this work a *high priority*; slightly more (61% n=25) thought it *should* have a *high priority*. In terms of successfully delivering this work while only 22% think HIV Scotland is *highly successful*, 53.7% (n=22) the agency is *moderately successful*. More detail in **appendix 13**.

4.60 In the second on-line questionnaire stakeholders who responded as individuals were asked to comment on the success of HIV Scotland in relation to a number of areas relating to how **HIV Scotland resources the HIV sector**. (More detail about each in **appendix 14**). Respondents reported that:

- When it comes to **success at providing training about HIV issues** (79 people responded to this question) 26.6% (n=21) rate the agency as *highly successful* and 32.9% (n=26) *moderately successful*; However a significant number, 38% (n=30) of respondents *do not know if HIV Scotland delivers this activity*
- When it comes to **success at providing information about HIV issues** (79 people responded to this question) most respondents note success for the agency: 38% (n=30) rate the agency as *highly successful* and 41.8% (n=33) *moderately successful*.
- When it comes to **success at providing on-line information, resources or materials about HIV issues** (79 people responded to this question) 24.1% (n=19) rate the agency as *highly successful* and 38% (n=30) *moderately successful*. While only 12.7% (n=10) think the agency is *not successful* a significant number 25.3% of respondents (n=20) *do not know if HIV Scotland delivers this activity*.
- When it comes to **success at producing resources or materials for professionals who need to know about HIV issues** (80 people responded

to this question) 20% (n=16) rate the agency as *highly successful* and 31.3% (n=25) *moderately successful*. While only 6.3% (n=5) think the agency is *not successful* a significant number, the largest percentage 42.5% of respondents (n=34) *do not know if HIV Scotland delivers this activity*.

- When it comes to **success at producing resources or materials about HIV for people and communities most affected by HIV** (79 people responded to this question) 20.3% (n=16) rate the agency as *highly successful* and 40.5% (n=32) *moderately successful*; However 10.1% (n=8) think the agency is *not successful* and a significant number, 29.1% of respondents (n=23) *do not know if HIV Scotland delivers this activity*
- When it comes to **success at supporting campaigns on HIV issues** (80 people responded to this question) 32.5% (n=26) rate the agency as *highly successful* and 37.5% (n=30) *moderately successful*. However 12.5% (n=10) think the agency is *not successful* and a significant number, 29.1% of respondents (n=23) *do not know if HIV Scotland delivers this activity*

What is missing from HIV Scotland's aims, objectives and organisation focus?

4.61 While some stakeholders are satisfied with the agency's statement of aims and key activities (responding that they address areas they want to see a national agency involved in) other stakeholders feel that the statements whilst relevant are either too broad or largely aspirational. For these contributors there is a need to revisit the statements to ensure that they are realistic, relevant, focused and achievable in the context of an emerging HIV Action Plan. One stakeholder describes HIV Scotland as "a small organisation with a huge task". Typically, other stakeholders expressed these views:

- "I think the organisation would benefit from honing in on what is realistic and achievable" (Stakeholder)
- "HIV Scotland should be encouraged to develop and adapt its present remit where and when necessary. The profile of HIV in Scotland is forever changing, and as a result, an organisation such as HIV Scotland must have the flexibility to move with these changes" (Stakeholder)

4.62 Stakeholders identify the need for HIV Scotland to remain flexible and responsive to emerging issues and challenges. However, across contributions from both external stakeholders and HIV Scotland Board and staff there is agreement that HIV Scotland should retain its clear organisational focus on HIV.

4.63 Across the Review stakeholders and HIV Scotland Board and staff identify a number of issues which could be more explicitly addressed in the context of agency aims or core activity. These include:

- Making commitments to establish and operate HIV Scotland as a membership organisation with the stated purpose of engaging with professional agencies and colleagues as well as people living with HIV.

- Clarifying an interest and commitment to connect the HIV policy agenda explicitly to policy areas beyond sexual health and blood-borne viruses, reflecting a commitment to connecting to the plethora of areas that impact on HIV positive people's lives.
- Making a commitment to supporting, protecting and growing service provision to communities and individuals most affected across Scotland. One stakeholder commented: "In a changing environment should there be an aim about protecting HIV services?" (Stakeholder)
- Making a commitment to support and involve people living with HIV in Scotland in policy and service developments; supporting HIV Scotland's claim to represent a diversity of views and most importantly those of HIV positive people themselves. One stakeholder said: "I was under the impression that HIV Scotland had a role to support the inclusion of people living with HIV, and to give them a voice in the policy process ... I hope it can be included as there is limited opportunity for people living with HIV to be heard". (Stakeholder)
- Making a commitment to engage with HIV as a global issue.
- Developing a set of aims and statements about activities which are described in terms of specific, measurable, achievable, realistic, time specific objectives which are negotiated and agreed with a membership base as well as with Scottish Government as funders.

Summary

4.64 This chapter has considered the degree to which HIV Scotland prioritises and successfully delivers on a number of stated aims and organisational activities. This reflection identifies the need to re-examine what is meant by the term the HIV sector and describes a more broad-based cross-sectoral service landscape within which HIV Scotland must operate. While many contributors report that HIV Scotland successfully delivers on aspects of its stated aims and organisation activity they also identify a need for the agency to re-build a membership base, and in particular improve relationships with voluntary sector stakeholders. HIV Scotland must also consider and renegotiate with a membership base how best to fulfil commitments to represent and advocate on behalf of the HIV sector and people living with HIV. Finally, the organisation would benefit from developing a set of aims and descriptions of organisational activity which are outlined in terms of specific, measurable, achievable, realistic, time specific objectives, negotiated and agreed with a membership base as well as with Scottish Government as funders.

5. HIV SCOTLAND: MANAGEMENT, PLANNING AND ORGANISATION

Key points summary

- HIV Scotland Board and staff recognise and value the knowledge and commitment brought to the work of the agency by each. There is a shared appreciation that for a small Board and a staff team with reduced capacity, in the midst of a Review, the pressures of doing the job required feel onerous. However, HIV Scotland's Board and staff have also identified a number of problematic issues
- A key problem is that relationship between the Board and the Chief Executive is difficult and deteriorating. There is a mutual lack of trust in each other's capacity to fulfil the roles required.
- The Board is engaged in, and feels overwhelmed by, day to day problems and does not focus on strategic issues and partnerships.
- There are no formal staff support and supervision structures in place nor annual appraisals.
- Partnership working groups established to steer HIV Scotland's projects HGS and AMEHP no longer meet. This is viewed by stakeholders as indicative of a lack of commitment by HIV Scotland to engage with partner agencies. Stakeholders and the agency itself recognise that work done in silos can mean that opportunities for work which is across populations might be lost.
- External stakeholders express concerns about a lack of communication about HIV Scotland's work. HIV Scotland Board and staff recognise the need for improved communication.
- Prior to this Review a temporary member of HIV Scotland staff conducted work which explored issues around communication and partnership work. A report was produced in April 2009 however this work has not been progressed. Board members report that they have no ownership of the work, that they have been poorly informed of its purpose or progress. Some staff members appear to have found the process and product unsettling. The Review team find the work to be insightful and positive and has a role to play in considerations of the agency's communication and work-planning.

Introduction

5.1 This chapter of the report explores HIV Scotland's approach to management, planning and organisation systems and issues around dissemination and communication about the agency's role and activity.

HIV Scotland management

5.2 HIV Scotland's management structure is outlined in chapter 3.

5.3 HIV Scotland Board members recognise and value the knowledge and commitment brought to the work of the agency by the Chief Executive and staff

team. In turn, staff members recognise the commitment of Board members. There is a mutual appreciation that for a small Board and a staff team with reduced capacity, in the midst of a Review, the pressures of doing the job required feel onerous.

5.4 HIV Scotland's Board and staff have also identified a number of problematic issues.

5.5 Currently, relationships between the Board and the Chief Executive are poor. There is a mutual lack of confidence and while communication day to day is polite, written communications evidence a relationship which is difficult and deteriorating. Board members have concerns about reporting to them on agency activity. They have concerns about a lack of detail in reporting and that not enough information is provided in advance of Board meetings. Board members express concerns about a lack of action on instructions given by them to the Chief Executive. They identify an immediate need to work on the relationship between Board and Chief Executive which would ensure that future communication, decision making and accountability is clearly established and understood.

5.6 Some stakeholders and HIV Scotland staff express concerns that the authority of the Chief Executive is undermined by a Board who do not appear to have trust in that person's capacity to fulfil the role required. There is a view that without authority and trust a senior manager cannot manage and that in a management vacuum staff management issues can become muddled. One Board member described the problem as follows:

- "It operated so well when things were going well, but when things go wrong, well there's no way to pick up problems. There's no effective management. No internal systems in place. As a trustee trying to do small stuff sucks you in". (Board member)

5.7 It appears that the Board is engaged in, and feels overwhelmed by, day to day problems and does not focus on strategic issues and partnerships. As an example of this distance from the work of the agency, Board members have discussed individually with the Review team their knowledge of the emerging HIV Action Plan, and the opportunities it presents for HIV Scotland, but they also identify that they have not discussed the plan or HIV Scotland's contribution to it *as a Board*. One Board member described the problem: "As a Board we are not a check and balance".

5.8 HIV Scotland staff report that there are no formal staff support and supervision structures in place nor annual appraisals. Systems are established for day to day management issues such as recording absences, timesheets and electronic diaries but commitments to using these varies across the team. Staff report a lack of confidence in the management and governance of the agency. One staff member commented:

- "HIV Scotland needs a strong Board that then authorises a senior manager to manage. It's messy when staff can access an individual Board member, this must stop. A line is required, proper lines of communication and management. We need a Board which clarifies direction and purpose".

5.9 There is an ongoing process of review of long-standing job descriptions and this is still to be completed. It is hoped by staff members that this results in clarity about roles, responsibilities, lines of communication and management. Existing staff are anxious about possible changes to the staff team structure as a result of the Review recommendations. Staff are keen to ensure that any changes which impact upon them be fully explained and understood.

Project work

5.10 Over the years, as a response to the needs and experiences of populations most affected by HIV in Scotland, the agency has developed a project approach and has established two strands of work: Healthy Gay Scotland (HGS) and African Minority Ethnic HIV Project (AMEHP). The work of these projects has been described earlier.

5.11 Initially both projects had steering groups established, made up of representatives of partner agencies, to help inform, steer and support that work. These groups no longer meet. In terms of specific initiatives *within* these work strands (for example the *Connected* resource) small working groups have been established. However, with regard to the failure to maintain the more strategic steering groups external stakeholders report that this is indicative of a lack of commitment by HIV Scotland to engaging with partner agencies in the management and delivery of HIV Scotland work. While there is support and discussion in the staff team about this project work, reporting to the Board is minimal and evaluation and review informal.

5.12 Whilst remaining supportive of the need to focus resources and interest on communities most at risk and most impacted upon by HIV the agency itself recognises that work done in silos can mean that opportunities for work which is across populations might be lost. From the point of view of some external stakeholders there is a view that such explicitly structured work streams means that other communities, populations or issues then fail to make it on to HIV Scotland's agenda.

5.13 The relationship between the HGS project and HIV Scotland is not well understood by some stakeholders. In the course of the Review some interviewees sought clarity about this and for some the perception is that HGS has become more visible and active than its host. Stakeholders identify a lack of activity by HGS in 2008/09 which they understand is explained to some extent by staff vacancies but may also indicate a lack of commitment by HIV Scotland to the work and to enabling partners to progress work themselves.

Purpose and communication

5.14 External stakeholders express concerns about a lack of communication about HIV Scotland's work. They recognise that organisational capacity for communication and partnership work will have been adversely affected by having staff vacancies and a small Board.

5.15 The agency has distributed an e-newsletter in October 2009 (to around 450 contacts) but this is the first of these newsletters this year.

5.16 HIV Scotland Board and staff also express concerns about a lack of effective work around communications. Staff identify the need for hard copy and on-line information which describes purpose, values, activity. Board members are unclear as to what and how HIV Scotland communicates with the HIV sector about its activities.

5.17 In 2008/early 2009 a temporary member of HIV Scotland staff conducted work which engaged external stakeholders and the HIV Scotland Board and staff in reflection and discussion about HIV Scotland. External stakeholders interviewed by the staff member confirmed what this Review also identifies; that while HIV Scotland's value lies in its knowledge of HIV issues and its influence in terms of national policy and strategy, communication with others must improve and partnerships with the voluntary sector have worsened over time.

5.18 What emerged from the work of this staff member was a document which was entitled 'About HIV Scotland' (latest draft dated 08.04.09). In that document the author identifies that: *"Integral to the success of the organisation is to ensure a positive reputation with key audiences. HIV Scotland must therefore retain parity between three key elements"*.

5.19 The document identifies that these key elements are:

- *What motivates us*: The document identifies that this includes describing the context, need for partnership and co-operation, and an articulation of vision, mission, aims, objectives, guiding principles, approach and agency values. Text for each of these areas is drafted by the author for further discussion.
- *What we provide (our products and services)*: The document identifies that this includes: detailed expert advice and advocacy; resources, information and training; signposting to evidence, experts and specific groups; and opportunities to engage with others in shaping policy and practice. Again, text for each of these areas is drafted by the author for discussion.
- *How we communicate*: The document identifies that communication lies at the heart of success of the agency and as such requires that attention be paid to the following areas: personal interactions; an integrated approach to external communications in terms of print, web, events, campaigns and distribution of material; and finally a cohesive approach to communications so that partners recognise (visually and in terms of tone) and trust a consistently professional output from the agency.

5.20 In addition the staff member also developed a series of 'Project Overview Sheets' which in draft describe for stakeholders the purpose, values, outcomes, activities and objectives of each HIV Scotland project. It is intended this would include projects such as HGS and AMEHP but also specific projects within HGS or AMEHP work streams. A template for further development was produced.

5.21 When these materials were made available to the Review it seemed that HIV Scotland was in a good place to identify problems and find solutions to some of the weaknesses in current approaches and practice. The materials, although in draft and with gaps, bring a clarity to HIV Scotland's current situation and the potential it has to fulfil its claim to be the independent voice for HIV in Scotland. However work has not progressed since the draft document of early April 2009 when this Review also began. Board members report that they have no ownership of the work, that they have been poorly informed of its purpose or progress. Some staff members appear to have found the process and product threatening to current approaches and understandings of their work.

5.22 The material has since sat 'on hold' with no further commitment to examine it. As far as the Review is aware it has not been discussed by the Board or staff team despite several references of its value by the Review over the period of work. The Review report will return to issues addressed in the paper in terms of recommendations but it is clear that at least on paper, and in terms of the analysis of this Review, the future of HIV Scotland will be enhanced by the recognition of the value of the work already done in terms of defining the agency's purpose and importance of effective communication.

5.23 In terms of other professional support HIV Scotland has an ongoing relationship with design and creatives consultancy Redpath Design who have been commissioned in the past to develop a logo and consider issues in relation to establishing a clearly identifiable brand for HIV Scotland.

Summary

5.24 This chapter has considered HIV Scotland's approach to management, planning and organisation systems and issues around dissemination and communication about the agency's role and activity. A number of problematic issues have been identified.

5.25 Areas requiring attention include unsatisfactory mechanisms for communication, decision making and accountability within the organisation. The Board is not functioning as a place for discussion and development of strategic issues. The agency lacks effective day-to-day management systems for staff.

5.26 The agency has developed a project approach and has established two strands of work: Healthy Gay Scotland (HGS) and African Minority Ethnic HIV Project (AMEHP). Staff vacancies have impacted negatively on the agency's capacity to deliver on some partnership commitments. Whilst remaining supportive of the need to focus resources and interest on communities most at risk and most impacted upon by HIV the agency itself recognises that work done in silos can mean that opportunities for work which is across populations might be lost. External stakeholders have a concern that other communities, populations or issues then fail to make it on to HIV Scotland's agenda.

5.27 External stakeholders report a lack of communication and clarity about HIV Scotland's activities. In 2008/09 the agency conducted some work exploring partner's views and issues in communication about HIV Scotland's purpose and key

activities. This work remains in draft and there are indications that the process has been difficult for Board and staff. Despite a lack of ownership of the process and outcomes the work done indicates capacity within the agency to identify problems and find solutions.

6. HIV SCOTLAND'S CONTRIBUTION TO SCOTTISH GOVERNMENT POLICY

Key points summary

- The resourcing by Government of a national HIV organisation is seen as a strong commitment to continuously improving policy and supporting the HIV sector.
- Stakeholders recognise that HIV Scotland's work over many years has contributed to raising knowledge and awareness amongst many agencies about HIV and its impact in Scotland; thus informing current debates and developments.
- Stakeholders who have had close engagement in the development of the HIV Action Plan in Scotland recognise and value the contribution of HIV Scotland, particularly the Chief Executive.
- However, some voluntary sector stakeholders question the ability and effectiveness of HIV Scotland at representing the sector's views during this process.
- The contribution of HIV Scotland's Chief Executive to the Scottish Public Health Network facilitated treatment and care needs assessment for people living with HIV is highly valued by partners in that process. They identify that as a result the voluntary sector features strongly in recommendations made.
- The contribution of HIV Scotland staff to working groups and debates in the process leading up to publication in 2005 of 'Respect and Responsibility' the national sexual health strategy is recognised and valued by other partners in the process.
- In terms of HIV Scotland's contribution to reducing the number of people in Scotland with HIV and improving health outcomes stakeholders stress the importance of a co-ordinated response to addressing HIV issues in Scotland and acknowledge the difficulties in quantifying the effectiveness of a single organisation such as HIV Scotland.
- However stakeholders identify specific aspects of HIV Scotland's work, often in partnership with others, that they consider of value. This includes resources developed within the Healthy Gay Scotland work stream, the agency's engagement with targeted social marketing campaigns for gay and bisexual men, and work to connect and inform Africans living in Scotland with groups and relevant information.
- HIV Scotland and stakeholders also identify a number of areas where the agency could do more; this is focused on improving partnerships and creating opportunities for dialogue between agencies, continuing a focus on prevention and supporting voluntary sector providers to evaluate practice, disseminate findings and promote learning.

Introduction

6.1 This chapter is concerned with HIV Scotland's contribution to a range of Scottish Government policy. Attention will be paid to a number of key areas:

- HIV Scotland's contribution to the development of an HIV Action Plan in Scotland; published November 25th 2009.
- HIV Scotland's contribution to policy development in the area of sexual health and wellbeing including the development of a national strategy for Scotland published in 2005 as 'Respect and Responsibility: Strategy and Action Plan for Improving Sexual Health'.
- Contributors also discuss HIV Scotland's contribution to overarching Scottish Government policy aims to reduce the number of people in Scotland with HIV and more generally improve health outcomes of the target group.

HIV Scotland and its role in policy development

6.2 Across contributions stakeholders identify the role of HIV Scotland in policy development and ensuring the recognition of HIV as an issue in Scotland.

- "The organisation ensures that HIV is recognised and resourced within the Scottish context". (Stakeholder)
- "HIV Scotland contributed greatly to both Respect and Responsibility and the HIV Action Plan". (Stakeholder)
- "I think the organisation is strong in respect of working with Government and making sure the right players are kept informed. HIV Scotland makes a strong contribution to the development of policy and should be commended for keeping HIV on the agenda". (Stakeholder)

HIV Scotland and the development of an HIV Action Plan in Scotland

6.3 The resourcing by Government of a national HIV organisation is seen by external stakeholders and HIV Scotland Board and staff as a strong commitment to continuously improving policy and supporting the HIV sector. Stakeholders also recognise that HIV Scotland's work over many years has contributed to raising knowledge and awareness amongst many agencies about HIV and its impact in Scotland; thus informing current debates and developments.

6.4 Stakeholders have a range of views on HIV Scotland's contribution to the development of the HIV Action Plan. This is informed by their own engagement in the process, in other words agency representatives who themselves have been part of meetings, consultations or events are aware of HIV Scotland's contributions. Those contributors who have not been personally or actively engaged are less aware of HIV Scotland's contributions and indeed feel distanced from the development of the HIV Action Plan in general.

6.5 Stakeholders who report positive views on HIV Scotland's contributions comment on the involvement of HIV Scotland staff. HIV Scotland's Chief Executive is identified

by contributors as being particularly well informed, measured and where appropriate challenging. HIV Scotland contributions are often described as bringing discussion back to the needs, best interests and rights of individuals living with HIV.

6.6 Some stakeholders from the voluntary sector report being dissatisfied with the efforts HIV Scotland has made to engage them and communicate their concerns about a lack of focus on actions relating to prevention in earlier drafts of the emerging HIV Action Plan. For some voluntary stakeholders the agency has focused too much time and resource on national policy work. One stakeholder commented:

- “HIV Scotland is too caught up in strategy and has forgotten to support organisations that have day-to-day issues. Community-based agencies and services have closed. This doesn’t look good”. (Stakeholder)

6.7 There are concerns amongst stakeholders about how the HIV Action Plan will influence and inform what is delivered *to individuals*. There are concerns that Scotland’s response to HIV is structured by health sector clinical silos (HIV as a sexual health *or* as a blood borne virus issue) or struggles over competition for resources or influence. Some hope has been expressed that HIV Scotland will take up a role of ensuring that policy commitments are translated into practice and that implementation can be monitored from the perspective of the benefits the plan brings to people living with HIV.

HIV Scotland and treatment and care needs assessment for people living with HIV

6.8 In 2006 the Chief Medical Officer for Scotland asked the Scottish Public Health Network to undertake a needs assessment to inform discussion and development of effective care and treatment for people living with HIV. HIV Scotland’s Chief Executive Officer was a member of the 10 member Project Group for this study. The report on this process is to be published alongside the HIV Action Plan in Scotland.

6.9 As a member HIV Scotland also established and facilitated a group of people living with HIV to discuss and feedback views on emerging findings from the needs assessment process.

6.10 While recognising the quality and evidence base which underpins current treatment and care services in Scotland further improvements are recommended by the report in the light of increased demand. These improvements include some key areas of interest for HIV Scotland which include better approaches to patient and wider public involvement; more holistic and integrated approaches to care and treatment with smooth care pathways for individuals living with HIV; good understanding of the importance and practice of confidentiality; and improved CPD for professional staff.

6.11 Finally the Project Group identifies the importance of the role of the voluntary sector and recommends that:

- At national and NHS Board level support for voluntary and community sector provision, cross-sectoral collaboration and joint working should be made;

- There should be improved collaboration between NHS staff and the voluntary sector which incorporates capacity building through joint training;
- All people living with HIV should have access, both directly and via HIV treatment and care services, to voluntary sector provision.

6.12 As part of its work on the national needs assessment, HIV Scotland has advocated successfully for standards in HIV prevention, diagnosis, treatment and care in Scotland, and is engaged with other bodies in working with NHS QIS in developing these over the next two year period, involving voluntary sector and people living with HIV as well as statutory sector partners.

HIV Scotland and ‘Respect and Responsibility: Strategy and Action Plan for Improving Sexual Health’

6.13 The contributions of HIV Scotland staff to working groups and debates in the process leading up to publication in 2005 are recognised and valued by other partners in the process. HIV Scotland’s Chief Executive played a role in both the main Reference Group for developments and in two sub groups looking at the needs of gay/bisexual/MSM and at HIV health promotion issues.

6.14 Across many contributions from stakeholders positive views about the engagement of HIV Scotland in the development of ‘Respect and Responsibility’ are tempered by disappointments that the national strategy does not respond adequately to meeting the challenges which HIV presents in Scotland. Stakeholders also identify that, in turn, the current HIV Action Plan developments do not reflect enough on links back to Respect and Responsibility.

6.15 HIV Scotland is represented on the National Sexual Health and HIV Advisory Committee (NSHHAC) which provides expert advice to Scottish Government and acts as a forum for developing policy and monitoring the implementation of Respect and Responsibility.

The effectiveness of HIV Scotland’s interventions in terms of reducing the number of people in Scotland with HIV and more generally health outcomes of the target group

6.16 In their contributions to this Review stakeholders stress the importance of a co-ordinated response to addressing HIV issues in Scotland and acknowledge the difficulties in quantifying the effectiveness of a single organisation such as HIV Scotland, particularly as it is not involved in direct service delivery.

6.17 HIV Scotland staff and external stakeholders agree that reducing the numbers of people with HIV is a key and complex challenge; in the short term stakeholders and HIV Scotland contributors agree that undiagnosed infections are falling because of cross-sector and multi-agency efforts to promote testing and reduce stigma.

6.18 HIV Scotland staff are hopeful that the HIV Action Plan in Scotland is a good starting point for improving how services for people living with HIV are delivered but staff identify some way to go in ensuring that services responding to other health

issues, for example cardiology or renal health or other communicable diseases, are also HIV aware and HIV positive-people 'friendly'.

6.19 HIV Scotland Board and staff raise a number of challenges which face policy makers and service providers; these include understanding the individual psychological, social and cultural responses which positive people have to their status, and the personalised responses they require from services providing treatment and care. The agency is keen to support partners to recognise the heterogeneous nature of the population and to bring evidence to stakeholders about a range of issues including mental and emotional wellbeing as well as behaviours in relation to areas such as managing treatment regimens.

6.20 HIV Scotland staff are keen to stress that no one thing can be done by one agency which in itself will assure reduced transmission and improved health outcomes. Staff interviewees stress HIV Scotland's commitment to a comprehensive, combined approach and a desire to create collaborative approaches to meet the challenges of HIV. As an example of the contribution the agency makes staff pointed to HIV Scotland's support for research, conferences and events and support for social marketing campaigns targeting gay and bisexual men on issues relating to HIV testing. (These have been described in more detail in chapter 3).

6.21 Stakeholders identify specific aspects of HIV Scotland's work often done in partnership with others that they consider of value in terms of work on prevention and on improving the health of those living with HIV.

- The Connected website and resource is seen as an important resource for those diagnosed with HIV as it responds to a need for high quality information post-diagnosis.
- HIV Scotland's contribution in NHS Lothian to the HIV Comeback Tour (a social marketing and peer education initiative for gay/bisexual/MSM) is described as excellent.
- The Healthy Gay Scotland Cocktales resource, produced in partnership with other agencies, is identified as being of high quality, focussing on HIV awareness and prevention for young gay/bisexual men.
- HIV Scotland's e-newsletter is identified as an important source of relevant and up to date information which informs the activities of other agencies concerned with prevention and health improvement. The mailing list for this newsletter has been 450 recipients. It is identified however that these are now less frequent with 1 edition in 2009.
- HIV Scotland's work on challenging stigma and discrimination is identified as central to Scotland's ability to improve efforts regarding prevention, treatment and care.
- HIV Scotland's identification of the needs of African communities in Scotland and efforts to build awareness and creative partnerships with those communities as well as with service providers and policy teams is identified as an important contribution to efforts to enhance prevention, promote testing and improve access to services.

6.22 Stakeholders identify that HIV Scotland works most effectively on its contribution to reducing the number of people in Scotland with HIV and improving

health outcomes when it is operating with a full staff team, when it is proactively identifying needs and interests, when it responds by bringing concerned people together, and when it provides support and resource to allow the development of new initiatives or resources.

6.23 Within HIV Scotland, Board and staff identify a number of work areas in which the agency could usefully increase activity to help reduce the number of people in Scotland with HIV and improve health outcomes:

- Lead and further galvanise efforts to promote an interest in and commitment to work on prevention.
- Encourage good needs assessment.
- Create opportunities for commissioners and senior managers to come together to discuss the challenges faced in improving Scotland's response to prevention, treatment and care.
- Shape the debate; create opportunities face-to-face and on-line where difficult and complex issues can be discussed.
- Create more ways to bring evidence and epidemiology to inform thinking and action with regard to both policy and services related to HIV issues.
- Support voluntary sector providers to evaluate practice, disseminate findings and promote learning.

Summary

6.24 This chapter has considered HIV Scotland's contribution to a range of Scottish Government policy.

6.25 The resourcing by Government of a national HIV organisation is seen by external stakeholders and HIV Scotland Board and staff as a strong commitment to continuously improving policy and supporting the HIV sector. Stakeholders also recognise that HIV Scotland's work over many years has contributed to raising knowledge and awareness amongst many agencies about HIV and its impact in Scotland; thus informing current debates and developments.

6.26 Agency contributions to the emerging HIV Action Plan in Scotland have been a significant area of work. HIV Scotland's Chief Executive is identified by contributors as being particularly well informed, measured and where appropriate challenging. Some voluntary sector stakeholders however report dissatisfaction with the efforts HIV Scotland has made to engage them and communicate their concerns.

6.27 HIV Scotland, via the Chief Executive officer has been integral to the Scottish Public Health Network treatment and care needs assessment for people living with HIV. The findings of the process include an identification of the role of the voluntary sector in these key areas.

6.28 The agency was involved in the development of Scotland's sexual health strategy 'Respect and Responsibility'. HIV Scotland's Chief Executive played a role in both the main Reference Group for developments and in two sub groups looking at the needs of gay/bisexual/MSM and at HIV health promotion issues.

6.29 In relation to HIV Scotland's contribution to reducing the number of people in Scotland with HIV and improving health outcomes the agency identifies that no one thing can be done by one agency which in itself will assure reduced transmission and improved health outcomes, however the agency and external stakeholders have identified a number of HIV Scotland areas of activity which, often through partnership work, contribute positively in this area.

7. HIV SCOTLAND: STRENGTHS AND WEAKNESSES

Key points summary

HIV Scotland has strengths in relation to:

- Knowledge, awareness and understanding of HIV issues in Scotland spanning the areas of prevention, treatment and care. The agency is strong on accessing and utilising research and evidence from a range of sources.
- The agency has established a constant presence on the HIV scene in Scotland; particularly in relation to its work with communities most at risk and disproportionately affected by HIV.
- HIV Scotland has a strong connection to Scottish Government policy-making and is well positioned to influence the policy making process.
- Recent work on needs assessment for NHS Forth Valley models an approach to an area of work that will be beneficial to partner agencies.
- The agency has a particular interest and commitment to action on prevention.
- The agency has been involved in initiating and supporting development of resources and has had some success at representing and advocating on behalf of the HIV sector and people living with HIV.

The agency needs to address its work in these areas of weakness:

- HIV Scotland needs to widen its policy reach or areas of interest. The agency should be proactive and seek to be *the* policy hub for HIV in Scotland.
- Being close to Government, and being funded by Government, means the agency needs to clarify and maintain its independence.
- In terms of HGS projects HIV Scotland needs to address which initiatives have lost purpose or momentum and which are best done by other partner agencies more connected to service delivery.
- Whilst responding to the epidemiology of HIV the agency should re-focus some attention and resource beyond gay/bisexual men and African communities to other at risk groups and communities.
- The agency needs to improve relationships and dialogue with key voluntary sector service providers.
- Stakeholders identify a crucial role for a national representative HIV agency in monitoring and engaging with the delivery of the HIV Action Plan in Scotland; but worry that a poorly connected HIV Scotland cannot fulfil such a role effectively.
- There are concerns about HIV Scotland's current level of activity and profile. It is accepted that part of the problem may be staff changes and vacancies but there are concerns that the agency has lost direction in terms of looking to its constituency and communicating effectively with it.
- It is hoped that HIV Scotland, particularly in the context of the HIV Action Plan will be active *nationally*.
- In broad terms the agency needs to re-build the staff team and increase capacity to respond to the interests and demands of the HIV sector.
- Staff management systems within the agency need to be improved.
- HIV Scotland is viewed as being weak on communication with its potential constituency of agencies, professionals and people living with HIV.

Introduction

7.1 This chapter reflects on HIV Scotland's strengths and weaknesses. This section of the report is informed by contributions from HIV Scotland Board and staff, by an examination of reports and publications provided by the agency, and by contributions from stakeholders via interviews and responses to on-line surveys. Where there are strengths and weaknesses they are considered under the following headings:

- Understanding HIV issues in Scotland
- Leadership in policy and strategic development
- Focusing on communities most at risk and disproportionately affected by HIV
- Representing the voluntary sector's response to the epidemic
- Developing capacity, activity and resources
- Advocating for HIV issues in Scotland and building strategic partnerships
- Building capacity and coordinating networks within the Scottish HIV sector
- Resourcing the HIV sector
- Management and organisation systems
- Dissemination and communication strategy

Key strengths

7.2 Contributors to the Review identify agency strengths as follows:

Understanding HIV issues in Scotland

7.3 Stakeholders recognise that HIV Scotland has an excellent knowledge, awareness and understanding of HIV issues. This spans the areas of prevention, treatment and care. HIV Scotland staff also recognise their strength in this area. The HIV Scotland staff team are informed and strong on accessing and utilising research and evidence from a range of sources.

7.4 For some stakeholders HIV Scotland is a first port of call for questions, enquiries or dilemmas inherent in work on HIV issues.

7.5 Staff identify limited success in relation to bringing people and agencies together to better utilise evidence and epidemiology to promote more complex and challenging discussion and debate.

7.6 One stakeholder described HIV Scotland as: "...like having an 'engine room' of learned people to maintain HIV on the agenda in ways which can be heard by policy makers and strategic bodies".

Leadership in policy and strategic development

7.7 The agency and its staff, both current and past team members, are clearly committed to the development of good policy and the development and maintenance of the best efforts regarding prevention, treatment and care. HIV Scotland has a strong connection to Scottish Government policy making and is well positioned to

influence the policy making process. Links with the Scottish Parliament, MSPs and staff are also good.

7.8 The agency's history of promoting effective work on prevention is valued and seen as increasingly crucial in debates about resourcing this area of work alongside treatment and care.

7.9 Recent work on needs assessment for NHS Forth Valley models an approach to an area of work that will be beneficial to partner agencies.

7.10 The agency has integrity; it is capable of being honest and challenging in its relationships with partners.

Focusing on communities most at risk and disproportionately affected by HIV

7.11 The agency is viewed positively as a constant presence on the HIV scene in Scotland. HIV Scotland has worked hard over many years to promote awareness and understanding of the needs, best interests, and rights of individuals and communities most affected by HIV in Scotland. HIV Scotland's project work, delivered by HGS and AMEHP, locates the agency in these target communities.

7.12 AMEHP is central in bringing awareness and opportunities to locate HIV issues in a broader health and wellbeing community context to African communities where there had been little recognition or success before. In turn community members are now better connected to opportunities to influence and inform policy and services.

7.13 The condoms by post scheme is valued by its users and recognised by stakeholders as an essential service for isolated or vulnerable men.

7.14 HIV Scotland's focus on stigma is welcome.

Developing capacity, activity and resources

7.15 HIV Scotland is a catalyst and mechanism by which excellent initiatives and resources have been developed. HIV Scotland's work to date on training, and specifically its draft Training programme, highlights a key area of work which with further development could build capacity across the HIV sector to respond to a range of HIV issues. Whilst recognising that the sector is smaller than it once was the agency has ensured in the past that smaller voluntary sector agencies have a voice in debates and developments.

Advocating for HIV issues in Scotland and building strategic partnerships

7.16 The agency makes claim to be an independent voice for HIV in Scotland. Whilst stakeholders identify the need to re-connect with a membership base this independence from both Government and the interests of any particular agency is fundamental to the operation and success of the organisation. One stakeholder identified this strength as follows:

- “As a ‘non service delivery’ agency it is easier to separate out agency agendas from sector agendas and therefore be an effective lobbying and campaigning organisation”. (Stakeholder)

7.17 Although limited in scope the agency has been good at engaging with positive people and connecting them to policy makers or others seeking to develop understanding or services which will benefit the HIV positive population.

Resourcing the HIV sector

7.18 Stakeholders recognise that when the agency is asked for specific information or advice the response is trusted as informed and detailed. Staff are available and will respond to requests for information and help. The agency acts as a useful first point of contact for those outside Scotland seeking information about HIV issues in Scotland.

Weaknesses

7.19 Contributors to the Review identify a number of agency weaknesses.

Leadership in policy and strategic development

7.20 Some stakeholders report that HIV Scotland’s work can be overly reactive, responding mainly to requests or Government agendas, rather than proactive and innovative. Stakeholders express a desire to see HIV Scotland filling a role as *the* policy hub for HIV in Scotland, prompting and provoking reflection and consideration of where Scotland should be in response to HIV; recognising that there is some way to go.

7.21 HIV Scotland is perceived by some as too close to Scottish Government, raising questions about the agency’s ability and interest in challenging the Government and statutory sector. One specific example for several stakeholders is a concern about challenging the medical or clinical models framing, defining or dominating responses to the epidemic. Some stakeholders raise the question: can an HIV Scotland funded by Government remain independent and effectively challenge convention?

7.22 Some stakeholders see a need for HIV Scotland to extend its policy reach and interest to give more attention to issues such as housing, benefits, local authority care services. Effectiveness in this area requires better partnerships.

Focusing on communities most at risk and disproportionately affected by HIV

7.23 Whilst recognising the importance of focusing work on those most at risk and disproportionately affected by HIV the relevance and necessity to organise these responses within the agency as projects (HGS and AMEHP) is disputed.

7.24 In terms of HGS the agency needs to address which initiatives have lost purpose or momentum and which are best done by other partner agencies more connected to service delivery.

7.25 There is a perception amongst stakeholders that HIV Scotland has focused in recent times on national policy and strategy and has not focused enough on highlighting and bringing together partnerships to respond to the needs of individuals living with HIV.

Representing the voluntary sector's response to the epidemic

7.26 Concerns about the quality and nature of partnerships between HIV Scotland and voluntary sector agencies with a focus on HIV issues are seen as undermining the potential HIV Scotland has in terms of understanding and then representing the experiences, views and needs of people living with HIV.

7.27 Key service providers in the HIV sector identify a crucial role for a national representative HIV agency in monitoring and engaging with the delivery of the HIV Action Plan in Scotland; but worry that a poorly connected HIV Scotland cannot fulfil such a role effectively.

Developing capacity, activity and resources

7.28 In terms of developing or providing information, promotional materials, websites and campaigns there are concerns amongst stakeholders in the voluntary sector that with poor communication there is a risk of not identifying or meeting current needs, or of duplication of effort.

7.29 Links and work with UK wide bodies could be enhanced, resulting in better liaison around resource development and dissemination.

Advocating for HIV issues in Scotland and building strategic partnerships

7.30 Within the agency there is recognition that partnerships have not been *strategic*. One staff member commented: "We don't have formal relationships. Specific pieces of work might have terms of reference but it all feels quite disparate".

7.31 There are concerns about HIV Scotland's current level of activity and profile. It is accepted that part of the problem may be staff changes and vacancies but there are concerns that the agency has lost direction in terms of looking to its constituency and communicating effectively with it. One stakeholder commented:

- "My overall impression is that the organisations profile has declined recently. I am not as aware of HIV Scotland's activities or presence as I was two or three years ago" (Stakeholder)

7.32 In 2006 HIV Scotland bid in partnership with another organisation for delivery of a service being commissioned by an NHS Board. Whilst unsuccessful this is viewed as problematic by some stakeholders as it suggests that HIV Scotland might be a competitor in terms of service provision. One stakeholder commented:

- "I was surprised to see HIV Scotland submit a tender for work at a local level. To me this was unexpected and did not reflect the national role of the organisation".

7.33 Stakeholders agree that HIV Scotland's role as a membership, umbrella or representative organisation is incompatible with engagement in service delivery.

7.34 A lack of networking activity and doubts as to whether HIV Scotland can lead the HIV sector in cooperative and inclusive ways is identified as undermining any efforts or intentions the agency might have regarding advocacy.

7.35 The agency has not addressed enough how the needs, experience and voice of people living with HIV are meaningfully brought to the policy making and service improvement agenda.

Building capacity and coordinating networks within the Scottish HIV sector

7.36 Stakeholders identify that in recent times HIV Scotland has been poor at providing opportunities for the HIV sector to interface with each other, whether that is face-to-face or virtually through the on-line portal which HIV Scotland could provide. One stakeholder commented:

- "I think that the changing environment has made networking and collaborative working a high priority for the sector and I would like to see HIV Scotland facilitating some of the conversations that might usefully happen"
(Stakeholder)

7.37 With a lack of national and regional coordination and identity some stakeholders report that there is a diminishing sense then that there is an 'HIV sector'. Without a sense of belonging there are concerns that it is difficult to collectively argue for the best prevention, treatment and care responses to HIV in Scotland.

7.38 There are concerns amongst some voluntary sector stakeholders that HIV Scotland has shifted its approach to partnership work; from an innovator and collaborator, to a manager and owner of what were perceived of as joint projects. As a result it is felt that some projects, particularly work related to HGS have become stuck. Partners in these projects feel undervalued and that there is a lack of trust. The external view is that a lack of staff capacity within HIV Scotland means these projects have lost energy, activity is slow and resources are losing currency. Describing difficulties with one particular partnership initiative one stakeholder commented:

- "The 'Connected' website was a strong resource but I was disappointed in terms of how it was managed after its launch. There seemed to be a lack of momentum and it effectively came to a halt. I am reluctant to promote the resource to newly diagnosed people as they need continuity and a resource that will be effectively managed and maintained at a high standard".
(Stakeholder)

7.39 Stakeholders identify a need for HIV Scotland to provide networking support and opportunities which are both regional and national; ensuring that those working and living with HIV in all parts of Scotland have their experiences and perspectives heard.

7.40 HIV Scotland on-line does not yet provide the virtual network it has the potential to deliver.

Resourcing the HIV sector

7.41 There are concerns that HIV Scotland has not given enough priority to work with NHS Boards, service providers or positive people out with areas which have to date been well served and have a long history of highly visible work on HIV/AIDS. Whilst recognising that the bulk of infections and diagnoses occur in the Lothians, Greater Glasgow and Clyde and other main cities it is hoped nonetheless that HIV Scotland, particularly in the context of the HIV Action Plan will be active *nationally*. One stakeholder expressed concerns as follows:

- “In Lothian and Glasgow HIV prevention and treatment is well established. There are obviously large gaps in provision elsewhere in Scotland, areas where MSM are at greater risk and face more stigmas. Perhaps HIV Scotland’s emphasis and time should be invested in these areas where efforts are most needed”. (Stakeholder)

7.42 HIV Scotland needs to do more to define what is meant by the ‘HIV sector’. The assumption is that this has, in the past, meant the community-based voluntary sector but now needs to address and include statutory sector work and those projects, initiatives or commissioned services which bring together voluntary and statutory sector providers. One stakeholder commented:

- “The agency needs to be objective in its approach to partnerships and to develop them with a view to growing the sector as a whole and benefiting people living with HIV in Scotland”. (Stakeholder)

Management and organisation systems

7.43 HIV Scotland Board members report a lack of knowledge about agency activity and ineffective reporting to them. Relationships between Board and Chief Executive are poor. Internal systems for staff management, support and supervision are not in place.

7.44 Some stakeholders report confusion about the relationship between HIV Scotland and the national health improvement projects it hosts HGS and AMEHP. In particular HGS has been perceived of as operating like an independent agency.

Dissemination and communication strategy

7.45 HIV Scotland Board and staff identify that the agency is not doing enough to promote and brand some of its work as HIV Scotland activity. While the agency should avoid notions of ownership of what is partnership work it could do more to communicate its contributions and achievements.

7.46 HIV Scotland is viewed as being weak on communication with its potential constituency of agencies, individual professionals and people living with and affected by HIV.

7.47 External stakeholders identify that HIV Scotland's website requires attention. It is suggested that the website contains a lack of useful factual information, advice and support for those affected by HIV. It is acknowledged that the website does signpost to other websites where high quality, relevant information regarding HIV can be obtained but, it is suggested that the website's credibility would improve with the provision of a broader range of concise advice and information.

Value for money

7.48 One of the purposes of the Review was to explore HIV Scotland's performance in providing value for money in relation to the funding made available by the Scottish Government. One staff member identified early in the Review process that "This Review needs to help the organisation find its place of maximum value: we haven't got there yet".

7.49 Undoubtedly the Board and staff team have struggled in the past year to 18 months to deliver on aims and activities Both Board and staff team have been coping with a number of vacancies, the agency has been less successful at delivering innovative work and relationships with some partners have deteriorated.

7.50 However a key strength of HIV Scotland is in its depth of knowledge and connection to the history of Scotland's policy and service response to HIV. The agency has shown its value and importance in the context of the development of an HIV Action Plan in Scotland.

7.51 The Review team concludes that it would be unfair and unhelpful to judge HIV Scotland's work based solely on the current difficulties it is experiencing, although they undoubtedly require to be addressed. HIV Scotland Board and staff are aware of the problems and understand that in order to reclaim and retain the confidence of partners and funders they must build on strengths and address the weaknesses identified here. In short the agency must ensure that following acceptance of the recommendations of this Review the quality of their relationships must improve, good governance must be assured and work programmes must clearly evidence a continued role and significance for the agency in informing, supporting and representing the HIV sector.

Summary

7.52 This chapter has considered agency strengths and weaknesses.

7.53 Strengths include an excellent knowledge, awareness and understanding of HIV issues in Scotland spanning the areas of prevention, treatment and care. The agency has a particular interest and commitment to action on prevention. The agency has established a constant presence on the HIV scene in Scotland; particularly in relation to its work with communities most at risk and disproportionately affected by HIV. The agency has been involved in initiating and

supporting development of resources and has had some success at representing and advocating on behalf of the HIV sector and people living with HIV.

7.54 Areas which could be improved upon include widening the policy reach or areas of interest which the agency has. In terms of HGS projects HIV Scotland needs to address which initiatives have lost purpose or momentum and which are best done by other partner agencies more connected to service delivery. The agency needs to improve relationships and dialogue with key voluntary sector service providers. In broad terms the agency needs to re-build the staff team and increase capacity to respond to the interests and demands of the HIV sector.

7.55 These issues are considered further in the final chapter where recommendations are made for the future of HIV Scotland.

8. RECOMMENDATIONS ON THE FUTURE OF HIV SCOTLAND

Key points summary

- The recommendations should be seen in the context of material presented in earlier chapters.
- Sixteen recommendations are made under the following headings:
 1. Maintain a focus on HIV
 2. Ensure a national perspective
 3. Help create policy and services which reflect the human rights and promote the human dignity of people living with HIV
 4. Ensure effective governance
 5. Re-build the staff team
 6. Re-build HIV Scotland as a membership organisation
 7. Communicate effectively with the membership
 8. Focus on policy, knowledge and advocacy/representation
 9. Support and help rebuild the HIV sector from the bottom up
 10. Support the HIV sector on-line
 11. Maintain a focus on prevention
 12. Maintain an interest in the voluntary sector
 13. Recognise those most at risk but avoid work in silos
 14. Represent and advocate on behalf of the HIV sector
 15. Support delivery of the HIV Action Plan
 16. Write a business plan

Introduction

8.1 In this final chapter of the Review report we make recommendations on the future direction of HIV Scotland. These recommendations should be seen in the context of the material presented in earlier chapters.

8.2 A key strength of HIV Scotland has been its presence on the scene across a period when HIV continues to impact on the lives of many people. The agency's work to help focus attention and effective responses, particularly in terms of communities most at risk has been invaluable. It's involvement in development of the HIV Action Plan in Scotland has been detailed and informative. In recent times the agency has struggled to maintain momentum and partnerships. In order to re-invigorate the agency's work there are a range of issues which must be addressed. Recommendations follow which aim to support the agency fulfil its claim to be the independent voice for HIV in Scotland.

Recommendation 1: Maintain a focus on HIV

8.3 The increase in transmission of HIV in Scotland, a growing population of people living with HIV and improved recognition of the challenges faced by them confirms the need for a national HIV membership based agency which supports and resources the HIV sector. The implementation of the HIV Action Plan in Scotland

underscores the need for such an agency. To ensure its relevance and clarity of purpose HIV Scotland must maintain its focus on HIV.

Recommendation 2: Ensure a national perspective

8.4 HIV is present across Scotland. In some urban/central belt areas policy and service responses have been developed as a reaction to a visible HIV positive population. However there are individuals and communities across Scotland who need to see improvements in prevention, treatment and care. It can also be claimed that major service providers operating in areas with relatively small numbers of people living with HIV have not adequately considered the needs of local people living with HIV. In this context HIV Scotland must respond by ensuring it has, and is seen to have, a national perspective.

Recommendation 3: Help create policy and services which reflect the human rights and promote the human dignity of people living with HIV

8.5 Individual contributors to this Review who have personal experiences of services have highlighted many professional practices which are exemplary but others which are disrespectful or indicative of ignorance. HIV Scotland's work should continue to be based on an explicit commitment to the rights and entitlements of people living with HIV. Whilst this sits comfortably alongside common notions of social justice and fairness which underpin much Scottish Government policy and the ethos of the voluntary sector it is nevertheless important to place values and principles at the heart of what the agency does, to articulate and express these clearly and often, and to use these as a basis for all activity.

Recommendation 4: Ensure effective governance

8.6 A priority for the agency is to address issues of governance. The Review recommends that changes are made to current arrangements to allow the Board to be more reflective of the HIV sector as well as increase its capacity to fulfil necessary functions. The Board needs to be made up of 14 people who bring knowledge, experience and a commitment to re-shape and genuinely steer the agency.

8.7 The Board should therefore have a member who comes from each of the following agencies who have a key role in the HIV sector. They might be a senior staff member or a Board member but should come from:

- National AIDS Trust
- Gay Men's Health
- Waverley Care
- Terrence Higgins Trust
- HIV/AIDS Carers and Family Service Providers
- LGBT Youth Scotland

8.8 Representing the statutory sector there should be:

- 3 members from NHS Boards (at least 2 of which should be territorial Health Boards)

8.9 It is important to recognise that while Board members will be sourced from particular agencies, and they should be people who know the HIV sector well and can bring an in-depth knowledge of their own agency, once they are members of the HIV Scotland Board their responsibilities lie in the area of steering *this* organisation and having the future of HIV Scotland as their core and shared task.

8.10 To move on to other members: meeting needs in terms of a skills base there should be at least one further Board member with skills/knowledge in each of the areas of:

- Human Resources/Personnel management
- Communications
- Finance
- Research
- HIV as a global/international issue

8.11 Finally, in addition to the 14 member Board it is recommended that the position of Chair should be advertised as a 2 day per month, unpaid commitment, seeking an individual who brings expertise in organisational management. While it would be advantageous if this person had a good knowledge of the voluntary sector and HIV issues this should not be essential.

8.12 The current Board and senior management must work with the short-term Change Manager and advisors to the Board (providing legal and financial guidance) to make these changes happen. Significant effort will be required to ensure the voluntary sector agencies named see the purpose of their membership and have confidence that engagement at this level will see results which respond to the criticisms they have made in the course of this Review and then, in time, benefit the HIV sector.

8.13 It is likely that a new Board for HIV Scotland will need to meet monthly in the first year. Board members should be clear that in their first 12 months in post a commitment of a minimum of a half day per month may be required.

8.14 The purpose of seeking to appoint a Chairperson who brings organisational management skills, and who can provide a significant amount of time, is in recognition of the amount of work and change to practices which are required by the agency. Recruitment of this person should be managed by an external HR company and selected by a small independent group of people who understand HIV Scotland's needs.

8.15 On appointment, Board members themselves will be supported by the Chair. The Chair should also have direct and regular contact with senior staff to ensure that they are clear about the intent and expectations of the Board.

Recommendation 5: Re-build the staff team

8.16 The skills, expertise and commitment of existing HIV Scotland staff must be considered alongside the needs of the agency as it seeks to reconnect with the HIV sector and make the most of the new context which the HIV Action Plan brings.

8.17 There is a job to be done in bringing new staff members on board to increase capacity but also to re-build confidence in, and the confidence of, the current staff team.

8.18 The fixed-term Change Manager should work with existing staff to ascertain where they see their strengths and interests and how they would like to see their role in a new phase of work for HIV Scotland.

8.19 The agency must establish staff support and supervision and annual appraisal and ensure that other systems such as diaries, timekeeping, record of sickness and leave etc work well.

8.20 The Change Manager should be in a position during their tenure to make proposals to a new HIV Scotland Board on a future staffing structure for HIV Scotland. Once agreed any new posts should be advertised. A key task is to match the staffing resource of the agency with an emerging work plan; ensuring that all posts reflect what the agency wants to do rather than what has been done in the past.

Recommendation 6: Re-build HIV Scotland as a membership organisation

8.21 The relevance and legitimacy of HIV Scotland lies not just in its expert knowledge of HIV issues but in its live and vibrant connection to agencies and individuals with an interest in HIV issues. A new HIV Scotland Board should be clear that there is an urgency required in terms of building a membership base that inform HIV Scotland's activities but are also informed by them.

8.22 Current arrangements allow for ordinary members (who must be voluntary or self help bodies working in the field of HIV and who can vote at an AGM) and associate members (who can be other individuals but who do not have a vote). The new Board should consider whether this remains a relevant and useful distinction in terms of a wider understanding of what the HIV sector is (in particular the need to consider statutory sector colleagues and agencies) and whether it engages adequately with individual HIV positive people.

8.23 Once established the membership needs nurtured and managed. This will require staff time and commitment but also creative approaches to engagement whether they be face-to-face or virtual. Board and staff should take some time to explore how other networks and membership systems work and find best practice which can be adopted.

Recommendation 7: Communicate effectively with the membership

8.24 Having rebuilt a membership base and trust with its constituents HIV Scotland must communicate effectively with them. The HIV Scotland website will be a tool for this work. A website cannot be all things to all people but the agency faces a challenge in that its constituency will be professionals (who themselves will have a range of confidence, understanding and roles) as well as positive people and their partners and families.

8.25 HIV Scotland needs to recognise what other service delivery agencies do well and signpost to them where appropriate, but it also needs to look at what would be unique and relevant for it to engage in on-line. It is reasonable to assume that when an individual or agency in Scotland has a question, worry or interest in HIV in Scotland that this agency's website is the first they find. But then what? Resources from the Monument Trust have allowed the agency to look at current difficulties with its on-line work but much of this has been about technical problems and addressing difficulties inherited from poor consideration of how several projects have utilised the web. The agency still needs to address the question of how to have a minimal, relevant, engaging and constantly updated web presence.

8.26 Other national bodies and initiatives have developed on-line networks which produce and disseminate regular e-updates with a mix of news, events and developments in the field. These need to be regular, informative, relevant and journalistic in style. As HIV Scotland rebuilds its membership it needs to commit time and resource to this area of work.

Recommendation 8: Focus on policy, knowledge and advocacy/representation

8.27 Across contributions to the Review there has been recognition of HIV Scotland's strengths in relation to policy and knowledge of HIV issues. Advocacy/representation is seen as essential but more problematic for HIV Scotland to date. (This is considered further below). These 3 areas should form the core of agency activity. The agency should not be involved in service delivery.

8.28 One area of activity, the *Condoms by Post* scheme, needs to be looked at and decisions made by the new Board about whether its provision is a relevant, perhaps unique example of what HIV Scotland can do for a vulnerable or marginalised group, or whether it should be seen as service provision and managed elsewhere.

Recommendation 9: Support and help rebuild the HIV sector from the bottom up

8.29 Some stakeholders express concerns that HIV Scotland is overly focused on national policy and strategy whilst there is a diminishing voluntary or community-based sector which lacks real support. While HIV Scotland cannot create new community provision it needs to commit some resource to fostering and supporting it where it exists. On occasion choices will need to be made; for example questioning the resource required to attend international conferences or to support international work when Scottish community based agencies or isolated individuals would benefit from support. HIV Scotland should therefore consider its community development

role and work with service delivery partners (both voluntary and statutory sector) to support them to respond to the needs which the agency identifies.

Recommendation 10: Support the HIV sector on-line

8.30 As highlighted elsewhere several HIV Scotland supported projects have on-line elements which have been problematic. Improved IT competence within HIV Scotland has meant that these difficulties are being addressed. While it is expected HIV Scotland will draw back from day-to-day management of some of these projects it would be useful and relevant for the agency to consider how it might retain an IT capacity so that support can be given to partners/members to support their on-line work.

Recommendation 11: Maintain a focus on prevention

8.31 Whilst being interested in a more integrated and comprehensive policy and service response to HIV covering prevention, treatment and care HIV Scotland should ensure a Scotland wide focus on prevention.

8.32 HIV Scotland has a long term interest in HIV prevention, an interest shared in particular by voluntary sector agencies. There are concerns amongst some stakeholders who have contributed to this Review that HIV prevention lacks profile and support in the context of an emerging HIV Action Plan. In response to this concern HIV Scotland should continue a keen interest in HIV prevention.

Recommendation 12: Maintain an interest in the voluntary sector

8.33 The nature of the *HIV sector* has already been discussed in the report; with recognition that the sector is now a mix of both voluntary and statutory sector elements, often integrated through shared work and contractual arrangements. The Review recommends that HIV Scotland continues to work across the HIV sector in the best interests of people living with HIV, but that the agency retains a particular interest in the voluntary sectors response to the epidemic, ensuring that in its activities HIV Scotland supports the sector and builds capacity to respond effectively and creatively to HIV in Scotland.

Recommendation 13: Recognise those most at risk but avoid work in silos

8.34 Scotland's response to HIV must continue to follow the epidemiology and it is right for HIV Scotland to continue to put efforts into responding to the impact of HIV on gay/bisexual/men who have sex with men and African communities. However the perception amongst some stakeholders is that this has sometimes meant that work with other groups and communities has been neglected.

8.35 In its emerging work plan HIV Scotland should make explicit commitments to at risk groups and communities but also recognise that work will also be undertaken with others also impacted upon by HIV.

8.36 The Review recommends that the agency no longer structures its work with gay/bisexual/MSM and African communities as the HGS and AMEHP projects, each

with fixed budgets and staff but instead integrates work with and for these communities into a full HIV Scotland work plan. To be clear, a great deal of the focus of HIV Scotland may well remain with these identifiable communities, but an agency-wide view of needs and actions will enable the Board and staff to make more of a commitment to shared issues and potential projects; for example exploring and addressing stigma, benefits, ageing etc.

Recommendation 14: Represent and advocate on behalf of the HIV sector

8.37 In the best interests of individuals, groups and communities affected by HIV it is important that agencies in the field work together to establish mechanisms for representation and advocacy.

8.38 HIV Scotland has struggled with notions of leadership, representation and advocacy. When relationships with others, particularly in the voluntary sector, are poor claims to lead, represent or advocate on behalf of others can be questioned or resisted.

8.39 The Review recommends that HIV Scotland does not use the language of *leadership* (currently used in aim 1) but instead discusses with partners what they would expect from a broad-based national membership organisation in terms of *representation* and *advocacy*; taking on board the many voices and perspectives that make up the HIV sector including people living with HIV.

8.40 In many circumstances agencies within the HIV sector can represent their own views; and on occasion they will draw on the views of their volunteers or people in receipt of support and services. HIV Scotland should work with partner agencies to help them improve their efforts at user involvement, representation and advocacy. HIV Scotland's role in advocacy on behalf of people living with HIV must be respectful of this agency-based representation and seek to be additional. There will be times when service providers do not reach individuals or groups who should have their say and HIV Scotland can fill a gap. There will be times when a national perspective is required and HIV Scotland can work with service providers to draw upon their user/membership base as well as reach those harder to engage.

8.41 It is hoped that in the context of new relationships, and a Board and membership which are themselves representative of the HIV sector that there will be a growing confidence that when HIV Scotland is at the table, particularly in national strategic forums, it can be trusted to represent the views of its membership.

8.42 Representation and advocacy are built on trust, it is hoped that HIV Scotland *and* other agencies are willing to make a commitment to re-building relationships and collectively addressing these issues.

Recommendation 15: Support delivery of the HIV Action Plan

8.43 HIV Scotland is identified in the HIV Action Plan in Scotland as a key partner and specifically as a link to the voluntary sector and the contributions it makes. With a full complement of Board members and staff team in place HIV Scotland needs to work on the detail of its support for implementation and delivery of the Plan.

8.44 The agency has already contributed significantly to informing the Plan and can bring knowledge and expertise to the subsequent work which will be done in terms of regional structures which will be established to deliver the Plan, deliver improved needs assessment, improve engagement with service users, and enhance planning, commissioning and evaluation.

8.45 The agency has also done some development work on a training programme which has potential to meet continuing professional development (CPD) needs in the HIV sector and beyond. This should be developed further.

8.46 Supporting delivery of the HIV Action Plan is a significant area of work and managing HIV Scotland's role, maintaining a balance between this work and other aspects of the agency's operations, will need close management by the Board working with the staff team.

Recommendation 16: Write a business plan

8.47 The agency has already done some work to clarify what it does, why and how although that paper (referred to in chapter 5 and entitled 'About HIV Scotland' latest draft dated 08.04.09) has not been adopted or developed by the Board. With the support of the staff team and short-term Change Manager the new Board should revisit this work to support the production of a business plan which sets objectives for the agency (in detail for 2009/10 but also looking to 2010/11 and 2011/12) which should be specific, measurable, achievable, realistic and linked to a timeline/date for delivery.

8.48 New funding arrangements with the Scottish Government and newly re-energised partnerships with the HIV sector require the clarity which a plan will bring. In turn, the Board and staff team of HIV Scotland will then have no doubts as to what is expected of them and what criteria will then be used to monitor and evaluate effectiveness of the agency.

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