

A report on a study exploring non-attendance at specialist clinical HIV services in Scotland

July 2011

Colin Morrison,
Kate Betney and
Cathy McCulloch;
The TASC Agency

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Finally, thank you to the individuals living with HIV who were interviewed and shared invaluable experiences and insights into services in Scotland.

Abbreviations/Explanation of terms

| | |
|----------------|--|
| AIDS | Acquired Immunodeficiency Syndrome |
| ART | Anti Retroviral Therapy; used to treat HIV infection |
| BASHH | British Association for Sexual Health and HIV |
| BBV | Blood Borne Virus; a virus that can be transmitted from an infected person to another person by blood-to-blood contact. The principle BBVs are HIV, hepatitis B and hepatitis C. |
| CD4 | Cluster of Differentiation 4: HIV uses CD4 to gain entry into host T-cells. HIV infection leads to a progressive reduction in the number of T cells expressing CD4. The CD4 count is used to decide when to begin treatment during HIV infection. CD4 tests are used to determine efficacy of anti retroviral therapy. |
| CPD | Continuing Professional Development is a term that describes the enhancement of skills or professional competence. |
| Co-morbidities | Two or more conditions that occur simultaneously within the same person. In the context of HIV, usually used to indicate conditions present in addition to HIV. |
| DNA | Meaning 'did not attend' and used as a term when a person fails to attend an appointment. |
| GUM | Genitourinary medicine |
| Hepatitis C | A viral infection of the liver caused by hepatitis C virus. |
| HIV | Human Immunodeficiency Virus. |
| HPS | Health Protection Scotland: HPS coordinate and administer HIV surveillance systems. |
| ID | Infectious Diseases; a clinical speciality which includes HIV. |
| ID Consultant | Infectious Diseases Consultants are responsible for HIV inpatient care as well as outpatient care with colleagues in GUM. |
| IV drug user | Intravenous drug use is the injecting of a drug directly into the vein. |
| MCN | Managed Clinical Networks. |
| MSM | Men who have sex with men. |
| NHS | National Health Service. |
| NHS QIS | Quality Improvement Scotland supports healthcare providers to improve the quality of services; since April 2011 is now Health Improvement Scotland. |
| ScotPHN | Scottish Public Health Network. |
| STI | Sexually transmitted infection. |
| Viral Load | The viral load test is a quantitative measurement of HIV nucleic acid that provides information that is used in conjunction with the CD4 cell count. Keeping the viral load levels as low as possible decreases the complications of HIV disease and slows the progression from HIV infection to AIDS. |

Executive summary

Context

Purpose and conduct of the study

A number of individuals living with HIV do not enter treatment or sustain their connection with specialist clinical services. This is of concern because health outcomes for these individuals will be compromised. The main question posed by the research was:

1. What are the reasons why some people living with HIV do not attend specialist clinical services?

Further questions also investigated were:

2. What is known about *specific* factors about patients and their impact on how individuals, groups or communities are attracted to or retained in specialist clinical services?
3. What do specialist clinical services do to help people living with HIV to engage with clinical services and what do they do which works against engagement?
4. What do voluntary sector or NHS/non-specialist clinical services do to help people living with HIV to engage with clinical services and what do they do which works against engagement?

A number of important ethical concerns have been considered in the design of the study. Ethics approval was sought and granted by the West of Scotland REC 5. Subsequently NHS R&D approval was also then sought via the NHS National Research Scotland Permissions Coordinating Centre and from NHS Boards from within which professional contacts working within the NHS were drawn; these were NHS Forth Valley, NHS Grampian, NHS Greater Glasgow and Clyde, NHS Lanarkshire, NHS Lothian and NHS Tayside.

Participants

Seventy professionals/stakeholders were recruited to participate in group discussions and individual interviews. Thirteen people living with HIV were recruited to take part in individual interviews.

Engagement with professional contributors from across sectors and services (NHS, Voluntary Sector and non-NHS statutory sector services) provided a picture of the factors which can be viewed as barriers to both service access and sustained engagement and provided opportunities to discuss what consideration service providers had given to these issues. There are limitations to the research in terms of professional participation; in speaking with professionals from various HIV treatment and care sectors experiences (or issues) affecting people's engagement inherently risk a level of (mis)interpretation by the professional, or reporting of a distorted (or partial) reality of the person's lived experience.

There have been challenges in the engagement of people living with HIV in this study and we have been less successful in engaging with participants than had been hoped. One specific difficulty is that we have not involved people who have disengaged totally from services, however the 13 people involved have each explored the experience of specialist clinical HIV services, conceptualising engagement with services as a journey from testing and diagnosis to ongoing treatment and care which may or may not include use of anti retroviral therapy. In each account there are or have been periods in which attendance and treatment adherence have been problematic. These accounts help us to be more aware that the individual's relationship with services and treatment adherence is more fluid and complex than simple notions of sustained or absolute engagement or non-engagement. With 13 participants findings should not be taken to be representative of the experience of *all* people living with HIV. They are, however, an accurate reflection of the lived experiences and types of issues that can impact on engagement with specialist HIV services.

With a small sample size of people living with HIV, and a degree of reporting 'by proxy' by professional contributors, the reporting should be recognised as an account and analysis of experience rather than an attempt to create generalisable fact. Nevertheless participants have provided rich, valuable insights into the reasons for non-engagement with services and how in turn, services might seek to respond.

Policy

In recent years the publication of a number of documents and policy developments in related areas have taken place and these have informed the work of this study; the importance and value of each is addressed in the full report. These include:

Treatment and Care Needs Assessment: People Living with HIV. In 2009 the Scottish Public Health Network published a key report which sought to identify the service needs of people living with HIV and to make proposals as to how needs could be met. Many of the issues raised informed the subsequent HIV Action Plan and are echoed in the findings of this report.

HIV Action Plan in Scotland December 2009 to March 2014. The Scottish Government published the HIV Action Plan (2009) with the intention of improving actions on prevention, diagnosis, treatment and care across statutory and voluntary sectors and services, to reduce levels of transmission and undiagnosed HIV and develop approaches to reporting, evaluation and research. The Action Plan recognised inconsistencies in services across Scotland and identified the need to focus on high risk groups. The social context of HIV was recognised and the Plan identified that some people living with HIV do not attend specialist clinical HIV services and in a specific action, Action 6, said that an investigation into these reasons would be undertaken. This key action, along with others in the original plan will be absorbed into a new overarching outcome framework for NHS Boards and their partners, the Scottish Government's *Sexual Health and Blood Borne Virus Framework 2011-2015*.

HIV in the context of BBV and the Hepatitis C Action Plan. In terms of Scotland's response to BBV a significant investment has been made in the development and delivery of the Hepatitis C Action Plan. Phase I of the Plan focussed on generating

the evidence based required for actions, Phase II (published in May 2008) looked to improve testing, treatment, care and support services with a focus on increasing the number of people in treatment.

Clinical Standards for HIV services. In September 2010 NHS QIS (now Health Improvement Scotland) published draft *Clinical Standards for HIV services* for consultation. The draft Standards reflect the six dimensions of The Healthcare Quality Strategy for NHS Scotland so that provision should be: person centred, safe, effective, efficient, equitable and timely.

Psychological services. To date there have been no UK wide standards for the provision of psychological support for people living with HIV. In April 2011 *Draft Standards for Psychological Support for adults living with HIV* were published. The draft standards define psychological support as: “any form of support which is aimed at helping people living with HIV to enhance their mental health and their cognitive and emotional wellbeing”. These draft standards also reflect the *Sexual Health and Blood Borne Virus Framework 2011-2015* recognition that “specialist clinical, psychological, social and peer support is critical in maintaining contact and support from the moment of initial diagnosis through to management of HIV as a long term chronic condition”.

1.3 Epidemiology

Allowing for known deaths and known or presumed migration of cases it is estimated that there are currently 4033 people living in Scotland who have been diagnosed HIV positive.

There has been a rise in the annual number of reports of HIV in Scotland; between 2000-2004, an average of 239 reports were received by HPS each year, between 2005-2009, this increased to 408 reports. In 2010, 360 cases were reported.

The main factors contributing to this rise have been the increase in the numbers of previously infected individuals from areas of high prevalence, such as sub-Saharan Africa, coming to Scotland coupled with a two and a half fold increase in individuals presenting for an HIV test (based on data from the four main NHS board testing areas, NHS Greater Glasgow and Clyde, NHS Lothian, NHS Grampian, and NHS Tayside) between 2003 and 2008 (latest data available).

The annual number of men who have sex with men (MSM) diagnosed with HIV has also seen a rise in recent years; this stems from a number of factors including increased HIV testing, particularly in the GUM clinic setting, and continued transmission of HIV. Among individuals presumed to have been infected in Scotland, MSM contact remains the primary method of transmission, accounting for 71% of cases reported since 2004.

The number of diagnoses among injecting drug users (IDUs) decreased following the introduction of harm reduction measures in the early 1990s and has remained relatively low since.

Currently the number of people living with diagnosed HIV is rising each year due to increased numbers of new diagnoses and decreasing deaths due to anti retroviral

therapies. Consequently, the number of HIV-infected individuals in specialist care and receiving anti-retroviral therapy in Scotland is increasing; Greater Glasgow and Clyde and Lothian NHS Boards manage the majority of cases.

More information on epidemiology of HIV in Scotland from Health Protection Scotland at <http://www.hps.scot.nhs.uk/bbvsti>

1.4 Attendance at HIV clinical services: what we know

Parallel to the work of this qualitative study Health Protection Scotland and NHS Health Scotland are working with HIV specialist clinical services in the context of the HIV Action Plan (Action 6) to ascertain the numbers of people living with HIV who are not engaging with specialist services. Of the estimated 4033 persons living in Scotland who have been diagnosed HIV positive HPS report that 3339 HIV infected individuals attended specialist services for monitoring and treatment during the period 1 January 2010 to 31 December 2010. This represents 83% of the estimated number of diagnosed cases currently living in Scotland. It is recognised however that more needs to be known about the estimate of 694 people not seen in 2010, who may have left Scotland/UK, may be attending services elsewhere, may have re-entered treatment and care but not yet been recorded, or who may have died. In other words this figure should be interpreted cautiously and read more accurately as people who it is thought did not attend in 2010, rather than be considered as patients lost to services. Further local work to audit case notes is imminent and will give a more accurate picture.

Specific factors in the lives of people living with HIV which impact on engagement with specialist clinical HIV services

Interviews with professionals and people living with HIV have enabled the study to identify a range of specific factors which interviewees believe impact on how individuals, groups or communities are attracted to or retained in specialist clinical services. These factors include:

- Mental Health, personal support and stigma.
- Knowledge, attitudes and experience of ART.
- Ethnicity, culture and faith.
- Migration/political status.
- Substance and alcohol misuse.
- Information and communication issues.
- Locality/geography.
- Poverty and employment.
- Being in prison.
- Caring responsibility/childcare.
- Other conditions or ill-health (Co-morbidity).

These are summarised below and addressed in full in the main study report.

Issues around **mental health** including personal feelings about status were raised across interviews with both professionals and people living with HIV. Interviewees discussed the person's reaction to diagnosis and the impact of living with HIV post-

diagnosis and in the longer term. Mental health was linked to treatment adherence where low mood or having to take medication daily was seen as a constant reminder of HIV status. Contributors have reported that psychological support services in Scotland are variable, resulting in services which are often reactive rather than proactively supporting the individual to manage their HIV.

Interviewees reported that people living with HIV can find themselves **without support and living in isolation**. HIV status can lead to rejection. The fear of rejection can leave the individual feeling unable to make or sustain relationships.

Professional interviewees have identified **stigma** as an important influence on engagement with services. Feelings of shame, heightened anxiety and fears about the loss of anonymity leave people feeling frightened. People living with HIV have also raised stigma as an experience; in relationships, employment and in the law. Finally, for some gay men and intravenous drug users issues of stigma as a consequence of their HIV status can be related to other fears and experiences about being judged or discriminated against; working together these experiences and fears can be a powerful barrier to connections with others and to services.

Professional interviewees have identified that **knowledge and attitudes towards ART** are influenced by anxieties about side effects and accuracy of information about current treatments. They reported that **decisions to start treatment** and the experience of managing treatment are influenced by relationships and opportunities for good communication between the person living with HIV and medical practitioners; this communication and trust is not always in place. Mental health is seen as a significant influence on treatment adherence. The issue of **choice not to attend services or adhere to treatments** is reported as a significant dilemma for professional interviewees. Mental health problems are seen as a key factor in some people's disengagement. Where the person living with HIV states an intention to disengage from services or treatments, professional interviewees identified a need to respect patient choice but also to design their response based on an assessment of individual circumstances and needs.

While people of African origin are not a homogenous group there were a range of issues relating to **ethnicity, culture and faith** which were reported by professional interviewees as influences on attendance and engagement with clinical services. Interviewees from specialist clinical HIV services reported that many positive people of African origin present late in terms of diagnosis and can experience rejection from faith based communities as a result of their HIV status. Professional interviewees expressed a range of concerns about engaging **women of African origin who are pregnant and HIV positive**, stating that diagnosis when pregnant can have a negative impact on personal relationships, that women can fear that they may be pressured to terminate a pregnancy or they may see the need to remain unidentified until late in the pregnancy so that deportation can be avoided. Interviewees reported that late diagnosis in pregnancy impacts significantly on treatment options to protect the foetus from HIV infection.

Migration/political status have been identified by professional participants as impacting on registration with GPs and with access to HIV services. Asylum seekers or individuals without leave to remain may not understand NHS systems and primary

care can exclude people by requiring identification and home addresses. Individuals can also be very mobile and personal circumstances can be complex and stressful. When this coincides with a HIV positive diagnosis, particularly a late diagnosis when the person is unwell, this can be a real challenge in terms of making and maintaining contact with HIV services. Interviewees from specialist clinical HIV services have reported they treat patients whose migration/political status means they have no entitlement to free health care, reported as a commitment to saving lives and preventing onward transmission but they also expressed concerns that with increasing numbers of people in such circumstances guidance which restricts services for a person with no entitlement to free health care/treatment may be enforced.

While the numbers of HIV clinical service attendees who are currently intravenous drug users (IDUs) has dropped (although a significant number of patients who were IDUs do have ongoing problems with opiates) **alcohol and recreational drug use** remain a concern and impact on clinic attendance and treatment adherence. Across professional interviews it was recognised that to support clinic attendance and adherence to treatment there is a need to address substance misuse and alcohol issues.

Specialist clinical HIV services and partner agencies reported that people living with HIV are given a lot of **verbal and written information** which the patient is required to understand in order to utilise clinic services and maintain treatment adherence; yet professional interviewees have also reported that awareness and assessment by services of the capacity of the individual to understand information may not be adequately considered.

Locality and geography have been raised as important factors by both professional interviewees and those living with HIV. Travelling to services is a significant challenge for people living in rural/island communities. Travelling long distances for short clinic appointments can be exhausting and impact negatively on attendance although the anonymity offered by larger city-based services is appreciated.

Professional interviewees and people living with HIV have reported that engagement with services can be impacted upon by both **poverty and employment status**. Both travel costs or loss of earnings if time off is required for clinic attendance have been raised as factors to be considered. A fear of disclosure of HIV status can mean that people will not follow up extra benefit or housing entitlement with the relevant agencies. Experiences of employment differ but attendance can be affected by the degree of support an employer gives. Despite legislation in this area interviewees gave accounts of people losing jobs, being refused volunteering opportunities or having their status declared to others by employers or colleagues.

Being HIV positive in prison is reported as a vulnerable position; inmates want assurances of confidentiality but there are complexities in accessing specialist services.

Professional interviewees and people living with HIV have identified a lack of recognition that some people living with HIV will also be a **carer for a partner, family member, child or friend** and this may impact on both physical and mental

health and wellbeing and potentially on their ability to engage with clinical services and manage treatment. This can be particularly so when a partner is also living with HIV or has died.

In terms of **other conditions or ill-health** (co-morbidity) professional interviewees and people living with HIV confirmed that when health deteriorates clinic attendance is difficult. Interviewees identified the importance of ongoing monitoring of HIV related and other conditions to ensure that appropriate support is available to help maintain clinic attendance.

Supporting engagement with services

Interviews with professionals and people living with HIV have enabled the study to identify how services support the engagement of people living with HIV with specialist clinical HIV services; factors are also identified which can work against engagement. Contributors have discussed the patient journey from testing through diagnosis and treatment and have addressed issues around retention in services and adherence to treatment. Contributions are reported as follows:

- Awareness and knowledge of HIV testing services.
- Testing and results: points of first engagement.
- The experience of attending the clinic.
- Building patient-practitioner relationships.
- Starting treatment and adherence.
- When a person fails to attend.
- Working with the Voluntary Sector.
- Working with GPs or non specialist NHS services.
- Working with other statutory services.
- Policy, service design and capacity issues

These key factors are summarised below and addressed in full in the main study report.

When it comes to **awareness, knowledge and access to HIV testing services** professional interviewees reported that there have been improvements in information provision about HIV testing which has been facilitated by good inter-agency partnership work. A challenge for services was reported as needing to promote testing further and engage those individuals who fear having a positive result confirmed. Professional interviewees viewed testing as a point of first engagement where, particularly if the result is positive, the individual can be connected to the information, support and advice they need. For specialist clinical HIV services, locating testing in specialist settings creates opportunities to ensure a personal relationship with the individual is established. At this point specialist settings also see value in the service users giving information about their GP; establishing the role they have in care.

Professional interviewees reported that factors which can undermine engagement with testing include a lack of capacity to meet demand, lengthy waiting times at clinics and a lack of privacy in some waiting rooms. Some interviewees, both professionals and people living with HIV, have raised concerns about the quality of

post result support and counselling. For professional interviewees there is a need to improve assessment of mental health at the point of testing and a need to improve the capacity of services to respond to identified mental health problems. Professional interviewees identified testing and a positive result as a point at which specialist clinical HIV services can overemphasise the importance and role of the HIV Consultant and fail to establish *the team* around the person.

In terms of **the experience of attending the clinic**, professional interviewees recognised the value in providing local clinic provision so that people living with HIV do not have too far to travel; although limits on resources and the ability to then provide access to a range of associated professional support was recognised. Professional interviewees and those living with HIV reported on the importance of experiencing a service that was flexible and personalised. Aspects of the experience of attending a clinic which need to be addressed in order to improve attendance were identified as: assuring anonymity in the waiting room by not using names publicly; extending clinic times to accommodate different needs; ensuring that professionals within the team read notes and communicate effectively so that the patient does not have to repeat information (particularly that which can be distressing); managing what is discussed (or undertaken) in appointments to avoid the individual feeling overwhelmed.

Continuing the notion of the patient's journey contributors identified certain actions which support engagement with specialist clinical HIV services through the **building of patient-practitioner relationships**. Across interviews with professionals and people living with HIV the role of the HIV Consultant was recognised as central but it was also questioned by some professional interviewees whether too much emphasis is placed on this relationship to the detriment of creating an effective team around the person living with HIV. Interviewees recognised that whoever takes responsibility for communication with the patient personal contact is valued. Planning and review of the individual's experience of services and their treatment and care was highlighted by professional interviewees as essential. As with other stages of the patient's journey the provision of assessment and access to support for mental wellbeing was reported as crucial in this relationship; however in reality this was reported as being location specific and often ad hoc.

Considering and starting **anti retroviral therapy and adherence to treatment** have been identified as key issues in the relationship between specialist clinical HIV services and the person living with HIV. Professional interviewees reported that how decisions are made and treatment adherence is addressed impacts on clinic attendance; where the patient is centrally involved in treatment decisions this supports adherence and continued engagement with the service. However both professional interviewees and people living with HIV have reported that the individual can feel pressure to commence treatment and that clinical services can fail to attend to the patient's mental health and preparedness to commence treatment.

Professional interviewees in specialist clinical HIV services report that between 15% and 40% of appointments result in a DNA. **When a person fails to attend** professional interviewees reported that clinics adopt a number of strategies which are often based on personal contact with the patient, contact with allied health professionals and their knowledge of the individual concerned. However it is reported

that services are more often re-active than proactive in identifying irregular attendees and responses can be ad hoc; non-attendance might not be actively addressed and can drift into several months and more missed appointments; responses can be overly dependent on guidance from or action by busy HIV Consultants.

In relation to **working with GPs or non specialist NHS services** professional interviewees from specialist HIV clinical services reported a positive intent to support GP engagement in the shared care of people living with HIV, particularly in relation to managing non HIV related health issues. These interviewees also recognised that there may be an increasing role for GPs in monitoring HIV in terms of CD4 counts and viral load when the HIV positive person is well. However professional interviewees and those living with HIV reported that experiences of GP services are varied and GPs can be resistant to shared care approaches. For patients, confidentiality and basic awareness of HIV as a condition remains a concern in non-specialist settings.

When it comes to **working with the Voluntary Sector** professional interviewees reported that relationships between specialist clinical HIV services and the Sector are developing positively but that more could be done. Interviewees from the Voluntary Sector recognised that their services have not traditionally played a direct role in promoting clinic attendance and treatment adherence. For some Voluntary Sector interviewees there is a tension between the ethos or perspective of the Sector's holistic and service-user focused approach and some practice in specialist clinical services where the perception is that the primary focus is on the treatment regime.

While interviewees from specialist HIV services reported they value the practical support which Voluntary Sector agencies can provide to the patient interviewees from across sectors reported that relationships between specialist services and Voluntary Sector agencies are dependent on the knowledge, awareness and commitment of the specialist service or individual HIV Consultant rather than planned strategically. Some professional interviewees reported a view that if Voluntary Sector services are as a passive partner, poorly integrated into the service landscape, then benefits for the person living with HIV are limited.

One issue identified as complex for both specialist services and Voluntary Sector is around information sharing and confidentiality; interviewees from specialist HIV services reported that people living with HIV themselves can be resistant to Voluntary Sector engagement because of fears about confidentiality and loss of anonymity. In terms of views of the Voluntary Sector it was reported by NHS/statutory sector interviewees that the Voluntary Sector itself might benefit from further reflection on problems with inter-agency competition (which undermines Sector wide cooperation) and with fragmentation of the sector's provision rather than a coherent approach to all HIV positive people.

In terms of the relationship between specialist clinical HIV services and other **statutory services** professional interviewees in clinical services expressed a positive view of Social Work services which can support individuals to stabilise factors which might adversely influence clinic attendance and treatment adherence.

However there is also a view that Social Work services can be complex and that they have moved too far away from direct service provision.

Discussion: issues and challenges for specialist clinical HIV services providers and partner organisations

Consideration of specific factors in the lives of people living with HIV, and how services themselves support service user engagement, has led to the identification of a number of issues and challenges for service providers, these include:

- Policy context and service design.
- Meeting the needs of people of African origin.
- Support for mental wellbeing.
- Holistic support and building a team around the person.
- The role of the Voluntary Sector.
- The role of GPs.
- A continued focus on testing.
- More inclusive communications.
- The importance of reception and waiting areas.
- Conclusion and reflective questions.

These issues are summarised below and addressed in full in the main study report.

The **policy context** has been identified by professional interviewees as supportive of service improvement but there remain questions about what future developments might bring; particularly in terms of locating HIV policy in the wider context of BBV policy. A key concern is that a BBV service becomes too broad in scope and loses specialism and the confidence of people living with HIV. This study confirms findings elsewhere ('Treatment and Care Needs Assessment: People Living with HIV' SPHN 2009) that **HIV service design** requires renewed focus and planning. This report has highlighted the need to address provision of and access to services (both specialist clinical HIV and Voluntary Sector) out with the main central belt urban centres. While professional interviewees have recognised the need to build an effective professional team around the person living with HIV there are also concerns amongst professional interviewees that the perceived nurse-led treatment-focus model of Hepatitis C services might be viewed as the way forward for HIV treatment and care.

Professional interviewees have reported a significant challenge in **meeting the needs of people of African origin**. A range of difficult issues are faced rooted in ethnicity, culture, faith, complexities of finding out positive status when pregnant, migration and political status. Voluntary Sector agencies have played a significant role in responding to these needs. It would seem however that work with this cohort of people living with HIV exemplifies a lack of resources and a need for improved service integration together with increased expertise within specialist clinical HIV services. Professional interviewees have reported that health providers face complex challenges when a person who seeks to access a service may have no entitlement to free health care, their approach to **patients with no access to funds** might be described as a 'don't ask don't tell' policy. This is likely to become increasingly unsustainable and a commitment may need to be made in Scotland that access to

HIV treatment and care is not linked to immigration policy, particularly where that treatment and care has a clear public health rationale, in saving lives and preventing onward transmission.

Support for mental health – promoting mental wellbeing and addressing mental health problems - has been a key theme throughout this study. Professional interviewees and people living with HIV have identified the need for improved assessment, awareness of the aspects of clinic attendance and treatment adherence with are stressful for patients, and the necessity of ongoing assessment and service provision throughout the individual's engagement with specialist clinical HIV services. There are also concerns about equality of access to support across the country and concerns that support for mental wellbeing might not always be available from appropriately experienced and competent staff.

Considering the physical, mental and social aspects of treatment and care professional interviewees and people living with HIV have emphasised the importance of seeing the life of the person living with HIV 'in the round'; identifying that what is required is **holistic support**, addressing areas such as employment, learning, emotional support and relationships as well as treatment, in order to help the individual live with HIV in the long term.

Professional interviewees and people living with HIV have described services frequently committed to personalised and individual care but provision is variable. Interviewees have recognised the value of **building a team around the person** so that support for them is shared, communication between professionals and across sectors is improved, and needs are more systematically assessed and met. While specialist clinical HIV service interviewees have reported a need to retain management of treatment and care, including prescribing ART, a shared care approach is thought to be supportive of clinic attendance and treatment adherence. To make this work services must address challenges inherent in information sharing and concerns for confidentiality which are presented as a barrier to more effective support for the person living with HIV.

In discussion of the role of the **Voluntary Sector** it has been reported that provision is dependent on location (with services mostly in the urban/central belt) and population (with service design and delivery still largely reflecting the differences between groups and communities rather than their shared characteristics). Professional interviewees have confirmed that Voluntary Sector services are often not well integrated into specialist clinical HIV service settings and some agencies in the Sector have not yet made clinic attendance or treatment adherence a focus in their relationships with service users.

The role of **GPs** is of increasing importance in HIV treatment and care; from HIV testing, to care for non-HIV related health matters for people living with HIV, to their role in monitoring CD4 and viral load and treatment. Whilst some interviewees have reported positive engagement with GPs, for others notions of shared care are some way off.

Professional interviewees participating on this study have reported that improving knowledge about and access to **HIV testing** has been the focus of work by both

statutory and Voluntary Sector agencies in recent years. For some professional interviewees this should remain a priority and requires an increased focus, with the view that if an individual is not tested and aware of status their health outcomes are compromised and there is increased risk of onward transmission.

Professional interviewees have described the importance of both verbal and written information given to service users throughout their patient journey but in terms of **commitment to inclusive communications** few have reported that they assess or consider levels of literacy or possible learning disability in their relationship with the person living with HIV.

Whilst recognising improvements, interviewees reported on the continued **importance of reception and waiting areas**, particularly in relation to the welcome an individual receives, to comfort, and to efforts to protect privacy and anonymity.

A need for **professional education** has been identified across interviews with the hope that this will address ignorance, increase awareness of the need for HIV testing and in order to refresh awareness of HIV in most affected communities. Professional interviewees also highlighted the need for **public education** which, in terms of promoting engagement with services, needs to target specific groups and communities and promote testing and treatment adherence.

Reflective Questions

The focus of this study has been on a small but significant population of people living with HIV who do not attend or have irregular attendance at specialist clinical HIV services; these matters have also been linked to treatment adherence. Without appropriate treatment and care the HIV positive person is more likely to become unwell, and if they do not adhere to treatment they will develop resistance: in both scenarios, increased viral load makes transmission more likely. The reflective questions which follow (with full text available in the main study report) are intended to be used by specialist clinical HIV services and their partners as well as those involved in HIV policy as part of their self-evaluation and planning for improvement. The questions posed are:

- Who is actually missing from services?
- What do we mean by non-attendance and why don't people attend?
- Are partnerships fit for purpose?
- What is the relationship between treatment and care?
- Do services really understand what 'being HIV positive' means to the individual?
- Is there a need for standards which address responses to irregular or non-attendance?

Who is actually 'missing' from services? The original brief for this study was established in the context of a lack of clarity about the numbers of people living with HIV who were considered to be 'missing' from specialist clinical HIV services. Subsequent work by HPS, local Clinicians and their teams and by this study in a limited number of cases has now clarified that there are significantly fewer people who are lost to services than originally thought. A further audit of individuals, case by

case, is however required and is currently proposed by BASHH. The recent finding by Health Protection Scotland on reduced numbers does not downplay the importance of a commitment to connect *all* people living with HIV with the treatment and care, but only to indicate that the 'problem' is not of the scale previously estimated. This in turn also allows us to focus more helpfully on access to services for a larger number of people for whom attendance and/or adherence remains a significant challenge.

What do we mean by non-attendance and why don't people attend? It is worth reflecting on the concepts of *attendance* and *non-attendance* and to clarify that even with clinic attendance one cannot presume treatment adherence. It has been shown from the contributions of professional interviewees and people living with HIV that living with HIV is impacted upon by a set of psychological, social, economic and cultural factors; some of these experiences are shared across communities. These experiences will influence how the person then 'lives' with their HIV and part of their lived experience will be the relationships they have with services including specialist clinical HIV services. However, focusing on the individual or a shared characteristic of a group or community also has its problems; it becomes easier then to blame that individual or group for non-attendance or non-adherence to treatment; so it is *their* chaotic lifestyle and choices, *their* faith or cultural practices, *their* troubled backgrounds which make it difficult to provide the service. This study has shown that the way professionals do things also matters: with some actions being supportive of clinic attendance and treatment adherence while others are not.

Are partnerships fit for purpose? This study has reported on a range of professional supports which exist to support treatment and care. However, what this study has also indicated is that working arrangements are often informal, responses re-active, and a lack of a team around the person makes identification, support and a pro-active approach toward service engagement more difficult. It has also been identified that the individual's access to additional support and services is dependent on where they live; some specialist clinical HIV services have little capacity to offer specialist help and Voluntary Sector services are located mostly in the urban, central belt; where the Voluntary Sector is present services are poorly integrated into treatment and care. When it comes to primary care, specialist clinical HIV staff and people living with HIV have described some good relationships with GPs committed to shared care approaches but again much remains to be done. It may be the case that relationships between services need to be more formalised, monitored and audited in order to drive change; it would certainly seem that how services and professionals within them work together would be of more benefit if they were built more consistently around the needs and entitlements of people living with HIV rather than the preferred practices of the individual professional or service.

What is the relationship between treatment and care? There is a sense from professional interviewees and the contributions of people living with HIV that treatment and care can be disjointed rather than connected. For some professional interviewees it has been clear that the focus of HIV policy and service provision should be on HIV testing and getting people into treatment; the concern might then be that this medical view of HIV does not pay enough attention to what 'care' means in the context of HIV services, what the relationship between treatment and care

then is, what *being HIV positive* means to the individual and any consideration of how *they* manage their condition.

Do services really understand what ‘being HIV positive’ means to the individual? Interviews with people living with HIV, and with some professional interviewees, have been a reminder that HIV remains highly stigmatised so that people fear the responses from family, friends, neighbours and some professional people. Stigma and fear lead to isolation and impact on mental health and the quality of life of the person living with HIV. Further, living with HIV can also mean managing ill-health from a number of associated chronic diseases or side effects from medication. Of course, many people do manage but it is important that professionals acknowledge that people living with HIV are coming to terms with and managing a condition with few comparisons. Professionals might describe HIV as a long-term *manageable* condition; it is less easy to live with it as such. In addition, HIV is not just an individual experience; it remains a serious communicable disease and a significant public health concern.

Is there a need for standards which address responses to irregular or non-attendance? A question which has arisen in interviewees with professional contributors is, in the context of services which are variable, and in recognition of each person as an individual: *how much effort or what systems should be expected to be in place (perhaps what should be obligatory) when it comes to responses to irregular or non-attendance?* While the recent NHS QIS draft *Clinical Standards for HIV services* considered many elements of the experience of the service user and the design and delivery of clinical services the standards did not clearly address what systems or responses should be in place when it comes to irregular or non-attendance.

1. Introduction

1.1 Purpose

A number of individuals living with HIV do not enter treatment or sustain their connection with specialist clinical services. This is of concern because outcomes for these individuals will be compromised.

The aim of this research was to engage with professionals and with people living with HIV to find out what the barriers and issues are which impact upon engagement with specialist clinical HIV services.

This research was commissioned by NHS Health Scotland. The research was conducted by independent research company The TASC Agency.

Professional stakeholders were recruited to participate in group discussions and individual interviews. Engagement with professional contributors from across specialist clinical HIV services, non-specialist NHS services, other Statutory Sector agencies and Voluntary Sector providers provided a picture of the factors which can be viewed as barriers to access and to sustained engagement with services and provided opportunities to discuss what consideration service providers had given to these issues.

People living with HIV were also recruited to take part in individual interviews. These interviews explored the individual's experience of specialist clinical HIV services, conceptualising their engagement and experience with services as a journey from testing and diagnosis through to ongoing treatment and care which may or may not include use of anti retroviral therapy (ART).

The findings from this work have been used to highlight features of effective practice, identify areas for improvement and pose reflective questions which help identify what HIV clinical services, non specialist NHS and Statutory services and HIV Voluntary Sector agencies could do to improve access, uptake and retention in specialist clinical HIV services.

1.2 Policy context

The publication of a number of documents has taken place in recent years which help inform the work of this study. These are identified below, with some focus given to issues which also arise in the course of this study.

1.2.1 Treatment and Care Need Assessment

In 2009 the Scottish Public Health Network published the report *Treatment and Care Needs Assessment: People Living with HIV*¹ which sought to identify the service needs of people living with HIV and to make proposals as to how needs could be met. The Assessment identified that with regard to HIV treatment and care services:

¹ Johnman, C. (2009) Treatment and Care Needs Assessment: People Living with HIV. Scottish Public Health Network (Scot PHN) at <http://www.nhstayside.scot.nhs.uk/BBVMCN/documents/ScotPHN%20report%20March%202009.pdf>

- Many services are operating clinics which cannot meet demand.
- There are variations in the models of care, personnel and services provided; this raises concerns about whether personnel have the up-to-date skills and knowledge appropriate to their roles and a lack of clarity about what a 'core' service should look like.
- There is a need to integrate sexual healthcare, including counselling and support, with HIV care to help prevent onward transmission and to support the personal and sexual health of people living with HIV.
- There is a need to ensure that all people living with HIV have access to a range of HIV treatment and care, requiring communication between services, new approaches to sharing resources and opportunities to develop specialist skills.
- The role of primary care varies across Scotland and should be addressed through more coordinated approaches to care.
- There is a lack of clear funding sources and strategic development.
- There is a need to improve patient management systems; with sensitivity to concerns about confidentiality.
- Staff within services need access to continuing professional development opportunities.
- Laboratories which serve specialist HIV services are struggling to meet demand and have a particular problem with the recruitment and retention of staff.
- Improvements must be made to the treatment and care of children living with HIV including addressing issues around transition to adult services.
- Voluntary Sector service provision varies across the country as does the quality of relationships between HIV services and the Sector; service access should be more equitable and collaboration needs to be improved.
- There has been a lack of opportunity for people living with HIV to influence services.

Many of the issues raised in this key report subsequently influenced the development of the HIV Action Plan and are echoed in the findings of this study.

1.2.2 HIV Action Plan

HIV was considered in actions presented in *Respect and Responsibility: A Strategy and Action Plan for Sexual Health*² and a number of professional bodies in the UK have developed guidelines and standards of care but, as the 2009 ScotPHN report (discussed above) also recognised, until 2009 there had been no consolidated Scottish national HIV treatment and care policies or standards.

In order to give a renewed focus on HIV the Scottish Government published the HIV Action Plan in Scotland: December 2009 to March 2014³ with the intention to improve actions on prevention, diagnosis, treatment and care across statutory and

² *Respect and Responsibility: A Strategy and Action Plan for Sexual Health* (2005) Scottish Executive at: <http://www.scotland.gov.uk/Resource/Doc/35596/0012575.pdf>

³ HIV Action Plan in Scotland: December 2009 to March 2014 (2009) Scottish Government at: <http://www.scotland.gov.uk/Publications/2009/11/24105426/0>

voluntary sectors and services, to reduce levels of transmission and undiagnosed HIV and develop approaches to reporting, evaluation and research.

The Action Plan recognised inconsistencies in services across Scotland and identified the need to focus on high risk groups, particularly gay/bisexual and men who have sex with men and people originating from high prevalence African countries, as well as to provide services for the general population. The social context of HIV was recognised, particularly in relation to the importance and impact of issues of stigma, mental health and wellbeing, homophobia, racism, substance misuse and differences in culture and beliefs. The Action Plan also identified that some people living with HIV do not attend specialist clinical HIV services and in a specific action, Action 6, said that an investigation into these reasons would be undertaken.

In terms of further need the Action Plan reported on the intention to explore and act on education and HIV awareness raising for professionals who have a role to play in prevention, treatment and care; including primary health care staff. The Plan also committed to action by NHS QIS to develop Standards for HIV Prevention, Diagnosis, Treatment and Care.

1.2.3 HIV in the context of BBV and the Hepatitis C Action Plan

The HIV Action Plan identified that NHS Board BBV Prevention budgets are used for HIV testing and proposed that greater effort was required on testing/diagnosis in helping prevent HIV transmission. The Plan also committed work to ascertain the level of BBV budget spend on other prevention activities and interventions.

In terms of Scotland's response to BBV a significant investment has been made in the development and delivery of the Hepatitis C Action Plan⁴. Phase I of the Plan addressed generating the evidence based required for actions, Phase II published in May 2008 looks to improve testing, treatment, care and support services with a focus on increasing the number of people in treatment. With regard to implementation of the Plan an investment of approximately £43 million was made over 3 years.

Of the 50,000 Scots infected with the Hepatitis C virus it is estimated that 90% have acquired the virus through injecting drug use. Phase II of the Plan recognised the challenges faced in promoting testing and treatment and identified the need for improved awareness and engagement with the issue amongst GPs and better integration of the range of social care, addiction and mental health services patients need. In addition, in relation to improving management of the implementation of the Plan it is recommended that each NHS Board develops Managed Clinical Networks (MCN). In the 2009 ScotPHN report (discussed above) it was asserted that the Hepatitis C Action Plan '...sets the model through which Hepatitis C services (and likely all future BBV services such as HIV) should be provided'.

⁴ 'Hepatitis C Action Plan for Scotland: Phase II: May 2008 - March 2011' at <http://www.scotland.gov.uk/Publications/2008/05/13103055/0>

1.2.4 Clinical Standards for HIV services

In September 2010 NHS QIS (now Health Improvement Scotland) published draft *Clinical Standards for HIV services* for consultation⁵. The draft Standards confirm the findings of the ScotPHN needs assessment from 2009 that the provision of HIV services is increasingly complex and that “variations in the models of care, personnel and services” persist, with “a lack of formal mechanisms to ensure equity of access to high quality treatment and care” (page 3). With this in mind a project group was charged with developing evidence-based standards that would assure quality, focusing on the themes defined within the HIV Action Plan: service organisation, prevention, recognition and diagnosis and treatment and care. Furthermore, the 11 Standards reflect the six dimensions of The Healthcare Quality Strategy for NHS Scotland⁶ so that provision should be: person centred, safe, effective, efficient, equitable and timely. Many of the areas addressed in the Standards will be highlighted in this report. Final standards are due for publication in July 2011.

1.2.5 Psychological services

To date there have been no UK wide standards for the provision of psychological support for people living with HIV. In the latter part of this study (April 2011) *Draft Standards for Psychological Support for adults living with HIV* have been published, developed by the British Psychological Society, the British HIV Association and the Medical Foundation for AIDS and Sexual Health. The draft standards define psychological support as: “any form of support which is aimed at helping people living with HIV to enhance their mental health and their cognitive and emotional wellbeing”. In terms of who provides such support and where it is acknowledged that support “is not only provided by psychologists but by a variety of professional groups (counsellors, nurses, psychiatrists and others) working in community settings, primary care and hospitals. Psychological support includes both the provision of a variety of talking therapies as well as appropriate medication”⁷. The standards were open for consultation until May 31st 2011.

These draft standards reflect the recognition in the Scottish Government’s *Sexual Health and Blood Borne Virus Framework 2011-2015* that “specialist clinical, psychological, social and peer support is critical in maintaining contact and support from the moment of initial diagnosis through to management of HIV as a long term chronic condition”. However the draft standards also recognise that provision of psychological support services is variable and routes into such provision may also vary.

The draft standards are intended to promote best practice and can be used in the provision of psychological support across statutory and Voluntary Sector provision. At the core of the model presented is a ‘stepped care model’ which recognises that while many people living with HIV can create their own support networks and adopt

⁵ Human Immunodeficiency Virus Services Draft Standards Sep 2010 at <http://www.healthcareimprovementscotland.org/default.aspx?page=11954>

⁶ The Scottish Government ‘The Healthcare Quality Strategy for NHS Scotland’ (2010) at <http://www.scotland.gov.uk/Resource/Doc/311667/0098354.pdf>

⁷ ‘Standards for psychological support for adults living with HIV: Draft for consultation’ (April 2011) at http://www.medfash.org.uk/publications/documents/consultation_draft_april2011.pdf

self management strategies others will need help. As such the model presents four levels of psychological support provision, each related to the requirements in terms of practitioner training and competency.

Whilst a draft document, the discussion which the standards will generate and the likely production of final standards in the course of 2011 will help a range of service providers here in Scotland to consider their responses to the mental health and wellbeing of people living with HIV which is raised as a significant issue in this report.

1.3 Epidemiology

There are currently 4033 people living in Scotland who have been diagnosed HIV positive. This recent estimated figure was reported in 'HIV infection and AIDS: Quarterly report to 31 March 2011 (ANSWER)⁸' and is based on review by Health Protection Scotland and refinement of data to improve accuracy with regards migration and mortality. There has been a rise in the annual number of reports of HIV in Scotland; between 2000-2004, an average of 239 reports were received by HPS each year, between 2005-2009, this increased to 408 reports. In 2010, 360 cases were reported.

The main factors contributing to this rise have been the increase in the numbers of previously infected individuals from areas of high prevalence, such as sub-Saharan Africa, coming to Scotland coupled with a two and a half fold increase in individuals presenting for an HIV test (based on data from the four main NHS board testing areas, NHS Greater Glasgow and Clyde, NHS Lothian, NHS Grampian, and NHS Tayside) between 2003 and 2008 (latest data available).

The annual number of men who have sex with men (MSM) diagnosed with HIV has also seen a rise in recent years; this stems from a number of factors including increased HIV testing, particularly in the GUM clinic setting, and continued transmission of HIV. Among individuals presumed to have been infected in Scotland, MSM contact remains the primary method of transmission, accounting for 71% of cases reported since 2004.

The number of diagnoses among injecting drug users (IDUs) decreased following the introduction of harm reduction measures in the early 1990s and has remained relatively low since.

Currently the number of people living with diagnosed HIV is rising each year due to increased numbers of new diagnoses and decreasing deaths due to anti retroviral therapies. Consequently, the number of HIV-infected individuals in specialist care and receiving anti-retroviral therapy in Scotland is increasing; Greater Glasgow and Clyde and Lothian NHS Boards manage the majority of cases.

During the first quarter of 2011 NHS Scotland laboratories reported positive HIV-antibody test results for 90 individuals not previously recorded as HIV positive. Results available to date for the latest 90 diagnosis help us understand the epidemiology of HIV in Scotland today. Of these 90 cases:

⁸ Health Protection Scotland 'HIV infection and AIDS: Quarterly report to 31 March 2011 (ANSWER)' at <http://www.hps.scot.nhs.uk/ewr/article.aspx>

- 66 (73%) are male
- 64 (71%) are aged between 25 and 44 years old
- In terms of probable route of transmission: 33 (37%) was men who have sex with men, 29 (32%) heterosexual intercourse; 3 (3%) injecting drug use. Of the heterosexual cases 12 (13% of the total of 90 people but 41% of known heterosexual transmissions) probably acquired their infection abroad, for 24 cases the transmission category is as yet undetermined.
- 31 (34%) new cases are from NHS Greater Glasgow and Clyde, 26 (29%) from Lothian, 9 (10%) from Tayside and 8 (9%) from NHS Grampian.

More information on epidemiology of HIV in Scotland from Health Protection Scotland at <http://www.hps.scot.nhs.uk/bbvsti>

1.4 Attendance at HIV clinical services: what we know

Parallel to the work of this qualitative study Health Protection Scotland and NHS Health Scotland are working with HIV specialist clinical services in the context of the HIV Action Plan (Action 6) to ascertain the numbers of people living with HIV who are not engaging with specialist services. Of the 4033 persons living in Scotland who have been diagnosed HIV positive HPS report that 3339 HIV infected individuals attended specialist services for monitoring and treatment during the period 1 January 2010 to 31 December 2010. This represents 83% of the estimated number of diagnosed cases currently living in Scotland. It is recognised however that more needs to be known about the estimate of 694 people not seen in 2010 for whom data may be inaccurate, who may have left Scotland/UK, may be attending services elsewhere, may have been entered on the database in error, may have re-entered treatment and care but not be recorded as such, or who may have died. In other words this figure should be interpreted cautiously and read more accurately as people who it is thought did not attend in 2010, rather than be considered as patients lost to services. Further local work to audit case notes is imminent and will give a more accurate picture.

1.5 Research questions

With the above context in mind the main question posed by the research was:

1. What are the reasons why some people living with HIV do not attend specialist clinical services?

Further questions also investigated were:

2. What is known about *specific* factors about patients and their impact on how individuals, groups or communities are attracted to or retained in specialist clinical services?
3. What do specialist clinical services do to help people living with HIV to engage with clinical services and what do they do which works against engagement?
4. What do voluntary sector or NHS/non-specialist clinical services do to help people living with HIV to engage with clinical services and what do they do which works against engagement?

2. About the research and research participants

The study was commissioned in July 2010, and Ethics approval granted in October 2010. This section of the report explains the process by which both ethical approval and NHS Research and Development (R&D) approval were sought and identifies the process of recruitment of professional people and people living with HIV.

2.1 Ethics and Research and Development approval

A number of important ethical considerations have been considered in the design of the study. These included the protection of the privacy of the individual and assurances of anonymity and confidentiality throughout the process. Ethics approval was sought and granted by the West of Scotland Research Ethics Committee 5. Subsequently NHS R&D approval was also then sought via the NHS National Research Scotland Permissions Coordinating Centre and from NHS GGC (where a lead reviewer was appointed), NHS Lothian, NHS Tayside, NHS Grampian and NHS Lanarkshire where numbers of NHS staff were recruited. NHS R&D approval from each Board was granted between November 2010 and April 2011; this defined when fieldwork in each locality could begin.

2.2 Engaging professionals working with people living with HIV

Professional engagement was undertaken with support from existing networks such as Scottish HIV and AIDS Group (SHIVAG) the WISH Network (Wellbeing in Sexual Health NHS Health Scotland) and through HIV Scotland (the national HIV policy charity for Scotland). Direct approaches were also made to a number of individuals and teams known to the research team and the commissioning Steering Group. Full project information for professionals was available online.

Professionals participated in either a group discussion (42 participants attending one of 6 sessions) or a semi-structured individual interview (28 participants), and were recruited from NHS specialist clinical HIV services, Non Specialist NHS services, Statutory Sector services, or the Voluntary Sector. While the group sessions covered the same issues and areas as the subsequent semi-structured individual interviews they were more general in nature and helped map out the key issues which could be explored in more depth in individual interviews. In general terms across our engagement with professional stakeholders via both group and individual interviews we aimed to explore 'the journey' which an individual with an HIV diagnosis might have, and asked participants to discuss and reflect on:

- how the individual might initially engage with services which provide testing
- informing the individual of their HIV positive status and what happens next
- how clinical services assess likely further engagement or adherence to treatment at the point of testing (and what they do with this knowledge)
- what is known about specific factors – including locality/geography, ethnicity, migration/political status, age, literacy, sexuality, substance use, gender or disability – and their impact on how individuals, groups or communities are attracted to or retained in specialist clinical services
- what clinical services do when an individual does not engage or subsequently disengages from clinical services

- how stigma and/or discrimination impact upon access/retention by specialist clinical services
- what approaches work to encourage attraction or retention in services and why they work: at the point of diagnosis and/or subsequently
- examples of information provision, partnerships or service design/delivery which stakeholders feel are improving access/retention.
- what has been tried and had little/no impact and why
- whether certain approaches work better for certain individuals, groups or communities
- the role which voluntary sector agencies play in support for people living with HIV
- ways in which voluntary sector agencies are usefully connected to specialist clinical services
- the role which other NHS/non-specialist clinical services (including GP based services) play in support for people living with HIV
- ways in which other NHS/non-specialist clinical services (including GP based services) are usefully connected to specialist clinical services
- the perceived and actual relationship between treatment and care
- from these discussions what is it – from the individual's perspective - about 'being HIV positive' that works against access or retention in clinical services.

Professional participants gave consent to being named as a contributor whilst it was agreed that no individual view or quote would be attributed to an individual.

Participants are listed in **appendix 1**. Interview schedules are in **appendix 2**.

2.3 Engaging people living with HIV

This was undertaken via contact with professional colleagues, through more targeted information disseminated by specialist clinical HIV service providers and by public advertisement, described further below.

2.3.1 Contact via professional colleagues in contact with people living with HIV

Professional colleagues from specialist clinical HIV services, NHS non-specialist services and Voluntary Sector services were asked to share study information provided by the research team with individuals they knew to be living with HIV and have or may have had difficulty engaging with specialist clinical HIV services. The information (a participant information sheet or invitation card, email or text with a link to the dedicated study information site explained the purpose of the research and provided researcher contact details. NHS Health Scotland also provided Voluntary Sector agencies with a small fund, coordinated by HIV Scotland, from which they could access some resource to support additional efforts to engage people living with HIV in the research.

2.3.2 Specialist clinical HIV service providers sent information to service users

Health Protection Scotland shared anonymised information with the research team about individuals who, according to HPS data, had been diagnosed as HIV positive but had not attended a clinic appointment since December 2008; this amounted to 317 individuals. The cut off date of December 2008 was chosen in that it indicated that the person had not attended for some time (rather than had missed 2 or 3 appointments) but yet suggested that the person may be more likely to still be in

Scotland and be living. Consultants across HIV clinical services in Scotland were then sent a request by HPS in relation to these individuals and asked whether, after further exploration of records held within the clinic, their non-attendance could be explained; for example had they in fact left the country, were they now accessing services elsewhere, or was it known that they had died. From the 317 identified, having reviewed clinic records, Clinicians reported that 262 individuals' non-attendance could be explained, or that these patients had now returned. This finding, particular to this study, has indicated that data held centrally about 'non-attendance' may be inaccurate and indicates the need for an audit of patient records and improved reporting to HPS so that accuracy can be improved. To return to this particular exercise, for the 55 remaining cases where non-attendance could not be explained, Clinicians (where they had personal contact information for these people, and permission to send information to them, 48 in total) sent an invitation which provided basic information about the study with a request to contact the research team if they would consider taking part in an interview. The study team received no contact from any of these individuals and so this approach did not lead to the recruitment of participants living with HIV.

2.3.3 Information was placed in a number of targeted press outlets

This included The Big Issue, Scots Gay and the Gazette.

2.3.4 Reflecting the approach with professional participants

Across our engagement with people living with HIV we aimed to explore 'the journey', which an individual with an HIV diagnosis may have had, and so interviewees were asked to discuss

- how they initially engaged with services which provided testing
- on being informed of their HIV positive status what happened next: considering what information and support was given which could/might/did impact on further access to services
- the extent to which specific factors – including locality/geography, ethnicity, migration/political status, age, literacy, sexuality, substance use, gender or disability – have impacted on their access to or retention in services
- whether they have experienced stigma and/or discrimination as a result of their HIV status, or whether they fear such responses, and how this might impact upon access/retention in specialist clinical services
- what any agency, service or individual has ever done that has helped them engage with clinical services at some point and what experiences they have had which has worked against engagement (and why so)
- what other agencies – Voluntary Sector or NHS/non-specialist clinical services – have helped along the way and how; specifically whether they helped or sought to help engagement with clinical services
- from these discussions what is it – from the individual's perspective - about 'being HIV positive' that works against access or retention in clinical services.

Interview schedules are in **appendix 2**.

There have been some specific challenges in the engagement of people living with HIV in this study and we have been less successful in engaging with participants

than had been hoped. One specific difficulty is that we have not involved people who have disengaged totally from services although as already highlighted it is still not clear how many people this might be. In speaking with people living with HIV who have participated we have also become more aware that their relationship with services and with treatment and treatment adherence is more fluid and complex than simple notions of sustained or absolute engagement or non-engagement. Every person living with HIV who has been interviewed has had a relevant and important story to tell and we have sought to learn from their experience. Whilst it was our intention that the research be respectful of the privacy of the individual, and focus on views of services, it has become clearer that in order to fully contextualise these conversations participants have had to tell a wider story and touch on feelings and emotions, relationships, experiences of rejection, discrimination and stigma which can remain upsetting. Knowing these experiences has made it easier to understand why recruiting people living with HIV in an in-depth individual interview has been difficult; participants have been generous in their contribution and have wanted to improve services for others, many other people will have backed away from participation because the very nature of discussions is just too difficult.

We are extremely grateful for the participation of the 13 people who gave time to speak with us in the context of in-depth one to one interviews. Participants have been open, honest and reflective. Their contributions remind us that the lived experience of HIV may be somewhat different from the increasing use of the phrase 'long term manageable condition' which can be found in the discussion and literature addressing HIV today⁹.

Of the 13 participants living with HIV these characteristics help us understand their diversity, so that of the 13:

- Three were women; one woman was of African origin.
- Nine were men, seven of whom were gay men; one contributor is currently in prison (none were of African origin).
- In terms of age, one participant is in his/her 20s, three in their 30s, five in their 40s and four in their 50s.
- In terms of place of residence, interviewees came from these NHS Board areas: Tayside (4), Lothian (3), Greater Glasgow and Clyde (2), Grampian (2), Fife (1) and Highland (1).
- In terms of diagnosis: 4 interviewees were diagnosed as HIV positive less than 5 years ago, 2 interviewees 6 to 10 years ago and 7 more than 10 years ago.
- 11 of the 13 participants are currently prescribed ART; adherence to medication varies at different times.
- Whilst this small group are currently known to services all were able to describe issues which impact currently, or have impacted in the past, on their connection with services. Whilst the report recognises the complex interface of issues which can influence periods of irregular or non-attendance with services or adherence to ART it is possible to say that the *main* issues which

⁹ For example see information presented by Terence Higgins Trust at: <http://www.myhiv.org.uk/HIV-and-you/Your-diagnosis/Long-term-diagnosed> or the Children's HIV Association at <http://www.chiva.org.uk/parents/understanding.html>

have affected this group's attendance/adherence include mental health problems (5 participants), periods of drug use/chaotic lifestyle (3 participants), resistance to commencing or continuing ART or feelings of a loss of control or conflict with a service (3 participants), imprisonment (1 participant) or relocation due to migration status (1 participant).

2.4 Limitations of the research

There are limitations to the research in terms of the participation of people living with HIV and that of professional contributors.

By engaging with a sub-population of HIV positive people, the research findings report on the experiences of a select group of people who have shared experiences of engagement and non-engagement with specialist clinical HIV services. In terms of the participation of people living with HIV the sample size was relatively small, with 13 people living with HIV taking part and as such findings should not be taken to be representative of the experience of *all* people living with HIV, nor should they be taken to be generalisable. They are, however, an accurate reflection of the lived experiences and types of issues that can impact on engagement with specialist HIV services.

Similarly, in speaking with professionals from various HIV treatment and care sectors, experiences (or issues) affecting people's engagement inherently risk a level of (mis)interpretation by the professional, or reporting of a distorted (or partial) reality of the person's lived experience.

With a small sample size of people living with HIV, and a degree of reporting 'by proxy' by professional contributors, the reporting should be recognised as an account and analysis of experience rather than an attempt to create generalisable fact. Nevertheless, the willingness of people living with HIV to discuss the prospect of HIV treatment in the context of their wider lives, and the participation of a range of professional participants from across services and sectors, has provided rich, valuable insights into the reasons for non-engagement with services and how in turn, services might seek to respond.

2.5 Use of quotes

All people living with HIV who have contributed to the study have been guaranteed anonymity. Direct quotes from people living with HIV used in the report are identified as such but no further individual or identifiable information is given. Although professional colleagues who have taken part in the study have been named in appendix 1 it was agreed that no individual's views, nor any direct quote, would be attributable to contributors. In order to give some context to the use of direct quotes from professionals when quotes are used they are identified by sector as one of the following: *Clinical Service* (meaning specialist clinical HIV service); *Voluntary Sector*; *Non Specialist NHS Service*; *Statutory Sector*.

3. Findings: Specific factors in the lives of people living with HIV and how they can impact on engagement with specialist clinical HIV services

This section of the report describes specific factors in the lives of people living with HIV which professional interviewees and/or people living with HIV (service users) themselves have identified as having an impact on how individuals, groups or communities are attracted to or retained in specialist clinical services. Throughout the reporting of views it is stated when contributions have come from professional interviewees or from people living with HIV. The contributions of professional colleagues account for most data collected and so in many instances it is professionals from across services and sectors who are reporting on the experiences of people living with HIV with whom they have service provider/service user relationship. The following issues and areas are discussed:

- Mental Health, personal support and stigma.
- Knowledge, attitudes and experience of ART.
- Ethnicity, culture and faith.
- Migration/political status.
- Substance and alcohol misuse.
- Information and communication issues.
- Locality/geography.
- Poverty and employment.
- Being in prison.
- Caring responsibility/childcare.
- Other conditions or ill-health (Co-morbidity).

3.1 Mental health, personal support and stigma

Discussion of mental health¹⁰ was prominent in interviews with professional contributors and with people living with HIV about what might impact on how the person living with HIV is attracted to or retained in specialist HIV clinical services. Professional interviewees identified mental health as a relevant concern across those groups or communities most impacted upon by HIV and reported that mental health problems may have been an issue since diagnosis, or may relate to earlier trauma in childhood or as an adult, for example in relation to the reasons the person may have had to flee a country of origin. One professional interview said:

‘If we’re thinking about people who have trouble attending sometimes it feels like every single patient, the most chaotic, have mental health issues and that’s what’s impacting’. (Clinical Service)

Interviewees living with HIV described concerns about mental health relating to both points of diagnosis, attendance for/undertaking treatment and longer term coping with their HIV status. One contributor said:

‘At first I didn’t take anything in. I felt ashamed, just wanted to chop my balls off, to protect me and everyone else. I was disgusted, scared, suicidal. The medical people were supportive, you get to know people. But eventually I had a nervous breakdown. I wrecked my house, drank a lot, none of it characteristic, so eventually I asked the GP for help. The GP got back in touch with (*clinical service named*). I go to counselling there. And gave me anti-depressants. It was these things I needed’. (Person living with HIV)

Both professional interviewees and people living with HIV identified that reactions to a positive diagnosis can include:

- *Shock*, so that the person cannot believe the diagnosis. In such circumstances interviewees reported that delivering post test counselling at this point may not be useful as the person is not accepting of the diagnosis and not yet processing what this means to them.
- *Denial*, so that the person hears the professional say they are HIV positive but they feel okay and may judge they do not need to connect with services. One contributor said: ‘Denial is important. If people start treatment, it means the clock is now ticking. People are not willing to face up to their illness’. (Clinical Service)

¹⁰ In the context of this study mental health is used as an umbrella term to refer to both the concepts of mental health problems (such as a mental illness or symptoms which interfere with emotional, cognitive or social function which might include problems such as depression or anxiety) and mental wellbeing understood as positive mental health or wellbeing (which might include a sense of control, having a purpose in life, a sense of belonging and positive relationships with others). More on these issues of definition are included in the publication ‘Mental Health Improvement Terminology and Working Understandings’ from the Mental Health Improvement Group NHS Health Scotland at <http://www.healthscotland.com/uploads/documents/13619-Terminology%20and%20Working%20Understandings%20-%20Final.pdf>

- *'Over-reaction'*, so that the person sees knowledge of their HIV status as a death sentence and cannot cope with the information or see a way forward in terms of treatment and care.
- *Anger*, so that the person has strong emotions toward a person they identify as perhaps responsible for becoming HIV positive. For one professional interviewee there was a need to recognise that following a diagnosis: "There is an aftermath" (Clinical Service).
- *Loss/Grief* can be experienced, perhaps for the life desired or expected and which the person can now feel has been taken away from them.
- *Flight*, so that on diagnosis a person can respond by wanting to get away from the place they live, wanting to be anonymous elsewhere, hoping that no-one will know or guess their status. This desire for anonymity and not wanting to recognise their status can mean re-engagement with a service in a new locality is avoided.

When it comes to maintaining attendance at a clinic or adhering to treatment professional interviewees and those living with HIV also reported that mental health problems can arise from:

- *HIV treatment fatigue* so that the person feels that enough is enough; they can no longer find the energy or commitment to a regime which feels overwhelming.
- *Guilt about being HIV positive and surviving* particularly where many people close to the person may have died.
- *Taking medication because the doctor wants you to* rather than believing in the value or importance of adherence.

In terms of mental health and managing HIV in the longer term one professional contributor said of patients:

'They can be ambivalent, may stop taking medications, they don't know if they want to live or die, regardless of other characteristics. The model we follow is a health one; we forget the emotional impact of getting HIV'.
(Clinical Service)

The need to recognise past experience and the interface with HIV diagnosis and how the individual lives with HIV was described by one professional contributor as the need to remember that: 'People have a story' (Voluntary Sector).

A concern for professional interviewees and those living with HIV was that where a person struggles with their status then engagement with clinical services can be a constant reminder of that status. On occasion this can mean that the person can be angry or upset by contact with the person who gave them their diagnosis, or the very need to adhere to medication can be a constant reminder of their HIV status or of past events.

Professional interviewees were also concerned about individuals whose depression or anxiety had not been formally identified or diagnosed and so for whom current mental health is not adequately addressed. One contributor said:

'Those who are low – depression, anxiety, isolated - and don't come, they can be under the radar.' (Clinical Service)

Finally, professional interviewees also highlighted a positive aspect of mental health and wellbeing with the view that with advances in drug treatments many people have responded positively to the possibility of managing their HIV in the longer term. One contributor said:

'The majority of patients feel very thankful to be alive; people never thought they would have a future. This has a positive impact. They come into the clinic three times a year, they can engage in other activities, especially an older cohort, to whom this is all routine.' (Clinical Service)

With mental health viewed as a core issue regarding barriers to engagement with services, interviewees (both professional and people living with HIV) reported personal support (or lack of it) as a key concern for the HIV positive person. Isolation is viewed as a result of the responses people fear about their HIV status and so they do not make or feel able to make friendships and relationships. In terms of sexual relationships interviewees recognise significant fears about disclosure and rejection. It is also recognised that tiredness and a lack of energy will impact at times on the individual's ability to make or sustain relationships and friendships; particularly if their HIV status is not shared.

Professional interviewees highlighted that people can be so anxious about disclosing their status that they can be living with a partner or other family member who is also positive but not know this. Each then lives in isolation.

Interviews with people living with HIV also highlighted the impact of an HIV diagnosis on loved ones and the isolation which can follow diagnosis. Interviewees described how disclosure of their HIV diagnosis and using services/treatment had impacted on family relationships, and the experience of isolation.

'Your family takes a lot of the anger, you lose them'. (Person living with HIV)

'HIV just finished the marriage, so that's all my support gone'. (Person living with HIV)

'My overriding question was "what have I done to my family"? I still ask this, for 10 years'. (Person living with HIV)

'It's not nice to be observed, monitored; [it] feels calculated and faceless. This on its own isolates you'. (Person living with HIV)

For one interviewee living with HIV in the long term a failure to understand and tackle the experience of isolation is a key failure of service responses to HIV. The interviewee said:

'What's the learning? What was valued as a result of all that dying? You have long terms survivors living in isolation, not as courageous strong

individuals, now just never acknowledged or recognised'. (Person living with HIV)

For people living with HIV retaining control over who knows their HIV status is crucial although for some there is a pressure (in the context of increasing discussion of HIV as a long term manageable condition) to disclose status, perhaps as a way to 'normalise' views of HIV. One contributor said:

'It irritates me that everybody should disclose. Whose business is it? Everybody has different circumstances, families, relationships. Living with it on the inside is different from living with it on the outside as a professional. You shouldn't expect positive people to tackle stigma by disclosure'. (Person living with HIV)

The need to control who knows about the individual's HIV status is driven largely by the stigma and discrimination which are viewed as powerful influences on the experience of 'being HIV positive'. Both stigma and discrimination are also reported by both professional interviews and those living with HIV as an influence on engagement with services; both are seen as real experiences but predominantly their impact is most powerful in terms of the person's fear of their effect on life. For interviewees living with HIV there was a shared view that knowledge of HIV status was something to be guarded about. Interviewees living with HIV said:

'Me being open about my status is my choice but if I did have something to lose I'd be careful. People can get something on you'. (Person living with HIV)

'Stigma doesn't worry me now but it did when the children were younger. I was aware of (voluntary sector agency named) since the year dot, but wouldn't use the drop in for fear of meeting someone, someone's mum or dad, for the kids' sakes I held back, because of stigma.' (Person living with HIV)

In relation to stigma professional contributors identify its powerful impact on some as the key issue to service access and retention, whilst for some although important it can be addressed through good information and assurances about practices of confidentiality and anonymity. Contributors said that:

'It's the key barrier to care'. (Clinical Service)

'People are generally scared'. (Clinical Service)

'Rather than leading to non-engagement, it leads to people wanting to make arrangements to safeguard their confidentiality'. (Clinical Service)

A key issue recognised by professional interviews then is that of confidentiality and the need to ensure in a service setting the service user's anonymity is maintained. Both professional interviewees and those living with HIV recognised a particularly difficult point of service provision is at reception and in waiting areas where practices (for example, saying the person's full name in a waiting room) and fears of disclosure

of identity can lead to people being over anxious and cause conflict in consultation/interaction with clinic staff.

Professional interviewees identified the importance of personal feelings of shame about HIV status and linked this with fear of stigma. Interviewees reported that where a person's anxiety is heightened it is a concern that they can overly worry about confidentiality or anonymity or misinterpret the practices of a clinical service.

Professional interviewees and people living with HIV reported examples where discrimination against HIV positive people has been real. For example where the participation of positive people in a smoking cessation programme was challenged because they would breathe into machines testing lung capacity which other patients would then use; in employment where a client had disclosed HIV status after being told he had a job, to be told days later this was no longer the case. One interviewee reported experiences of the impact of laws around criminalisation of transmission and demonisation by the press. Another reported verbal harassment and attacks on property which resulted in having to move home.

Professional interviewees from the Voluntary Sector reported that service users have reported stigmatisation where staff within clinical specialist HIV services are experienced as unfriendly when they are aware of the patient's previous drug use. However this is contrasted by other experiences where service users report positively that fears of such judgemental attitudes have not been their experience. People living with HIV also worry about stigma and discrimination within clinical and voluntary sector services; one contributor said:

'You can feel it in (*clinical service named*) and even in (*voluntary sector service named*); people get to know you, they ask you questions. HIV means certain labels like about your sex life'. (Person living with HIV)

Professional interviewees and those living with HIV identified that whilst HIV clinical services can easily be identified for the most part as 'gay friendly' it is important to remember that for some gay men the double stigma of being HIV positive whilst also coming out to others about their sexuality may be overwhelming. Interviewees living with HIV also reflected both on this 'double stigma' and on stigma experienced by HIV positive gay/bisexual men within the LGBT community, illustrated below.

One heterosexual man living with HIV reported:

'People look at me differently when they know. Then for heterosexuals there's this stigma about being worried that people will think you're gay' (Person living with HIV)

One gay man living with HIV reported:

'You still get a lot of nasty stigma on the gay scene. It's abominable. You'd think they'd know what it means. Even positive gay guys discriminate against positive guys. It makes it hard to trust people and form relationships'. (Person living with HIV)

Finally many interviewees highlighted the specific issue of stigma amongst African communities; this is returned to shortly.

3.2 Knowledge, attitudes and experience of ART

Professional interviewees recognised that knowledge about, or attitudes towards anti retroviral therapies are informed by a number of things.

In terms of side effects clinical service providers recognised that some anxieties about ART are based on possible side effects (for example impacts on memory, diet, physical appearance or incontinence) and some on fears or misinformation.

Professional interviewees recognised that some people who have had a partner or friend who has had to manage medication in the past might be led to think the treatment course remains the same, when in fact the medications have changed and when individual responses to the same do differ. Professional interviewees reported that a fear of the side effects of ART might influence people's willingness to find out their status when they may be ill and suspect they are positive.

Professional interviewees who provide support to positive people considering or starting treatment report that some do not feel listened to when they try to talk about concerns. Voluntary sector interviewees report that when they accompany a person to a consultation the positive person reports that medical staff listen more to them and are more likely to discuss concerns. One contributor said:

'Some clinicians brush off side effects, they don't listen to patients'
(Voluntary Sector)

Professional interviewees recognise that a failure to communicate about early or ongoing fears and experiences can mean that HIV positive person tells the clinical service they are taking their medication when they are not.

Linking to earlier discussion of the importance of mental wellbeing, professional interviewees and those living with HIV report that taking medication can feel like relinquishing control to doctors and to HIV and that routinely taking medication is a constant reminder of an HIV positive status. For some people there is also an imperative to hide status by looking well, avoiding ill-health and taking treatments secretly. Contributors said:

'The problem with HIV is it's never ending. We're in it together so we need to work it out. They can't push me into treatment because there's no way back from that, it would be lifelong, it takes away my choices. It's not good to feel you have no choices and you're just in a situation'. (Person living with HIV)

'It can get so bad some nights you just think "I need a break". Making the choice to take a break eases the pain'. (Person living with HIV)

'I haven't told anyone. I work with all males, being ill isn't an option'.
(Person living with HIV)

Professional interviewees also recognised that stopping or ‘taking breaks’ from treatment can help the individual regain control despite the negative consequences which the health professional wants them to understand. In relation to treatment adherence one interviewee living with HIV said:

‘I don’t stick to the ART regime, I use alternatives. I had a year off last year; they don’t like it but they do recognise it’s my decision. The drugs alleviated fears but just added to the symptoms so I play with the doses. We’re a cohort of needy, fearful people. In the early days I handed my power over, they gave me back hope and side effects’. (Person living with HIV)

A concern for professional interviewees however is that, for some people living with HIV, stopping treatment can be linked to mental health problems. One professional contributor said:

‘Not taking medication is a way of punishing themselves, they feel they don’t deserve to be well, and then we don’t see them until they feel very unwell’. (Clinical Service)

This issue of choice not to attend services/adhere to treatments was a significant dilemma for professional interviewees who were clear that this is a matter where individuals need personalised responses from services. While one professional interviewee expressed a concern that too much time and resource is spent on keeping irregular or non-attendees engaged with a service, for others HIV requires a focus on the individual that needs to be persistent and personalised, not just for their treatment and care but because HIV presents a special public health challenge:

‘Our public health responsibility makes this condition different. If their viral load is high and they’re having sex we need to do as much as we can’. (Clinical Service)

While recognising the need to understand the mental health and other concerns or pressures a person may be under, professional interviewees also reported that there is a need to respect the individual patient’s decision not to attend specialist clinical services or adhere to treatment. Contributors said:

‘We have to accept that patients have a right to informed choice – sure we will work on an issue but still it’s their right. Through support we can explore and identify issues that the patient and doctor can then discuss, understand concerns, but we respect their choice, it can be challenging’. (Clinical Service)

‘There’s a risk of pathologising people – that they are the problem. Some people will have specific health, perhaps mental health issues, but others are making what they see as rational decisions’. (Voluntary Sector)

3.3 Ethnicity, culture and faith

Issues of ethnicity, culture and faith were viewed by professional interviewees as a strong influence on attendance and treatment adherence for HIV positive people of African origin. While it was stressed that it is important to see African people as a heterogeneous group there are a range of issues relating to ethnicity and cultural or religious practices which were reported by professional interviewees as influences on attendance and engagement with clinical services as follows:

- People may not have an understanding of the NHS and how it works; they may have no-one to help navigate them through who does what, where and why.
- People of African origin may not see engagement with services in terms of prevention. Culturally, and because of the cost of health services in their country of origin there may be a view that you go to hospital/doctor when you are ill. An important consequence of this for HIV testing may mean that individuals only test positive when they are ill.
- Interviewees report that people of African origin can fear the response they will get from health professionals when they want to talk about religious/cultural issues; suspecting that health professionals will dismiss or react negatively to the way they think about HIV, influenced by information and messages they get from faith leaders or other community members. For example the newly diagnosed person might believe HIV is a punishment or that prayer will cure them. If these experiences or beliefs are dismissed outright, communication between the patient and clinician is undermined.
- Misinformation can abound in some communities where being HIV positive is a judgement on behaviour, where there is a mistrust of treatments, where information about current treatments is inaccurate (and based on experiences of poorer treatments in a country of origin) and where a service's commitment to confidentiality is not understood.
- Professional interviewees also report that the behaviour of people of African origin can be misunderstood; for example a person who does not maintain eye contact as a matter of respect can be misunderstood by a practitioner in the UK as being disrespectful or inattentive, or the difficulty an individual might have in keeping to fixed appointment times when culturally this has not been a norm for them.
- A specific issue indentified for some people is the taking of blood and feelings that when this is painful the health professional means to hurt them.
- Professional interviewees also highlighted the fact that people of African origin may have seen many friends and family members die and that such experiences can leave the person with a pessimistic view of life with HIV and the relevance or viability of anti retroviral therapy.

Voluntary Sector contributors report HIV positive people being excluded from or having to leave their faith community because their HIV status becomes known. Professional interviewees have concerns about the role of faith leaders who offer a cure for HIV through prayer or who dissuade individuals from using HIV services or anti retroviral treatment.

Professional interviewees expressed a range of concerns about engaging women of African origin who are pregnant and HIV positive with concerns about the dispersal

of women who are asylum-seekers late in their pregnancy, moving them from other supports. There are also particular issues for women of African origin who find out their HIV status when they are pregnant. This can have significant negative impacts on primary relationships which can end as a result of knowledge of their status, leaving them isolated and coping both with a diagnosis and pregnancy. Professional interviewees report that fears remain amongst women of African origin that engaging with services early in their pregnancy, and receiving a HIV positive diagnosis, means they will be convinced or forced to terminate the pregnancy.

In terms of pregnancy professional interviewees also reported that women of African origin can fear that engaging with NHS services will lead to deportation. Women may know however that at 32 weeks pregnant they cannot be deported and so engage with antenatal services at that point, however presenting then, and being diagnosed as HIV positive, means it is too late to start anti retroviral therapy to protect the foetus from HIV infection.

Professional interviewees identified issues in providing interpreting services for minority groups. They identified increasing demand which needs to be met by professional services rather than friends or family members who can mistranslate, use the power of their position to judge the patient or breach confidentiality.

Professional interviewees identified the need for continued work on HIV education for people of African and Indian/Pakistani origin where regular contact with countries of origin takes place and where exposure to the virus can be a risk.

Finally, professional interviewees also raised concerns that white indigenous Scottish and heterosexual people living with HIV can feel 'there is nowhere to go' (Voluntary Sector) for support and information as services, particularly in the Voluntary Sector, are focused on gay/bisexual/MSM and African communities.

3.4 Migration/political status

Professional interviewees report that registering with GP services can be difficult for individuals without leave to remain. Voluntary sector interviewees report that some GP practices ask for passports or proof of address and as a result people, including those who may be unwell, can be unable or frightened to register and so fail to access primary health care. Professional interviewees report that there is a fear amongst asylum seekers of having to pay for health services generally but for HIV treatment and care specifically.

Professional interviewees report that people who are asylum-seekers fear that their engagement with a health provider, including HIV clinical services, will be reported across official agencies including the Home Office. While interviewees from HIV clinical services and Voluntary Sector agencies report they inform people this does not happen they suggest this should be reinforced at all points of contact with people.

Interviewees recognise that people with migration issues are often very mobile and that personal circumstances can be stressful. Contacting people with changing addresses and mobile numbers can be difficult. When this coincides with an HIV

positive diagnosis, particularly a late diagnosis when the person is unwell, this can be a real challenge in terms of making and maintaining contact with HIV services.

Professional interviewees highlighted the diverse nature of people who have come to the UK; some people may have complex and traumatic experiences but others, most likely from other EU and non EU European countries will often come to study or to work and whilst they may have some difficulty understanding and accessing services their needs may be better met with provision of good information and signposting.

Professional interviewees reported that there are complex issues for people who are detained or who fear deportation. One issue can be access to treatment where the person is detained without notice, again being detained can separate the individual from their medication which may be at another address, it is also possible that an individual can be in treatment in Scotland but moved out of Scotland to be detained and at that point it is not known whether treatment will be continued. There are also issues in terms of the choice to start treatment. Clinicians report that guidance is provided that they should not start a patient who is likely to be deported on ART. Clinical services report this is not followed, and that decisions are made on patient need in negotiation with the individual. There are concerns that with increasing numbers of people whose status is unknown or who are at risk of deportation that guidance about not providing a service for a person with no entitlement to free health services or accessing treatments may be enforced. One professional interviewee expressed a view as follows:

‘I don’t ask about ethnicity or visa status data. I don’t want to be in a situation where I have to make choices. It doesn’t make sense to leave a person untreated and infectious. So it’s an unspoken agreement – people know we won’t ask. But I’m worried the system will come back on us – enforce ‘no entitlement to funds’ (Clinical Service)

3.5 Substance and alcohol misuse

Professional interviewees identify that substance and alcohol misuse impact significantly on engagement with clinical services.

While the number of HIV clinical service attendees who are currently intravenous drug users (IDUs) has dropped (although a significant number of patients who were IDUs do have ongoing problems with opiates) alcohol and recreational drug use remain a concern. Professional interviewees reported that for some individuals ART adherence is seen as less of a priority than recreational drug use. Alcohol misuse can mean chaotic lifestyles and difficulties with maintaining appointments and treatments. Interviewees report that drug and alcohol problems can result in psychoses which make treatment and clinic attendance difficult. Across professional interviews it was recognised that to support clinic attendance and adherence to treatment there is a need to address substance misuse and alcohol issues; however there are concerns that generic drug or alcohol services might not understand the HIV related needs of the individual or that the person living with HIV may have some anxiety about generic services and their understanding of and attitude toward HIV. One professional interviewee stated:

‘Alcohol equals chaos. This is where failure is more likely. People with alcohol issues do very badly with HIV. We try to signpost to generic addictions services. It’s not easy’” (Clinical Service)

3.6 Information and communication issues

While contributors recognised that service users are given a lot of written and verbal information, particularly in terms of treatment, few interviewees raised learning disability as a matter for consideration in how a person might be attracted to or retained in specialist clinical services or manage adherence to ART. One interviewee highlighted particular concerns for the person who may have never had an assessment, but whose mild learning disabilities will impact on awareness and understanding of services and management of their HIV.

Professional interviewees have identified that literacy problems, whether an inability to read/write or a learning difficulty such as dyslexia, make it harder to access and understand the information required to be able to access services, utilise what is available and understand and manage treatment options. This in turn was seen to undermine the patient’s sense of self-efficacy and management of their HIV. Interviewees identified that HIV is a condition which requires the patient to take and process a great deal of information, much of which can be in written format. Often a significant amount of information is given on a positive diagnosis when the person (and their ability to understand and utilise information) may not be known to the clinical service.

Professional interviewees report that it is difficult to know or ascertain the person’s literacy levels and where people know they have a problem it is suspected that they can be embarrassed to say.

It is thought that information about medication can be at too complex a level for many people and that if they cannot understand what is given to them they do not know what questions to ask.

Professional interviewees identified that a lot of information about living with HIV and treatments is well written, with stories that people relate to, but that with so much information available on-line it can be hard for some people to distinguish between helpful and inaccurate information.

3.7 Locality/geography

Professional interviewees identified that travelling to services is a significant challenge for people living in rural/island communities. In particular the use of public transport can mean, for some service users, travelling for 2 to 3 hours and using several buses.

While it was recognised that long distances travelled for short clinic appointments can be exhausting and impact negatively on attendance it was also recognised that to protect confidentiality and anonymity HIV positive people living in rural settings may choose to attend city/urban clinics. One interviewee living with HIV said:

'In a small rural community it's important people don't know I'm HIV positive. This is a massive issue. People can't find out. Stigma is dangerous to you and your family'. (Person living with HIV)

Clinic staff report that travel costs can be met but this is dependent on individual staff informing the service user of this option or on them asking.

Professional interviewees identified that there are now occasions on which service users have been told that they cannot attend a particular clinic because their home address is not within the NHS Board providing the clinic. It was assumed that this was because Health Boards do not want to assume the care and the associated costs of treatment for those not resident in their area. Professional interviewees expressed concern that where patient choice to use a specialist clinical HIV service were informed by the desire for confidentiality/anonymity and a resultant (perceived or actual) necessity to travel, a denial of service in another area might mean an individual can be lost to services. Interviewees working in clinical services report that arrangements can be made so that a Board will pay for a resident using another Board for HIV clinical services, recognising that the service there is more able to meet needs. Practice in this area appears to be decided locally.

Some clinical service providers recognise that larger/urban centres are more able to provide a breadth of services; so that time with the Consultant can be supported by access to counselling, dietician or pharmacist. In such instances a balance needs to be struck between what the individual patient is able to manage in terms of travel and their needs for a broader, more holistic 'one stop' service.

3.8 Poverty, employment and benefits

Professional interviewees identified that maintaining a connection with clinical services is impacted upon by poverty. Particular issues for the individual can include travel costs or loss of earnings. In terms of some people living with HIV professional interviewees reported a fear of disclosure of their HIV status can mean that people will not follow up extra benefit or housing entitlement with the relevant government or advice agencies.

Professional interviewees expressed concerns about the rate of unemployment amongst HIV service users and the associated challenges they face living on benefits.

Professional interviewees reported that on hearing a positive diagnosis people can stop work; that despite treatment options many still 'hear' the diagnosis as impacting negatively on their ability to maintain their life as it is.

From their engagement with HIV positive people, professionals view a range of experiences when it comes to the HIV positive person in employment. They report that some people work in jobs/sectors where employers are flexible and unquestioning when it comes to attendance at medical appointments or during periods of ill-health – but many others do not. Working shifts or in jobs where absences or time out for clinic appointments are challenged makes managing HIV and attendance at clinical services more complex.

Professionals recognise the importance of the choices a person makes about disclosing HIV status at work. Interviewees living with HIV and professional interviewees gave accounts of people losing jobs, being refused volunteering opportunities or having their status declared to others by employers or colleagues.

It was also reported by professional interviewees that some people use their work 'to disappear into' (clinical service provider) so that being immersed in work helps them to be less focused or preoccupied with their HIV status. One consequence however can be that people lose contact or irregularly attend clinical services.

People living with HIV report new challenges in terms of living with HIV and pressure to reduce benefits and return to work; this is particularly challenging for people living with HIV in the long term and has consequences for broader issues of health and wellbeing and treatment adherence. As this report is published HIV Scotland is collecting responses on behalf of HIV voluntary sector agencies in Scotland to enable National Aids Trust (NAT) to document the impact of the migration from Incapacity Benefit (IB) to Employment and Support Allowance (ESA) upon people living with HIV across the UK.

People living with HIV reported as follows:

'You hear 'we'll get them back to work'. For 20 years you told me I was going to die then you tell me to get a job. I lived with the fear, did the voluntary work, educated myself and others to live and die with it. I went back to study. Who's going to help me manage work?' (Person living with HIV)

'I'm half way through my Hep C treatment, keeping to my HIV treatment, and I've just had my benefits slashed. They've pulled the plug on me even though I could be a success story. I was at my GP yesterday and the benefit agency hasn't even been in touch, seems like an arbitrary decision, people could die because of their actions. I'm capable of communicating and getting help but its clear there's no interface between agencies'.
(Person living with HIV)

3.9 Being in prison

Discussing the experience of male prisoners professional interviewees reported that prisoners who are HIV positive are "in a very vulnerable place" (Non-specialist NHS Service) identifying that prisoners may fear being identified as gay and/or positive or that imprisonment itself might impact on attitudes towards treatment adherence. One interviewee said:

'I went through a bad patch, saw no point in continuing ART. I had been charged, was on remand in (prison named), and stopped taking ART'.
(Person living with HIV)

In terms of clinic attendance or treatment men may be resistant to disclosing status (if known before they entered prison) and so are vulnerable to falling out of engagement with specialist HIV services. Professional interviewees reported that as a prisoner must ask for access to specialist HIV services they may take time to

establish whether staff within the establishment or health professionals can be trusted to manage information of HIV status in confidence.

Where prisoners move between prison establishments professional interviewees reported that communication with specialist HIV services can be poor and so the clinical service itself needs to be proactive in tracking and continuing engagement.

Professional interviewees highlighted the current changes to health service management in the Scottish Prison system with the shift toward direct provision/management within the NHS and that this should be an opportunity to promote improved engagement with services.

3.10 Caring responsibilities

Professional interviewees people living with HIV identified a lack of recognition that some people living with HIV will also be a carer for a partner, family member, child or friend and this may impact on both physical and mental health and wellbeing and potentially on their ability to engage with clinical services and manage treatment. This can be particularly so when a partner is also living with HIV or has died. One interviewee living with HIV said:

‘I had been rigid in my attendance and adherence to treatment but it became difficult because of the care. It became intermittent and then it stopped. I felt it wasn’t right to go back. Time passed, I wasn’t really conscious of that, I was trying to rationalise it, but the reality was I was depressed, trying to deny my status after he died, I didn’t care if things got tough, too bad. Treatment was just a reminder of my status.’ (Person living with HIV)

Childcare is seen as a barrier to engagement with services for a small number of women. Interviewees reported that carers of children under 5 years old may have to take them to the clinic and into the examination room.

Professional interviewees also reported fears amongst some HIV positive women that where services know of their status this might influence decisions made about child welfare. Interviewees with an interest in family and social welfare issues report a lack of support offered to parents who are HIV positive to help them in their parenting role.

3.11 Other conditions or ill-health (Co-morbidity)

The 2009 ScotPHN report *Treatment and Care Needs Assessment: People Living with HIV* recognised that: ‘As morbidity and mortality from opportunistic infection becomes rarer (again as a result of ART), patients are likely to suffer ill-health from a number of chronic diseases, for example: cardiovascular disease or cancers - both of which are being seen increasingly’. Professional interviewees in this study confirmed that when health deteriorates clinic attendance is difficult; highlighting that for some individuals poor memory, tiredness, weariness, general feelings of being ‘wiped out’, and mood swings can be a cause of non-attendance. Professional interviewees identified the importance of ongoing monitoring of HIV related and other conditions to ensure that appropriate support is available to support clinic attendance.

For people living with HIV it is important that in the treatment of other conditions there is a good understanding of HIV but that treatment of other conditions is undertaken in a holistic way. Discussing the management of diabetes one interviewee living with HIV said:

'It's important to see an HIV based dietician, I would go somewhere else but only if I felt comfortable and they had the knowledge about HIV, otherwise I'd think twice'. (Person living with HIV)

4. Findings: Supporting engagement with services

This section of the report describes actions which support the engagement of people living with HIV with specialist clinical HIV services; a number of factors are also identified which can work against engagement. Across engagement with people living with HIV and with professionals the study has aimed to explore 'the journey' which an individual with an HIV diagnosis may have had and so this section of the report considers awareness and knowledge of testing through diagnosis and treatment, with issues around retention in services and adherence to treatment also considered.

Throughout the reporting of views it is stated when contributions have come from professional interviewees or from people living with HIV. The contributions of professional colleagues account for most data collected and so in many instances it is professionals from across services and sectors who are reporting on the experiences of people living with HIV with whom they have a service provider/service user relationship.

Reporting is organised and makes recommendation around the following issues and areas:

- Awareness and knowledge of HIV testing services.
- Testing and results: points of first engagement.
- The experience of attending the clinic.
- Building patient-practitioner relationships.
- Starting treatment and adherence.
- When a person fails to attend.
- Working with the Voluntary Sector.
- Working with GPs or non specialist NHS services.
- Working with other statutory services.
- Policy, service design and capacity issues

4.1 Awareness and knowledge of HIV testing services

Contributors have identified certain actions around awareness and knowledge of HIV testing services which support engagement with specialist clinical HIV services when an HIV positive result is confirmed:

4.1.1 Improvements in information provision about HIV testing

Professional interviewees identified that by working together clinical services, non-specialist services and Voluntary Sector partners had brought about improvements in information provision; this included the importance of knowing your status and where to go for a test. It was also stated that the provision of information in minority/community languages and the provision of information on-line were helpful.

4.1.2 The value of promoting regular sexual health check-ups

Professional interviewees highlighted the importance of promoting check-ups and identified that actions in this regard had been particularly successful with regard to gay/bisexual men, particularly men aged 30+. Whilst welcoming increasing numbers of gay/bisexual men who attend for sexual health check-ups and testing, some interviewees questioned whether this was a broad-based development, and if it was now embedded in the behaviour of gay/bisexual men, or whether HIV testing increases could be accounted for by men who repeat test.

It has also been possible to identify factors in terms of awareness and knowledge of testing services which can undermine post-result engagement with specialist clinical HIV services:

4.1.3 Fear of having a positive result confirmed

Professional interviewees recognised that some people will not engage with services and HIV testing when they suspect they may be HIV positive for fear of having a positive result confirmed. It was thought that this mix of fear and denial could well be because the person knows once a positive result is confirmed there is, so to speak, no way back. (Further issues regarding mental health, personal support and stigma are discussed in section 3.1.1) It was reported that some people will come for a test and then not return. One contributor said:

‘Some people, who are tested, are worried, but don’t want their infection confirmed – they feel once on the wheel they can’t get back off. Some people are scared to hear a positive result’. (Clinical Service)

4.2 Testing and results: points of first engagement

In relation to testing and receiving results, conceptualised as the first point of ‘the journey’ with specialist clinical HIV services, contributors have identified certain actions which support engagement with specialist services:

4.2.1 Availability of testing

Professional interviews identified that same day testing and opt-out rather than opt-in testing in general sexual health screening have enhanced access to HIV testing.

4.2.2 Locating testing in specialist clinical settings

While Voluntary Sector interviewees called for more testing out with formal GUM/ID settings – something they feel is resisted by specialist clinical HIV service providers – in turn specialist providers consider that testing in GUM/ID settings establishes the relationship with specialist clinical HIV services which follows a positive result. One contributor said:

‘If we do the test the connection is established’. (Clinical Service)

Interviewees from specialist clinical HIV services also feel that they have the resource to give time to the patient receiving the diagnosis and the opportunity to access a range of staff, for example counsellors or health advisors, who bring an area of expertise they might need. Further, assessing the individual at this stage allows the team to decide how much information to give and how to follow up. (The impact on the individual of receiving a positive result is discussed earlier in section 3.1). One contributor said

‘Our response depends on the patient. It is very individual’. (Clinical Service)

Professional interviewees from specialist clinical HIV services reported that where HIV testing and positive results are given in other hospital based non- specialist settings, the engagement of GUM/ID staff is dependent on the practice of colleagues in these other clinical settings. Interviewees from specialist clinical HIV services considered that best practice would mean involving them in giving positive results.

4.2.3 Proving personal contact details

It is reported that these are confirmed at the point of giving results; it was reported that it would be very rare for someone to be tested and for clinical services to be unable to contact them in some way. In terms of asking newly diagnosed people for GP contact details and permissions to communicate results and other relevant treatment information specialist providers report that GP contact details are now actively sought and in a majority of cases gained. (The role of GPs and issues around GP involvement in treatment and care are discussed further in section 4.8)

4.2.4 The importance of establishing the relationship with the patient

Interviewees from specialist clinical HIV services identified the importance of establishing a relationship with someone at the key point of diagnosis. This was particularly important for a person requiring immediate consideration of ART. In some specialist clinical settings peer support was highlighted as an available service. (The need to build patient-practitioner relationships is considered further in section 4.4)

It has also been possible to identify factors which can undermine engagement with specialist clinical HIV services at the point of testing and receiving results:

4.2.5 Lack of capacity

In some specialist clinical settings professional interviewees reported there is a lack of capacity to cope with demand on drop-in sessions. This means that some people

are turned away. While it is not known what might have brought the person to the drop-in it is also not known whether or when a person who cannot be seen might return.

4.2.6 Waiting times and a lack of privacy

At the point of testing professional interviewees report that the person can have their first experience of the lack of privacy in some waiting rooms. They might also have to wait for some time or they may have to take time off work. Feelings of stress and anxiety can be exacerbated.

4.2.7 Post result support and counselling

Professional interviewees report a range of concerns about post result support and counselling. In some settings this is seen as poor, in others it is viewed as ineffective because the individual is, at that point, not in a position to hear and understand the support or information being given. It was reported that immediate post result support is reduced in terms of impact or usefulness where it is conducted without an assessment of the individual's immediate reaction, mental health, prior experiences and health beliefs (discussed earlier in section 3.1 regarding general issues of mental wellbeing and with particular reference to people of African origin in section 3.3). Where post result support is poor professional interviewees reported that there are increased risks of immediate loss to services or longer term damage to relationships with the patient. Contributors said:

'They give this immediate counselling and information but it's not effective, it's too early, not effective at this early stage. Follow up needs to come at the correct time for each individual. It's like they do it for everybody in the same way and then blame the individual for not coming back.' (Voluntary Sector provider)

'There's no specialist counsellor. There's an informal agreement with the local psychologist, but it's never used'. (Clinical Service)

'In this one hospital you're given the result, then referred to a counsellor for a brief time, and given literature. It is left up to the HIV positive person to contact anyone else for back up. It's not good enough – no help is offered, for example staff could phone a Voluntary Sector agency for the patient.' (Voluntary Sector)

'Positive people are given a pack of information within a fortnight of diagnosis. This is often binned. There is no second opportunity. We are not convinced this is the optimum time to give such a pack, nor that pack contents are comprehensive'. (Voluntary Sector)

One interviewee living with HIV described the following experience (from 2010) of a lack of post-result support:

'They weren't even looking for HIV, and then suggested I should get a test. I said yes, go ahead. Then they phoned on the Friday afternoon and asked me if I wanted the results on the phone so I said yes. I was totally gutted, just thought I was dead. I told my partner but there was nowhere for her to go for a test then. I went to the hospital, the doctor explained

drugs and managing HIV. It wasn't information I needed: it was a shoulder. I was there for an hour then I was left alone. We were on our own. My advice? Don't tell someone on the phone on a Friday afternoon'. (Person living with HIV)

4.2.8 Professional support for mental wellbeing

Professional interviewees saw value in the provision of peer support but there were some concerns that this should not replace the provision of professional support at key stages, including at point of testing and receiving results.

'Buddying or peer support is good but you need to differentiate between this and the qualified counsellor and support you might need'. (Voluntary Sector)

4.2.9 Managing and updating information resources

Interviewees identified the value of the Connected¹¹ resource for gay/bisexual/MSM but it was reported that this needs updated. Discussion of this resource with Voluntary Sector interviewees also highlighted that it is unclear whether specialist clinical HIV services disseminate resources in a planned way or whether particular information or support materials are dependent on individual clinic staff knowing about them and supporting their use. One contributor said:

'I suspect when the clinic has none left they don't ask for more anyway' (Voluntary Sector)

4.3 The experience of attending the clinic

When it comes to the experience of attending a specialist clinical HIV setting contributors have identified certain actions which support engagement:

4.3.1 Local clinic provision

Where possible, where resources permit, and where there is a large enough body of patients, professional interviewees saw value in providing more localised specialist HIV clinics in NHS Boards where patients might have to travel significant distances. Interviewees recognised that this provision might be less frequent than provided by a central hub, and might be limited in terms of access to other specialists such as Pharmacist or Dietician, but nonetheless welcomed in terms of patient convenience and choice. Providers of such services were also keen to state that patients should be given the choice of travelling to the more central clinic if they want other services or greater assurances of anonymity. (Ways in which locality or geography impact on clinic attendance are highlighted earlier in section 3.7)

4.3.2 Flexible and personalised services

Interviewees working in specialist clinical HIV services described flexible and personalised services which seek to accommodate the individual, particularly those who are extremely anxious about attending or being seen by others. Staff also described approaches such as: accommodating people who find appointment systems difficult by seeing them if/when they turn up; welcoming partners, family

¹¹ Resource available on line at <http://www.connectedscotland.co.uk>

members or friends who are supporting the positive person; meeting patients in non clinical settings. The focus for these staff was clearly on doing everything they possibly could do to keep a vulnerable patient in treatment.

4.3.3 Specialist Pharmacist support within HIV services

Professional interviewees identified that this specialist support was valued by other professionals and HIV+ people. One contributor described the contribution as follows:

'We have specialist Pharmacists; they are good at chatting to patients, giving advice on medication. We have a room in the pharmacy where patients can speak privately to them. It's especially good for 'this is what you do'. It is a very good support for us, and also we can call on the pharmacist to give advice. Before every HIV clinic we have a multi-disciplinary team meeting about the patients coming that day and this includes the Pharmacist'. (Clinical Service)

4.3.4 GP contacts

Clinical services report high rates (85% - 100%) of patients providing GP contact details. This is seen as invaluable in terms of keeping GPs up to date where information is useful for ongoing non-specialist health care, but also invaluable in seeking to re-establish contact with someone who misses appointments.

It has also been possible to identify factors which can undermine engagement with specialist clinical HIV services:

4.3.5 Limited clinic times

Professional interviewees reported that current clinic arrangements can be difficult for some patients to manage. One contributor said:

'Some people have to take annual leave to be here and wait. People don't begrudge that but longer hours would make it easier for some people'. (Clinical Service)

4.3.6 Repeating your story and difficult questions

Voluntary Sector interviewees reported that patients can be upset by staff asking them to repeat information which is distressing; it is reported this has included how they became HIV positive. This kind of questioning can also come from medical students. Both professional interviewees and people living with HIV suggested that practitioners read case notes to garner information before meeting and where information has to be renewed or reviewed they consider the impact questions may have on the individual.

4.3.7 Too much can happen in one appointment

Professional interviewees recognised a dilemma in terms of how much the patient might need or want in terms of information or access to different aspects of a specialist clinical HIV service, and how much they can manage. Both professional interviewees and people living with HIV reported that there can be too many people to see and too much information to take in. People living with HIV talked about the

need for good preparation for clinic visits in order to have questions answered and needs met, but that such pre-consultation preparation can be stressful. One contributor said:

'You need to be prepared for an appointment. I write down a list before I go or you forget or get distracted and you're out the door. But I know that people don't want to think about it, it's an uncomfortable place. You want to protect yourself, don't want to think about it. It can be depressing.'
(Person living with HIV)

4.3.8 The importance of reception staff and waiting areas

Professional interviewees and those interviewees living with HIV were aware that the staff member who presents as the first point of contact matters in every service. Across interviews contributors recognised that reception staff can be both a huge asset to a service – being friendly, efficient and discreet – but on occasion can still be stressed and unsympathetic. The quality of waiting areas in different clinical services varies and while there have been efforts to improve these in many settings some remain cramped and reception areas can lack privacy; particularly when a person's name is said when inviting them to a consultation room. Interviewees reported that a poor initial experience can mean losing an individual to that service. Contributors said:

'I recognise they are busy but they could be warmer, they're doing okay but they're a bit distant, they could smile, it feels like a conveyor belt, you can't forget to see the person'. (Voluntary Sector)

'Feedback is that at specific clinics people are not necessarily discreet. For example they'll say 'oh you are for the HIV clinic' out loud.' (Voluntary Sector)

'They call you by your name, I'm not from here, my name makes me feel like I'm known as an unusual case'. (Person living with HIV)

'People often use the reception test – if they don't pass you don't register' (Voluntary Sector)

4.3.9 Use of translators/interpreters

One interviewee, living with HIV, and who does not speak English as a first language identified the need for translation, particularly when the individual first engages with services and may need to take on board a lot of information and make choices about treatment. This interviewee reported however that use of other clinic staff as interpreters or the organisation of appointments for people who speak the same language at the same time undermines commitments to confidentiality, anonymity and independence of the interpreter.

'Going to the clinic is a risk of disclosure. At one point they were organising the interpreter and putting all the (nationality named) people one after the other so I was even more likely to meet other (nationality named) people'. (Person living with HIV)

4.4 Building patient-practitioner relationships

Continuing the notion of the patient's journey contributors identified certain actions which support engagement with specialist clinical HIV services through the building of patient-practitioner relationships:

4.4.1 A commitment to maintaining individual contact

Professional interviewees recognised the need for individual contact after significant appointments where, for example, treatment options, commencing ART or changes to treatment have been discussed; they reported using the telephone to follow up and check in with the patient. This can ensure that there is not a long period in which the patient has unanswered questions or mismanages or stops taking medications.

4.4.2 The role of the Consultant

Voluntary sector interviewees report the value and esteem which service users have for their HIV consultant; this relationship can represent or define their connection with a service. One interviewee said:

'In the past I had difficulty with one treatment. They made me depressed, I didn't want to take them, I felt bloated, I had to eat when taking them, it was horrid. I thought 'I'm just going to stop taking them'. But I was able to phone the consultant, who said, come in, and he said, stop treatment for a wee while, and he looked for something else. That relationship with the consultant is really important.' (Person living with HIV)

This key relationship was recognised across professional interviews as both positive in the sense that the person wants to be confident and reassured about the quality of the service, and problematic in that it is increasingly difficult for each patient to see the consultant every time they attend the clinic. One contributor said:

'Having a relationship with the consultant is important. It makes people feel cared for. Lots of times people who have to see another consultant are very uncomfortable'. (Voluntary Sector)

4.4.3 Provision of psychological services/mental health assessment and support

Interviewees based in specialist clinical HIV services reported that effective early and ongoing assessment and support around the psychological needs of the patient underpin attendance and treatment adherence. Mental health support can address coming to terms with HIV status, maintaining drug regime, work issues, stigma, relationships and related health issues such as pain management. In some locations opportunities are being provided for staff to take up training on motivational interviewing (a counseling approach which is seen as client-centered and which intends to encourage the patient to decide for him/herself (intrinsic motivation) to change behavior by exploring and resolving ambivalence about an issue – for example attending a clinic or commencing therapy). (The importance of mental health has been discussed more fully in section 3.1)

4.4.4 Annual review

In some specialist clinical HIV services more systematic approaches to annual review of the patients' engagement with and experience of treatment and care is

being developed. This process is described as being independently facilitated by a member of the clinical team but not the lead consultant known to the patient, which it is believed will support the opportunity for the patient to express views on the service.

It has also been possible to identify factors which can undermine engagement with specialist clinical HIV services.

4.4.5 A loss of relationships

For people who have lived with HIV in the longer term there is a sense of loss of the personal relationships which have been built with staff when there are staff changes and when teams grow to accommodate increased patient numbers. Whilst recognising that demands have increased one interviewee highlighted that

“The service has lost something for me. It’s impersonal, but relationships and respect broke down boundaries. Anonymity creates boundaries. It’s like care is withdrawn. (Person living with HIV)

4.4.6 Inadequate provision of psychological services/mental health assessment and support

Whilst on the one hand professional interviewees identified the necessity of psychological assessment and support they also highlighted a lack of resource, particularly in terms of early assessment and the need to focus services on most evident need. Professional interviewees identified that systems and tools may be in place to undertake assessment at key points, including annual review, but this may not happen. Interviewees reported that psychological services and support varies across the country and that while members of the clinic team might be able to give support there may be a lack of staff with appropriate mental health training/qualification. Interviewees were concerned that referral to specialist staff is ad hoc.

4.4.7 The role of the ‘team’ in treatment and care

Interviewees reported that service users would benefit from the development and involvement of the wider clinic based team who know them, in planning and delivering care. One example would be involving more of the team, for example Pharmacist, Dietician or Counsellor at key points such as commencing ART.

4.4.8 Expressing concerns or complaints

Voluntary Sector interviewees expressed unease about processes whereby service users can raise concerns or make formal complaints about specialist clinical HIV services. Whilst recognising the role that external agencies can play in supporting and building relationships between a provider and a patient one contributor described anxiety about complaints as follows:

‘There’s a sense for some people that if you question or challenge you’re labelled as troublesome and your passage through the service isn’t as easy as others’. (Voluntary Sector)

4.5 Starting treatment and adherence

In terms of starting anti retroviral therapy and maintaining adherence to treatment contributors identified certain actions which support engagement with specialist clinical HIV services (For more discussion of these issues see the earlier section 3.2 on knowledge, attitudes and experiences of ART)

4.5.1 Patient involvement in treatment decisions

Professional interviewees reported that service users are more likely to benefit from and adhere to ART if they are central to decisions to commence the treatment. Interviewees identified the time which conversations about starting treatment can take; this can mean that clinicians may start discussions about treatment options long before they are deemed necessary so that the individual has the information and feels that the decision is ultimately theirs to make. Interviewees reported that decisions are influenced significantly by the mental health/mood of the individual concerned and that a patient needs stability in their life in order to maximise benefit and adherence. Once successfully established on a treatment programme interviewees reported that benefits sustain adherence. Contributors said:

'The biggest issue for us is adherence and the biggest obstacle is mood. Depressed people don't take their pills. This needs to be addressed before we can manage their HIV.' (Clinical Service)

'It can take years to engage someone and get them to the point of accepting or agreeing to starting ART'. (Clinical Service)

'Discussion of ART is a key point. You hope you've established a relationship. You try to make it their choice though you do feel you are tricking them. You have to trust your doctor; if you don't believe the information and then there are side effects this feels intolerable. In the context of this relationship the doctor has to ask "have you prepared the patient"?' (Clinical Service)

'Don't start any treatment if any distraction is going on. It's important to get the background of the person stable'. (Clinical Service)

'Treatment should only start when the patient is ready and adherence is most likely. We use our best treatments first. If their heart's not in it and they get partial treatment, it's worse than no treatment because resistance is irreversible, this is a big problem'. (Clinical Service)

'Once on treatment the patient benefits from seeing and recognising progress and so increased CD4 counts, lower viral load, weight gain are all important markers which can be discussed'. (Clinical Service)

Interviewees living with HIV also clarified the importance of their role in treatment decisions. One contributor said:

'A doctor, not my usual consultant, spoke to the pharmacist 'she'll take this at this time, and that at that time'. I got angry. So I got up and said 'No, the drugs have to fit in to my life, not me into the needs of the drug'. I feel because of my involvement with (*voluntary sector agency*), that

empowered me, felt I could challenge that doctor, felt I have a right to challenge, not just accept... My own consultant is always interested in my life. He sees me as a person '. (Person living with HIV)

4.5.2 Links to mental health assessment and support

Emphasising the importance of both assessment and the provision of support to address mental health problems (also highlighted above) one contributor identified the value of good provision in terms of treatment and adherence:

'There is also the stigma associated with poor mental health. We recognise that some people in the past did not get how much mental health was affected by diagnosis. Now we want to do a mental health assessment of everyone. As part of the treatment plan, we can include a psychologist for so many months *before* the patient needs treatment we prepare them to accept treatment'. (Clinical Service)

4.5.3 Personalised support on commencing treatment

Interviewees in a specialist HIV setting reported that reviewing patients lost to treatment revealed that people can often stop treatments after 7-10 days and so rather than waiting to see the patient at their next formal clinic date members of the team now pro-actively make telephone contact and discuss how treatment is going. It is believed this increases patient confidence, provides an opportunity to deal with side effects, prevents treatment failure and supports attendance at subsequent clinic appointments.

4.5.4 Home delivery of ART

Specialist clinical service interviewees reported that for the person who is well and adhering to treatment but finds it difficult to attend clinic appointments it is possible to minimise attendance by providing home delivery of medication whilst monitoring the person at less frequent intervals.

It has also been possible to identify factors which can undermine engagement with specialist clinical HIV services:

4.5.6 Research

Interviewees living with HIV pointed to a lack of research and trials which looked beyond current treatment. This undermined confidence in services. There was a willingness to support such research. Contributors said:

'Leading the world on health care? No. There's no trials, no research. I asked about trials elsewhere, the doctor didn't know about it. He has a talk about the pills, takes more blood then disappears out the door'. (Person living with HIV)

'I was part of a medical trial in the early days... there doesn't seem to be much in the way of hospital research now. Maybe now the medication is so good they just don't need to here?' (Person living with HIV)

4.5.7 Pressure to take ART

Across professional interviews and in interviews with people living with HIV it was reported that the person living with HIV can feel pressure to start ART. It was reported that some Consultants can be driven with the best intention to make the patient well but that in doing so they do not allow the person to make the decision. Both professional interviewees and people living with HIV reported that people living with HIV feel their Consultant can be overly focused on CD4 count and viral load rather than on the individual's health and wellbeing in the round. Professional interviewees also reported that patients can be convinced of the need to start treatment without other significant and likely disruptive issues (such as mental health problems or difficulties with housing) being addressed. For some interviewees, both professional and people living with HIV, the assertion that specialist clinical HIV services help patients to make key decisions about treatment is not evidenced by some practice. Contributors said:

'They wanted me to be healthy but I can manage that. Instead of information I was being pressured; with different versions about the impact of ART and the progress of the infection. I wouldn't trust them. They tell me statistics, that's just statistics; it's not my story... It's difficult to deal with what feels like a whole system – you're not looking for hassle'. (Person living with HIV)

'There can be an obsession with numbers and counts' (Clinical Service)

'People may not have housing, support etc., but still there is an emphasis on getting them treated. An integrated care plan emphasises a personal journey, rather than targets. In one case the Psychiatrist wanted a client not to take treatment until other issues were sorted out, but the hospital treated him anyway and the care plan was ignored.' (Clinical Service)

'The Consultants' focus seems very much to be on ART. They can put pressure on other services to get a client onto ART. The client's choice to say no can be seen as obstructive. There can be a sense that Consultants' input can be highly moralised. Of course there is the drive to make people well again – but it can drive people away'. (Voluntary Sector)

'While there is a theoretical emphasis on the patient deciding for themselves, and discussing treatment, in reality it is the doctor that has the knowledge, patients don't have so much choice. Some voluntary organisations imply that the patient decides, but it doesn't happen. Inside the clinic doctors have their own preferences'. (Statutory Sector)

4.5.8 Mistrust of the pharmaceutical industry

For some interviewees living with HIV there is a mistrust of the drive they feel in services to have people living with HIV on anti retroviral treatments; a concern is that data is shared with pharmaceutical companies and the individual loses control. One contributor said:

'I feel like they want to recruit me as a treatment-naive patient. My results would be reported to the drug company'. (Person living with HIV)

4.6 When a person fails to attend

Professional interviewees in specialist clinical HIV services report that between 15% and 40% of appointments result in a DNA (did not attend). Contributors identified certain actions which as a response to non attendance might support (re)engagement:

4.6.1 Preventing DNAs

Professional interviewees reported several approaches to address the numbers of people not attending. These include: encouraging patients to make their own appointments rather than sending appointments which might not suit them; phoning or texting individuals the day before or morning of their appointment; offering the service user the choice of accessing a different member of clinic staff where there has been conflict between patient and staff member.

4.6.2 Responding to DNAs

The following approaches to follow-up when a person does not attend were reported by professional interviewees: Clinic staff can telephone the individual and ask them to re-arrange their appointment; staff might also contact another agency who is also involved with the patient (if they have previously given permission for contacts) to ascertain how they are and find out if there are current issues which might affect clinic attendance. One contributor said:

‘We follow them up if they don’t attend. We were just on the phone yesterday, to addiction services, about a patient. Through such services we can find out how people are. We pull out all the stops. But we can’t bully folk’. (Clinical Service)

When clinic staff have particular concerns about a person who does not attend, and concerns are heightened when the individual is known to be or have been ill or is likely to run out of medication, then contact might be made with the GP or on occasion, clinic staff might visit the person at home.

‘Sometimes when people are difficult to engage, we go to the home and do bloods at home’. (Clinical Service)

‘The social worker worked very closely with specialist nurses to support people who might be chaotic’. (Clinical Service)

It has also been possible to identify factors which can undermine engagement with specialist clinical HIV services.

4.6.3 Services are reactive rather than proactive

Professional interviewees reported that specialist clinical services could best be described as reactive rather than proactive in their dealing with non attendance. In this sense one contributor said: ‘DNA starts a response’. (Clinical Service)

An interviewee living with HIV who has failed to attend recent appointments described the following circumstance. The interviewee recognised that the clinic is

being respectful of his immediate choice regarding non-attendance but the sense was that he simply wanted someone to ask why:

'There's no contact from the hospital other than to say I've got an appointment the next day. I told them I'm not coming and not to phone me so they haven't. Nobody has asked why. I've got to get through this on my own'. (Person living with HIV)

Responses are ad hoc and often dependent on direction from Consultants:
From professional interviews it is clear that there is no one system in terms of DNAs but rather an ad hoc response dependent on the setting and on one member of the team highlighting that a response is required. Responses seem largely dependent on direction from the Consultant seeking or directing or approving action. It is reported that in some settings a focus on an individual who is not attending (and *not* on ART) might not be a priority until they have failed to attend for one year. For the person who is using ART a focus on non attendance is more explicit as it is known they are nearing the end of their available medication.

4.6.4 Pressure to lower DNA rates

Professional interviewees reported pressure from hospital management to reduce DNA rates in specialist clinical HIV services. There is some anxiety that services will be required to stop sending appointments to those who repeatedly fail to attend and that this will undermine efforts to sustain engagement.

Addressing DNAs without losing patients:

Professional interviewees reported some concern that reactions to patients who do not attend might only exacerbate their loss to the service. One contributor said:

'If we tightened up on DNA it would help – we don't have a stick and carrot – how could we toughen up? We might only affect the most vulnerable and put them off; they need a safety net if we were to be stricter on non-attendance'. (Clinical Service)

4.6.5 Resources to support proactive and reactive approaches

Interviewees from specialist clinical settings reported a lack of resources to utilise new technology such as texting or staff time to follow up all non-attendees by telephone. One contributor said:

'If we had the capacity we could phone everybody who misses an appointment, or we could do more pre-appointment text alerts like a lot of dentists and GPs do now. But we'd need more staff'. (Clinical Service)

4.6.6 DNA leading to discharge from the clinic

One specialist clinical setting reported their response to patients who do not attend after 2 or 3 appointments is to send a letter to the patient, communicate with their GP and then subsequently discharge the person from the clinic. If on ART and they do not attend treatment will stop, this will be explained in the letter. This setting estimates that this is the approach taken with 10 to 12 patients per year.

4.7 Working with the Voluntary Sector

Contributors also explored the role of Voluntary Sector agencies and how this supports engagement with specialist clinical HIV services.

4.7.1 Improving relationships and enhancing understanding

Professional interviewees report that relationships between specialist clinical HIV services and the Voluntary Sector are developing positively. From Voluntary Sector interviewees the sense is that there is still some way to go to maximise the relationship for the benefit of people living with HIV; particularly for people of African origin.

4.7.2 Promoting testing and providing information about HIV, clinical services and ART

Professional interviewees acknowledged the role played by the Voluntary Sector in promoting HIV testing – both in terms of the importance of testing and how to access testing – and in some contexts the provision of up to date information about HIV, clinical services and ART. One contributor from the Sector said:

‘We put a lot of effort into explaining why folk should go to clinic and take meds and we address misinformation and gossip that can spread between HIV positive people about treatments or members of staff in a clinic’.
(Voluntary Sector)

4.7.3 Providing support for individuals

Professional interviewees reported knowledge of a range of Voluntary Sector services which provided support including peer support, buddying, advocacy and practical assistance with accompanying a person to clinic appointments. Interviewees from specialist clinical HIV services acknowledged in particular that practical support with transport and having someone to accompany you can have a positive impact on attendance. In terms of support one contributor said:

‘People need someone to talk to so that the person can work out what they want from their relationship with a service or health professional’.
(Voluntary Sector)

‘Without practical help, some people just wouldn’t get here’ (Clinical Service)

Interviewees living with HIV also pointed to the support provided by the Sector. One contributor said:

‘I was scared to come across other people who had AIDS. When I was diagnosed I wouldn’t have used anything. Then I met other positive people because they helped with the transport (agency named) provided. Then they got me volunteering. Staff were incredible. Now I’ve used them for benefits support, but it’s more than just welfare rights, it was someone to talk to’. (Person living with HIV)

4.7.4 Work with faith leaders

Reflecting on the needs of people of African origin (see earlier section 3.3 for more) professional interviewees reported that Voluntary Sector work is leading engagement with faith leaders (addressing HIV knowledge and their role in relation to support for people living with HIV) and the production of information for people whose faith impacts upon their response to or management of HIV.

4.7.5 A focus on the most vulnerable

Voluntary Sector interviewees identified that their interest and support is often directed at the most vulnerable people who in turn are most likely to experience difficulty with clinic attendance and treatment adherence.

It has also been possible to identify factors which, in consideration of the role of the Voluntary Sector, can undermine engagement with specialist clinical HIV services.

4.7.6 Clinic attendance and/or treatment adherence might not be recognised as a focus for services

While the interest of a specific clinic-based Voluntary Sector service might be on issues of attendance or adherence (see 4.7.2 above), many Voluntary Sector interviewees reported that they just do not ask individuals about their engagement with clinical services unless the matter is raised by the HIV positive person. Interviewees considered that this was not a matter of policy but simply a lack of identification that this was a matter in which they should have an interest or make explicit.

4.7.7 Engagement with the Voluntary Sector is guided by the knowledge or preference of the medical professional

Voluntary Sector contributors reported that whether colleagues in clinical services utilise Voluntary Sector support for a patient can be guided by the preference of the individual practitioner; rather than Voluntary Sector support and services being accessed/utilised as the norm, strategically and as an entitlement. Views of the Sector as a passive partner, dependent on the interest of the clinical provider as gatekeeper are viewed as a block to meeting the needs of vulnerable patients.

4.7.8 Confidentiality seen as a block to Voluntary Sector engagement in specialist clinical HIV service provision

Whilst specialist clinical HIV services engage with Voluntary Sector services in different ways in different locations, professional interviewees have reported that Voluntary Sector providers generally operate at arm's length and are not integrated into clinic teams or their operational systems. From clinic to clinic Voluntary Sector staff may or may not be involved in discussing the needs of service users and referral to a service provided by the Sector is at the behest of the clinical provider. Specifically, professional interviewees based in clinical HIV services cite patient fears about breaches of confidentiality and the desire for anonymity as a reason why Voluntary Sector services/workers are not fully integrated into clinical teams or service provision. In relation of people of African origin one contributor said:

'People say they don't want Voluntary Sector staff in the clinic, they don't want to be seen by people from their own community' (Clinical Service)

4.7.9 Conflict over expectations of the Voluntary Sector role

Although not integrated into service provision the expectation of professional interviewees based in clinical HIV services is that Voluntary Sector agencies will help with attendance and adherence. A view was also expressed that clinical services would like the Voluntary Sector to provide more practical support for patients such as transport, but it is suspected that the sector might want to be more involved in other interventions such as support around mental health, work on stigma or work with communities most affected by HIV including African communities and LGBT communities. One contributor said:

'They can be really helpful with practical supports. But instead it feels like they want to do something more subtle and difficult'. (Clinical Service)

For one Voluntary Sector contributor a view was expressed that:

'They (specialist clinical HIV services) should look to their own practices, we can only help'. (Voluntary Sector)

4.7.10 Ethos and patient choice

For some Voluntary Sector interviewees there is a tension between the ethos or perspective of the Sector's approach to work with people (understood to be holistic, personalised and service user focused) and some practice in specialist clinical HIV services where the focus is viewed as getting the patient to fit into a treatment regime.

4.7.11 Challenging practices and a sense of vulnerability

Voluntary Sector agencies reported feeling vulnerable in their partnerships with statutory services in the sense that they are contracted for fixed periods and feel that if they are perceived to be demanding or critical their services might not be welcome. Interviewees from the Sector reported that a greater integration into clinic based teams would permit a focus on the patient rather than sector differences. One contributor saw the benefit of more formal relationships as follows:

'Advocacy by voluntary agencies is vital, but can be an add on. Relationships between services is good, but perhaps should be formalised in service level agreements. Problematic issues need to be considered more formally, so it's better reported and addressed and change can be tracked'. (Voluntary Sector)

4.7.12 Competition rather than cooperation

While some professional interviewees described a dearth of Voluntary Sector provision in their locality (particularly out with Edinburgh and Glasgow) some interviewees (from across sectors including the Voluntary Sector itself) feared that relationships between agencies in the Sector were characterised more by competition than cooperation. In such circumstances interviewees reported it can be

difficult to ascertain who does what, where, why and most effectively. There were also concerns expressed about duplication of services in some areas.

4.7.13 Fragmentation as a legacy of HIV Voluntary Sector development

Whilst on the one hand professional interviewees celebrated the knowledge and expertise of Voluntary Sector agencies in terms of specific populations most affected by HIV professional interviewees also reported that the Sector can appear to be somewhat fragmented, with agencies focusing on one population where in fact issues and interests may be shared across most affected communities. In the context of increasing diagnosis some professional interviewees reported a lack of targeted Voluntary Sector provision for the population of HIV positive people who are white indigenous heterosexual Scots.

4.7.14 A reduction in provision

For some of the people living with HIV interviewed in the study there is a view that Voluntary Sector provision has reduced and is more formalised and time-limited. One contributor said:

‘I used to be able to drop in at (*agency named*) 3 days a week – you could chill, talk, get information, lunch, just listen, share experiences. It was an opportunity to check out treatments, to hear others, to clue you up. Now it’s just one day and likely to go. You can get formal one to one but it’s the informal, the opportunity to talk... What are we going to end up with? Google? A call centre in Mumbai? It’s a problem, a lot of people who don’t have the ability to find their way through this will struggle’. (Person living with HIV)

4.8 Working with GPs or non specialist NHS services

The relationship between specialist clinical HIV services and non specialist NHS services, including GPs, is examined in this section of the report. Contributors identified certain actions in relation to the role of GPs or non specialist NHS services which support engagement with specialist clinical HIV services:

4.8.1 Relationships are improving

Professional interviewees reported that relationships between specialist clinical HIV services and other NHS services, statutory sector and Voluntary Sector services are, on the whole, developing positively. However this varies, is dependent on location and appears to be driven by the commitment of individual professionals or teams (across sectors) to build awareness and trust. Where good relationships exist it is reported that an improved knowledge of a range of provision subsequently supports a more shared approach to care and treatment for the individual.

4.8.2 A positive intent to support GP engagement, promote shared care and ‘normalise’ HIV treatment

Across professional interviews there was a desire to see improved connections between specialist clinical HIV services and GP services; this was seen as beneficial for the person living with HIV because they would then be able to access local health provision for day-to-day matters not necessarily HIV related. In order to undertake what might be seen as a routine GP/patient relationship in regard to the person living

with HIV interviewees recognised the need to increase GP confidence and competence so that decisions could be made about when to refer back to the specialist clinical HIV service or not. Interviewees reported initiatives to develop a statement of policy regarding what 'shared care' means, commitments to regular communications about treatments and opportunities for training. One contributor said:

'We see HIV now as a chronic illness, and want to normalise it, through being relentlessly normal. In the past, clinics treated everything. Now we should only provide good, appropriate care, and refer to other agencies appropriately, for example GPs. We have to work to make this acceptable. GPs are ideally placed to meet most patients' needs. We are ghettoising HIV patients when we treat them differently from other patients... Chronic disease management uses the model of a pyramid. At the wide base is the GP's work, as it narrows there is a shared approach, GP and specialist, and at the top it is the specialist's work'. (Clinical Service)

It has also been possible to identify factors which, in terms of work with GPs and non-specialist NHS services, can undermine engagement with specialist clinical HIV services.

4.8.3 Difficulties in registering with a GP

Professional interviewees reported that refugees/asylum seekers can experience difficulty registering at a GP practice. Interviewees reported that in some settings reception staff ask for passports and evidence of fixed place of residence before permitting registration; for HIV positive people this raises fears about the State knowing their personal health information and excludes those who may be undocumented migrants or have been refused leave to remain. Interviewees see an imbalance between a humane response to a person needing medical care as well as a failure to consider wider public health issues where the person is HIV positive. (Migration and political status as issues in engagement with services are also discussed in section 3.4) One contributor asked:

'Are they trying to filter out who they might see as difficult or complex patients?' (Voluntary Sector)

4.8.4 Poor prior experience of GP services

Professional interviewees reported that HIV positive people who have been IV drug users or who have experienced mental ill-health can experience GP services negatively where they feel judged and where staff are unwelcoming; this can result in an over dependence on specialist clinical HIV services for healthcare. One contributor said:

'If clients have been users before, and felt stigmatised by those GP services, there's an over-dependence on specialist clinical services and that Consultant.' (Statutory Service)

4.8.5 GPs and HIV testing

Professional interviewees from specialist clinical HIV settings report that some people who come for HIV testing have previously requested an HIV test from their

GP and this has been refused, with the person being directed to specialist services instead. It is reported this can vary within a Practice. Some interviewees suggested GP lack of involvement in HIV testing might in some instances be based on funding issues rather than patient care. In relation to longer term engagement with specialist HIV services difficulties with accessing to testing are considered by professional interviewees to have a negative impact. Contributors said:

'It varies even within a health centre. Some GPs can't be bothered, and some can'. (Voluntary Sector)

'GPs are not paid to test for HIV, but part of their standard screening should include HIV'. (Voluntary Sector)

'GPs might do HIV testing if they got paid for it, it might normalise it in GPs minds'. (Clinical Service)

4.8.6 Patient agreement to providing GP contact details and communication between HIV services and the GP

Although the majority of people attending specialist services provide GP contact information a minority, up to 15% in some settings, do not. Professional interviewees report that the ability to communicate with the GP is in the best interests of the patient and will enhance health outcomes.

One person living with HIV said:

'They tried to convince me to disclose to the GP, finally I agreed. I see a different GP every time but I think the main GP is okay though about my HIV status. I suspect the other staff there see HIV positive people as a walking bio-hazard'. (Person living with HIV)

One professional contributor said:

'GPs not knowing can mean it's hard to fulfil our duty of care' (Clinical Service)

Interviews with people living with HIV confirmed that there remain concerns about attitudes toward HIV in GP practices. Professional interviewees reported they understood the concerns of a small number of patients are primarily about confidentiality. In the view of some specialist clinical HIV service providers these concerns (whilst understood) are no longer legitimate and should be challenged. The NHS QIS draft *Clinical Standards for HIV services (9.6)* propose that 'Any reasons for non disclosure to the patient's GP are discussed with the patient and documented annually'.

Where permission is not given to engage with GPs, specialist clinical services are still offered with the exception of the practice of one Consultant who has reported that patients are *required* to provide GP details and to agree to communication with the GP. Where patients are resistant it is reported that efforts are made to ascertain what the difficulty is, solutions are presented, but ultimately it is reported:

'I won't look after people if they won't let us inform the GP'. (Clinical Service)

4.8.7 When GPs are resistant to shared care approaches

While interviewees based in specialist clinical HIV services report most patients agree to GP notification and contact, some GPs remain resistant to notions of shared care of HIV positive people. While some relationships with GPs are seen as positive, others may not be. A refusal to deal with day to day health concerns for the person living with HIV means some GPs refer the individual to the clinic for all health matters. One professional contributor said:

'Ideally the GP should be first port of call, but at best it's patchy, and for many atrocious, both ends of the spectrum'. (Clinical Service)

One interviewee living with HIV said:

'Sometimes they treat you differently, when they know you are HIV positive. My leg was swollen because of HIV, I went to the GP, he said I must lose weight, and must see the HIV consultant. He didn't help me, and sometimes he depressed me'. (Person living with HIV)

4.8.8 Poor communication

Interviewees in specialist clinical HIV services reported that efforts are made to inform GPs of treatment but that few acknowledge this or get back with questions which might indicate an active interest.

4.8.9 Staff need training

Across professional interviewees contributors expressed concerns about a lack of knowledge and awareness of HIV amongst professional colleagues – not just in identifying a presenting illness as HIV related but also in relation to the experience of living with HIV. Interviewees from specialist clinical HIV settings reported a range of training/CPD opportunities for non-specialist NHS staff about HIV treatment and care but that interest and attendance varies. As a result GPs and non HIV specialists can fail to see a presenting illness as an indication of possible HIV infection.

'The GP has a very important and difficult role, it is very important to teach them about HIV. It would be important to influence GP teaching and training. They are surprised when people present late, who are from non-high risk groups'. (Clinical Service)

'The HIV Action Plan should be taken further forward; we want professionals to be fully aware of these challenges. If we don't address this problem now, it will get worse. It has slipped off the radar'. (Clinical Service)

'There's a need for a lot of training and awareness raising to make NHS workers gain an understanding of what it means to be diagnosed positive. A lot of people are still not interested, so it is hard to sensitively manage a person's interaction with general services. Also people feel isolated, and

they don't want to keep repeating their story to a lot of people.' (Statutory Service)

4.8.10 The role of GPs in monitoring HIV

Professional interviewees expressed different opinions about the efficacy of GPs being involved in providing monitoring of HIV in terms of CD4 and viral load. On the one hand interviewees reported that barriers to GP involvement included GPs not having the necessary equipment and likely delays in transporting blood samples to the laboratory. For some professional interviewees these barriers are not insurmountable. No professional interviewees saw the prospect of GP involvement in prescribing ART because of budgetary considerations although a shared view was also that HIV Consultants retained the necessary knowledge required for prescription in this field.

The role of other NHS specialist services regarding testing and awareness of HIV: Professional interviewees reported an increase in HIV testing by other specialist services (some have introduced a policy of testing all patients) but there is a continued concern that other clinicians can still fail to see possible HIV related conditions which are presented in their clinics. Interviewees suggested that other NHS specialist services should be made aware of HIV related illnesses, specifically when they present in high risk communities.

4.9 Working with other statutory services

Finally, contributors also explored the role of statutory sector agencies and how this supports engagement with specialist clinical HIV services:

4.9.1 Positive view of Social Work

Across professional interviews there was an appreciation of the important role of Social Work services in the provision of community based support which can stabilise an individual and allow them to engage more constructively with specialist clinical HIV services. One contributor said:

'They can stabilise people, sort their housing, the crucial bits. Things like support after prison, benefits, housing, it all matters'. (Clinical Service)

4.9.2 Understanding the person in their home/community context

Professional interviewees reported benefits in seeing people in their own home environment; it was reported this makes follow up after non-attendance more effective.

It has also been possible to identify factors which can undermine engagement with specialist clinical HIV services.

4.9.3 Perspectives on partnership working

Professional interviewees from out with specialist clinical services reported on the importance of social work/community-based supports but that staff within specialist clinical HIV services can have a limited view and so fail to utilise services in the best interests of patients. This is also seen as undermining self-management.

'The nurses see Social Work in a very limited way – they think we are doing only housing, they don't see the emotional support we give. They have a limited view. We see a person more often, deal with feelings of loss, mental health issues etc. The referral rate from clinic is very low'. (Statutory Service)

'Clinical services can over support someone, particularly longer term patients'. (Clinical Service)

4.9.4 Views of Social Work services as complex and moving away from direct service provision

Professional interviewees out with Social Work services reported concerns that there was a lack of direct service provision and that contact with a local team led to referral on to other teams or agencies which was perceived as complicated for both professional and client. One professional contributor said:

'There's a feeling that in Social Work there is a lot of complicated referring – rather than doing direct work – that's what it feels like. This means a complexity of services for users'. (Statutory Service)

One person living with HIV said:

'The hospital referred me to Social Work and pointed me at (voluntary organisation named) but it seems like there's limited time and resources. Seems like everyone is a referral service, people who do something is limited'. (Person living with HIV)

4.9.5 The need to improve engagement with people of African origin

Professional interviewees reported a sense of a lack of connection between community based statutory sector services, for example Social Work or community based mental health services, and people of African origin who are living with HIV. It was reported that services can find it difficult to understand and access networks of people. While expressed as a concern it was also recognised that simply not enough is known. One contributor said:

'More knowledge on African networks would be of interest to all service providers'. (Statutory Service)

4.9.6 Improving the capacity of community based psychological support

Interviewees suggested that capacity to support patients in the community with mental health concerns relating to their HIV might benefit from enhancement.

4.9.7 Lack of communications between hospital admittance (e.g. social admission) and community supports

Professional interviewees from out with specialist clinical services reported that clinicians can decide on a hospital admission when this might not be in the best interests of the individual as a way to deal with legitimate concerns about isolation. In particular, multiple short-term admissions are reported as undermining community-based work with the person.

4.10 Policy, service design and capacity issues

Finally, professional contributors also explored a number of issues around policy (see section 1.2) service design and capacity within some Boards which are considered to impact on service access and engagement.

4.10.1 Locating HIV in the broader context of BBV policy and responses to Hep C
Professional interviewees expressed concern about whether locating HIV services in a broader BBV service might mean that a service becomes too broad in scope and loses specialism and the confidence of people living with HIV. Professional interviewees expressed concerns that funding for Hepatitis C testing and treatment, tied to targets and time limited, is restricting longer term planning and more integrated approaches to BBV work. In terms of people who are co-infected and living with HIV and Hepatitis C some professional interviewees expressed concern about the pressure which they feel people can be put under to engage with Hepatitis C treatment. The impact of the treatment on day to day health was thought by some interviewees to be poorly explained to people. In terms of service design it was suggested that the model of Hepatitis C services is not the best way forward for HIV. One contributor said:

‘Perhaps this means we might lose clarity and focus, perhaps the Hep C model has built up too quickly with the resources made available. We can’t replicate that in HIV services’. (Clinical Service)

4.10.2 Specific service design factors

There are a number of other factors relating to service design highlighted by contributors to this study, these also reflect the findings of The Scottish Public Health Network (2009) report *Treatment and Care Needs Assessment: People Living with HIV* and the NHS QIS *Draft Clinical Standards for HIV Services* (2010:10) which recognised that current specialist clinical HIV service design is “often historical and ad hoc, and requires renewed focus and planning”. Standard 9 of the draft Standards proposes that “All patients with HIV have access to a comprehensive and integrated range of local, regional and national HIV services”. In recognition of a lack of specialist HIV service in some localities the emphasis is therefore on more regional approaches. In the context of this study, with a focus on attendance at specialist clinical HIV services, service design was of concern with regard to two particular issues: access to HIV services through GUM or ID services and provision out with the main urban centres.

4.10.3 Access to HIV services through GUM or ID provision

One professional interviewee recognised that in terms of the provision of HIV services: ‘There have been territoriality issues in the past, between GUM and Infectious Diseases’ (Clinical Service) Interviewees have also reported that historically gay/bisexual men may have been more likely to attend GUM clinics for a broader sexual health service and would perceive a GUM based service as more likely to be ‘gay-friendly’ whilst intravenous drug users may have come to HIV services because of HIV or other blood borne virus issues and so have accessed HIV treatment and care through ID teams. The recent increase of people of African origin to services means that where discreet services are available choices about

routes into HIV services might be informed by word of mouth or the route proposed by a primary care or other NHS service provided testing. In areas where there have been fewer resources available professional interviewees have reported that the model emerging is more likely to reflect a more streamlined service with fewer distinctions in terms of HIV services. While some professional interviews were supportive of patient choice which potentially discreet services bring it was also recognised that in the longer term this may become less sustainable.

4.10.4 Providing specialist clinical HIV services out with the main urban centres

Professional interviewees have raised several issues concerning the service needs of the increasing numbers of people who are being diagnosed with HIV who do not live in Scotland's cities. Some interviewees reported a sense of professional isolation when working in rural settings, unable to find support from colleagues working in the field and with their client group day to day. One contributor said: 'I don't know of any rural HIV network'. (Clinical Service)

In terms of people living with HIV professional interviewees reported much reduced capacity to facilitate access to additional expertise from mental health practitioners, Pharmacists, Dieticians or Dentists who have knowledge, confidence and experience in working with HIV positive patients. Equally, out with the specialist clinical HIV service there are fewer specialist supports for people living with HIV in terms of housing or social work. This lack of local additional support also extends to the Voluntary Sector where agencies - because they are often funded to meet the needs of a particular targeted community rather than the HIV population as a whole - are less likely to be commissioned to provide a service for what is deemed to be a smaller number of individuals.

Professional interviewees also reported that creative approaches can be adopted when providing a service out with the city; they saw some value in the close relationships a small team can build with individual patients, this means that difficulties with attendance or treatment adherence can be addressed with personal contact; it is also reported that services provided by larger Boards with more resource can be accessed where the patient is able and willing to travel. However, interviewees reported that as numbers increase sustaining services in smaller NHS Boards is becoming more challenging. Professional interviewees said:

'Who is paying attention to the numbers in places like this? They are certainly noticing the drugs budget costs going up but not thinking about staff and whether the service is struggling'. (Clinical Service)

'The stress is showing'. (Clinical Service)

5. Discussion: issues and challenges for specialist clinical HIV services providers and partner organisations

This section of the report provides further analysis of the results reported in earlier sections and identifies underlying issues and challenges which face specialist clinical HIV services and other agencies interested in promoting or enabling clinic attendance and treatment adherence. The following issues and areas are discussed:

- Policy context and service design.
- Meeting the needs of people of African origin.
- Support for mental wellbeing.
- Holistic support and building a team around the person.
- The role of the Voluntary Sector.
- The role of GPs.
- A continued focus on testing.
- More inclusive communications.
- The importance of reception and waiting areas.
- Conclusion and reflective questions.

5.1 Policy context and service design

Section 1.2 highlighted a number of recent developments in terms of policy and the development of standards for HIV treatment and care. Whilst on the one hand professional interviewees were of the view that the policy context was supportive of service improvement there were concerns expressed about the location of HIV policy and service provision in the wider context of BBV policy and particularly in relation to the significant focus on Hepatitis C and what this might mean for HIV services. Specifically, there is a need for further reflection on whether what is perceived of as the nurse-led treatment-focus model of Hepatitis C services is the best way forward for HIV treatment and care.

Contributors have also highlighted service design issues including improved integration of services (or from the patient perspective a more seamless journey through service provision across providers), issues regarding routes into HIV services through GUM or ID services, and the capacity of specialist clinical HIV service provision out with the main urban centres. These matters are identified elsewhere in the findings of The Scottish Public Health Network (2009) report *Treatment and Care Needs Assessment: People Living with HIV* and the NHS QIS *Draft Clinical Standards for HIV Services* and in terms of core principles which should govern Managed Clinical Networks identified as early as 1999 by the Scottish Executive¹² where there is a call for services which work “in a co-ordinated manner, unconstrained by existing professional and Health Board boundaries, to ensure equitable provision of high quality clinically effective services throughout Scotland”.

For more on study findings in relation to these issues see sections 1.2; 3.7; 4.10.

5.2 Meeting the needs of people of African origin

The cohort of people living with HIV in Scotland has had one significant change in recent years with the impact of HIV diagnoses in the different groups and communities which make up what is often collectively referred to as people of African origin. Interviewees contributing to this study have identified a range of difficult issues rooted in ethnicity, culture, faith, complexities of finding out positive status when pregnant, migration and political status. One interviewee living with HIV described circumstances as follows:

‘Some people from an African culture, African, they think being HIV positive means you were a prostitute, they will think badly of you, there are great fears that family and relatives will know, will think badly of you, you have to keep it to yourself and not go to the clinic... In groups, some people say they have to hide their tablets. It is easier for me, because I have high blood pressure, so I can say that the tablets are for that. Some people can't take tablets in front of other people’. (Person living with HIV)

¹² Scottish Executive Department of Health NHS MEL (1999)10 Introduction of Managed Clinical Networks within the NHS in Scotland at http://www.sehd.scot.nhs.uk/mels/1999_10.htm

5.2.1 Engaging with issues of faith and culture

It would appear that while there is an increasing understanding of the issues specialist clinical HIV services struggle to engage with faith and cultural issues which are a block to treatment and care. Voluntary Sector agencies have begun to develop services and seek to support clinical services in meeting the needs of people of African origin, and while once again the individual commitment of staff within clinical services is evident in some locations, work with this cohort of people living with HIV exemplifies a lack of resources and poor service integration where the Voluntary Sector worker is seen as external and the patient fears loss of confidentiality. The findings of this report would suggest that specialist clinical HIV services should reflect further on this population and consider what could be done to improve connection with services.

5.2.2 Improving understanding of data around irregular and non-attendance

While professional interviewees in this study suggest that people of African origin are often most difficult to engage in services it is not known whether they are in fact disproportionately represented in figures for irregular or non-attendance at specialist clinical HIV services, as work around improving and auditing data progresses this would be a useful focus of attention.

5.2.3 Patients with no access to funds

As reported earlier health providers face complex challenges when a person who seeks to access a service may have no entitlement to free health care. It was reported earlier that some GP practices are asking for passports and evidence of place of residence before permitting non UK nationals to register and that this is acting as a barrier to engagement with primary health care and potentially to HIV testing. In specialist clinical HIV services it appears there is a 'don't ask don't tell' policy and so HIV testing, treatment and care is provided regardless of status. Where it is known the person is at risk of deportation or leaving the country it is reported treatment options will be discussed so that as far as possible a regime can be maintained if the person must leave.

It would seem that practice across specialist clinical HIV services means that treatment and care are provided regardless of immigration status and it is recognised that discussing status and the requirement to seek the patient to pay for treatment would be a significant barrier to services. People of African origin who are connecting with HIV services are recognised as being amongst the most vulnerable people living with HIV, perhaps presenting when they are pregnant and often when they are ill. In these circumstances treatment is an urgent requirement and a human rights and public health issue.

The case for access to HIV treatment for undocumented migrants and those refused leave to remain has been made elsewhere¹³. Whilst there are clearly issues about access to primary health care in the context of increasing numbers of people with

¹³ For example see the briefing prepared by Terence Higgins Trust and the National AIDS Trust (2006) 'Note on access to HIV treatment for undocumented migrants and those refused leave to remain' at:

<http://www.tht.org.uk/binarylibrary/westminsterhallbriefingonaccess.pdf>

HIV diagnoses, and the cost of anti retroviral treatments a 'don't ask don't tell' policy might become increasingly unsustainable and a commitment may need to be made in Scotland to a view that access to HIV treatment and care is not linked to immigration policy, particularly where that treatment and care saves lives and prevents onward transmission.

For more on study findings in relation to these issues see sections 3.3; 3.4; 4.7

5.3 Support for mental wellbeing

As stated in section 3.1 mental wellbeing is understood as positive mental health or wellbeing which might include a sense of control, having a purpose in life, a sense of belonging and positive relationships with others. In the draft 'Standards for psychological support for adults living with HIV' (discussed in section 1.2) it is reported that HIV "tends to be concentrated in highly vulnerable, marginalised and stigmatised populations who are at greater risk of mental health disorders than the general population" and that "HIV continues to be a challenging and stressful condition for many people". Further while problems such as anxiety or depression may come at any time other problems may be linked to HIV disease progression or side-effects of some anti retroviral medication. Groups or communities most at risk and in need of psychological support are considered to be those over 50, those with both physical and learning disabilities, those who are diagnosed after the point treatment should have begun (known as 'late presenters'), those with religious beliefs, pregnant women and parents of children who are also living with HIV and other marginalised groups such as asylum seekers, prisoners, those with pre-existing mental health problems and those working as prostitutes.

Mental health has been recognised throughout this study as a key factor influencing clinic attendance and treatment adherence yet in the context of this study interviewees identified that the provision of support for is variable; one professional interviewee identified that in Scotland 'a major issue is the provision of psychological services' (Clinical Service). Before highlighting some of the key issues requiring further consideration it is worth hearing one contribution from an interviewee from this study reflecting on an experience immediately post diagnosis:

'It was tough before Christmas. My partner had left. I got in touch. They said they'd get me in to see a psychiatrist. The letter came after Christmas for an appointment mid February so I told them to forget it; I'll get myself out of it. Every day I cry, it just wells up. Medical treatment might be there but there's nobody who cares. There's no support. They just push the pills... Someone should have come to the house and sat us down. You can treat anything but it's the stuff that goes on in your head, in your life, if you're stressed big time it's going to affect you. I asked about support groups and he looked at me like I was mad". (Person living with HIV)

5.3.1 Identifying stressors

Professional staff and people living with HIV would benefit from an acknowledgement that clinic attendance and treatment adherence are themselves stressful. Examples such as the impact of taking treatments every day as a reminder of HIV status, or meeting the medical professional who gave you your HIV positive test result every time you attend the clinic have been highlighted in section 3.2.

Professional interviewees have shown some recognition of these issues in interviews, typically one contributor said: 'Patients report increased anxiety before an appointment'. (Clinical Service) What is not clear is the extent to which attention to such detail can be given to patients who do not exhibit obvious distress at the time of contact.

5.3.2 Provision is dependent on location and competence

As indicated above it is a failure to identify a need for support which is a concern for both professional interviewees and those living with HIV. This is thought to arise because of a poor understanding of the mental health needs of people living with HIV and/or a lack of resources to assess or address need unless there is a presenting issue. One contributor said:

'I see those who other health professionals see as distressed. There are plenty of others whose distress is not obvious, they say yes to things when it's not how they're feeling.' (Clinical Service)

Professional interviewees also reported on the importance of providing services which are staffed by appropriately experienced and competent staff; but that this is not always available and the competency of staff supporting people living with HIV in specialist clinical HIV services or a partner Voluntary Sector or non-specialist provider may not be known.

5.3.3 Addressing patient resistance to referral and support services

Professional interviewees reported that access to psychological services/mental health support is not routine so that an individual who is stressed or in need of support may need to be referred on to another person, team or service for that assessment or support. In working through this process some interviewees described how the individual can be lost, because they may decline a referral or not attend another service. For some professional interviewees access to psychological support needs to be experienced as a normal part of service provision and that moving between professional colleagues would benefit from being 'seamless' in the experience of the patient; the challenge then is to normalise routine mental health assessment and the provision of psychological support which many will benefit from in the course of living with HIV.

For more on study findings in relation to these issues see sections 3.1; 3.2; 3.5; 3.10; 3.11; 4.1; 4.2; 4.4; 4.5; 4.9

5.4 Holistic support and building a team around the person

Whilst this report has a primary focus on access to and use of specialist clinical HIV services, and related issues of treatment adherence, it has been clear throughout the process and across interviews that for people living with HIV to be supported in the longer term there is a need for services to work together in terms of both treatment and care so that HIV is neither the only part of the person's life that matters, nor that its significance is underplayed. Further, for the person living with HIV feelings of self efficacy and control are of importance and as such should be of interest to the professionals engaged in their treatment and care. One interviewee said.

'I have to organise this myself. I have my personal belief system, I want a holistic approach to my health, my life' (Person living with HIV)

5.4.1 'Life in the round' and the usefulness and relevance of monitoring CD4 and viral load

In interviews with professionals and with people living with HIV it has been recognised that clinic attendance and the monitoring of CD4 and viral load are increasingly being used as a way to motivate the individual to maintain attendance/treatment, so that people living with HIV literally 'see' progress. For people living with HIV in the longer term however interviewees have questioned whether this can be sustained as people become fatigued by the commitment to treatment. One contributor said:

'I think what does viral load mean to me in reality? It's got psychological significance but it's only a monitor. So I have stopped going for periods but then I realise it's the only monitor I have, so I take the drugs, maintain the results, then I stop, have a holiday. Every morning the drugs are a constant reminder, I'd rather live without it.' (Person living with HIV)

Considering the physical, mental and social aspects of treatment and care professional interviewees and people living with HIV have emphasised the importance of taking a holistic view of the life of the person living with HIV so that whilst monitoring of CD4 and viral load is part of treatment and care the person living with HIV in the longer term will face the challenge of addressing life beyond HIV. Contributors have said:

'Approaches that give opportunities to organise and construct life, to get back into training, employment or learning – these help contextualise discussions about taking control of one's life'. (Statutory service)

'It's a holistic approach, personalised, individualised – it's about doing what feels right, human'. (Clinical Service)

5.4.2 Building the team around the person in order to address non attendance

HIV Consultants and their nursing teams have described their commitment to providing a very personal service for HIV positive people where relationships are built over time and there is a strong sense of responsibility felt toward patients. The need for professional agencies and services to work more effectively together has also been identified by professional interviewees from across sectors, although the extent to which this is managed satisfactorily has been challenged by people living with HIV. Contributors have reported:

'Communication between services is key to meeting individual need – knowing each other on cases as well as general networking is important.' (Statutory Service)

'I'm being told about integrated services but I'm not seeing it'. (Person living with HIV)

In terms of the interest of this study it has been reported that when it comes to responding to non-attendance rather than this being the task of 'the team' responses are often ad-hoc. One contributor said:

'It all comes down to me picking up on things, there's no real system, I need to remember. There is a high DNA rate but no systematic route to deal with those not attending. It totally depends on my individual knowledge'. (Clinical Service)

With increasing numbers of diagnoses professional interviewees recognised continuing this informal approach is a significant pressure on a small number of highly skilled and motivated, but nevertheless, very busy individuals; particularly when this comes to an increasing number of people who are using ART and for whom adherence (necessarily linked to clinic attendance and monitoring of their condition) is a key issue. With this challenge in mind efforts were described across settings which focus on introducing the patient to a team who provide information, support and clinical care. From contributions in the course of this study these 'teams' are primarily considered to be those within the specialist clinical HIV service itself - nurses, psychological services, health advisors, pharmacists. Interviewees from specialist settings have reported that increasingly specialist clinical HIV services need to look toward increasing use of specialist nurse-led clinics with less regular access to Consultants, particularly when the individual is well and when relevant adhering to treatment.

5.4.3 Challenges to the notion of a team around the person

Challenges come when further consideration is given to the role of other potentially core professionals: from the Voluntary Sector, community based statutory sector and GPs. A number of issues regarding GP and Voluntary Sector involvement in treatment and care are considered in other sections of this report (see 4.7, 4.8, 5.5, 5.6) but more generally broadening engagement will require a shift in regard to two areas: how much a Consultant and their closely allied team engage, manage and communicate *with the patient* about what treatment and care means and who provides it *and* the extent to which the core clinical team commit to a more seamless and integrated idea of service provision by fully engaging colleagues across sectors/services in delivery of the treatment/care plan. Several challenges have been recognised by contributors to this study in relation to both, these are now discussed.

5.4.4 The need for a specialist service

Interviewees from specialist clinical HIV services have sought to clarify that while services must change, and this includes looking to the role of partner agencies, the need for *a specialist service* at the heart of treatment and care must not be undermined. HIV treatment and care is seen as a complex area, many of the issues raised in this study would support such an assertion. One contributor said:

'Whilst we can't go on the way we've done and we need to focus on nurse-led follow up, our specialism means we are the best placed to look after these patients'. (Clinical Service)

5.4.5 Retaining prescribing of ART in specialist services

Professional interviewees from specialist clinical HIV services reported that both in terms of knowledge and expertise and with regard to budgetary requirements key decisions about use of anti retroviral therapies need to remain with the HIV Consultant in consultation with the individual patient. In this sense the 'team' might provide all the other supports a person living with HIV might require in terms of their involvement with treatment decisions – for example information provision, counselling, advocacy.

5.4.6 Longer term patients

Interviewees in clinical HIV settings recognise that longer term patients, who will have historically been able to see the Consultant (often the same person) on every visit, can struggle with this concept of a team engaging in their care, with feelings that a visit when you do not see your Consultant is less useful. Professional interviewees reported that managing any transition in how care is provided for these patients is a key task.

5.4.7 Allocating a link-person

Professional interviewees reported that current discussion around the development of QIS Scotland standards for HIV care propose allocation of a link person to help support and coordinate care; whilst seen as important interviewees recognised problems with resources (if this person had to be from within specialist clinical HIV services) and concerns that while for other conditions this role might be played by the GP for HIV this was thought to be inappropriate. Ultimately then, whilst a positive idea, a link person might not be the only answer to much broader issues of establishing the team around the person.

5.4.8 Information sharing and confidentiality

At the heart of any discussion of holistic support and building a more integrated team of professionals around the service user there are often concerns about information sharing and confidentiality. Generally professionals see the importance of patient agreement to information sharing but there is also an understanding that how information sharing is described (in terms of practice and the benefits it brings) makes a difference to the view the person living with HIV might have about it. In the context of this study professional interviewees in specialist clinical HIV settings have cited the fears of patients as being a primary reason why professionals out with that team have limited access to information, including information about non-attendance at services. Professional interviewees reported that they understood why knowledge of HIV status would be one of the most important pieces of information the individual would seek to control, but there was also recognition that where information is shared appropriately care is enhanced. One contributor, reflecting that current systems permit access to only elements of a person's records, said:

'People need convinced that they can't demarcate their HIV condition. Care is better if information is shared. New electronic records systems will give levels of access to information, so it's still possible to drop out of HIV care because access to this information for many health professionals you are in touch with will be limited'. (Clinical Service)

From professional interviewees it also reported that a major reason for not engaging the HIV positive person with Voluntary Sector or other non-specialist services is the patient's mistrust of what will be done with knowledge of their HIV status. One contributor said:

'After diagnosis I'd recommend contact with (voluntary organisation named) but they'll often say no thanks. I don't know how many people come to us via (voluntary organisation) but I wouldn't get one of their workers to contact a patient unless the person has agreed'. (Clinical Service)

Part of this problem would appear to be because connecting the person with the information provision, advocacy or support they need is conceptualised as a referral to an external agency; so that rather than being part of 'the team' this other person or service represents a loss of control over private information and a risk of disclosure to others. One contributor said: 'Information sharing is complex and restrictive'. (Voluntary Sector)

If all the needs of a person living with HIV can/could be met in the specialist clinical HIV service these issues are of little relevance. However for the vulnerable individual, whose attendance and treatment adherence are irregular or impacted upon by the issues this report has identified, then it matters how relationships between services are understood, explained and experienced. It seems that a team cannot be built around a person and holistic approaches adopted until issues of information sharing and confidentiality are addressed.

For more on study findings in relation to these issues see sections 3.1; 3.5; 3.6; 3.9; 3.11; 4.3; 4.4; 4.5; 4.6; 4.7; 4.8; 4.9.

5.5 The role of the Voluntary Sector

There are several issues which are raised by this report about the role of the Voluntary Sector in promoting or enabling clinic attendance and treatment adherence. Ideas of holistic support and building a team around the person, discussed above, have clear implications for the involvement of Voluntary Sector in prevention, treatment and care. A number of further issues are now discussed which also need to be addressed by Voluntary Sector agencies in terms of how they support people living with HIV but they should also provide a basis for further discussion between Voluntary Sector agencies and specialist clinical HIV service providers about more coherent approaches to treatment and care.

5.5.1 Sector provision is dependent on location and population

Voluntary Sector services which focus on the needs of people living with HIV are not available and accessible throughout Scotland. Interviewees living with HIV said:

'One voluntary sector agency told me I'm not in their area but from my point of view they get funded by a 'national' health service'. (Person living with HIV)

'I moved to a rural community and (voluntary sector agency named) pulled the resource because there was no local funding or contract'. (Person living with HIV)

Whilst there is an increasing amount of good information available on-line the provision of direct support by the Voluntary Sector is largely focused on urban/central belt provision. Traditionally the Sector's work has also been defined by populations most impacted upon by HIV and to a great extent agencies are defined by the particular population they have historically engaged with. Some agencies have recognised the changes in Scotland's HIV population; in particular developing services for people of African origin (see 5.5.4 below).

5.5.2 The role of voluntary sector agencies in routinely discussing clinic attendance and treatment adherence

Interviewees from Voluntary Sector agencies have reported that they rarely either talk about or initiate discussion about clinic attendance or treatment adherence; unless an individual chooses to raise a related issue. Some interviewees from the Sector viewed these issues as a private matter, and they do not want to be perceived of as intrusive. This raises questions about whether the Sector might consider normalising discussion of these areas, in order that the person living with HIV can access information or support if and when they need it.

5.5.3 The relationship between specialist clinical HIV services and Voluntary Sector agencies is location specific and constrained

From professional interviewees it is understood that the nature of current engagement between the Sector and local clinical HIV services is dependent on history (what has been done before and how that was perceived) and the extent to which both services see some useful interface in terms of benefit for patients. Whether services work together, and how they work together, is dependent on individual professional relationships. In some places interviewees report good working relationships but on the whole Voluntary Sector interviewees have reported that when it comes to specialist clinical HIV service design and delivery they are largely peripheral and passive and there has been a lack of opportunity to engage in ways which would allow them to focus more productively on the needs of vulnerable individuals. As discussed earlier, Voluntary Sector interviewees report that anxieties about information sharing and confidentiality hinder the development of more integrated service provision.

5.5.4 Developing further links with minority ethnic communities and faith groups

One area of interest and joint approaches developing between sectors is an interest in meeting the needs of people of African origin. In particular direct work with community and faith leaders is already underway but professional interviewees from across sectors agreed this needs strengthened, and that whilst led to date by Voluntary Sector agencies there is perhaps a need to connect communities/faith groups and community leaders directly with specialist clinical HIV services to support efforts to de-stigmatise HIV diagnosis, treatment and care whilst respecting cultural heritage and practices.

For more on study findings in relation to these issues see sections 3.1; 3.3; 4.1; 4.2; 4.7.

5.6 The role of GPs

There are several issues which are raised by this report about the role of GPs in promoting or enabling clinic attendance and treatment adherence. As with discussion about the Voluntary Sector in the previous section ideas of holistic support and building a team around the person have implications for primary care. A number of further issues are now discussed which address the GP role in supporting people living with HIV; again, these issues can also help frame further discussion between GPs and specialist clinical HIV service providers about more coherent approaches to treatment and care.

5.6.1 Increased HIV testing by GPs

Professional interviewees in one specialist clinical HIV setting reported that 30% of new HIV patients were people who had tested with their GP. While these interviewees were generally supportive of increasing access to HIV testing in primary health care settings there were concerns about the quality of the post result information or support a person might receive; and concerns that where a person is offered an HIV test, and they refuse, follow up or a continued dialogue might not take place. There were also concerns about the time it might take to make a referral and get a first appointment at a specialist clinic, all the time leaving the person coping with diagnosis.

‘Given what we know about undiagnosed HIV in the population, we need GPs to be more up to speed’. (Clinical Service)

‘Yes, guidance tells us that its within the capability of any medical practitioner to do testing, and we know late diagnosis is a problem so more testing is a good thing, but we don’t know what’s happening in terms of the quality of what is provided. We also don’t know what happens when a person is offered a HIV test in a primary care setting and they refuse. I suspect back up and information in primary care settings is variable and poor”. (Clinical Service)

5.6.2 Managing non-HIV related health matters

Interviewees in specialist clinical HIV settings reported a range of experiences in terms of engaging with GPs and encouraging people living with HIV to manage non-HIV related health care matters in the context of the GP practice. While examples of increasing confidence and shared-care approaches were reported this is dependent on the commitment of the GP and the confidence the HIV positive person has in this approach. With increasing numbers of diagnoses, increasing pressures as a result of co-morbidities, pressures to make shared-care approaches work will only grow. One contributor said:

‘There’s mixed views amongst people about the shared care concept – it’s not being bought into – feels more like disjointed care’ (Clinical Service)

People living with HIV interviewed in this study reported that specialist clinical HIV services are encouraging people to use GP services for non-HIV related issues but

that the interest or capability of the GPs to fulfil such a role is variable, with some continually referring the positive person back to specialist services for care. People living with HIV were also concerned about the time available in GP appointments and the quality of GP care where there was a lack of clarity about areas of responsibility. Interviewees said:

'The minute you walk in it's a mad rush to get me out the door again. You feel you can't stay. You can tell when someone isn't interested in your HIV. I asked for more than a 10 minute slot and they said no'. (Person living with HIV)

'So the clinic will say go to your GP, so the GP is fine, I get what I want like tests for things, but it's a guessing game. The GP is slow. I used to get things like my eyes tested at the clinic, now they don't. It used to be part of the package. They don't weigh me now, all this small monitoring stuff has gone. If I want anything I have to ask. There's no cohesion between the clinic and the GP, like say for testing for cholesterol. I have to ask who's monitoring what. I'm capable of asking but is that right? I'm my case manager'. (Person living with HIV)

5.6.3 Managing HIV treatment and monitoring HIV

While one professional interviewee stated that: 'The future of HIV care lies with GPs, new drugs make life a lot simpler, the question is are they ready?' (Clinical Provider) the view of most professional interviewees was that while GPs have a key role in providing health care on non-HIV related matters, prescription of anti retroviral treatments and drug management should remain with specialist clinical HIV services. In consideration of the monitoring of CD4 and viral load for patients who are well professional interviewees held different opinions and barriers to GP involvement in monitoring patients were reported to include GP willingness and confidence to do so and whether GP practices could meet technical standards and get samples to the laboratory without error.

For people living with HIV interviewed in this study the involvement of GPs in managing HIV treatment and monitoring HIV was varied. Where there is confidence in the GP interviewees are interested in increasing their role in monitoring of CD4 and viral load. Some interviewees had asked GPs for this to be undertaken and had been told this was not possible whilst one interviewee reported this was now provided as part of a plan to cut down on significant travel to the specialist clinical service. One interviewee expressed the following view:

'I thought it would go to the GPs – bloods, meds there, so I wouldn't need to go to the hospital but I see they'd need a lot of knowledge, so I don't see it going that way. Diabetes has, but this feels different, maybe in the future. With my GP, in this practice, I would be happy with that, might be simpler. I get all my other prescriptions through the GP and I collect it from the chemist, don't see why they couldn't do this with my ART'. (Person living with HIV)

For more on study findings in relation to these issues see sections 3.4; 3.11; 4.2; 4.3; 4.6; 4.8.

5.7 A continued focus on testing

The NHS QIS Draft Clinical Standards for HIV services (see section 1.2) identify the importance of HIV testing in order to prevent onward transmission and maximise benefit from treatment and care. Professional interviewees participating in this study have reported that improving knowledge and about and access to HIV testing has been the focus of work by both statutory and Voluntary Sector agencies in recent years. They have also reported that while there is a sense that amongst some gay/bisexual/MSM regular sexual health checks are being normalised further progress could be made, and when it comes to people of African origin too many people are presenting late.

Amongst professional interviewees from specialist clinical HIV service settings there was a view that if resources are to be used to maximum benefit further emphasis should be placed on improving awareness of testing and increasing the numbers of people (particularly gay/bisexual/MSM and people of African origin) testing in Scotland. Interviewees recognised that some aspects of promoting testing should focus on medical professionals in non-specialist settings, including primary care, so that they were aware of other conditions which might present and which might indicate risk of HIV infection. A common view was that focusing on the undiagnosed would be of more benefit than an over-emphasis on the smaller numbers of people known to be positive but failing to access services. Contributors said:

“You can’t be lost to follow up if you’ve never been in the system, never been tested” (Voluntary Sector).

‘We should be focused on those undiagnosed and very late presenters who come in very ill’ (Clinical Service)

For more on study findings in relation to these issues see sections 3.1; 3.3; 3.6; 4.1; 4.2

5.8 More inclusive communications

Professional interviewees have described the importance of both verbal and written information given to service users throughout their patient journey but in terms of commitments to inclusiveness few have reported that they assess or consider levels of literacy or possible learning disability in their relationship with the person living with HIV. This suggests that in early engagement with a service any assessment of the individual’s needs should consider such matters.

For more on study findings in relation to these issues see sections 3.6 and 4.1.

5.9 The role of reception staff and the importance of waiting areas

Reception/Administration staff have a key role to play in supporting clinic attendance and interviewees report that additional resources and the introduction of some degree of technology would allow staff to give more time to pre-appointment contact with known irregular attendees or to use techniques which are now common to primary care and community dentistry such as texting before appointments or after DNAs. Whilst recognising efforts which have been made, professional interviewees and people living with HIV have identified that some focus should remain on

improving the experience of patients in reception and waiting areas in HIV clinical services. In addition to physical space and the introduction of strategies to address rates of DNAs the efficiency and manner of administration and medical staff in reception/waiting areas remains important. In the course of this study practices such as turning people away from busy drop-in clinics without giving any information about other ways to engage with a service and medical staff using people's full names to call them to consultations have been observed.

For more on study findings in relation to these issues see sections 3.1; 4.2 and 4.3.

5.10 Conclusion and reflective questions

The focus of this study has been on irregular and non-attendance at specialist clinical HIV services; these matters have also been linked to treatment adherence. Non-attendance matters because we know that without appropriate treatment and care the HIV positive person is more likely to become unwell, if they do not adhere to treatment they will develop resistance, and in both scenarios increased viral load makes transmission more likely.

DNA rates vary across specialist clinical HIV services as do service responses to irregular or non-attendance. When a local service develops a particular approach to an issue it can bring out the best in that service; some of the individual and personalised approaches to irregular and non-attendance described in the course of this study exemplify the commitment and care professionals bring to their work. On the other hand what might be described as ad hoc arrangements can result in poor practice whereby irregular attendees are under the radar, their needs are not assessed, their care has drifted; unless a member of the clinic team remembers or finds the time to make contact little is known about how they are managing. Further, localised practices can mean that it is possible that non-attendance is seen simplistically as a consequence of chaos or a lack of co-operation or as 'patient choice' rather than an indication of the need *for* intervention and support.

If responses to irregular or non-attendance are overly dependent on individual practices, if they are inconsistent across a service and certainly lack coherence nationally, is it possible to identify particular issues which, if considered further, might improve practice? In 2009 the ScotPHN report *Treatment and Care Needs Assessment: People Living with HIV* recognised that "HIV treatment and care services in Scotland provide high quality, evidence based and BHIVA guideline appropriate ART therapy" but in addition that "it is important that services are responsive now and in the future, to the challenges of the complex social, psychological as well as physical needs of people living with HIV and their ability to benefit from such care". The earlier discussion section of the report highlighted a number of areas that require further attention; this final section of the report poses a number of reflective questions for further consideration.

This section is intended to be used by specialist clinical HIV services and their partners as well as those involved in HIV policy as part of their self-evaluation and planning for improvement.

5.10.1 Who is actually 'missing' from services?

The original brief for this study was established in the context of a lack of clarity about the numbers of people living with HIV who were considered to be 'missing' from specialist clinical HIV services; the inference drawn from data of cumulative cases of HIV in Scotland by 2010 suggested that up to 1100 people were currently not engaging with clinical HIV services. Subsequent work by HPS and local Clinicians and their teams, looking at data collection and the detail of clinical records, has now clarified that there are significantly fewer people who are lost to services. Although exact numbers are still not known from the data examined by TASC, supported by HPS, of 317 individuals who had not attended a clinic appointment since December 2008 it has been possible to identify that 262 can be accounted for because they actually returned to services, have left the country, are accessing services elsewhere or have died; this leaves 55 people and it is perhaps accurate to think of these individuals as not known to services but for whom additional information may still be missing which might explain their non-attendance. A further audit of individuals, case by case, is required. This focus on reduced numbers is not to downplay the importance of a commitment to connect *all* people living with HIV with the treatment and care, but only to indicate that the 'problem' is not of the scale previously estimated. This in turn allows us to focus more helpfully on access to services for a larger number of people for whom attendance and/or adherence remains a significant challenge.

5.10.2 What do we mean by non-attendance and why don't people attend?

It is worth reflecting on the concepts of *attendance* and *non-attendance* and to clarify that even with clinic attendance one cannot presume treatment adherence.

From this study it would appear that there is not one simple explanation for non-attendance (or non-adherence) nor one solution but instead a need to understand the individual whilst also planning, designing and delivering a service which seeks to attract and retain some of the most vulnerable people living in Scotland. If non-attendance is not just simply 'you come or you don't come to clinic appointments' what might it look like for the individual? A few examples follow: a person might test positive feel well and not return to services for some time as they come to terms with their status; they might test positive whilst presenting with an HIV related illness, receive treatment for that presenting illness and choose to take some time out before returning; they might have been living with HIV and using ART for some time, feel well and decide to take time out of both treatment and clinic attendance; they might need to return to their country of origin for a period because of family commitments; perhaps life becomes chaotic because of drug use and they leave the area until they return unwell and re-engage with services. Presenting these 'pen-pictures' could continue, but it is clear the reasons for non-attendance are as diverse as the people who use specialist clinical HIV services.

It has been shown from the contributions of professional interviewees and people living with HIV that living with HIV is impacted upon by a set of psychological, social, economic and cultural factors; some of these experiences are shared across communities. These experiences will influence how the person then 'lives' with their HIV; and part of their lived experience will be the relationships they have with services including specialist clinical HIV services.

However, focusing on the individual or a shared characteristic of a group or community also has its problems; it becomes easier then to allocate blame to that individual or group for non-attendance or non-adherence to treatment; so it is *their* chaotic lifestyle and choices, *their* faith or cultural practices, *their* troubled backgrounds which make it difficult to provide the service. This study has shown that the way professionals do things also matters: with some actions being supportive of clinic attendance and treatment adherence while others are not.

5.10.3 Are partnerships fit for purpose?

This study has reported on the varied role on non-specialist NHS staff (including GPs) and the Voluntary Sector, and of course a range of professional supports can and do exist within many specialist clinical HIV services where the skills of specialist staff can be pulled into care. However, what this study has also indicated is that working arrangements are often informal, responses re-active, and a lack of a team around the person makes identification, support and a pro-active approach toward service engagement more difficult. It has also been identified that the individual's access to additional support and services is dependent on where they live with some specialist clinical HIV services having little capacity to offer specialist help or access to Voluntary Sector services which are located mostly in the urban, central belt. Interviewees have also reported that where the Voluntary Sector is present services can be poorly integrated into treatment and care. When it comes to primary care, specialist clinical HIV interviewees and people living with HIV have described some good relationships with GPs committed to shared care approaches but again much remains to be done.

This would suggest we need a national view of the relationships which exist between specialist clinical HIV services and exiting/potential partner services and agencies across sectors. It would help to map who is doing what and why, allowing an identification of the gaps. It may be the case that relationships between services need to be more formalised, monitored and audited in order to drive change. It would certainly seem that how services and professionals within them work together would be of more benefit if they were built more consistently around the needs and entitlements of people living with HIV rather than the preferred practices of the individual professional or service.

5.10.4 What is the relationship between treatment and care?

There is a sense from professional interviewees and the contributions of people living with HIV that treatment and care can be disjointed rather than connected. In some professional interviews it has been clear that the focus of HIV policy and service provision should be on HIV testing and getting people into treatment; the concern might then be that this medical view of HIV pays scant attention to what *being HIV positive* means to the individual and any consideration of how *they* manage their condition. From the interviews conducted in this study it would seem that further discussion needs to be encouraged in the context of service review and development about what 'care' means and subsequently greater attention to the relationship between treatment and care. On the importance of these issues contributors said:

'We have to engage people in care, then we are in a place to engage them in treatment. We need to respect that some people do care without treatment, but its care that must be established.' (Clinical Service)

'I respect the individualised and personalised approach of good clinical services but care would imply opportunities to talk and get support beyond treatment – so use of nurses, health advisors, psychological support, social care. All the additional issues even though people are less ill these days'. (Voluntary Sector)

'I haven't had 'care' from medical professionals but I have from other services... medical knowledge takes over. It's all about the meds.' (Person living with HIV)

5.10.5 Do services really understand what 'being HIV positive' means to the individual?

Interviews with people living with HIV, and with some professional interviewees, have been a reminder that HIV remains highly stigmatised and people fear the responses from family, friends, neighbours and some professional people. Stigma and fear lead to isolation and impact on mental well being and the quality of life of the person living with HIV. Further, living with HIV can also mean managing ill-health from a number of associated chronic diseases or side effects from medication. Of course, many people do manage but it is important that professionals acknowledge that people living with HIV are coming to terms with and managing a condition with few comparisons. Professionals might describe HIV as a long-term *manageable* condition; it is less easy to live with it as such. In addition, HIV is not just an individual experience; it remains a serious communicable disease and a significant public health concern. Further recognition, reflection and discussion of these issues will improve relationships with service users and in turn access to and engagement with services. People living with HIV have reported the following in the course of this study:

'The message is its 'chronic' and 'manageable' because of the medication. But it isn't doing the healing'. (Person living with HIV)

'It's about how to manage it and still have a life. There's a whole industry running around me – but they get weekends off, I don't. I have to manage it because it gets bigger and bigger and it eclipses the sun. You just become preoccupied. I work hard to keep it all in perspective'. (Person living with HIV)

'Most of living with HIV isn't about you, it's about the people around you, love you, and how they see you. Once they're told you can't take it back. It's devastating to them, even now every aspect of managing this upsets people'. (Person living with HIV)

5.10.6 Is there a need for standards which address responses to irregular or non-attendance?

A question which has arisen in interviewees with professional contributors is, in the context of services which are variable, and in recognition of each person as an individual: *how much effort or what systems should be expected to be in place (perhaps what should be obligatory) when it comes to responses to irregular or non-attendance?* While the recent NHS QIS draft *Clinical Standards for HIV services* considered many elements of the experience of the service user and the design and delivery of clinical services, for example promoting the need for regular multidisciplinary meetings (9.7) or that there should be a documented care plan agreed with the patient and available to the multidisciplinary team (9.11) the standards did not clearly address what systems or responses should be in place when it comes to irregular or non-attendance. Perhaps it was intended to be implicit in the drive for improved record keeping, planning and multidisciplinary approaches that these issues might be addressed. However had the issues been addressed explicitly a number of the good practices described in this report might have been recognised and steps toward best practice reflected in the approach which the draft standards took in the development of a number of quality statements which defined what might be achieved over levels D, C, B or A; with D as the minimum level of quality expected.

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Appendices

Appendix 1: A list of professional participants

| First name | Surname | Agency |
|------------|-------------|--|
| Dr Sarah | Allstaff | NHS Tayside |
| Colin | Anderson | NHS Lanarkshire |
| Dr Steve | Baguley | NHS Grampian |
| Claire | Baillie | Dumfries and Galloway Integrated Substance Service |
| Martha | Baillie | Waverley Care |
| Hosanna | Bankhead | Terrence Higgins Trust Scotland |
| Katherine | Bethell | NHS Lothian |
| Neil | Bird | Waverley Care |
| Linda | Buchan | Scottish Prison Service |
| David | Cameron | Waverley Care |
| Marion | Chatterley | Waverley Care |
| Dr Dan | Clutterbuck | NHS Borders |
| Charlie | Dudum | City of Edinburgh |
| Dr Morgan | Evans | NHS Tayside |
| Dr Tony | France | NHS Tayside |
| Nicholas | Frith | Waverley Care |
| Gillian | Forbes | NHS Borders |
| Andrew | Gardiner | HIV Scotland |
| Mark | Girvan | NHS Greater Glasgow and Clyde |
| Karen | Hamilton | Waverley Care |
| Peter | Harrison | NHS Lothian |
| Kirstie | Henderson | HIV Scotland |
| Dr. Mary | Hepburn | NHS GGC |
| Alessandro | Insalaco | Dundee |
| Katai | Kasengele | Waverley Care |
| Janice | Kenny | Fife Council |
| Roy | Kilpatrick | HIV Scotland |
| Chris | Kimber | Terrence Higgins Trust Scotland |
| Willie | Kirk | NHS Lanarkshire |
| Isbah | Khan | Princess Royal Trust Lanarkshire Carers Centre |
| Alison | Lord | Terrence Higgins Trust Scotland |
| Patricia | Lornie | NHS Tayside |
| Michael | Marr | Waverley Care |
| Dr Audrey | Mathers | NHS Lothian |
| Laura | Mathers | NHS Greater Glasgow and Clyde |
| Ian | McAdam | City of Edinburgh |
| Liz | MCCann | NHS Lanarkshire |
| Angus | McCurrach | Drugs Action Aberdeen |
| Dr Natasha | McDonald | NHS Greater Glasgow and Clyde |
| Paula | McFadyen | Waverley Care |

| | | |
|----------------|------------|---|
| Colin | McKay | Independent |
| Kelly | McKnight | Waverley Care |
| Katrina | Mitchell | Waverley Care |
| Gabrielle | Mora | Waverley Care |
| Neil | Munro | Positive Help |
| Nathan | Mwesigwa | Waverley Care |
| Fiona | Nicoll | NHS Lothian |
| Steve | O'Donnell | Gay Men's Health |
| Angela | Parsons | Waverley Care |
| Dr S. Erica | Peters | NHS Greater Glasgow and Clyde |
| Jacqui | Pollock | HIV-AIDS Carers and Family Service Provider Scotland |
| Nick | Putnam | HIV Scotland |
| Karen | Robertson | NHS Lanarkshire |
| Kay | Rodgers | North Lanarkshire Council |
| Dr Gordon | Scott | NHS Lothian |
| Kapulu | Simonde | Waverley Care |
| Sharon | Smillie | C Plus/Positive Support |
| Ibrahim Hamani | Souley | HIV Scotland |
| Veronica | Souter | Aberdeenshire Council |
| Vaughan | Statham | NHS Lothian |
| Angela | Stevenson | NHS Lothian |
| Margaret | Totten | HIV-AIDS Carers and Family Service Provider Scotland |
| James | Whyte | Gay Men's Health |
| Dr. David | Wilks | NHS Lothian |
| Lynne | Williamson | Waverley Care |
| David | Wilson | NHS Lanarkshire |
| Dr Andrew | Winter | NHS Greater Glasgow and Clyde |
| Dr Roger | Wong | NHS Greater Glasgow and Clyde |
| Maureen | Woods | NHS Lanarkshire |
| Mildred | Zimunya | Waverley Care |

Appendix 2: Interview schedules

i. Interview guide: People living with HIV

Introduction: This what we will do when we start

- We will check you have the information about the research and that you have or will sign the consent form.
- We will explain again how confidentiality and anonymity works; this means we will not use your name or write anything that will identify who you are.
- We will explain that the purpose of the interview is to find out more about how you have kept in touch with HIV clinical services and accessed and taken anti-retroviral therapies. Maybe there have been times where you haven't used HIV clinical services or taken your ART.
- We will remind you that there are no right or wrong answers; it's your experience of services that we are interested in hearing about.
- We will explain that we will take some notes as we talk. We do not use a tape recorder. If you want to stop at anytime that's okay just say.
- We will check if you have any questions before we start.

These are the questions we want to ask. They might not all be questions you can answer, that's okay, but they will help guide our conversation.

1. Can you tell me how you initially found the service which provided your HIV testing?
2. When they told you you were positive what else did they do, tell you or give you?
3. Specifically, what did you understand at that point about the clinical services you should go to or treatments you should consider?
4. Do you attend any HIV clinical services at the moment?
 - *If yes*, in the past have you ever had difficulty in keeping up regular attendance – what makes it difficult? You are attending just now, so what is it that helps you keep this up?
 - *If no*, what makes it difficult to keep up regular attendance just now? In the past have you attended the clinic? If at some time you have, what helped you to come then?
5. Are you using any anti-retroviral therapies at the moment?
 - *If yes*, in the past have you ever had difficulty in keeping up with your ART – what makes it difficult? You are taking ART just now, so what is it that helps you keep this up?
 - *If no*, what makes it difficult to keep up with your ART? In the past have you taken ART? If at some time you have, what helped you to take them then?

6. Has there ever been any agency, service or individual that has ever done something that has helped you to engage with clinical services at some point – if there is tell us more?
7. On the contrary, have you ever had any experience which has put you off or stopped you from using clinical services - if there is tell us more?
8. What *other* agencies – voluntary sector or other NHS services – have helped along the way and how? Specifically, has a service or a worker helped or tried to help you keep attending the clinic or with taking ART?
9. Do you feel you have ever experienced stigma or discrimination because you are HIV positive? Do you ever worry about this? If you have had experience or worry about it does it impact upon how you use clinical services or take your treatment?
10. Do you think that there is anything else about being HIV positive that makes it difficult to keep in touch with clinical services or take your treatments?

We will end the interview by checking these things:

- Do you have any questions?
- We will tell you how you can get the final report (email, hard copy or via our dedicated site) and when this is likely.
- We will give you some useful information about services.
- Thank you and we will give you your voucher/payment.

ii. Interview guide: Professionals

Introduction: This what we will do when we start

- Check you have all the information you need and have understood and signed (or will sign) the consent form.
- Check understanding of confidentiality and anonymity but that as a professional interviewee you will be named in a contributor list in an appendix to the final report: *for example Dr. Mary Smith, GP, NHS Grampian.*
- Explain the purpose of the interview is to find out more about the interviewees views on what helps retain, and what hinders, access to HIV specialist clinical services.
- Remind you there are no right or wrong answers; it's your experience that we are interested in hearing about.
- Remind you that we have provided a list of questions in advance but that we may not cover them all, but will draw on the range of questions as is appropriate.
- In terms of recording explain that we do not use a tape recorder but that the interviewer will take notes as we talk. If you want to stop at anytime that's okay just say.
- Ask: Any questions before we start?

Core questions: These are the questions we want to ask. They might not all be questions you can answer, that's okay, but they will help guide our conversation.

1. Please clarify your post and its main responsibilities; particularly in relation to services for people living with HIV.
2. Can you tell me your understanding of how individuals who wish to take an HIV test do so?
3. On informing an individual of their positive result what happens next in terms of the service(s) you have knowledge of?
4. At the point of testing and a positive result what do you know about how HIV clinical services assess likely further engagement with clinical services or adherence to treatment? What do they do with this knowledge? What could they do?
5. What do you know about the specific circumstances or characteristics of individuals, groups or communities which might impact on how they are attracted to or retained in specialist clinical services? For example: Does/Can locality/geography, ethnicity, migration/political status, age, literacy, sexuality, substance use, gender, disability, economic or other personal circumstances play a role?
6. Could you identify anything about 'being HIV positive' that works against access or retention in clinical services and access/use of ART?
7. How does stigma and/or discrimination impact upon access/retention by specialist clinical services and access/use of ART?
8. What do clinical services do when an individual does not engage or subsequently disengages from clinical services?
9. What approaches (information provision, partnerships or service design/delivery or others) work to encourage attraction or retention in services (at the point of diagnosis and/or subsequently)? Can you give an example(s)? Why do you think they work?
10. Are there certain approaches that work better for certain individuals, groups or communities?
11. Do you know of other approaches which have been tried but had little/no impact and why so?
12. How would you describe the links/connections between voluntary sector agencies and specialist HIV clinical services? How would you describe the voluntary sector's role in supporting people living with HIV to engage with specialist clinical services and ART? Should the role they play change?

13. How would you describe the links/connections between NHS/non-specialist clinical services (including GP based services) and specialist HIV clinical services? How would you describe the role which NHS/non-specialist clinical services (including GP based services) play in supporting people living with HIV to engage with specialist clinical services and ART? Should the role they play change?

14. Thinking about people living with HIV; what is the perceived and actual relationship between treatment and care?

We will end the interview by checking these things:

- Check whether you have any questions.
- We will tell you how you can get the final report (email, hard copy or via our dedicated site) and when this is likely.
- We will discuss recruitment of people living with HIV – can you assist? If so we will provide further information.
- Thank you

Appendix 3: Useful articles, reports and publications

The commission for this study did not include a literature/research review however in the course of designing and delivering the project a number of articles, reports, publications came to the attention of the study team. This appendix lists relevant Scottish, UK and some international material, giving basic information about content/findings and where possible a link to where the article, report or publication can be accessed. On line links necessarily change in time but as at publication we have strived for accuracy.

Much of our information has been sourced via **HIV Scotland** and **National AIDS Map**.

HIV Scotland is the national HIV policy charity for Scotland. The agency states “We want a society which is well-informed about HIV with excellent prevention and treatment services. We provide expertise to inform and deliver strong policies”. To register with HIV Scotland and receive regular information visit their site at: <http://www.hivscotland.com> Via the HIV Scotland site at it is possible to access a range of useful articles and publications.

A further key source of information is **National AIDS Map**. NAM states its purpose as: “NAM works to change lives by sharing information about HIV and AIDS. We believe that, wherever you are in the world, having independent, clear and accurate information is vital in the fight against HIV and AIDS. It enables individuals and communities affected by HIV to protect themselves, care for others, advocate for better services and challenge stigma and discrimination. We produce useful information that you can trust, and make sure it is there for anyone who needs it”.

The NAM site provides latest news on HIV internationally, and comprehensive information on topics including testing and health monitoring, hepatitis and HIV, HI treatment, families and children, health problems, transmission and prevention, healthy living and social and legal issues. Linked to its comprehensive web resource NAM produces weekly e bulletins which are free. To subscribe go here: <http://www.aidsmap.com/bulletins>

We have organised the material we have found useful under these categories: testing, prevention, treatment/care and mental health/alcohol/substance abuse and ‘other’ background reports we have found valuable. Of course an article, report or publication may cover matters across these categories and so this initial grouping is only an indication of the primary focus. To restate – this is not a comprehensive review but an acknowledgement of material we have found informative.

Testing

P Flowers et al (2003)

Re-appraising HIV testing: An exploration of the psychosocial costs and benefits associated with learning one's HIV status in a purposive sample of Scottish gay men.

British Journal of Health Psychology Volume 8 Issue 2 pages 179-194

<http://onlinelibrary.wiley.com/doi/10.1348/135910703321649150/abstract>

About the article: The HIV test can resolve doubt and anxiety for some men, but only when 'not knowing' is experienced as less tolerable than an imagined positive result.. It is argued that the development of HIV testing policy must start with a perspective grounded in an understanding and appreciation of these complexities.

TR Chadborn et al (2004)

No Time to Wait: How many HIV-infected homosexual men are diagnosed late and consequently die?

AIDS Volume 19 Issue 5 pages 513-520

<http://www.ncbi.nlm.nih.gov/pubmed/15764857>

About the report: The report examines trends around late diagnosis and consequences of such; concluding that the continued late diagnosis of one in four MSM means these individuals lose the option to start therapy early, miss opportunities to prevent further transmission and are approximately 10 times more likely to die within a year of diagnosis.

V Cree (2008)

It's good to go for a test

Available via the HIV Scotland site at <http://www.hivscotland.com/data-and-research/research-library>

About the report: The report presents findings of the evaluation of Waverley Care's HIV Awareness campaign which was targeted at African communities in Glasgow.

LM McDaid and GJ Hart (2011)

Increased HIV testing and reduced undiagnosed infection among gay men in Scotland, 2005-8: Support for the opt-out testing policy?

Available via the HIV Scotland site at <http://www.hivscotland.com/data-and-research/research-library>

About the article: There was a substantial increase in recent HIV testing between 2005 and 2008. Lower proportions of undiagnosed infection among the most recent HIV-positive testers suggest frequent testing could play a role in reducing undiagnosed HIV and should remain central to HIV prevention efforts.

Prevention

LR Metsch et al (2008)

HIV Transmission Risk Behaviours among HIV-Infected Persons Who Are Successfully Linked to Care

Clinical Infectious Diseases Volume 47 pages 577-584

<http://www.ncbi.nlm.nih.gov/pubmed/18624629>

About the article: The study examined the relationship between receipt of medical care for human immunodeficiency virus (HIV) infection and HIV transmission risk behaviour among persons who had received a recent diagnosis of HIV infection. It concludes that being in HIV care is associated with a reduced prevalence of sexual risk behaviour among persons living with HIV infection. Persons linked to care can benefit from prevention services available in primary care settings. (US study)

L Williamson et al (2008)

Young women and limits to the normalisation of condom use: a qualitative study

Available via the HIV Scotland site at <http://www.hivscotland.com/data-and-research/research-library>

About the article: Encouraging condom use among young women is a major focus of HIV/STI prevention efforts but the degree to which they see themselves as being at risk limits their use of the method. In this paper, authors examine the extent to which condom use has become normalised among young women from Scotland.

GJ Hart and J Elford (2010)

Sexual risk behaviour of men who have sex with men: emerging patterns and new challenges.

Current Opinion in Infectious Diseases February 2010 Volume 23(1) pages 39-44

<http://www.ncbi.nlm.nih.gov/pubmed/19949328>

About the article: ART means that an increasing number of men who have sex with men are living with HIV. This review focuses on continuing transmission of HIV, risk factors for HIV-negative MSM, risk behaviour and risk reduction interventions among HIV-positive MSM, sexually transmitted infections, HIV and ageing and new and emerging populations of MSM communities.

LM McDaid and GJ Hart (2010)

Sexual risk behaviour for transmission of HIV in men who have sex with men: recent findings and potential interventions

Current Opinion in HIV & AIDS Volume 5 Issue 4 pages 311–315

<http://www.rectalmicrobicides.org/docs/Sexual%20risk%20behavior%20for%20transmission%20of%20HIV%20in%20MSM%20-%20McDaid.pdf>

About the article: Men who have sex with men (MSM) remain one of the groups most at risk of HIV, particularly in countries with concentrated epidemics. Authors review findings from behavioural research with MSM and discuss the potential of behavioural interventions.

LM McDaid and GJ Hart (2010)

Contact with HIV prevention services highest in gay and bisexual men at greatest risk: cross-sectional survey in Scotland

Available via the HIV Scotland site at <http://www.hivscotland.com/data-and-research/research-library>

About the article: Men who have sex with men remain the group most at risk of acquiring HIV and new HIV prevention strategies are needed. The authors examine what contact MSM currently have with HIV prevention activities and assess the extent to which these could be utilised further. They argue offering combination prevention, including outreach by peer health workers, increased uptake of sexual health services delivering behavioural and biomedical interventions, and supported by social marketing to ensure continued community engagement and support, could be the way forward.

C Knussen et al (2010)

HIV-related sexual risk behaviour between 1996 and 2008, according to age, among men who have sex with men (Scotland)

Available via the HIV Scotland site at <http://www.hivscotland.com/data-and-research/research-library>

About the article: HIV-related sexual risk behaviour did not change significantly between 2002-08 among MSM after increases noted between 200-02. A minority of MSM continues to engage in relatively high levels of sexual risk, and younger generations appear to be at particular risk. This represents a public health concern and highlights the need for targeted age-specific interventions.

A Kurth et al (2011)

Combination HIV Prevention: Significance, Challenges, and Opportunities

Available via the HIV Scotland site at <http://www.hivscotland.com/data-and-research/research-library>

About the article: A package of interventions are required to protect against HIV transmission and acquisition: including knowledge of HIV serostatus, behavioural risk reduction, condoms, male circumcision, needle exchange, treatment of curable sexually transmitted infections, and use of systemic and topical antiretroviral medications by both HIV-infected and uninfected persons. (US study)

D Inegbenebor (2010)

Good sex, bad sex, the African way

African HIV Policy Network

A report developed as part of the Pan London HIV prevention programme providing an insight into the views of Africans in the UK on sex and safer sex.

EM Gardner et al (2010)

The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection

Clinical Infectious Diseases Volume 52 Issue 6 pages 793-800

<http://cid.oxfordjournals.org/content/52/6/793.short?rss=1>

About the article: To benefit from ART individuals need to know that they are HIV infected, engage in regular HIV care, and adhere to ART. Test-and-treat strategies for HIV prevention suggest that expanded testing and earlier treatment could decrease HIV transmission. However, poor engagement in care will limit the

effectiveness of test-and-treat strategies. This study reviews the spectrum of engagement in care and applies this to help understand the challenges that poor engagement in care will pose to test-and-treat strategies for HIV prevention. (US study)

Treatment and care

SL Catz et al (1999)

Predictors of outpatient medical appointment attendance among persons with HIV

AIDS Care Volume 11 Issue 3 1999 pages 361-373

<http://www.tandfonline.com/doi/abs/10.1080/09540129947983>

About the article: Clinic-based assessments of social and environmental barriers to adherence might include identifying culturally and age relevant beliefs about treatment efficacy, service provision and disease processes. Also, given that initial behaviour is one of the strongest predictors of continued adherence among other chronic disease patients the finding that the healthiest people living with HIV have the lowest rates of adherence to medical appointments argues for early intervention. Interventions specifically targeting support systems are likely to be effective for promoting appointment adherence.

C Arici et al (2002)

Factors associated with the failure of HIV-positive persons to return for scheduled medical visits

HIV Clinical Trials Volume 3 pages 52–57

<http://thomasland.metapress.com/content/2xakvbt89nu96vak>

About the article: The study reports that patients with a history of IDU, patients without AIDS diagnosis, and patients with higher CD4 counts are more likely to fail to return for scheduled medical visits. The highest risk of failure occurs in the first 6 months after enrolment. (Italian study)

L Doyal and J Anderson (2003)

My Heart is Loaded

Available at:

http://mambo.org.uk/VirtualContent/133911/My_Heart_is_Loaded_African_Women_with_HIV_Surviving_in_London.pdf

This report explores the circumstances of a group of African women with HIV living in London.

LJ Hadow et al (2003)

Patients lost to follow up: experience of an HIV clinic

Sexually Transmitted Infections Volume 79 pages 349-350

<http://sti.bmj.com/content/79/4/349.3.extract>

About the article: Study reports that patients lost to follow up in this London based study were likely to be younger and born outside UK. Authors suggest that there is no clinical importance for the patient who is symptom free and not on ART and does not attend for one year. Such patients might be better managed in Primary Care.

MM Holstad et al (2006)

Motivating HIV positive women to adhere to antiretroviral therapy and risk reduction behavior: the KHARMA Project

Online Journal of Issues in Nursing Volume11(1) Pages 78-94

http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Volume112006/No1Jan06/tpc29_416063.aspx

About the article: Authors report that HIV+ women who are on ART require education and encouragement to attain and maintain a high level of adherence. Nurses have fundamental skills in place to learn Motivational Interviewing and advanced group facilitation techniques and deal with sensitive issues, such as sexual behavior. Nurse-led motivational groups are designed to empower women to overcome barriers to prescribed medication adherence and to practice risk reduction behaviors with emphasis on the importance of caring for the self. (US study)

E Lanoy et al (2006)

Predictors identified for losses to follow-up among HIV-sero-positive patients

Journal of Clinical Epidemiology Volume 59 pages 829-835

<http://www.ncbi.nlm.nih.gov/pubmed/16828676>

About the article: This study aims to describe predictors of loss to follow-up in the French Hospital Database on HIV infection. It concludes that recently diagnosed patients, IDU and immigrants are more often lost to follow up and should receive particular attention. (French study)

S Coleman et al (2007)

Retention challenges for a community-based HIV primary care clinic and implications for intervention

AIDS Patient Care and STDs Volume 21 Number 9 pages 691–701

<http://www.ncbi.nlm.nih.gov/pubmed/17919096>

About the article: The study sought to elucidate factors involved in loss to follow-up. Survey respondents reported that the greatest perceived barriers to care were personal/cultural, structural, and financial in nature. The authors propose patient surveys for organisational self-assessment to effect operational changes that minimize barriers to care. A risk assessment tool based on evidence-based methods can be implemented to identify high-risk patients for innovative outreach interventions. (US study)

TP Giordano et al (2007)

Retention in care: a challenge to survival with HIV infection.

Clinical Infectious Diseases Volume 44 pages 1493–1499

<http://www.ncbi.nlm.nih.gov/pubmed/17479948>

The authors report that the effect of poor retention in care on survival is not known, and so they sought to quantify that relationship. Patients with poor retention in care did not achieve the same CD4 cell count, plasma HIV concentration, and survival benefits as those who were retained in care. They conclude that strategies to retain persons in long term care need to be developed, tested, and implemented to maximize the benefit of medical care. (US study)

Health Protection Agency (2008)

Sexually transmitted infections in black African and black Caribbean communities in the UK: 2008 report

Available via the HIV Scotland site at <http://www.hivscotland.com/data-and-research/research-library>

About the report: Amongst findings is that in terms of the percentage of late diagnoses, that is after a point when treatment should have begun, among new diagnoses of HIV in 2007 was highest among black Africans (42%). Twenty-seven percent of HIV diagnoses among people of Caribbean origin were late.

A Wells (2008)

Whispers and closed doors: The experiences of gay men living long-term with HIV

Available via the HIV Scotland site at <http://www.hivscotland.com/data-and-research/research-library>

This research aimed to develop a deeper understanding of what it was like to live with HIV at a time when there was no cure or treatment for the virus and how that lived experience may have changed following the introduction of effective treatments.

GP Bisson and JSA Stringer (2009)

Lost but not forgotten - the economics of improving patient retention in AIDS treatment programs

PLoS Medicine Volume 6 Issue 10: e1000174

<http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1000174>

About the article: The article highlights the cost effectiveness of preventing loss to follow-up in HIV treatment programmes in Africa. (US study)

MJ Mugavero et al (2009)

Missed visits and mortality among patients establishing initial outpatient HIV treatment

Clinical Infectious Diseases Volume 48 pages 248–56.

<http://www.ncbi.nlm.nih.gov/pubmed/19072715>

About the study: Patients who missed visits within the first year after initiating outpatient treatment for HIV infection had more than twice the rate of long-term mortality, compared with those patients who attended all scheduled appointments. Authors propose that early missed visits are not causally responsible for the higher observed mortality but identify those patients who are more likely to exhibit health behaviours that portend increased subsequent mortality. (US study)

C Morley (2009)

Lost to care: the mystery of the disappearing patients

Available from NAM at: <http://www.aidsmap.com/Lost-to-care-the-mystery-of-the-disappearing-patients/page/1412542/>

About the research: This research explores why people disappear from care and highlights that few people see HIV as a purely clinical issue in their lives and that people living with HIV need to be better informed about the consequences of non adherence to treatment. Authors identify that more needs to be done to understand

non-attendance, improve data collection and the role of non specialist HIV services in supporting attendance and treatment adherence.

B Ndiaye et al (2009)

Characteristics of and outcomes in HIV-infected patients who return to care after loss to follow-up

AIDS: 24 August 2009 Volume 23 Issue 13 pages 1786-1789

http://journals.lww.com/aidsonline/Fulltext/2009/08240/Characteristics_of_and_outcomes_in_HIV_infected.21.aspx

About the article: HIV positive patients who return to care after being lost to follow-up are five times more likely to die in the short term than patients who remain in HIV care continuously. (French study)

SM Gerver et al (2010)

High rate of loss to clinical follow up among African HIV infected patients attending a London clinic: a retrospective analysis of a clinical cohort

Journal of International AIDS Society Volume 13: 29

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2924265/>

About the article: One in five HIV-infected patients from a London clinic were lost to follow up. Black African ethnicity was identified as a factor. There is a need for HIV clinics to establish systems for monitoring and tracing loss-to-follow up patients and to implement strategies to improve retention.

C Bourne et al (2011)

Short message service reminder intervention doubles sexually transmitted infection/HIV re-testing rates among men who have sex with men

Available via the HIV Scotland site at <http://www.hivscotland.com/data-and-research/research-library>

About the article: The SMS reminder programme started in late 2008 at a large Australian sexual health clinic. (Australian study)

M Davis and P Flowers (2011)

Love and HIV serodiscordance in gay men's accounts of life with their regular partners

Culture, Health and Sexuality Volume 13, Issue 7, 2011 pages 737-749

<http://www.ncbi.nlm.nih.gov/pubmed/21331963>

About the article: This paper examines discourse on serodiscordant relationships in interviews with 16 HIV-positive and 3 HIV-negative gay men living in Scotland.

C pop-Eleches et al (2011)

Mobile phone technologies improve adherence to antiretroviral treatment in a resource-limited setting: a randomised controlled trial of text message reminders

AIDS Volume 25 (6) pages 825-834

<http://www.ncbi.nlm.nih.gov/pubmed/21252632>

About the article: This study tested the efficacy of short message service (SMS) reminders on adherence to ART among patients attending a rural clinic in Kenya. These results suggest that SMS reminders may be an important tool to achieve optimal treatment response in resource-limited settings. (US study)

George House Trust (2011)

Social and economic circumstances impact on HIV treatment outcomes in US, Canada, Brazil, Australia

George House Trust at

http://www.ghg.org.uk/news/article/39147/25/01/2011/Disadvantage_Affects_HIV_Futures

Article draws on evidence from different sources, concluding that social and economic circumstances have an impact on the outcomes of HIV-positive patients. Investigators monitored patients whose HIV was diagnosed soon after their infection occurred. During eight years of follow-up, women had poorer outcomes than men, and non-white patients living in southern US states were the group most likely to experience HIV-related illnesses.

SC Kalichman (2011)

HIV treatment adherence in women living with HIV/AIDS: research based on the Information-Motivation-Behavioural Skills model of health behaviour

The Journal of the Association of Nurses in AIDS Care

Jul-Aug Volume 12(4); pages 58-67

<http://www.ncbi.nlm.nih.gov/pubmed/11486721>

About the article: The authors examined cognitive and behavioural factors associated with HIV treatment adherence in a convenience sample of 112 women. Interventions that enhance treatment adherence motivation and build adherence skills may help improve HIV treatment adherence in women receiving anti-HIV therapies. (US study)

GR Kaufmann et al (2011)

Interruptions of cART limits CD4 T-cell recovery and increases the risk of opportunistic complications and death

AIDS Volume 25(4) pages 441-451

<http://www.ncbi.nlm.nih.gov/pubmed/21206265>

About the article: ART recovers CD4 T lymphocytes which protects against opportunistic complications. The study concludes that CD4 T-cell recovery was smaller in persons with treatment interruptions more than 6 months. To achieve best outcomes authors suggest early initiation of ART and avoiding treatment interruptions.

HB Krentz et al (2011)

Adverse health effects for individuals who move between HIV care centres

Journal of Acquired Immune Deficiency Syndrome Volume 57 pages 51-54

<http://www.ncbi.nlm.nih.gov/pubmed/21346587>

About the study: Study reports that patients who move and have to find a new HIV clinic have poorer outcomes than individuals who remain in continuous care at the same centre. Authors conclude that efforts to transfer across seamlessly will help avoid negative consequences. (Canadian study)

Mental health, alcohol and substance abuse

The People Living with HIV Stigma Index (2009)

Give Stigma the Index Finger: Scotland Report 2009

Available at <http://www.stigmaindex.org/50/analysis/uk.html>

The report highlights the main findings from The People Living with HIV Stigma index in Scotland – research to document the experiences of HIV related stigma.

J Tetrault et al (2010)

Substance Abuse and HIV: Treatment Challenges

Available via the HIV Scotland site at <http://www.hivscotland.com/data-and-research/research-library>

Alcohol and substance abuse are common in patients with HIV infection and often complicate treatment in a number of ways. Appropriate treatment of both alcohol and substance abuse can result in improved adherence to antiretroviral therapy and decreased high-risk behaviours. (US study)

National AIDS Trust (2010)

Psychological Support Services for people living with HIV

Available at:

<http://www.nat.org.uk/Media%20library/Files/Policy/2010/Psychological%20support%20July%202010%20updated.pdf>

In 2009, NAT undertook a project looking into the issue of psychological support for people living with HIV. The report focuses on the discussions at a related expert seminar, highlighting the key issues which arose and areas of debate and draws some conclusions on the basis of these discussions and presents recommendations for action.

AW Carrico et al (2011)

Psychiatric Risk Factors for HIV Disease Progression

Journal of Acquired Immune Deficiency Syndromes Volume 56(2) pages146-150

<http://www.medscape.com/viewarticle/738780>

About the article: Depression and substance use predict hastened HIV disease progression, but the underlying biological or behavioural mechanisms that explain these effects are not fully understood. The study concludes that inconsistent patterns of ART utilization may partially explain the effects of depression and stimulant use on hastened HIV disease progression. (US study)

Other

National AIDS Trust (2008)

HIV and the UK Asylum Pathway

Available at <http://www.nat.org.uk/Media%20library/Files/PDF%20documents/HIV-and-the-UK-Asylum-Pathway.pdf>

This is an overview of the pathway an asylum seeker takes in the UK from application to either integration or removal.

National AIDS Trust (2008)

The Myth of HIV Health Tourism

Available at <http://www.nat.org.uk/Media%20library/Files/PDF%20documents/Myth-of-HIV-Health-Tourism-Oct-2008.pdf>

A report that addresses and refutes allegations of HIV health tourism to the UK

G Mulvey/Scottish Refugee Council (2009)

Refugee and Asylum Seeker Research in Scotland: A Literature Review

Available at

http://www.scottishrefugeecouncil.org.uk/assets/0000/0100/Literature_Review_2009.pdf

This literature review is an attempt to highlight the 'state of the art' with regard to asylum and refugee research in a Scottish context.

National AIDS Trust (2009)

Poverty and HIV 2006-2009

Available at

<http://www.nat.org.uk/media/Files/Information%20and%20resources%20-%20publications/Poverty%20and%20HIV%202006-2009.pdf>

The report explores the relationship between poverty and HIV and highlights policies which may alleviate or exacerbate this poverty. 20 policy recommendations are made.