Centre for AIDS Research

Living with HIV/AIDS
in Hampshire and the Isle of Wight

An Assessment of Needs
2005 - 2006

University
of Southampton

The Project Specification : October 2004

"The changing nature of the HIV epidemic, and the growing diversity of groups affected, present the NHS and other service providers with a need to review service provision and plan for future needs. It is therefore essential to undertake a thorough and wide-ranging assessment of the needs of people living with HIV in the twenty-first century in Hampshire and the IoW.

The key purpose of the needs assessment survey is to consider service development issues. We need to explore what services are needed, what services are being used, and the experience of current service users. We also need to consider issues and problems faced by service providers.

The evidence gathered from the survey will inform commissioning and planning arrangements for HIV and other services across Hampshire and IoW."

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Dr Emma J Treby
Professor Michael J Clark
Olga S. Maslovskaya

University of Southampton

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Contents

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Portsmouth Health, Housing and Social Care (Adult Services)
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Southampton City PCT
Portsmouth City PCT
New Forest PCT
Eastleigh Test Valley South PCT
Mid-Hampshire PCT
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The University of Southampton (Research Support and Governance Office)

Members of the Project Steering Group:

Robert Staite (chairman)	Hampshire County Council, Commissioning Officer-Substance Misuse & HIV/AIDS
Donna Bone	Positive Action, Managing Executive
Brian Bridger	Positive Action, Client Services Manager
Rob Carroll	Mid Hampshire Primary Care Trust, Head of Health Promotion and Sexual Health Service Development Manager
Darryl Clarke	The Ribbons Centre, Client Services Manager
Ginny Cranshaw	The Ribbons Centre, Centre Co-ordinator
Neil Dacombe	Positive Voice, Coordinator
Mark Hutchinson	Portsmouth County Council
Caroline Munro	Hampshire County Council, Hampshire County HIV Development Worker and HIV Social Worker
Julie Powis	Groundswell, Project Manager
Glenn Turner	Southampton City PCT, Head of Health Promotion

A background to the challenge of HIVAIDS

The number of people living with HIV/AIDS has increased and continues to increase in Hampshire and the Isle of Wight (H&IOW), as it has elsewhere in the UK. Such increases represent new infections (within-County and in-migration), recent diagnoses of previous infections and the long-term survival of those diagnosed in previous years. The effectiveness of antiretroviral therapy has reduced the number of deaths from HIV-related illness and resulted in a situation where people are living longer and potentially in relatively good health. There is a common sentiment, expressed in many different ways, that whereas an HIV diagnosis used to be the precursor to managing the process of dying it is now represents the start of procedures to manage living and lifestyle.

Although HIV can now be managed with antiretroviral drugs to relieve symptoms and delay the onset of AIDS, there are many other needs that may be altered rather than reduced by the availability of therapy. Increasingly, these needs are social and emotional rather than medical, and with the significant change in the social profile of the County's people living with HIV/AIDS (PLWHA), notably the increase in the proportion of infected immigrant people, social support requirements may escalate. The care and support available to PLWHA can be seen as falling into three categories:

- Medical services are largely channelled through the NHS Genito-Urinary Medicine (GUM) Clinics, some of which provide broad and general GUM support and some have specialised to the extent of being specific HIV Clinics.
- Social service provision through Social Services at County and Local Authority level, and involving a broad range of social, benefits, housing and immigration services.
- Specialist care, advice and support offered through organisations in the voluntary sector, operating on a mix of charitable income and grants from the public sector, and involving a broad range of emotional, practical, social, benefits, housing and immigration support.

It is clear that the over-riding characteristic of both need and provision is diversity. The markedly different circumstances of PLWHA across the County and the IOW (H&IOW) promote very different sets of personal priorities, requirements and abilities to respond. Contrasted personal lifestyles and attitudes further shape the way in which individuals prefer to use services – or, indeed, whether they wish to use services at all. And those services themselves are configured and constrained by a range of organisational structures, procedures and resources, some of which have been inherited from the HIV/AIDS situation prevailing some years ago.

An introduction to the survey

To date, the access to, and provision of, care in H&IOW have not been assessed to see if they meet the needs of this constantly-changing client group. This research project aims to explore whether their needs are being met by service providers, whether care and support is reaching all of the client groups and whether improvements could be made in terms of the access to and provision of care and services. The report offers and evaluates options for models of care provision and highlights where support and services are lacking. All service providers involved in this study are invited to use the project outcomes to initiate a debate aimed at reviewing and refining their services, and this process should benefit all people living with HIV in Hampshire and the Isle of Wight.

The research strategy included quantitative and qualitative data collection from service users via questionnaires, focus group discussions and one-to-one interviews, together with service provider one-to-one interviews. It was considered critical to undertake qualitative data collection as the aim was to assess 'needs' which are opinion- and value-based. An exclusively quantitative study would not have been able to provide such a depth of understanding as it would not have provided a vehicle to discuss feelings, perceptions and problems in a conversational manner.

The purpose of the questionnaire was to gain knowledge of the services each participant used and did not use and their reasons for (not) doing so. This helped to gain an understanding of the most-needed services and where improvements in access and provision could be made. It also revealed whether participants from particular groups (e.g. gay and bisexual men, intravenous drug users, immigrants and asylum seekers, pregnant women and young people attending GUM clinics) had different needs. Focus groups and in-depth interviews with service users provided a second stage of data collection that was required to address wider issues of health and social care amongst diverse groups in more depth than a questionnaire could provide. The discussions and interviews were strictly confidential, voluntary and anonymous.

Many participants (both service users and providers) commented that they felt pleased and empowered by the process of voicing their concerns and hence making a difference to the service that they receive. Nevertheless, it is possible that the more hard-to-reach individuals living with HIV/AIDS were not accessed successfully in the research process. Unless PLWHA were using at least one of the services, then it was not possible to engage them in the research. It is therefore important to acknowledge that although the research reflects a diverse cross-section of individuals, the hardest-to-reach groups may not be adequately represented.

Questionnaire data were analysed via categorical analysis and cross-tabulation to ascertain key trends e.g. under-utilised services, in-demand services, differing needs of diverse groups and the barriers to access and use of services. Focus group and interview data were analysed with NVivo - qualitative research software which enabled textual coding and categorization of data into key themes/issues. This technique enables interpretation and structuring of meaning from diverse data sources.

A summary of the responses

In order for attention and action to be focused where they are most needed, it is necessary to make value judgements about the questions that were of greatest concern to the providers and users. A small number of issues emerged time and time again. They may be articulated in different ways, but they both permeate and dominate the debate. Above all else, these are the unavoidable challenges that flow from this project. In every case, they involve a fundamental concern surrounded by a host of associated implications: it is this grouping of topics that makes it possible to converge on just six core issues:

- Specialist versus generalist models of care and support delivery
- The relationship between medical and social care and support
- Organisational options for equitable access to care and support
- The challenge of delivery within a spatially-diverse environment
- Responding to diversity of personal circumstance and need
- Immigration – the long term challenge of transient needs.

The first three of these issues can be seen as key contentions in which there is a spectrum of opinion, often polarised into strongly and significantly contrasted viewpoints. Fascinatingly, these opinions do not split neatly along any conventional or stereotypical line. It is not a matter of providers against users, professionals against volunteers, medics against social providers, men against women, or locals against immigrants. The simple fact is that opinions differ, significantly. Diversity rules, and the real challenge is that management, resource and logistic constraints, particularly in the formal sectors, make it difficult to respond by offering diverse services that are made available as a matter of personal choice.

The remaining three issues can best be viewed as underlying dimensions which colour and constrain the needs of the users and the delivery capacity of the providers. They are complex issues, often buried deeper than the key contentions, but they tend to attract consensus rather than contention. While this convergence should in principle be a spur to action, it can have the opposite effect – with a sense that the issue is known, respected but to an extent taken for granted as a given. We attempt to indicate that even with these external issues, it is possible to devise interventions which address needs more effectively than is currently the case. To do less is to risk failing in the mission to provide equitable access to care and support.

At the end of the process, what have we actually learned about the challenge of living with HIV/AIDS in H&IOW? What should we be doing next? One of the risks of the evidence-led approach is that information can be overwhelmed by data, and trends can disappear in a welter of detail. Issues that are mentioned many times by many people tend to catch the attention, but a point made once may be more important. The big question, of course, the extent to which people living with HIV/AIDS in H&IOW are well-served, and whether they are satisfied with that service. Great satisfaction can be taken from the generally positive response of participants from all the communities concerned (PLWHA and providers): the honesty and frankness of their responses was extremely impressive and there was very rarely any sense of reserve. Punches were not pulled, and verbal blows were struck when this was felt necessary, so the many generous comments that were made can be regarded as a genuine indication of satisfaction. At the same time, there were many points where respondents voiced real concerns and made pointed criticisms – with providers being every bit as likely as users to voice dissatisfaction with both the present system and the perceived trends.

There is genuine appreciation of the general principle of open access for all, of the availability of free medical consultation and drugs, and of those many professionals in both the formal and voluntary sectors who have devised systems flexible enough to fit with the needs and capacities of PLWHA. Choice is widely appreciated – including choice of clinics and of consultants (including access to female consultants), clinical nurses and health advisors. In many senses, choice sooths perceived lack of optimum service. Some individuals, sometimes well-informed and influential, have voted with their feet and sought care elsewhere, notably in London or Brighton, but the great majority have not. Eulogies of committed, enthusiastic and sympathetic staff and volunteers emerge from our interviews in every sector of the HIV/AIDS response system. Key people make the system work and make the individual feel good: their loss is sensed as a threat, and often triggers retrenchment or downgrading of service. The best people make the system work for them and their clients, not vice versa – a truism that applies in all contexts at all times. Not only are key personnel critical to the design and delivery of individual services, but they are also widely seen as the catalysts and facilitators of inter-service integration. Despite this very widespread support for front-line workers, however, there are still too many reports of people who are uninformed, insensitive and unsympathetic towards PLWHA.

To what extent can problems of service delivery and access be attributed to lack of funding? The question is often asked, and answers inferred, but the situation defies simple characterisation. Budget pressures are very real across the sectors, and are doubtless cutting into services. Few people assume that service provision could be unrestrained. Yet there is a sense that some of the restructuring of services, supportive in a general way of strategic moves towards mainstreaming HIV/AIDS, may be based on misconceived ideas that general service provision is cheaper than the maintenance of specialist provision (albeit part-time or more geographically extensive). The diversity of people with HIV is not fully represented in the current support group provision. Or perhaps it is fairer to say that the perception is that they do not provide a rounded service. This affects smaller groups such as heterosexual white British PLWHA, but also the hardest to reach groups including black African men. Also, it must be remembered that the needs vary across the County. There appears to be less need for support groups in areas where the users are employed and in a stable family environment (e.g. Winchester and Basingstoke areas), but what about those who still crave involvement with others in the same situation as themselves? There can be extreme isolation for those who are perhaps single, or at least do not fit into the box, and on-line communities then become the only alternative.

The survey has also revealed a frequent lack of co-ordination between the different service sectors, and even between components of the same service sector but across geographical divides. There are implications here for the concept of a regional centre, as services have not demonstrated any great success in developing a joined-up approach at present. This links into the "signposting" issue, the role of providing a gateway to the range of available services, and this appears to be where voluntary support groups are plugging the gap where they can. It is often these groups that guide users towards Social Services or counselling, or alert them to a particularly amenable dentist or GP. But such services should be universal rather than ad hoc, and they should not be reliant on an individual attending a particular voluntary group. There is a need for a virtual network that is understood by all service providers so that they are able to articulate it to their users. This network might most appropriately be at the level of the area (Southampton or Portsmouth) so as to match the needs of particular sets of users, but also at the regional level to support providers and cater for those many users who do not fit into the major urban groupings.

Scale has been seen to play an all-pervading role. Designations for excellence and specialism (which combine to offer the most up to date and highest quality service) require a client population that exceeds a given (but undefined) operational threshold. Whether or not the combined service provision of H&IOW reaches this threshold is a moot point, and there is only a point in trying to determine it if there is a genuine appetite for a hierarchical hybrid service delivery model. Integration would be required at a level far exceeding anything so far achieved or attempted. Competition (inter-sector and inter-site) would need to be replaced by co-operation. People in the non-urban areas might become more remote from specialist services (though closer to routine services). But the prize is very enticing. The prize is a unique model of service delivery with genuine excellence at its peak.

Named posts overall, and the highly-committed individuals who usually (but not quite always) occupy them, have often been the key to empowering such inter-sector and inter-service integration as has been achieved. They breathe life into the concept of a holistic service – yet they appear to be undergoing a systematic dismantling. The point has been repeatedly made that, in some cases at least, this is a false economy – though structural, operational and cultural change is certainly not in itself disadvantageous. The lesson appears to be that strategic planning is proceeding in an ad hoc and rather non-strategic way, and that the principle of integration is being vaunted with scant respect for the practice of inter-sector consultation, let alone genuine joint participation. The voluntary sector has been taken for granted throughout this report. It has been variously praised and criticised, but no-one has questioned its role or importance. It, too, is undergoing change – and change almost always involves stress as new roles, responsibilities and hierarchies emerge. PLWHA do not always want access to voluntary services, either because they are in the fortunate position of having no unmet needs, or because there are cultural or social barriers to their seeking personal networking. But those who do want voluntary support are very pleased with the service they receive except in a very few cases (usually relating to the new marginal groups, white heterosexuals or bisexuals for example). Their commitment and flexibility, and their willingness to work around the system, are major assets.

Though there are times when information overload appears to be a problem, the overwhelming evidence of the survey is that users both perceive and experience a lack of information. In the case of preventative guidance (essentially safer sex information), this deficiency frequently emerges as a complaint that HIV/AIDS has slipped out of the headlines (particularly, off the TV screens) and that preventative messages and supplies need to be widely and freely available at the point of need. Despite all the many advances made, the survey has still revealed frequent cases of service providers (social services, nurses, GPs, dentists) and employers who are drastically misinformed with respect to HIV/AIDS, leading to inappropriate, offensive and even disruptive behaviour. Ironically, the extreme discretion inherent in the service delivery of some providers may be perpetuating the cycle of secrecy and misinformation, and this supports moves towards mainstreaming HIV/AIDS, at least in part. Quite separately, this report has frequently referred to a drastic lack of awareness by PLWHA (particularly when newly diagnosed) of the services available to them. Indeed, we have not met one single person (user or provider) who could confidently be said to be aware of the full range of options. Under these circumstances it is literally impossible for PLWHA to make informed choices, and one of the basic tenets of care delivery is thus missed. The survey has revealed an extremely mixed experience of PLWHA with respect to employment. Some have been extremely fortunate, and are productively employed following disclosure. A disturbing number report that disclosure has been a barrier to new or retained employment, and it is clear that employers are effectively discriminating in practice despite the prevailing principles of human rights.

This HIV Needs Assessment project was undertaken within the framework of an operational Service Level contract with the commissioning authorities, and a series of professional procedure contracts with a number of Ethics Committees. But in many ways the most important guide and constraint on the study has been the moral contract between the researchers and the respondents to the questionnaire and interview surveys. This has taken the form of an implicit and explicit commitment that the many voices of the respondents would be heard and considered. But how can we be sure that what is heard is seriously considered? And what is the chance that this consideration will lead to the development or maintenance of best practice, ensuring a good or better deal for service users and providers alike?

The way forward

There's never a right time, but there's unlikely to be any time that's better than now. All of the service providers are undergoing restructuring and redirection, so there is currently an unparalleled opportunity to ensure that, as the new organisational and funding roles and partnerships clarify and firm up, they do so in a way that meets as many as possible of the needs revealed in this survey. To achieve this, however, will take flexibility, determination and energy on a grand scale. Cherished norms may have to be sacrificed, but in a spirit of co-operation it should be possible to create in H&IOW a genuine exemplar of innovative best practice for HIV support beyond the metropolis. The key to planned action in response to the survey is the creation and empowerment of an operational structure through which to make choices, decide priorities and commission activity. Such a *Network for HIV Care and Support* would take on the responsibility for rolling out the tasks identified in this report as well as establishing an ongoing review of HIV needs. It would, of course, be for the *Network for HIV Care and Support* to determine its own agenda and priorities – and, indeed, this is the very essence of stakeholder engagement. However, in order to provide an illustration of the kind of profile and task load that might emerge, a proposal has been developed for a 3-year mission which tackles the report's options in a sequential manner.

If the *Network for HIV Care and Support* is to function effectively – whether in providing routine steer to existing programmes or lobbying for major strategic change – it will need a robust and resourced position in the newly-emerging organisational structures of the various sectors. Its work cannot wait for reorganisation to be completed (not least, because it is never completed), but the *Network* should prioritise identifying new opportunities to embed its role and targets in the new governance structures. As a starting point, information provision can achieve high service-user impact without requiring either high-level strategic buy-in or major long-term strategic funding. The *Network* could thus focus on regenerating and expanding the existing "signposting" services which point users towards services that they might consider accessing. Furthermore, all that the service users widely feel that "HIV risk promotion" is slipping down the agenda – locally and nationally. They see this as threatening, despite the fact that few of them actually report not knowing what the risks are. More specifically, as the demographic profile of HIV+ status widens to include many more transient immigrant groups, it is essential to regard awareness and risk promotion as being permanent functions.

Perhaps the Year 1 priority for the *Network* would be to review and refine cross-sector organisational structures. The immediacy of this task is to catch the current wave of organisational change and ride it. Any delay in this vital task will mean that new structures and roles bed down without incorporating HIV/AIDS needs, and short-term tweaking will then be very difficult. Once the organisational foundations of the *Network for HIV Care and Support* have been established, it will be appropriate for the Year 2 agenda to focus on the margins, so that by the end of that year the service is comprehensive, the challenge of emergent new immigrant groups has been fully scoped, and the stakeholders (providers and users alike) have had an opportunity to assess the implications and consider the options. If the aim of a Needs Assessment is to identify the most "needy" individuals, then the spotlight of isolation and lack of support falls strongly on the least privileged parts of the immigrant group and on some of the new margins such as those occupied by small numbers of white heterosexuals and bisexuals.

Year 3 of the operation of a new *Network for HIV Care and Support* is so far ahead that any agenda-setting is likely to be conjecture at best and pure speculation at worst. Nevertheless, if the development of strategy is to remain coherent and progressive, it might adopt two priorities. First, the process of mainstreaming HIV/AIDS (progressively normalising the lives of PLWHA and drawing their particular service needs into the general scope of service provision where appropriate) should be planned and prioritised rather than being achieved entirely on the back of other changes such as post loss or redefinition. The *Network for HIV Care and Support* will be well placed to undertake this review. Second, on the assumption that the mainstreaming process is not used to dismantle HIV/AIDS-specific services, it is possible to question whether a fully integrated H&IOW-wide inter-sector HIV support service might be able to seek recognition and funding as a Centre of Excellence. The notion of creating such a "centre" outside a major metropolis, with all of its scale advantages, is contentious but innovative. Whether or not it succeeded, the debate would be a fitting close of the chapter opened by this HIV Needs Assessment. It would allow the development of a genuine exemplar of best practice, and would breathe life into the commitment to listen to the voices of those who live with HIV/AIDS in Hampshire and the Isle of Wight.

There's never a right time, but there's unlikely to be any time that's better than now.

Acronyms & References

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
BME	Black and Minority Ethnic
BP	Body Positive (Dorset)
CAB	Citizen Advice Bureau
CAR	Centre for AIDS Research (University of Southampton)
DDA	Disability Discrimination Act
EU	the European Union
F	Female
GCHS	Gay Community Health Service
GMHP	Gay Men Health Project
GP	General Practitioner
GU	Genito-Urinary
GUM	Genito-Urinary Medicine
Haemo Centre	Haemophilia Centre
HAART	Highly Active Antiretroviral Therapy
HEP	Hepatitis
H&IOW	Hampshire and the Isle of Wight
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug Use
IDUs	Injecting Drug Users
IOW	the Isle of Wight
M	Male
MSM	Men who Have Sex with Men
MTCT	Mother-to-Child Transmission
NASS	National Asylum Support Service
NHS	National Health Service
PA	Positive Action
PCT	Primary Care Trust
PLWHA	People Living with HIV/AIDS
PPP	Public-Private Partnership
PTA	Parent Teacher Association
PV	Positive Voice
R&D	Research and Development
RC	Ribbons Centre
REC	Research Ethics Committee
SOPHID	Survey of Prevalent HIV Infections Diagnosed
SS	Social Services
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections
THT	Terrence Higgins Trust
TV	Television
UK	the United Kingdom
UNAIDS	Joint United Nations Programme on HIV/AIDS
URL	Uniform Resource Locator (= web/internet address)
USA	the United States of America

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SOPHID, Centre for Infections, Health Protection Agency: 2006

Tender for the Needs Assessment Project, Southampton City PCT: 2004

1: The Challenge of HIV

1.1 Context

There is a strong indication that the number of people living with HIV/AIDS has increased and continues to increase in Hampshire and the Isle of Wight (H&IOW), as it has elsewhere in the UK. For example, the report *Focus on Prevention: HIV and Other Sexually Transmitted Infection in the United Kingdom in 2003*[1], indicates that the number of people diagnosed with HIV or seen for care in 2003 in Hampshire and the Isle of Wight was 564. The SOPHID (*Survey of Prevalent HIV Infections Diagnosed) data for 2004*[2], however, suggest that 667 people in Hampshire and Isle of Wight were diagnosed with HIV infection or seen for medical HIV-related care in 2004. The *HIV diagnoses surveillance tables: data to the end of September 2005*[3] demonstrates even more starkly the ramping-up of HIV diagnoses in the early years of the Millennium, a trend widely attributed in particular to accelerated in-migration of vulnerable groups. Even when the assumed under-reporting of infection and the unreported movement of individuals into and out of H&IOW are acknowledged, it is clear that in numerical terms the challenge is increasing.

Such increases are a consequence of new infections (within-H&IOW and in-migration), recent diagnoses of previous infections and the long-term survival of those diagnosed in previous years. The effectiveness of antiretroviral therapy has reduced the number of deaths from HIV related illness and resulted in a situation where people are living longer and potentially in relatively good health. There is a common sentiment, expressed in many different ways, that whereas an HIV diagnosis used to be the precursor to managing the process of dying it is now represents the start of procedures to manage living and lifestyle. Indeed, it can be argued that the term AIDS is itself a provocative throw-back to a time when HIV+ status led inevitably to AIDS, and that the term has little value in the UK today. This viewpoint signifies the substantial success of medical intervention, but carries threatening overtones if (as is often the case) it is allowed to trivialise perceptions of the implications of HIV+ status. There are signs that some vulnerable people no longer regard the threat as such a high constraint as it once was on their personal activities, and that some service providers are downgrading the priority status of people living with HIV/AIDS (PLWHA). Both these tendencies need to be approached with care, as is discussed below, and for this reason the present report uses the term HIV/AIDS throughout.

Although HIV can now be managed with antiretroviral drugs to relieve symptoms and delay the onset of AIDS, there are many other needs that may be

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[1] Focus on Prevention: HIV and Other Sexually Transmitted Infection in the United Kingdom in 2003, Health Protection Agency: 2004: p.16

[2] SOPHID, Centre for Infections, Health Protection Agency: 2006

[3] HIV diagnoses surveillance tables (Hampshire and the Isle of Wight): data to the end of September 2005, Health Protection Agency: 2005

> *“Although HIV can now be managed with antiretroviral drugs to relieve symptoms and delay the onset of AIDS, there are many other needs that may be altered rather than reduced by the availability of therapy.”*

altered rather than reduced by the availability of therapy. Increasingly, these needs are social and emotional rather than medical, and with the significant change in the social profile of the County’s PLWHA, notably the increase in the proportion of infected immigrant people, social support requirements may escalate. The Invitation to Tender for this Needs Assessment[4] stated that:

> *“The diversity of the groups affected is likely to result in a diverse range of needs and the likelihood that many needs are not being met by existing services”.*

This acknowledgement of diversity and of the possibility of a pattern of provision that does not meet all aspects of need provides the background to the current assessment.

1.2 Background

The care and support available to people living with HIV/AIDS can be seen as falling into three categories:

- Medical services are largely channelled through the NHS Genito-Urinary Medicine (GUM) Clinics, some of which provide broad and general GUM support and some have specialised to the extent of being specific HIV Clinics.
- Social service provision through Social Services at County and Local Authority level, and involving a broad range of social, benefits, housing and immigration services.
- Specialist care, advice and support offered through organisations in the voluntary sector, operating on a mix of charitable income and grants from the public sector, and involving a broad range of emotional, practical, social, benefits, housing and immigration support.

It is clear that the over-riding characteristic of both need and provision is diversity. The markedly different circumstances of PLWHA across the County and on the IOW promote very different sets of personal priorities, requirements and capacities to respond. Contrasted personal lifestyles and attitudes further shape the way in which individuals prefer to use services – or, indeed, whether they wish to use services at all. And those services themselves are configured and constrained by a range of organisational structures, procedures and resources, some of which have been inherited from the HIV/AIDS scene prevailing some years ago.

To add to this overall present-day diversity, there is a strong sense of change. Both service providers and service users (mainly but not exclusively PLWHA) are consciously or intuitively responding to the impact of a range of dynamic external circumstances, particularly:

- It has already been noted that absolute numbers of diagnosed PLWHA in H&IOW have increased steadily. This raises the pressure on services (through absolute demand, which impacts on the availability and quality of support), but can also make service provision (volume, frequency and distribution) more cost-effective at the per-person level.
- At the same time, the general availability of anti-retroviral therapies in the UK, changes in therapeutic regime and continuing improvements in monitoring procedures, have combined to change the face of HIV/AIDS over the last 20 years. In the UK, positive HIV status is no longer the precursor to illness and premature death, but rather the beginning of long-term life-sustaining therapy and, for some, social support.
- The profile of PLWHA has changed, both nationally and locally. Once dominated by gay men, mainly British by birth and infection, the HIV+ community now includes a broad representation of heterosexual and immigrant people with substantially different needs, and in some cases with very different approaches to disclosure and to accessing support.
- Organisational and funding structures in the NHS and Social Services are in flux. In part, this is a familiar process of periodic management review and response, but at the same time it may reflect more fundamental shifts in the overall balance

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[4] *Tender for the Needs Assessment Project, Southampton City PCT: 2004*

between public and private sectors, together with political and professional changes in approaches to health care and social support.

To date, the access to, and provision of, care in H&IOW have not been assessed to see if they meet the needs of this constantly changing client group. It is the responsibility of all organisations involved in providing care and support to those living with HIV to ensure that they are providing an adequate type and level of care, and that all those in need have equitable access to it. This research project aims to explore whether the needs of people living with HIV in H&IOW are being met by service providers, whether care and support is reaching all of the client groups and whether improvements could be made in terms of the access to and provision of care and services. The report offers and evaluates options for models of care provision and highlights where support and services are lacking. All service providers involved in this study are invited to use the project outcomes to initiate a debate aimed at reviewing and refining their services, and this process should benefit all people living with HIV in Hampshire and the Isle of Wight.

> *It is the responsibility of all organisations involved in providing care and support to those living with HIV to ensure that they are providing an adequate type and level of care, and that all those in need have equitable access to it.*

2: Designing the Survey

2.1 Background

There has been an increase in the number and diversity of PLWHA in H&IOW in recent years, at the same time, the needs of PLWHA have slowly changed. The medical and social support needs of PLWHA in H&IOW have never been assessed. This research methodology was therefore designed to fill this gap in knowledge. The overall aim of the project was to assess the needs of people living with HIV in H&IOW in order to reveal the requests and requirements of these service users. The research question for this project can be articulated as follows:

To assess whether the medical, social and other needs of people living with HIV in Hampshire and the Isle of Wight are being adequately provided for by the NHS, Social Services, other statutory services and voluntary support groups.

2.2 Research Design and Methodology

The research strategy included quantitative and qualitative data collection from service users via questionnaires, focus group discussions and one-to-one interviews, together with service provider one-to-one interviews. It was considered critical to undertake qualitative data collection as the aim was to assess 'needs' which are opinion and value-based. An exclusively quantitative study would not have been able to provide such a depth of understanding as it would not have provided a vehicle to discuss feelings, perceptions and problems in a conversational manner.

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The questionnaire was designed for completion by PLWHA living in H&IOW. The purpose of the questionnaire was to gain knowledge of the services each participant used and did not use and their reasons for (not) doing so. This helped to gain a clear understanding of the most needed services and where improvements in access and provision could be made. It also revealed whether participants from particular groups e.g. gay and bisexual men, intravenous drug users, immigrants and asylum seekers, pregnant women and young people attending GUM clinics had different needs.

The questionnaire was piloted with PLWHA (accessed through voluntary support groups: 30 pilot questionnaires were distributed via the Ribbons Centre and Positive Voice). 16 responses to the pilot questionnaire were received. These responses came from a diverse range of people and some included comments on the wording of the questions and as well as completed answers. These comments were taken into account when producing the final version of the questionnaire which was directed by the project's steering group members. The format and design were considered carefully so as to be as accessible as possible i.e. suitable font size and type. See Appendix 1 for questionnaire template. The questionnaire was available for service users to access between April and August 2006 and of the 76 questionnaire returns, there were 74 valid responses, so more than 10% of PLWHA in H&IOW responded, the characteristics of respondents are broadly similar to the whole population of people living with HIV in relation to sex, age, ethnicity and other factors (see Tables 1 - 3). However some groups, such as African men, are under represented.

For recruitment purposes, leaflets explaining the purpose of the questionnaire were left on tables at voluntary support groups, they also were distributed via Medical Practitioners at GUM clinics across H&IOW. Posters explaining the purpose of the project were placed on the notice boards in GUM clinics across the region covered by the project and in the support group centres. The project was advertised on the CAR website and some of the service providers' websites. Questionnaires were available to pick up from voluntary support organisations (Ribbons Centre, Groundswell, Positive Voice, Positive Action, Inscape, Body Positive Dorset, Seeds of Africa), from GUM clinics across H&IOW, and from the Centre for AIDS Research (University of Southampton) for the period of time of 4 months (April – August 2006). The questionnaire included a stamped addressed envelope for participants to be able to send the questionnaire back confidentially. When participants had completed the questionnaire, the final page asked if they were willing to take part in further focus group discussions or one-to-one interviews. If they agreed to do so, they were asked to leave a preferred mode of contact for the research team to follow up.

Focus groups and in-depth interviews with service users were undertaken with a sample of service users who volunteered to participate (via their questionnaire returns). This second stage of data collection was required in order to address wider issues of health and social care needs amongst diverse groups in more depth than a questionnaire could provide. The focus group discussions and in-depth interviews were strictly confidential, voluntary and anonymous. The locations for the interviews and focus group discussions were guided by the participants' needs. For example, some participants expressed the preference for a telephone interview, rather than a face-to-face discussion. The focus group and interview schedules were tailored to the participants in question and hence there was not a standardised organisational structure and template for this part of the research process. In total, 16 interviews and two focus groups were undertaken for this stage of the research.

In-depth interviews with service providers from medical and social care service providers (NHS – GUM clinics, Social services, other statutory services providing social care e.g. housing, immigration, and specialist voluntary support groups) helped to understand what services they provided and where they felt services could be improved. Frimley Park GUM and Farnham Road GUM were not included despite providing primary care to a significant number of Hampshire residents (the ethics approval was covering only access to GUM clinics in Hampshire and the Isle of Wight). Interviews were undertaken at a location to suit the participant – either in their place of work or in meeting rooms within the University of Southampton. Some interviews were conducted over the phone at the participant's request. In total, 38 service providers were interviewed.

The strategy of interviewing service providers as well as service users was critical. In talking to service providers it was possible to understand the complexity of service provision, including the existing barriers such as government funding, structures of governance and local priorities and to relate that to the requirements of the users.

2.3 Data Sampling

Participation in this research was entirely voluntary for all participants, whether service providers or users. However, it was still important to ensure that participants of the study adequately represented the population under research.

Interviews with service providers used a strategic sampling approach to ensure good geographical coverage across the area under study and include the variety of provider types i.e. NHS, Local Government and voluntary sector) and roles e.g. HIV consultant, health advisor, dentist etc. A full list of interviewee locations and roles can be found in Appendix 2.

Participation by service users was required to be entirely voluntary and hence it was a random sampling approach. The main criteria for inclusion of participants was H&IOW residence, that is why many people who were using services in H&IOW (e.g. some PA clients) were excluded from the assessment as they were not H&IOW residents. However, the recruitment process was designed to ensure as many PLWHA were made aware of the project as possible – with the project being publicised in GUM clinics, online on a variety of websites and through voluntary support groups throughout the area involved in the project. The focus groups also required participants to volunteer, however, research via focus groups included strategic sampling of particular groups - black African women and gay men; given that these two groups represent the majority of PLWHA and accessing services in this area.

2.4 Analysis of data

Questionnaire data were analysed via categorical analysis and cross-tabulation to ascertain key trends e.g. under-utilised services, in-demand services, differing needs of diverse groups and the barriers to access and use of services. The results have been displayed in tabular format in section 3.

Focus group and interview data were analysed with NVivo - qualitative research software which enabled textual coding and categorization of data into key themes/issues. This technique enables interpretation and structuring of meaning from diverse data sources. Transcription of quotations from interviews was undertaken with basic correction to English language without adjustment of meaning. In negative and positive comments about people or organisations identifiable information about people or organisations was replaced where appropriate by suitable equivalents with generic meanings.

Given that focus group discussions were structured to focus on key themes and/or groups, the resulting data provided depth and further explanation to questionnaire findings. This process of comparing results from

Table 1: Needs assessment vs SOPHID data[1] by gender

N.B. This table does not include children 0-14 years from the SOPHID data.

Survey & year	**Male**		**Female**		**Overall Total**
	Number	**Percent**	**Number**	**Percent**	
SOPHID 1997	195	85.9%	32	14.1%	227
SOPHID 1998	175	81%	41	19%	216
SOPHID 1999	197	79.4%	51	20.6%	248
SOPHID 2000	219	74.7%	74	25.3%	293
SOPHID 2001	246	75.9%	78	24.1%	324
SOPHID 2002	287	67.5%	138	32.5%	425
SOPHID 2003	349	63.2%	203	36.8%	552
SOPHID 2004	407	62.8%	241	37.2%	648
Needs Assessment	**48**	**64.9%**	**26**	**35.1%**	**74**

Table 2: Needs assessment vs SOPHID data[2] by age

N.B. This table does not include children 0-14 years from the SOPHID data.
Component percentages are expressed on a per-gender basis.

Age Group								**Total**		**Overall Total**
15-24		**25-39**		**40-54**		**55+**				
M	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**Male**	**Female**	
1 **2.1%**	**1** **3.8%**	**25** **52.1%**	**12** **46.1%**	**13** **27.1%**	**11** **42.3%**	**9** **18.7%**	**2** **7.7%**	**48** **64.9%**	**26** **35.1%**	**74 (Needs Assessment)**
11 2.7%	21 8.7%	186 45.7%	161 66.8%	154 37.8%	46 19.1%	56 13.7%	13 5.4%	407 62.8%	241 37.2%	648 (SOPHID 2004)
16 4.6%	18 8.9%	164 47.0%	135 66.5%	126 36.1%	41 20.2%	43 12.3%	9 4.4%	349 63.2%	203 36.8%	552 (SOPHID 2003)
12 4.2%	18 13.0%	142 49.5%	82 59.4%	105 36.6%	31 22.5%	28 9.7%	7 5.1%	287 67.5%	138 32.5%	425 (SOPHID 2002)
10 4.1%	7 9.0%	117 47.6%	50 64.1%	92 37.4%	17 21.8%	27 11.0%	4 5.1%	246 75.9%	78 24.1%	324 (SOPHID 2001)
10 4.6	7 9.4%	103 47.0%	49 66.2%	85 38.8%	13 17.6%	21 9.6%	5 6.7%	219 74.7%	74 25.3%	293 (SOPHID 2000)
12 6.1%	6 11.8%	101 51.3%	33 64.7%	64 32.5%	8 15.7%	20 10.1%	4 7.8%	197 79.4%	51 20.6%	248 (SOPHID 1999)
8 4.6%	6 14.6%	93 53.1%	25 61.0%	60 34.3%	7 17.1%	14 8.0%	3 7.3%	175 81%	41 19%	216 (SOPHID 1998)
15 7.7%	5 15.6%	106 54.3%	21 65.6%	62 31.8%	4 12.5%	11 5.6%	2 6.2%	195 85.9% (1 – unknown)	32 14.1%	227 (SOPHID 1997)

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[1] *SOPHID, Centre for Infections, Health Protection Agency: 2006.*

[2] *SOPHID, Centre for Infections, Health Protection Agency: 2006*

Table 3 Needs assessment vs SOPHID data[1] by ethnicity

N.B. For SOPHID data children are included. For Needs Assessment data only adults are included. Component percentages are expressed on a per-gender basis.

	Sex	Needs Assessment	2004	2003	2002	2001	2000	1999	1998	1997
White	**M**	44	310	270	230	211	200	185	167	191
		91.7%	74.7	75.8	78.5	83.7	89.7	93.0	94.3	97.4
	F	8	60	48	43	34	41	33	28	22
		30.8%	23.8	23.1	30.5	43.6	55.4	62.3	66.7	66.7
Black Caribbean	**M**	1	0	4	5	3	1	1	0	0
		2.1%	0	1.1	1.7	1.2	0.4	0.5	0	0
	F	2	3	2	3	0	1	0	0	0
		7.7%	1.2	1.0	2.1	0	1.3	0	0	0
Black-African	**M**	2	80	64	31	18	8	3	2	2
		1.2%	19.3	18.0	10.6	7.1	3.6	1.5	1.1	1.0
	F	12	168	145	85	39	28	16	11	10
		16.1%	66.7	69.7	60.3	50.0	37.8	30.2	26.2	30.3
Black other	**M**	1	0	0	2	0	0	0	0	0
		2.1%	0	0	0.7	0	0	0	0	0
	F	4	2	2	1	0	0	0	0	0
		15.4%	0.8	1.0	0.7	0	0	0	0	0
India Pakistan Bangladesh	**M**	0	4	4	3	3	3	3	3	0
		0%	1.0	1.1	1.0	1.2	1.3	1.5	1.7	0
	F	0	2	2	2	2	2	1	1	0
		0%	0.8	1.0	1.4	2.6	2.7	1.9	2.1	0
Other/ Mixed	**M**	0	12	7	13	6	6	6	3	1
		0%	2.9	2.0	4.4	2.7	2.7	3.0	1.7	0.5
	F	0	10	7	3	1	1	3	2	1
		0%	4.0	3.4	2.1	1.3	1.3	5.7	1.8	3.0
Other Asian/ Oriental	**M**	0	7	5	5	7	3	0	0	0
		0%	1.7	1.4	1.7	2.8	1.3	0	0	0
	F	0	7	2	4	1	1	0	0	0
		0%	2.8	1.0	2.8	1.3	1.3	0	0	0
Not Known	**M**	0	2	2	4	4	2	1	2	2
		0%	0.5	0.6	1.4	1.6	0.9	0.5	1.1	1.0
	F	0	0	0	0	1	0	0	0	0
		0%	0	0	0	1.3	0	0	0	0
Sub-total	**M**	48	415	356	293	252	223	199	177	196
		64.9%	62.2	63	67.5	76.4	75.1	79	80.8	85.6
	F	26	252	208	141	78	74	53	42	33
		35.1%	37.8	37	32.5	23.6	24.9	21	19.2	14.4
Total		**74**	**667**	**564**	**434**	**330**	**297**	**252**	**219**	**229**

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[1] *SOPHID, Centre for Infections, Health Protection Agency: 2006.*

different data collection techniques (triangulation) is an established methodological technique to ensure the validity and robustness of findings and interpretations of such.

2.5 Anonymity and security of data

All questionnaire data were collected anonymously. All other data from service user participants i.e. from focus groups and in-depth interviews were anonymised at the point of data entry. Data from service providers were anonymised when requested.

All data are stored anonymously, on password-protected computers and any paperwork is kept in a locked cabinet and within a locked room only accessible to research staff. Following the publication of the final report, all data will be kept confidentially by the University of Southampton in line with the University of Southampton Data Protection Policy. The security of the computing system was assured as were all University computers.

2.6 Limitations

Any research is subject to bias. However, the research proposal and methodology were subject to rigorous ethical review through NHS ethical approval; an organisation independent to HIV/AIDS service provision undertook the research; all efforts were made to ensure that the research was conducted in a rigorous and objective fashion; robust and established analytical techniques were used to ensure that some research findings were not prioritised over others; and participation in this research project was entirely voluntary and no-one was be asked to participate in this research project against his or her will. These were considered essential requirements to reduce any potential bias

It is possible that the more hard to reach individuals living with HIV/AIDS were not accessed successfully in the research process. Unless PLWHA were accessing at least one of the services, then it was not possible to engage them in the research. It is therefore important to acknowledge that although the research engaged with a diverse cross-section of individuals, the hardest to reach groups may not be adequately represented in this research.

Whilst it could be argued that engagement with potential participants had the potential to be somewhat constrained by the ethical approval system, it must be remembered that ethical issues (and hence the rights and sensitivities of the research participants) should always be considered above the wishes of the researchers to improve their data quality. All efforts were made to ensure that participants felt comfortable with the research and it is likely to benefit participants in the sense that an opportunity has been given to voice their opinions and explain their needs to an independent organisation. Many participants commented that they felt pleased and empowered by the process of voicing their concerns and hence making a difference to the service that they receive.

2.7 Ethical considerations

Ethical issues were of critical importance to this project. The project researchers are aware that the priorities for any research are fairness, respect and trust for all involved parties. For the purposes of this study the following steps were undertaken to address the main ethical issues: confidentiality, anonymity, equality, the involvement of potentially vulnerable groups and an appreciation of personal sensitivities to the issues being discussed:

- Participants were only recruited through service providers (GUM clinics - via posters, leaflets), voluntary support groups and associations (via posters, leaflets, questionnaires and web advert). They were able to pick up a copy of a questionnaire either at the Centre for AIDS Research or at a support group centre or GUM clinic where confidentiality and anonymity were ensured.

- Translation services were made available if requested, to ensure understanding for those who do not speak English and thus to avoid exclusion.

- All participants were treated equally, irrespective of race, religion, gender, age, ability or sexuality. The study met the Hampshire Equalities policy and NHS ethical and R&D approvals.

- All questionnaires, interviews and focus groups with service users were anonymous and confidential. All questionnaire data were collected anonymously. All other data from service user participants i.e. from focus groups and in-depth interviews were anonymised at the point of data entry. Data from service providers were anonymised when requested.

- All data were stored anonymously, on password-protected computers and any paperwork was kept in a locked cabinet and within a locked room only accessible to research staff. When the final report is published, all data will be stored by the University of Southampton in line with the University Data Protection Policy (all data will be stored anonymously and securely by the University of Southampton for 15 years). The security of the

> *Many participants commented that they felt pleased and empowered by the process of voicing their concerns and hence making a difference to the service that they receive.*

computing system is assured as are all University computers.

- No personal data have been disclosed to anyone who is not involved in the project. CAR researchers have previous experience of serving as confidential data-contractors for the NHS.

- No payments were provided to participants other than travel expenses (therefore all participants took part voluntarily and were not influenced by any form of payment).

- There was acknowledgement that, although participation in this project was entirely voluntary, some service user participants might be distressed by their involvement in the research. The project involved many people from vulnerable groups who carried the burden of HIV+ status together with other issues such as being an immigrant or asylum seeker or other group subject to discrimination and stigma. A procedure to manage potential distress was agreed: if participants became distressed, the researchers encouraged them to discuss their concerns with individuals specialising in these areas to include their voluntary support worker, social worker, GP or consultant.

- It was decided not to include the substantial H&IOW population of prison inmates in the survey, both because of the complex additional ethical constraints and because many of the services provided by those commissioning this survey were not of relevance to them. However, it should be noted that discharge from a prison term is a time of great vulnerability when HIV-related advice and support may be crucial. At this stage, ex-prisoners join the H&IOW community of PLWHA in significant numbers, and present a challenge to the providers.

The project involved many people from vulnerable groups who carried the burden of HIV+ status together with other issues such as being an immigrant or asylum seeker or other group subject to discrimination and stigma.

3: A summary of the survey results

3.1 Questionnaire results

QUESTION 1
Age

Age Group								Total		Overall Total
15-24		25-39		40-54		55+		M	F	
M	F	M	F	M	F	M	F			
1	1	25	12	13	11	9	2	48	26	74
2.1%	3.8%	52.1%	46.1%	27.1%	42.3%	18.7%	7.7%	64.9%	35.1%	

HIV/AIDS affects all groups of people. The most affected groups are 25-39 (50% of the respondents) and 40-54 (32% of the respondents). 18.7% of males are from the age group 55+.

QUESTION 2
Which area do you live in?

Area around Basingstoke:

Area	**Male**	**Female**	**Total**
Basingstoke	5	5	10
Aldershot	3	2	5
Ashvale	0	1	1
Farnborough	0	2	2
GU12	1	1	2
GU14	1	0	1
GU34	1	0	1
GU35	1	0	1
RG22	1	0	1
RG23	1	0	1
Selborne	0	1	1
TOTAL	14	12	26

Area around Portsmouth:

Area	**Male**	**Female**	**Total**
Portsmouth	4	1	5
Havant	2	0	2
PO6	0	1	1
PO1	0	1	1
PO13	1	0	1
Southsea	1	0	1
TOTAL	8	3	11

Area around Southampton:

Area	Male	Female	Total
Southampton	7	3	10
SO14	0	3	3
SO15	1	2	3
SO16	2	0	2
SO17	2	0	2
SO18	3	0	3
SO19	1	0	1
SO22	1	0	1
SO24	0	1	1
SO40	1	1	2
TOTAL	18	10	28

Area around Winchester:

Area	Male	Female	Total
Winchester	3	0	3
Andover	1	0	1
Chandlers Ford	1	0	1
Total	5	0	5

Isle of Wight:

Area	Male	Female	Total
East Cowes	1	0	1
PO33	1	0	1
Total	2	0	2

Live outside Hampshire but receive services in Hamsphire:

Area	Male	Female	Total
Bournemouth	1	0	1
Coventry	0	1	1
Total	1	1	2

QUESTION 3

Gender

	Male		Female		Total
	Number	%	Number	%	
Survey	48	64.9%	26	35.1%	74

QUESTION 4

Your preferred sexual partner would be

Preference	Male	Female	Total
Same sex (homosexual)	36 75%	0 0	36 48.6%
Opposite sex (heterosexual)	10 20.8%	25 96.1%	35 47.3%
Either sex (bisexual)	2 4.2%	1 3.8%	3 4%
Total	48	26	74

The sample shows that HIV does not mainly affect homosexual males in the UK as it used to be in the past. Nowadays HIV affects different groups of people (males and females, homosexual, heterosexual and bisexual).

QUESTION 5

Relationship Status

Status	Male	Female	Total
Married	2 4.2	8 29.6%	10 13.3
Living w/ partner	15 31.2	2 7.4	17 22.7%
Single	23 47.9%	5 18.5%	28 37.3%
Divorced	2 4.2%	4 14.8%	6 8%
Widowed	2 4.2%	5 18.5%	7 9.3%
Other	4 8.3%	3 11.1%	7 9.3%
TOTAL	48	27 (ticks)	75 (ticks)

NB: One female ticked 2 options: single and divorced.
For other, people specified: Civil partner (M); living with my 16 year old granddaughter (F); long-term relationship (M); my husband is in Africa (F); partner – not living with (M); separated (F); with a boyfriend (F); with a partner but not living with partner (M).

Status	Homosexual	Heterosexual	Bisexual	Total
Married	1 2.8%	1 10%	0 0%	2 4.2%
Living with partner	13 36.1%	2 20%	0 0%	15 31.2%
Single	20 55.6%	2 20%	1 50%	23 47.9%
Divorced	0 0%	1 10%	1 50%	2 4.2%
Widowed	0 0%	2 20%	0 0%	2 4.2%
Other	2 5.6%	2 20%	0 0%	4 8.3%
Total	36	10	2	48

In the sample 29.6% of females are married, 18.5% are widowed and 18.5% are single. 47.9% of all males are single (55.6% of homosexual males are single) and 31.2% of all males live with partners (36.1% of homosexual males live with partners).

QUESTION 6

Dependents

Number of children under the age of 18

No. of children	Male	Female	Total
0	40 83.3%	5 19.2%	45 60.8%
1	2 4.2%	11 43.3%	13 17.6%
2	3 6.2%	3 11.5%	6 8.1%
3	0 0%	2 7.7%	2 2.7%
4 or more	0 0%	2 7.7%	2 2.7%
Unknown	3 6.2%	3 11.5%	6 8.1%
TOTAL	48	26	74

83.3% of males do not have children under 18. 70.2% of females have 1 or more children under 18.

Number of children above the age of 18

No. of adults	Male	Female	Total
0	35 72.9%	7 26.9%	42 56.7%
1	2 4.2%	8 30.8%	10 13.5%
2	2 4.2%	1 3.8%	3 4.0%
3	0 0%	1 3.8%	1 1.3%
4 or more	0 0%	0 0%	0 0%
Unknown	9 18.7%	9 34.6%	18 24.3%
TOTAL	48	26	74

72.9% of males and 26.9% of females do not have adult dependents. 30.8% of females have 1 adult dependent.

QUESTION 7

Where do those dependents live?

Dependents living with you:

Number	Male	Female	Total
0	1 2.1%	1 3.8%	2 2.7%
1	3 6.3%	4 15.4%	7 9.5%
2	0 0%	7 26.9%	7 9.5%
3	0 0%	3 11.5%	3 4.1%
Unknown	44 91.7%	11 42.3%	55 74.3%
TOTAL	48	26	74

Dependents living elsewhere:

Number	Male	Female	Total
0	1 2.1%	0 0%	1 1.4%
1	1 2.1%	4 15.4%	5 6.8%
2	4 8.3%	1 3.8%	5 6.8%
3	0 0%	2 7.7%	2 2.7%
5	0 0%	1 3.8%	1 1.4%
Unknown	42 87.5%	18 69.2%	60 81.1%
TOTAL	48	26	74

53.8% of females have 1-3 dependents living with them; 30.7% females have 1-5 dependents living elsewhere.

QUESTION 8

Are any of your dependents HIV positive?

Response	Male	Female	Total
Yes	2 4.2%	2 7.7%	4 5.4%
No	14 29.2%	14 53.8%	28 37.8%
Do not know	3 6.3%	5 19.2%	8 10.8%
No answer	29 60.4%	5 19.2%	34 54.1%
TOTAL	48	26	74

QUESTION 9

Do you live alone?

Response	Male	Female	Total
Yes	22 45.8%	9 34.6%	31 41.9%
No	24 50.0%	17 65.4%	41 55.4%
Unknown	2 4.2%	0 0%	2 2.7%
TOTAL	48	26	74

QUESTION 9a

If NO, who do you live with?

Response	Male	Female	Total
Partner	13 56.5%	9 50.0%	22 53.6%

Relative	2 8.7%	4 22.2%	6 14.6%
Carer	1 4.3%	0 0%	1 2.4%
Friend	4 17.4%	4 22.2%	8 19.5%
Other	3 13.0%	1 5.5%	4 9.7%
TOTAL	23	18	41

For other, people specified: civil partner (M); ex-partner (M); husband (F); I live with my daughter, my son and my grandson (F); live with partner about half the week (M); my baby (F); my children (F).

53.6% of people (56.5% of males and 50% of females) live with partners. 22.2% of females live with relatives and 22.2% of females live with friends.

QUESTION 10

Country of Birth

Western Europe

Country	**Male**	**Female**	**Total**
UK	41 85.4%	7 26.9%	48 64.9%
W Europe TOTAL	43 89.6%	8 30.7%	51 69.0%
Asia/Oceania	2 4.2%	0 0%	2 2.8%
Caribbean	1 2.1%	2 7.6%	3 4.2%
Africa	2 4.2%	16 61.5%	18 24.3%
TOTAL	48	26	74

85.4% of males were born in the UK, 61.5% of females were born in Africa.

QUESTION 11

Nationality

European and Dual (one being British)

Nationality	**Male**	**Female**	**Total**
British	43 89.6%	6 23.1%	49 66.2%
British + Canadian	0 0%	1 3.8%	1 1.4%
British + Irish	0 0%	1 3.8%	1 1.4%
Irish	0 0%	1 3.8%	1 1.4%
British + New Zealand	1 2.1%	0 0%	1 1.4%
Total European + dual	44 91.7%	9 34.6%	53 71.8%

Caribbean

Country	**Male**	**Female**	**Total**
Jamaican	0 0%	1 3.8%	1 1.4
St Lucian	1 2.1%	0 0%	1 1.4%
Trinidadian	0 0%	1 3.8%	1 1.4
Caribbean TOTAL	1 2.1%	2 7.6%	3 4.2%

African

Country	**Male**	**Female**	**Total**
Malawian	0 0%	1 3.8%	1 1.4%
South African	0 0%	2 7.7%	2 2.7%
Zambian	0 0%	2 7.7%	2 2.8%
Zimbabwean	2 4.2%	8 30.8%	10 13.5%
African (country not known)	0 0%	1 3.8%	1 1.4%
Africa TOTAL	2 4.2%	14 53.8%	16 21.7%
Unknown	1 2.1%	1 3.8%	2 2.7%
Grand TOTAL	48	26	74

71.8% of people have European nationalities, 4% have Caribbean nationalities, and 21.7% have African nationalities. 91.7% of males have European nationalities (all of them have British nationality, one of them has dual nationality). 53.8% of females have African nationalities.

QUESTION 12

Ethnic groups

The sample shows that HIV affects people from different ethnic groups and not only white males as it used to be the case in the early days of HIV/AIDS in the UK.

Ethnicity (Number/*Percentage*)																		Total
White		**Black Caribbean**		**Black African**		**Black Other**		**Indian Pakistani Bangladeshi**		**Other mixed**		**Other Asian**		**Not known**		**M**	**F**	
M	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**			
44	8	1	2	2	12	1	4	0	0	0	0	0	0	0	0	48	26	74
91.7	*30.8*	*2.1*	*7.7*	*4.2*	*46.1*	*2.1*	*15.4*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*0*	*64.9*	*35.1*	*100*

In the sample 91.7% of males are of white ethnic background, 69.2% of females are of black background (African, Caribbean or other). 30.8% of females are of white ethnic background and 8.4% of males are of black background (African, Caribbean or other).

QUESTION 13

Employment status

Status	Male	Female	Total
Full time	22 44.9%	8 28.6%	30 39.0%
Part time	3 6.1%	2 7.1%	5 6.5%
Self-employed	0 0%	1 3.6%	1 1.3%
Retired	5 10.2%	1 3.6%	6 7.8%
Student	0 0%	2 7.1%	2 2.6%
Job seeking	2 4.1%	2 7.1%	4 5.2%
Unable to work	17 34.7%	12 42.8%	29 37.7%
TOTAL	49 ticks	28 ticks	77 ticks

NB: 3 people ticked 2 boxes for the employment status: 1 female – part-time job and student; 1 female – seeking employment and student; 1 male – retired and unable to work.

39% of males and females have full time employment and 37.7% of males and females are unable to work. 44.9% of males have full time employment and 28.6% of females have full time employment; 34.7 % of males are unable to work and 42.8% of females are unable to work.

QUESTION 13a

If you are unable to work, please tell us why

Reason	Male	Female	Total
Immigration status	2 8.7%	6 37.5%	8 20.5%
Illness/medical appointments	11 47.8%	4 25%	15 38.5%
Would lose benefits	2 8.7%	0 0%	2 5.1%
Responsibilities as a carer	0 0%	2 12.5%	2 5.1%
Lack of skills	1 4.3%	2 12.5%	3 7.7%
Lack of confidence	3 13.0%	0 0%	3 7.7%
Other	4 17.4%	2 12.5%	6 15.4%
TOTAL	23	16	39

NB: more people stated reasons for them being unable to work than people who ticked that they are unable to work in the previous question. For other people specified: co-existing disability (haemophilia A) (M); disabled (M); employable but awaiting decision on my visa application (M); expecting a baby 8 month pregnant (F); mentally ill (M); mother (F); negative outlook (disclosure) (M).
Further information given by participants:

- *I have a poor memory because of my HIV and fall over (M)*
- *Outcast/ stereotype (M)*
- *Prone to various medical complaints (M)*

38.5% of males and females of those who said they were unable to work attributed this to illness and 20.5% to immigration status. 47.8% of all males are unable to work due to illness, 13% are unable to work due to lack of confidence, 8.7% due to immigration status and 8.7% are worried that they would lose benefits. 37.5% of all females are unable to work due to immigration status, 25% are unable to work due to illness, 12.5% have responsibility as a carer and 12.5% are unable to work due to lack of skills.

QUESTION 14

Housing status

Status	Male	Female	Total
Own home	21 43.7%	7 26.9%	28 37.8%
Private rented	12 25.0%	4 15.4%	16 21.6%
Housing Association	10 20.8%	5 19.2%	15 20.3%
Hostel	0 0%	2 7.7%	2 2.7%

Sharing with friends/others	2	1	3
	4.2%	3.8%	4.1%
NASS accommodation	0	0	0
	0%	0%	0%
Supported accommodation	0	2	2
	0%	7.7%	2.7%
Other	3	4	7
	6.2%	15.4%	9.5%
No answer	0	1	1
	0%	3.8%	1.3%
TOTAL	48	26	74

*For **Other** people specified: army (F); council flat (F); housing co-operative/ own flat (M); living with partner (M); living with parents (F) (M); staying with friends – no payment (F).*

43.7% males and 26.9% females live in their own homes. 25% males and 15.4% females live in private rented accommodations and 20.8% males and 19.2% females live in housing associations. Housing status can affect abilities of people to manage their HIV status.

QUESTION 15

Is your current housing status affecting your ability to manage your HIV status?

	Male	Female	Total
Yes	3	8	11
	6.2%	30.8%	14.9%
No	40	16	56
	83.3%	61.5%	75.5%
Don't know	3	2	5
	6.2%	7.7%	6.8%
No answer	2	0	2
	4.2%	0%	2.7%
TOTAL	48	26	74

Housing status can affect people's ability to manage their HIV status. For 75 % males and females their current housing status is not affecting their ability to manage their HIV status. For 83.3 % of males the status is not affecting their ability to manage their HIV. For 30.8% of females the status is affecting their ability to manage their HIV.

QUESTION 15a

If YES, please explain

Fear that people will find out:

- I don't take my medication properly sometimes I cannot take them because people will be present at the house.
- There is no privacy as this accommodation is shared. Therefore letters and medication have to be kept in secret.
- Worried about family other than partner finding out.

Costs of living, work:

- Cost of running a home outweighs the need for counselling/ HIV supports group interactions affecting reintegration to social and working socialising.
- High living costs i.e. rent, council tax etc. makes it very difficult to keep up healthy diet.
- Full time employment and having a mortgage to pay does have stress on my health - working hard.

Other:

- I am constantly on the move have no permanent accommodation.
- It is very dirty and there is a problem with the plumbing.
- My friends know my situation with HIV.
- Need my own place, living with a friend who has small kids. I feel it is not fair on her and the family, though they don't live with us, but they visit a lot.

QUESTION 16

When were you diagnosed as HIV+?

	Male	Female	Total
Newly diagnosed (2005-2006)	10	7	17
	20.8%	26.9%	23.0%
Long-term diagnosis (1983-2004)	38	18	56
	79.2%	69.2%	75.5%
Not known	0	1	1
	0%	3.8%	1.3%
TOTAL	48	26	74

Year	Male	Female	Total
2006	3	1	4
	6.3%	3.8%	5.4%
2005	7	6	13
	14.6%	23%	17.6%
2004	8	3	11
	16.7%	11.5%	14.9%
2003	5	1	6
	10.4%	3.8%	8.1%
2002	7	2	9
	14.6%	7.7%	12.2%
2001	2	4	6
	4.2%	15.4%	8.1%
2000	0	2	2
	0%	7.7%	2.7%
1999	2	1	3
	4.2%	3.8%	4%
1998	1	1	2
	2.1%	3.8%	2.7%
1997	3	1	4
	6.3%	3.8%	5.4%
1996	4	1	5
	8.3%	3.8%	6.8%
1994	1	0	1
	2.1%	0%	1.3%
1993	1	0	1
	2.1%	0%	1.3%
1992	1	0	1
	2.1%	0%	1.3%
1990	0	1	1
	0%	3.8%	1.3%

1987	1	0	1
	2.1%	0%	1.3%
1986	1	1	2
	2.1%	3.8%	2.7%
1983	1	0	1
	2.1%	0%	1.3%
Not known	0	1	1
	0%	3.8%	1.3%
Total	48	26	74

Data collection through questionnaires for the project was finished in August 2006 so the year 2006 only represents period of time from January - August 2006.

75.7% of respondents were diagnosed with HIV in 2004 or earlier (long-term diagnoses), 23% were diagnosed in 2005 and 2006 (newly diagnosed).

QUESTION 17

How did you become aware of your HIV status?

	Male	Female	Total
Routine HIV test	22	6	28
	45.8%	23.1%	37.8%
Test during pregnancy	0	3	3
	0%	11.5%	4.1%
Test for unknown illness	17	8	25
	35.4%	30.8%	33.8%
Partner diagnosed	2	1	3
	4.2%	3.8%	4.1%
Other	6	5	11
	12.5%	19.2%	14.9%
No answer	1	3	4
	2.1%	11.5%	5.4%
TOTAL	48	26	74

For **other,** people specified:

- *Exposure to possible HIV source abroad*
- *HIV test during screening for health insurance*
- *I asked a doctor for the test (x2)*
- *I was ill (x2)*
- *Informed about an ex partner by friend*
- *Life Insurance*
- *Partner unwell*
- *Test for immigration application*
- *Testing due to Haemophilia*
- *Went for P.E.P. but had to have HIV test first*
- *When my baby boy passed away.*
- *While in Hospital*
- *Wife diagnosed first - then I was called*

37.8% of males and females became aware of their HIV status through routine HIV test. 33.8% of males and females became aware of the HIV through testing for unknown illness. 45.8% of males became aware of their HIV status through routine HIV test. 35.4% of males and 30.8% of females became aware of their HIV status through testing for unknown illness. These numbers provide the support for the argument about necessity of HIV-testing to become routine (as it now is in ante-natal clinics).

QUESTION 18

In which country do you think you became infected?

Africa

Country	**Male**	**Female**	**Total**
Africa	1	2	3
Malawi	0	1	1
Morocco	1	0	1
Nigeria	1	0	1
South Africa	1	3	4
Zambia	0	1	1
Zimbabwe	1	7	8
Africa TOTAL	5	14	19
	10.4%	53.8%	25.7%

Caribbean

Country	**Male**	**Female**	**Total**
Barbados	0	1	1
Jamaica	0	1	1
Tobago	0	1	1
Caribbean TOTAL	0	3	3
	0%	11.5%	4.0%

Europe / USA

Country	**Male**	**Female**	**Total**
UK	40	8	48
Ibiza (Spain)	1	0	1
USA	1	0	1
Europe/USA TOTAL	41	8	50
	85.4%	30.8%	67.6%
Not sure/do not know	1	1	2
Grand TOTAL	48	26	74

35.1% of all respondents believe that they acquired their infection outside the UK.

53.8% of females think they became infected in Africa, 85.4% of males think they became infected in Europe (83.3% in the UK). 67.6% of overall total think they became infected in Europe or the USA and 25.7% think they became infected in Africa.

These results support the argument that the prevention messages about HIV in the UK should be stronger for both homosexual and heterosexual people. Many people have the misconception that there is no danger of HIV in the UK: many people are convinced that HIV is in Africa and Asia but not here.

QUESTION 19

How did the infection probably occur?

Probable route of infection											Total	
MSM	**Injecting drug use**		**Sex men/women**		**Blood & blood product**		**MTCT**		**Other/ not known**		**M**	**F**
M	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**	**M**	**F**		
37 69.8%	4 7.5%	1 3.3%	6 11.3%	19 63.9%	3 5.7%	3 10.0%	0 0%	0 0%	3 5.7%	7 23.3%	53 (total number of of routes ticked)	30 (total number of routes ticked)

NB: 3 males stated 2 probable routes, 1 male mentioned 3 probable routes, 4 females stated 2 probable routes. All 4 males report needle use as one of the routes and sex between man and man or man and woman for the second route, the person who reported 3 probable routes also states the possibility of becoming infected via blood products. 3 out of 4 females report sex between man and woman as one of the routes of transmission, two females report that they were possibly infected via blood products, one person reports needle use as a possible route, another person reports possible infection via instruments in medical procedure and one person reports possibly becoming infected as a result of rape. One of the routes was stated as "needle use", which was interpreted differently by different people, some people meant IDU, others meant needle use in medical procedures.

For **other** routes, people specified:
I do not know (x5)
Needle stick injury (x1)
Non-consensual sexual intercourse between man and woman (x1)
Rape (x1)
Possibly instruments in medical procedure (x1)
Treatment after road accident at clinic known to have AIDS problem. I was unconscious! (x1)

Needs Assessment vs SOPHID data[1] by Probable Route of Infection

Route	**M/F**	**Needs Assessment**	**SOPHID**							
			2004	**2003**	**2002**	**2001**	**2000**	**1999**	**1998**	**1997**
1	M	**37** **69.8%**	226 54.4%	189 53.1%	166 56.6%	151 59.9%	142 63.7%	123 61.8%	116 65.5%	130 66.3%
2	M	**4** **7.5%**	13 3.1%	11 3.1%	6 2%	7 2.8%	6 2.7%	10 5%	8 4.5%	13 6.6%
2	F	**1** **3.3%**	6 2.4%	4 1.9%	3 2.1%	5 6.4%	8 10.8%	6 11.3%	4 9.5%	6 18.2%
3	M	**6** **11.3%**	138 33.2%	122 34.3%	86 29.3%	59 23.4%	38 17%	29 14.6%	22 12.4%	25 12.7%
3	F	**19** **63.3%**	228 90.5%	193 92.8%	130 92.1%	69 88.5%	56 75.7%	37 69.8%	31 73.8%	25 75.7%
4	M	**3** **5.7%**	19 4.6%	22 6.2%	19 6.5%	18 7.1%	20 9%	24 12%	24 13.5%	27 13.8%
4	F	**3** **10%**	2 0.8%	2 1%	1 0.7%	1 1.3%	2 2.7%	3 5.7%	2 4.8%	1 3%
5	M	**0**	8 1.9%	7 2%	6 2%	6 2.4%	4 1.8%	2 1%	2 1.1%	1 0.5%
5	F	**0**	11 4.4%	5 2.4%	3 2.1%	0	0	2 3.8%	1 2.4%	1 3%
6	M	**3** **5.7%**	11 2.6%	5 1.4%	10 3.4%	11 4.4%	13 5.8%	11 5.5%	5 2.8%	0
6	F	**7** **23.3%**	5 2%	4 1.9%	4 2.8%	3 3.8%	8 10.8%	5 9.4%	4 9.5%	0
Total	M	53 (ticks)	415	356	293	252	223	199	177	196
Total	F	30 (ticks)	252	208	141	78	74	53	42	33
TOTAL	**M+F**	**83 (ticks)**	**667**	**564**	**434**	**330**	**297**	**252**	**219**	**229**

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[1] *SOPHID, Centre for Infections, Health Protection Agency: 2006.*

Route 1 - sex between men
Route 2 – injecting drug use
Route 3 – sex between men and women
Route 4 – blood/ blood products recipient
Route 5 – MTCT
Route 6 – other/ not known.

The data show that 81.1% of males were infected through sexual intercourse (homosexual (69.8%) or heterosexual (11.3%)); 63.3% of females were infected through heterosexual sexual intercourse. It shows that HIV in the UK does not only affect homosexual males, it affects heterosexual people too. Sex between men and sex between men and women are the main two routes of HIV infection. Heterosexual infections are underrepresented in the data in comparison to the SOPHID data. The reason for this could be that 23.3% of females and 5.7% of males reported other or not known route of infection.

QUESTION 20
Were you first diagnosed in this country?

	Male	Female	Total
Yes	46 95.8%	22 84.6%	68 91.9%
No	2 4.2%	4 15.4%	6 8.1%
TOTAL	48	26	74

91.9% of people were diagnosed in this country

QUESTION 21
Before your diagnosis, were you informed of how to prevent HIV infection?

	Male	Female	Total
Yes	39 81.2%	20 76.9%	59 79.7%
No	5 10.4%	5 19.2%	10 13.5%
Don't know	3 6.2%	1 3.8%	4 5.4%
No answer	1 2.1%	0 0%	1 1.3%
TOTAL	48	26	74

79.7% of people were informed of how to prevent HIV infection before their diagnosis.

If yes, please state methods of prevention sources:

Condoms and safer sex:
- Use of condoms (8 people)
- Condoms, no sharing of needles
- Protective sex
- Safe sex (x2)
- Safe sex. Condoms (x2)
- Using condoms from medical centres
- Using condoms. Avoiding needle stick injury

16 respondents from those who said that they were informed of how to prevent HIV infection before their diagnosis (27%) mentioned "condoms and safer sex".

Information for gay men:
- Gay Men's Health Project, etc
- Gay press

3 respondents from those who said that they were informed of how to prevent HIV infection before their diagnosis (5.1%) mentioned "information for gay men".

GUM:
- GCHS, GU Med Soton
- GU Department
- Leaflets from GMHP and through counselling during previous health screens at GUM clinic. Was aware of basics from "Tombstone" campaign in the 80s.

3 respondents from those who said that they were informed of how to prevent HIV infection before their diagnosis (5.1%) mentioned "GUM".

Media: TV, radio, magazines, etc:
- Media, health advice, social events, etc
- Media, magazines
- Media. Work knowledge
- Television, Media, Bill Boards, Back of condoms, Health support worker
- TV adverts some years ago
- TV. Radio. Leaflets
- TV, internet
- Word of mouth, TV, leaflets, posters, etc
- Word of mouth, TV, Documentaries.

9 respondents from those who said that they were informed of how to prevent HIV infection before their diagnosis (15.2%) mentioned "media".

Sex in long-term relationship:
- Long-term relationship, no safe sex after a year the partner cheated, became infected and passed it on to me.
- Man using condoms - but one never knows if husband is faithful. At the time, knowledge of HIV in Africa was very limited

School:
- School

Other:
- Trained as nurse and worked as health promotion specialist
- I was only 8 (haemophiliac)
- Related to (...) [occupation]

QUESTION 21a **continues overleaf**

QUESTION 21a

If YES, which services gave you the information and in what form?

Service	Leaflet	One-to-one discussion	Workshop or training	Other	TOTAL ticks
GUM	31	17	1	0	49
Family Planning Clinic	5	2	0	0	7
School / College	12	1	8	0	21
GP	5	7	1	0	13
Social Services	5	5	0	0	10
Social or Interest Group	4	4	3	0	11
Voluntary Organisation	9	7	3	1	20
TV	18	1	1	14	34
Radio	13	1	1	6	21
Newspaper / magazine	25	1	1	4	31
Internet site / chat room	4	4	0	2	10
Sexual partners	2	12	0	0	14
Friends	7	13	0	0	20
Family	4	7	0	0	11
Youth service	1	2	1	0	4
Religious organisation	1	4	0	0	5
Prison Service	0	0	0	0	0
Gay Community health service	15	7	4	1	27
Gay pubs / clubs	22	6	1	0	29
Other	1	1	0	1	3
TOTAL ticks	184	102	25	29	340

For ***other,*** *people specified:*

- *Audio-visual*
- *At gay venues*
- *At GMFA London*
- *Documentaries*
- *Involved with HIV/AIDS prevention*
- *Company doctor*

Sources of information on HIV prevention which were more often accessed were GUM clinics, schools and colleges, voluntary organisations, TV, radio, newspapers and magazines, from friends, from gay community health services and gay pubs and clubs.

Information on HIV prevention provided in GUM clinics and especially in voluntary support organisations is most probably coming when it is too late for HIV prevention. Data suggest that the most frequent form of accessing of HIV prevention message is through leaflets (leaflets were mentioned 184 times) and through one-to-one discussions (mentioned 102 times); workshops or training were mentioned only 25 times.

QUESTION 22

To what extent do you think the following factors may have contributed to your being infected with HIV?

	Greatly			May have			Did not			Not sure		
Factor	**Total**	**M**	**F**	**Total**	**M**	**F**	**Total**	**M**	**F**	**Total**	**M**	**F**
Lack of sex information at school/college	4	3	1	9	8	1	24	19	5	5	3	2
Lack of info on relationships at school/college	4	3	1	8	6	2	25	21	4	3	2	1
Lack of confidence in negotiating safe sex	8	4	4	13	9	4	26	23	3	1	0	1
Lack of information in media	4	3	1	6	5	1	27	23	4	3	2	1
Lack of information from	5	2	3	2	0	2	29	26	3	3	1	2

health settings												
Use of alcohol	12	11	1	15	13	2	20	15	5	1	0	1
Use of recreational drugs	9	9	0	6	6	0	25	20	5	1	0	1
Drinks being spiked	1	1	0	1	1	0	33	28	5	1	0	1
Lack of access to condoms	4	1	3	4	2	2	28	24	4	2	1	1
Didn't think it could ever happen to me	18	9	9	18	13	5	11	9	2	3	1	2
Took a risk	19	15	4	17	15	2	10	8	2	2	0	2

Other for Males:

Long-term relationship and trust

- *Being human and having trust*
- *Married then found out when wife diagnosed*
- *Trusting someone in a relationship*

Condom failure or unsafe sex:

- *Condom broke. Bad luck. Sex can only be safer, not fail safe*
- *Condom failure*
- *How about depression. Don't like condoms*
- *Increasing acceptance of unsafe sex*

Blood or blood products:

- *Government f*** up*
- *Routine use of blood products for medical condition*
- *Working in a known high risk country and having an accident*
- *(realise) did not think I had taken risk – probably following dentistry*

Other for Females:

Long-term relationships and trust:

- *Husband*
- *I was married*
- *Partner was unfaithful*
- *Trusting my partner*

Unsafe sex:

- *It was all down to me, don't blame anyone but myself*
- *Was blackmailed into having sex.*
- *Self-confidence issue:*
- *General lack of self-confidence/ worth*

Although the sample is small, some tentative differences do emerge. For males – important factors contributing to them becoming infected are use of alcohol and recreational drugs, also lack of confidence in negotiating a safer sex. Crucial factors are "took a risk" and "never thought it could happen to me". For females –"never thought it could happen to me" is a prevailing sentiment.

QUESTION 23

Do you think any of these sources of information or awareness could be improved?

	Male	**Female**	**Total**
Yes	15 31.2%	10 38.5%	25 33.8%
No	11 22.9%	5 19.2%	16 21.6%
Don't know	15 31.2%	9 34.6%	24 32.4%
No answer	7 14.6%	2 7.7%	9 12.2%
TOTAL	48	26	74

33.8% of respondents think that HIV prevention messages could be improved, 32.4% do not know, and 21.6% think that they could not be improved.

QUESTION 23a

If YES, how could these services have been improved?

Information, media, messages, awareness

- *More info*
- *Radio, TV*
- *Lack of info on safe sex for heterosexuals and transmission of HIV.*
- *Must be talked about*
- *There seems to be an attitude in today's society that HIV won't happen to me. The message needs to be harder hitting.*
- *With the exception of GUM and specific voluntary organisations there is no information or outreach and professionals, including GPs have little or no knowledge of HIV infection or treatments.*
- *Positive communication.*
- *More info at primary care – e.g. at GPs*
- *More information at GPs' premises. Renewed information in the media. Info updated in relation to current thinking.*
- *Internet info/webcasts. The printed info is fairly bland - it doesn't make you think about the consequences of HIV - like effect on health, partner's health, would your partner stay around. I get the general impression that HIV gay guys "try" to avoid HIV+ guys.*
- *More information supplied at the GP.*
- *In the area I live people need awareness, not to ignore reality to today's health, culture wise. By involving everybody in AIDS awareness. Not being exclusive to other cultures.*

HIV Knowledge

- With the exception of GUM and specific voluntary organisations there is no information or outreach and professionals, including GPs have little or no *knowledge of HIV infection or treatments.*

TV adverts

- *To be honest, since I have been diagnosed, I have noticed more articles, TV appearances informing of you about HIV, there are a lot of warnings. Think adverts could be created that shock (like the drink driving adverts) put these adverts on channels that teenagers watch, e.g. Sky music channels. Even put shocking adverts on Channels like Trouble and Nickelodeon, but adverts have been made like this but have later been banned for being too shocking. But we all need a shock to listen!!!*
- *Intense daily TV commercials that hit the core hard.*
- *1980's adverts need to be updated and re-aired.*
- *Constant adverts*
- *Re-run of AIDS/HIV adverts on TV. Poster information. Late night awareness in Gay Bars/ clubs.*
- *Media coverage has changed since 1980's. Much more focussed on Africa, Russia, Asia etc, people are dying. Nothing said about safe sex in the UK.*

Safer sex education at schools; campaigns

- *Encouraging school children to become more confident in negotiating safer sex through specifically addressing this issue during lessons. Talking to pupils younger e.g. 11+.*
- *Awareness needs to be much better raised in schools.*
- *More government and local campaigns. Schools/ Colleges etc. Promotion of safe sex. Keeping HIV support centres funded and health care services.*
- *Education from an early age at school is a must. PTAs and Boards of Governors need to face up to reality that talks on HIV/AIDS are not a promotion of sexual lifestyle or promiscuity.*

Prisons

- *Access to condoms in prisons.*

Other:

- *There is always room for improvement. It is just finding the right way in each case.*
- *When I went to GUM Clinic in (…) [location] straight after incident, I was tested for STDs but not given any reason to think HIV was an issue. I was told to "go home and get on with my life". Perhaps this could be addressed?*
- *Didn't lie about knowledge to haemophiliacs in UK.*
- *Not to trust partners. People should wear condoms and only stop using them when both are tested and cleared from the infection (e.g. for child bearing)*

QUESTION 24

Which GUM clinic do you use?

Clinic	Male	Female	Total
Andover	0	0	0
Basingstoke	9	4	13 16.9%
Bournemouth	1	0	1 1.3%
Brighton	1	0	1 1.3%
Frimley	4	3	7 9.1%
Guildford	1	2	3 3.6%
Isle of Wight	2	0	2 2.6%
London (Chelsea & Westminster)	3	1	4 5.2%
Portsmouth	10	5	15 19.5%
Southampton	15	8	23 29.9%
Winchester	3	3	6 7.8%
Other	2	0	2 2.6%
TOTAL	51 ticks	26 ticks	77 ticks

For ***other:*** *London – St Thomas; Portsmouth for GUM but London for HIV care; None.*

NB: There are 2 haemophiliacs (male) who are not using any GUM clinic but getting all services through haemophilia centre. One female is using GUM clinic but did not state which one. 4 males and 1 female stated that they are using 2 clinics: 2 males are using Portsmouth and Southampton, one female is using Portsmouth and Guildford, one male is using Portsmouth and London Chelsea & Westminster; and one male is using Portsmouth and London St Thomas.

76.7% of respondents are using clinics within the H&IOW area.
5.2% of the sample are using GUM clinics in London.

Needs Assessment vs SOPHID data by Strategic Health Authority of Treatment

Strategic Health Authority of Treatment	Needs Assessment	SOPHID 2004
Avon, Gloucestershire and Wiltshire	0	1 0.1%
County Durham and Tees Valley	0	1 0.1%
Dorset and Somerset	1 1.3%	6 0.9%
Greater Manchester	0	1 0.1%
H&IOW	57 77%	495 74.2%
Norfolk, Suffolk and Cambridgeshire	0	1 0.1%
London (North Central, North East, North West, South East, South West)	4 5.4%	74 11.1%
Surrey and Sussex	10 13.5%	80 12%
Thames Valley	0	6

		0.9%
West Yorkshire	0	1
		0.1%
Wales, South East	0	1
		0.1%
Other	2	0
	2.7%	
Total	74 (ticks)	667

NB Two respondents are not residents of the H&IOW strategic health authority, their responses were excluded from the table.

Comparison of the data with the SOPHID data 2004 suggests that people who are using GUM clinics in London are underrepresented in our sample. Some of the respondents stated “other” instead of “London” but they specified clinics in London later.

QUESTION 24a
Which services do you access at this clinic?

Service	Total ticks
HIV monitoring & blood testing	64
HIV drug treatment	48
Nutrition advice for HIV & related issues	14
Treatment for other infections related to HIV	27
Medication advice and support	34
Other	8

For other:
- *Ante-natal clinic*
- *Compassionate reliable honest support*
- *Counselling and general support and advice*
- *Counselling and will see nutritionist soon*
- *Not on meds and nutrition never got a mention. Do they offer it?*
- *None*
- *Rehab support after cancer*
- *Services provided through haemophilia centre*
- *Treatment and monitoring during pregnancy*
- *Unknown – have only been diagnosed a month ago*

Majority of people use GUM clinics for HIV monitoring and blood testing and for HIV drug treatment.

QUESTION 24b
When did you last visit a GUM clinic?

	Total ticks
Within the last week	34
Within the last 4 weeks	16
Within the last 3 months	22
Within the last 6 months	5
Within the last year	2
Over a year ago	3

Majority of people visit GUM clinic at least once every months.

QUESTION 24c
If you do not use a GUM clinic, please explain why

- *All service needs met via Basingstoke Haemo Centre*
- *I visit the GUM clinic a lot more now I am in (...) [location] as (...) is not a nice place to go!!*

Haemophiliacs are not using GUM clinics for HIV treatment and care, as care is provided by the Haemophilia Centre in Basingstoke.

QUESTION 25
Do you use the following health-related and emotional support services?

Service	Total ticks
HIV health advisor	30
HIV counsellor	15
Other counsellor	8
HIV pharmacist	14
Dental care (HIV dentist)	18
HIV clinical nurse specialist	23
Mental health services	4
GP for HIV issues	16
Other	8

For other, people mentioned:
- *Groundswell*
- *HIV drop-in centre, Ribbons*
- *HIV social worker*
- *HIV specialist consultant*
- *Monitoring consultant*
- *Obstetrician*
- *PA*
- *PA/ GUM doctor*
- *Ribbons Centre*
- *Social Worker*

Many people are using HIV health advisor and HIV clinical nurse specialist services where these exist.

QUESTION 25a
What are you using those health-related and emotional support services for?

Service	Total ticks
HIV monitoring or blood testing	41
HIV drug treatment	32
HIV nutrition advice	10
Treatment for other HIV-related infections	15
Medication advice and support	26
Other	12

For other, people mentioned:

- *Collect condoms*
- *Counselling*
- *Counselling and general medical care*
- *Dental treatment*
- *Discussion groups*
- *Emotional support*
- *General emotional support (x2)*
- *General support*
- *None available in Andover. Only location known is Southampton/Winchester*
- *Psycho-dynamic counselling*
- *Sexual and mental (psychological) issues*
- *Social support*
- *Support with coming to terms*
- *Talk*

People visit these services predominantly for HIV monitoring and blood testing and for HIV drug treatment and medical advice.

QUESTION 25b

When did you last visit a GUM clinic?

	Total ticks
Within the last week	29
Within the last 4 weeks	12
Within the last 3 months	14
Within the last 6 months	4
Within the last year	3
Over a year ago	0

Majority of people visit these health-related and emotional support services at least once every 3 months.

QUESTION 25c

If you do not use these health-related and emotional support services, please explain why

- *No need - get on with life and live. The question of sexual relationship does not apply - recently widowed! Partner was very supportive. Not related to AIDS*
- *Have adequate support from partner and family and sufficient medical knowledge to cope. Haven't identified a need for any yet.*
- *I don't use them in particular only have a chat/chitchat, when collecting results. I feel I don't need these services because I'm coping with living with HIV perfectly fine on my own, although at times I feel alone. I wouldn't mind an occasional meeting with a counsellor or other HIV sufferers.*
- *Don't need to. Groundswell looks after me.*
- *I do use a lot of internet for information and support. Currently buying own condoms. Still feel uncomfortable as I work in the same area.*
- *Didn't know they exist. (x2)*
- *The services are not available and where available they have waiting lists for example, counselling. I can't get nutritional advice, dentist help. The waiting list is too long for me to even be put on - told to go to voluntary services.*
- *Don't trust GP's confidentiality. Whenever I ask about gay friendly/HIV friendly GPs - told that there is no info. Other services not offered/asked for.*
- *Testing done by haemophilia centre - no other support needed.*
- *Travelling time approx 2 hours each way by train. Initial cost of train fare (£21.80) min. Exhaustion insured by travelling plus deterred by ineffective support and poor attitude to new and unknown members (…) [voluntary support organisation].*
- *Currently I am quite healthy, not on medication and have a fab family/support network.*
- *Not yet on HAART, there is little mental health support available to meet my needs. There is no substitute for the emotional support from others with HIV.*

The main reasons for not using health related and emotional support services are: people are coping with living with HIV on their own; they have adequate support from partners or family; some people did not know that these services existed or were available; for some people distance was a problem.

QUESTION 26

Do you use the following social care and voluntary services?

Clinic	Male	Female	Total
Gay community advice/support centre	4	0	4
Inscape	1	0	1
HIV social worker	8	5	13
Ribbons Centre	18	7	25
Positive Action - Aldershot	12	6	18
Positive Action - Portsmouth	4	2	6
Positive Voice	10	1	11
Groundswell	3	5	8
Positively Caring	0	0	0
Body Positive - Dorset	2	0	2

Many people use Ribbons Centre, Positive Action in Aldershot, HIV social worker and Positive Voice. One person reported using Inscape, 2 people reported using Body Positive Dorset and nobody reported using Positively Caring. 55 respondents (74.3%) reported using at least one of the services listed. 19 respondents (25.7%) did not report using any of the social care and voluntary services listed.

QUESTION 26a

Which services do you access at these social care and voluntary organisations?

Service	Total ticks
Nutrition advice for HIV & related issues	11
Social and emotional support	42
Help at home	10
Housing advice	12
Financial/benefits advice	22
Access to immigration advice	7
Safer sex information	13
Other	6

For other, people mention:

- *Advice, emotional support*
- *CAB Aldershot*
- *Community Action*
- *Complementary therapy*
- *None*
- *Nothing*
- *Therapies*
- *They help me at Ribbons to give me strength*

Majority of people use these social care and voluntary organisations for social and emotional support and financial and benefits advice.

QUESTION 26b

When did you last visit these social care and voluntary organisations?

	Total ticks
Within the last week	35
Within the last 4 weeks	7
Within the last 3 months	6
Within the last 6 months	4
Within the last year	2
Over a year ago	1

Majority of people use those services at least once every 3 months.

QUESTION 26c

If you do not use these social care and voluntary support services, please explain why

Unsatisfaction or different problems with services:

- I do attend (….) [*voluntary support organisation*] but there is very little going on there.
- They do not offer the needs I have had in the past from previous staff, only a therapy maybe once in 6 weeks.
- (…..) [*voluntary support organisation*] No-one spoke to me. I was ignored and made to feel very isolated. My self-confidence was badly affected by this experience and (…….) [*event mentioned*]
- Did use (….) [*voluntary support organisation*] but don't feel comfortable any more
- Shyness and have an aversion to transvestites/ transsexuals who seem to frequent these services as "patients" and volunteers - dressed up. I know of other HIV patients who do not attend for the same reason. We are seeking normal situations in which to relax and feel at home. Why can't they leave their dresses at home.

Distance:

- Most are too distant! You want me to drive from (...) to Bournemouth/Aldershot every week? I went to (...) [support organisation] Portsmouth once - not been since. A lot of these I don't need currently or they are too distant. I've already said why I don't use GP.
- Travelling time approx 2 hours each way by train. Initial cost of train fare (£21.80) min. Exhaustion insured by travelling plus deterred by ineffective support and poor attitude to new and unknown members (…) [*voluntary support organisation*].
- I feel that they are too far away for me to travel to and I do not feel that the benefit of these services would justify me giving up spare time, which is a limited enough resource at present as I have a full-time job.
- I find it hard to get to the place as I don't drive at the moment and am out of work.

Do not need the support from these services:

- Never felt I needed the support of a support service. Carried on with life as normal and decided not to live as a "victim".
- No need. I am fully employed and part time self employed. With drug therapy able to have a full and active life.
- No need for them yet (x5)
- I don't use them in particular only have a chat/ chitchat, when collecting results. I feel I don't need these services because I'm coping with living with HIV perfectly fine on my own, although at times I feel alone. I wouldn't mind an occasional meeting with a counsellor or other HIV sufferers.
- All my needs are covered by the Health Adviser at the GUM Clinic.

Do not know about them:

- I don't know of any which is next to me or in my area. Please help. Need to join one of them especially - Ribbons Centre.
- Did not know most of them existed. (x2)

Other:

- I use these services regularly as they are not available at a statutory level.
- Risk of being identified (….)
- I feel privileged to be knowledgeable, able to work and

have my family's identity to protect. Instead I want to give back to the service.

- I would be interested in mutual support services, but understand they are often immigrant or homosexual or drugs-focussed. None of these issues are relevant to me. Don't have any information about support available. Also, I prefer not to think about HIV day to day.
- Work too many hours at present but want to volunteer at BP Dorset when relocated fully.
- Did use (….) [*support organisation*]. No longer go.

People do not use services because either they do not need them at the moment or at all or because services are too far away and travelling to them is a problem due to different reasons (full-time job, money, etc.), or they do not know that those services do exist. Some people tried some of the services but do not like them for different reasons (focused on specific groups, feel isolated, etc). Somebody reported that they do not want to be identified.

QUESTION 27

How important do you consider these service providers to be?

Provider	Essential	Important	Not important	Not needed
GUM clinic	62	10	1	0
HIV health advisor	39	19	2	5
HIV counsellor	36	17	4	6
Other counsellor	11	20	9	13
HIV pharmacist	32	19	4	7
HIV dentist	32	21	6	4
HIV clinical nurse specialist	31	17	3	5
Mental health services	21	18	5	9
GP for HIV issues	22	17	8	7
Gay advice/support centre or project	18	15	8	8
Inscape	2	12	2	19
HIV social worker	26	13	8	9
Local social worker	8	18	7	10
Ribbons Centre	23	16	5	9
Positive Action - Aldershot	18	15	7	10
Positive Action - Portsmouth	13	10	5	10
Groundswell	10	15	7	9
Positive Voice	13	12	8	6
Positively Caring	6	11	8	9
Body Positive - Dorset	8	9	7	10

Many people identified GUM clinic, HIV health advisor, HIV counsellor, HIV pharmacist, HIV dentist, HIV clinical nurse, HIV social worker, GPs, mental health services and Ribbons Centre as being essential.

QUESTION 28

Are you aware of the services available to you locally?

Service	Aware & used	Aware but not used	Not aware
Drug therapy	25	20	22
Treatment of HIV-related infections	25	23	17
Nutrition advice	11	31	23
Counselling	27	28	11
Dental care	24	18	18
Support/advice centre	31	20	10
GP	38	21	3
GUM/HIV clinic	64	7	1
Social services support	18	29	15
Voluntary HIV services and support	30	24	17
Mental health services and support	6	30	24
Gay community health projects & servicest	13	28	17
Other	2	4	6

For other, people mentioned:

- *Not sure what is meant by Voluntary HIV Services*
- *Positive Voice*
- *Self-help groups*
- *Terence Higgins Trust*

Many people are not aware of different services which are provided (lack of information about existing services).

QUESTION 29

Are you satisfied with the services you are receiving?

Service	Very Good	Adequate	Not adequate	Not available	Have not used
Drug therapy	38	5	2	0	25
Treatment of HIV-related infections	24	14	5	0	25

Nutrition advice	6	11	13	3	32
Counselling	21	14	8	4	23
Dental care	17	6	10	5	30
GP	19	16	14	0	14
GUM/HIV clinic	51	17	3	0	2
Social Services / support	13	5	8	3	33
Voluntary HIV services / support	29	5	7	3	25
Mental Health Services / support	4	6	4	5	44
Gay community health projects / services	12	6	2	2	37
Other	0	0	0	0	6

*For **other**, people specified:*

- *At my first follow-up after initial diagnosis, the doctor seemed slightly unprepared for some of my questions. Also came across as slightly blasé at some points.*
- *Happy with London - the above replies apply to Hampshire services.*

Majority of people are satisfied with GUM clinics and drug therapy provided to them. Voluntary support services, counselling and treatment for other infections related to HIV status are also described as “very good” by a number of people. Nutrition advice, counselling and GP have people on the both sides: some of them are satisfied but some of them think that those services are not adequate.

QUESTION 29a

If you have ticked “have not used” for any service, please could you explain why

Either do not need or do not know about them:

- Either don't currently need it or don't know about it. (x2)
- Not yet on medication, don't have any HIV related infections, have not yet arranged nutritionist appointments, have private dentist who I have not yet discussed my HIV status. Have not yet disclosed to GP. I work full-time shouldn't really need Social Services. I'm not aware of which voluntary services are available. Although I have had depression before, I'm managing OK at the moment.
- Counselling have not used. Didn't feel I was getting help I needed at the time. Some like Nutrition Advice, never knew they existed. Dental Care, never knew existed.
- GP - not used for confidentiality/HIV/gay friendly reasons. Nutrition - never offered. Not particularly out/into gay scene. Social services offer what? Not a drug user. I haven't used because I don't know they're available or don't need them.
- Drug therapy - not needed. Nutrition, counselling, dental - not aware they are available.
- I haven't had any other infections and I don't need counselling or mental health or gay community help. I didn't know about dental care.

Not aware of the services:

- I have not used dental facilities recently because there is no dentist available. The one I used to visit is now on cash basis. As for support, Mental Services etc. I have no idea where these facilities are or if they are available.
- HIV drug therapy. Unaware of the service nutrition advice. Was never given or offered any dental care. Thought it was covered by normal dentist. Social Services support, (…) [*person*] called round once in a blue moon so I gave up on (…) [*person*]. Mental health services. Don’t think I was offered any service. Gay community health projects. Unaware/what is involved? No information.
- I have not used Dental care - don't even know that it's available.
- Was not aware of the organisations. (x2)
- I really am not aware of any counselling services offered or support. The only support I have had is when I have asked to see the Health Advisor for specific reason. And I feel there is so much that I can benefit from counselling for I have suffered stigma, humiliation and isolation in the past year.
- I did not know about the Dentist.

Do not need or have not used yet:

- No need yet. (x12)
- I don't do drugs, have no requirements for dental care at present, don't need counselling etc. Will access these things if required in the future.
- Have not had to use because they did not apply to my needs at the moment, as for Dental care, could not get registered with a local NHS dentist recently.
- Drug therapy - not on medication. Other Infections - have had none. Dental Care - use my own dentist. Social Services - no need to use. Mental Health Services - not needed now.
- Do not need nutrition advice.
- Not services that I have had the need to use.
- I have only just been infected, so these services are not yet an issue.
- Simply have not used yet, or no experience of them.
- Don't need counselling (but have had in past). Don't need any support services.
- Not needed to use as other agencies have helped.
- I don't need to use social services or mental health services. I am lucky to be able to work and lead an almost normal life.
- I do not feel the need to use many of these services as I feel that I have adequate personal resources available to me. Also I would prefer not to spend a large amount of my time talking about or listening to advice about my illness and becoming a "professional patient".
- Not on drug therapy yet. Want teeth done but can't afford it. Haven't needed social services support yet.
- No recent infections and discuss diet at GUM. Not

gay.

- I haven't had a need as of yet and I am heterosexual.
- Have not suffered infections related to HIV. No dental problems. Don't need gay community health project as well as social and mental health services.

Other:

- SS okay but problems when wife dying with (…) [*location*] office.
- Don't, or am not aware of any related illnesses. Have suffered from depression and blood pressure because of loss of my family long before diagnosis.
- Not on therapy: Will not disclose to my GP as family also use GP.
- There is no social worker
- Drug therapy not needed as it is provided with care at (…) [*name*] Unit (…) [*location*] HIV Social worker not around in Southampton. No important things like people's care, which should be more important. Many people have complained but no action is taken ever!
- Not on drugs, not had other infections, cannot afford decent meals, afraid of disclosure to dentist, not mental, not gay.
- I am not on combination therapy at moment so I am being monitored although need counselling and assistance emotionally. I have been told the waiting list is too long and I won't be seen and have been told to use voluntary organisations.
- All medication controlled via Haemo Centre with advice from HIV doctor associated via Haemo Centre.
- I do not yet require drug therapy and have not yet had any HIV-related infections. I am pretty clued up about nutrition anyway. Don't yet think I need counselling - would seek it out if I change my mind. Tried the dentist and hated it - found it really depressing. Don't require social or mental health services. Am not gay. Don't know what voluntary services are available for heterosexual females/males. Often seem dominated by homosexual health, which is fine, of course, but not relevant for me.
- I am accepting of my status and for reasons of aversion as explained earlier.
- Not gay. No mental health problem. No employment problem (have used housing service in past) and would like to transfer to another city but not sure how to access help.
- Not needed them. Also fear risk of being identified.
- Would like to find out more about these services. I have been told about them but not the extra push to come into contact with them. I would like to join these services as a voluntary worker to speak to people/do presentations to new sufferers of how to live with HIV and that it is not all bad.
- Not been advised of anything especially my immigration status. I once asked my doctor and she said she did not know much. My problem is, back home there is no medication, and miss my son. I would love to live here so that I get my medication.
- I did not know nutritional advice was available. I don't feel comfortable with the particular counsellor or the mental health worker working in the HIV field. I have used the general mental health services and found them very useful.

The majority of people have not used certain services because they either did not need them or were not aware of them. There is a perception that there are no groups for heterosexual males and females, no specific services available for them. Immigration status can be a problem for accessing some services (social services).

QUESTION 30

Do you travel outside Hampshire to access any of the services you receive?

	Male	Female	Total
Yes	10 20.8%	5 19.2%	15 20.3%
No	36 75.0%	21 80.8%	57 77.0%
No answer	2 4.5%	0 0%	2 2.7%
TOTAL	48	26	74

20.3% of participants travel outside Hampshire to access services.

If YES, please list the services you travel to, and where they are located:

Service	Location
Lypodystrophy clinic	London: St Thomas's and Chelsea & Westminster
GUM	London: Chelsea & Westminster
GP	Bournemouth
GUM	Frimley (x2)
GUM, GP, Dentist, Counselling	Bournemouth
GUM	Guildford (x2
Terence Higgins Trust	Woking
GUM (HIV-specific)	Brighton
Primary HIV health care	London: Chelsea & Westminster
HIV clinic/drug treatment antenatal care	London: Chelsea & Westminster

Main locations for getting services outside Hampshire are London, Guildford, Frimley Park, Brighton and Bournemouth.

If you have answered YES to the previous question, why do you access these services away from your local travel area?

Service	Total ticks
Local services not adequate	7
Location of drug trials	2
Friends use the service	2
Same location as job	1
HIV specialist service	9
Friendliness of staff	8
Anonymity	2
Other	8

*For **other**, people mention:*

- *Live there*
- *Nearest*

- *Nothing available in present location*
- *Other services available at THT (counselling)*
- *Specialist expertise and 2nd opinion*
- *Specialist services for pregnant women*
- *Used to live in area*

Please could you explain your reasons for using services outside your local area in more detail

- *Only services to be accessed are found in either Winchester/Southampton or Aldershot. None available in Andover.*
- *This is the closest to Basingstoke*
- *Although I still use my local services, now we have set up our own Support Group called "Seeds of Africa" which will be able to access the services as we need them for we are the people in need.*
- *It was explained to me that Chelsea and Westminster could handle my care much better than (...) [GUM clinic] as I am pregnant.*
- *I am treated as an individual person at Chelsea and Westminster with a friendly and personal sexual health service. In (…) [location] I am treated as a number not as a human patient.*
- *Frimley Park GU Clinic nearest and very close to Hampshire border.*
- *I tried the local GUM but they are too pressured, not good enough service and say they do not have funding for up to date drugs. More trials are available in Brighton.*
- *There is no available service for counselling except THT. Also work in (...) [location] and hospitals in Hants have a poor reputation (inc. Social Services).*
- *I am reluctant to change my support and medical services. "Better the devil you know".*
- *I went once looking for a place of acceptance but I never fitted. I feel there is no support for me. Mostly used by the Gay community. I am not gay. I am married with children.*
- *Because my area is remote and has no big hospital.*

The main reasons for using services outside Hampshire:

- Distance (closer to home)
- Services are not available locally
- Pregnancy care
- Attitude in London (friendliness of staff)
- Better quality of services there
- Access to trials

QUESTION 31

What information relating to HIV do you require?

Service	Yes, I need this	No, I do not need	Don't know
Treatment / therapy support	42	9	3
HIV and effects on the body infections	42	9	3
Safer sex	19	26	4
Relationships	19	26	3
Sexual problems	17	24	7
Coping with recent diagnosis	17	26	2
How to live healthily with HIV	44	8	3
Avoiding other infections	37	15	2
Who to tell and how to tell	28	22	1
Other	4	3	7

*For **other,** people specified:*

- *All ticked as needed have been needed at some time*
- *DDA and employment rights and law*
- *Help and support during pregnancy*
- *HIV and pregnancy, breastfeeding, etc*

Big proportion of people stated that they require information on treatment/ therapy support, HIV and the effects on the body, how to live healthy with HIV, avoiding other infections and who to tell and how to tell.

NB: With reference to Q31 and Q32: 14 people have not answered these questions because of a mistake on some questionnaires (it stated: go to question 33)

QUESTION 32

What services do you require?

Service	Yes, I need this	No, I do not need	Don't know
Emotional support	34	13	5
Counselling	23	18	6
Depression / mental health support	18	22	6
Health services	32	11	3
Benefits, allowances & other financial support advice	26	23	2
Housing & accommodation advice	19	33	1
Employment opportunities	17	30	4
Training & further education	15	34	2
Street (recreational) drug support	2	41	3
Alcohol support	2	41	1
Support for children	10	38	2
Immigration issues advice	14	37	1
Legal services	11	30	7
Support to live at home	15	29	4
Support by others with HIV	26	15	5
Other	1	1	1

*For **other,** people specified:*

- *Dental*
- *Getting these and have had*
- *Really need support by others with HIV*

Services which do not seem to be needed by the users: street (recreational) drug support and alcohol support.

Services ranked in order	Needed
Emotional support	34
Health services	32

Support by others with HIV	26
Benefits, allowances and other financial support advice	26
Counselling	23
Housing and accommodation advice	19
Depression/Mental health support	18
Employment opportunities	17
Training and further education	15
Support to live at home	15
Immigration issues advice	14
Legal services	11
Support for children	10
Street (recreational) drug support	2
Alcohol support	2
Other	1

Services ranked in order	**Not needed**
Street (recreational) drug support	41
Alcohol support	41
Support for children	38
Immigration issues advice	37
Training and further education	34
Housing and accommodation advice	33
Employment opportunities	30
Legal services	30
Support to live at home	29
Benefits, allowances and other financial support advice	23
Depression/Mental health support	22
Counselling	18
Support by others with HIV	15
Emotional support	13
Health services	11
Other	1

Services which do not seem to be needed by the users: street (recreational) drug support and alcohol support. It appears that significant number of people require emotional support including counselling and mental health support.

QUESTION 32a

Please add any comments on why you need these services and what you hope to gain from them

***NB**: 14 people have not answered this question because of the mistake on some questionnaires (it stated: go to question 33 instead of go to question 31).*

- *Have not found any personal need.*
- *We need these places so as to try to lessen the number of people with HIV*
- *Education and what is in store for us.*
- *I want to meet others with HIV, so we can help each other get through HIV. Also it is interesting to see how others are dealing with HIV. It would just help me. Sometimes I cry about HIV because I feel alone, but I always think there are people far worse off than me, but sometimes I would like focus groups etc explaining more about HIV.*
- *I am a professional, meaning I have a full time health professional job. Who wants to be nursed by someone who is HIV+. Colleagues do not understand HIV. I want to practice my nursing but where. What is exposed prone procedure? I need to change my job. I have been a nurse for years. so what is there for me now that I am infected?*
- *Would like to move to another city - have contacted local HIV group for support letter/housing association and other city Council Housing department. Not sure if anything else can be done but waiting list for Brighton is up to 5 years.*
- *I have been diagnosed one month. The GU Staff and Health Advisor have been good, offering support, but I don't know what questions to ask or what support I need. Most information I have found on the web and am not sure how current this is as sites aren't usually dated.*
- *I do feel quite isolated as I have only spoken to 3 other HIV+ people and am only very slightly in touch with one of them. I am possibly legally challenging a decision about pensions with my employer so advice would be welcome. Would be interested in "who to tell" with regards to my rights and responsibilities, e.g. dentists, employer/colleagues.*
- *I am currently accessing these services*
- *Teeth are awful!! Have not smiled in 10 years because they so embarrassing.*
- *Meals on wheels should be available to people who suffer like me. Take-aways are not very nutritious when I am unable to care for myself.*
- *I work full-time and maintain this by maximum support from Positive Action and THT. I need counselling to be able to cope with diagnosis. With support from them I am able to remain at work with constant support. My GP is not interested in my diagnosis and cannot tell my dentist (he doesn't have HIV patients). GUM etc do not have funding for other support and therefore is provided by Charity.*
- *I hope one day I can bring my children to live with me.*
- *The support centres like Ribbons and PA are a great emotional support. They give back what has gone from the other diagnoses. Many people like me become isolated and depressed. There is help to overcome this and give some quality back.*
- *I am very alone and I need social meeting to meet other people.*
- *Well, I said before that I think depression was a factor in my HIV infection and is an on going issue - so that's why I've ticked counsellors/mental health. Also I've already said I haven't disclosed to GP - because don't trust their confidentiality or gay/hiv friendliness.*
- *As ticked over leaf, these services will help better my life now and live a healthier stress free long life.*
- *Services ticked would go to help reintegration and coping with confidence back into work and social life.*
- *I would like to be employed as to occupy my mind, because I feel I am still quite capable of taking care of myself. At the moment I feel depressed and suffer from low self-esteem because of being unable to look after myself. I would feel much better mentally and physically if I was able to have self control. At the moment I feel like a robot.*
- *More Immigration Support – NASS*
- *I need these services because I need to feel free and to support myself in what I need. To associate with others. To avoid stress and upset everyday thinking how to survive.*
- *-Firstly, I would like to sort out my immigration status. So that I can work for myself and support my child also I would love to have my son with me but in my situation I am afraid that I will be sent home. I will definitely die. So please I really need help with my immigration. Also I need to achieve many goals but due to my status I can't.*

People stated that they needed:

- More information about services and quality information about HIV
- To meet others with HIV
- To know about their legal rights and responsibilities
- To have "meals on wheels"
- To have emotional support and counselling to be able to live and to work
- To have more immigration support.

QUESTION 33
How important do you consider these service?

Service	Essential	Important	Not important	Not needed
HIV drug treatment	60	5	0	4
HIV monitoring / blood testing	62	6	0	0
Treatment of HIV-related infections	59	9	1	3
Nutrition advice for HIV-related issues	29	29	5	5
Social and emotional support	38	20	4	5
Complementary therapies	27	24	12	2
Help at home	9	24	11	19
Housing advice	18	22	9	15
Financial / benefits advice	21	24	5	13
Immigration advice	18	11	18	19
Other	3	1	1	0

For other, people specified:

- *Advice for moving overseas*
- *Children*
- *It is all very good*
- *Mental health support*
- *Some were important but not now*

Almost everybody who answered this question agrees that HIV drug treatment, HIV monitoring/ blood testing, treatment for other infections are essential. People are divided into two camps on their opinion on nutrition advice, social and emotional support, complementary therapies, help at home, housing advice, financial/ benefits advice and immigration advice. Some of them need those services and some of them do not need them, it depends on the demographic characteristics of people and their needs.

QUESTION 34
How important do you consider these service?

Service	Yes	Some of group	No	Not applic.
Partner	45	0	1	21
Children	9	0	15	32
Parents	32	5	19	7
Wider family	16	24	22	1
Friends	21	31	11	0
Employer	16	4	19	16
Work colleagues	7	10	21	15
GP	59	3	4	2
Dentist	35	1	15	6
Other	7	1	0	0

For other, people specified:

- *1 child*
- *Colleagues at Ribbons Centre*
- *Ex-wife*
- *Ex- partners*
- *GUM instructed to tell family doctor*
- *Housing – army*
- *Optician*
- *PA*
- *RC users*
- *Social Worker*
- *Solicitor*

Many people revealed their HIV status to their GP, friends (or some of the group), partners, parents and wider families (or some of the group) and dentists. Not many people revealed their HIV status to their employers, work colleagues and children (the numbers here could be smaller due to the fact that not everybody had jobs or children).

QUESTION 35
Of the people you have told, who have you received most help from?

Many people got most support from family, friends, or partners. Some people got support from GPs, siblings, other medical practitioners, RC, Groundswell, PA, social worker, employers, work colleagues. Some people do not get any support from anybody. Some people stated that for example friends can be really nasty and turn into enemies.

QUESTION 36
Have you experienced any negative responses / attitudes towards you because of your HIV status?

	Male	Female	Total
Yes	23	12	35 47.3%
No	24	12	36 48.6%
No answer	1	2	3 4.0%
TOTAL	48	26	74

If YES, please explain:

Dentist:

- *I told my dentist for health and safety reasons. He now makes any excuse not to treat me or tries to refer me to the hospital.*
- *Problems with dentists.*
- *NHS Dentist - Receptionist. Dentist OK I think.*

Doctors, nurses, etc.:

- *Many doctors still have stigma about HIV*
- *Practice nurse at GP surgery gave me a filthy look and was very abrupt when I told her before she took blood for routine test.*
- *Shock and disbelief of medical staff (some) HIV highlighted on my notes for everyone to read!*
- *I told my dermatologist. They were unprofessional, tutted under their breath and said "that was silly". Also asked how I got it and whether I was gay - a sweeping generalisation of the HIV community.*

Employers:

- *My line manager had no idea how to treat me. I went through hell for them. I had to change career. I fought it but how long?*
- *Not hugely, but I really, really fear this. Refused full pension in current employment which is currently being challenged. Poor initial occupational health support.*
- *Some of my senior management treat me very harshly, almost to the point of making me want to leave.*
- *Sacked on two occasions due to "illness".*

Partners:

- *Previous partner. Prospective partner's worried about transmission. Gossip amongst people who know me that I am trying to kill men.*
- *Sexual partners*
- *Sexual partners/potential relationship partners*
- *From potential sexual partners*
- *Most of this has been in my "Gay" Community and only to do with sexual partners.*

Relatives:

- *Brother read rubbish on internet and assumed it to be true, holocaust den.... is on internet as is also rubbish which caused family ructions.*
- *Mother disowned me on religious beliefs.*
- *If I told my family they would not like it.*
- *Loss of friendship and family issues*

Friends:

- *I have had some friends disappear and was evicted from shared housing due to people thinking I would infect them. I'm excluded from the local gay community.*
- *Friends walking away from me.*
- *I have lost friends and been made very alone.*
- *Being rejected from friends. Very depressed for to long. Panic attacks. Can't cope sometimes.*
- *Friends*
- *Loss of friendship and family issues*

Social Services:

- *From social services, because they are aware of your condition, they speak to you with no respect. Well "I don't use their services".*

Other:

- *No because nobody knows or needs to know.*
- *At (…) [name of the university] University they told me that I was not welcome if I was HIV. I felt so embarrassed and put off.*
- *Too long to list. I will say face to face so I can say it all, but it was cruel and I only had HIV for a month so I was dealing with it plus a lot of abuse early on which thought I would break, but only made me stronger.*
- *Trying to get life insurance has been difficult.*
- *Some people don't understand and are scared of it.*
- *And being straight at (…) [voluntary support organisation]*
- *Sympathy to aggression*
- *At the gym*
- *People don't want to know you and stay away.*
- *Some people have not understood and not wanted to get to know me based on my HIV status.*
- *Because I haven't disclosed generally*
- *Described as a diseased homo.*

Negative responses came from friends, families, dentists, some other medical professions, employers, sexual partners.

QUESTION 37

If you answered YES to the previous question, how do you think this situation could be improved?

- *I just need to get my own place to live.*
- *Don't know. (2 people)*
- *Evidence that using contraception prevents the virus being passed on and nothing to fear just by making a conversation.*
- *Better education for doctors. I also told a doctor who'll be operating on me under local anaesthesia. He was very understanding and I expected a similar reaction from my dermatologist. I should have been more forceful when they questioned me but was taken aback by their attitude at the time.*
- *It could be improved with really good support from (…) [support organisation] and to understand clients' needs.*
- *Hospital notes to be confidential to be available to only those who need to know. Stigma is still Rife!*
- *By accepting that this is a world wide problem. How do we all put our heads together and help reduce the spread.*
- *Knowledge and understanding. More information on a one-to-one basis.*
- *Mandatory training for employers.*
- *Better attitudes and awareness. Things like World Aids days.*
- *Yes, with more public education and up to date information. The last public Aids awareness was in the early 90's and things have changed a great deal since. The general public should be made more aware of current issues surrounding HIV.*
- *It can't.*
- *Better info/education in the wider community.*
- *People are not all the same so one cannot blame them.*
- *More up to date info for reception staff and assistants. Suspect dentist also not well-informed.*
- *Better training for primary care staff.*
- *By communication by media and informing.*
- *Evaluation!*
- *Public awareness and greater understanding*
- *More education and responsive services to the emotional and social needs of the wider community rather than just physical symptoms.*
- *Who knows.....*
- *Send them on an HIV awareness course and one on how to treat staff!*

- *A re-evaluation of the risks posed to dentists treating HIV+ patients. Adequate sterilization of dental instruments.*
- *By monitoring the internet although a useful toolkit is used analytically and not believing everything you read like to papers.*
- *National employment policy with my profession. Better education for the nation - at schools, employment induction, media coverage etc.*
- *Better access to safe sex information. More support for people who come out as HIV positive so that we are more visible in community.*
- *More health education for employers. For now that am infected which employer will give me a job not even insurance.*
- *Some people could benefit from more information on TV and things but most just don't want to understand and won't be changed.*
- *Let insurers know that people with HIV can live for 25 years or more.*
- *Not really now, but at the time I wasn't really given any counselling or told much about how to deal with it. I really needed help at the time. I wanted to end it because I was being bullied about it. I thought it was the worst thing, but now I'm cool and HIV is part of me so why hide away.*
- *I did not know about the HIV dentist so I will look into it.*
- *I don't know really, but what I do is I don't tell anyone about my problem until I am asked. I wanted to be fair and transparent with them, but the response I got was really embarrassing. I told my GP about this experience.*

The situation could be improved by:

- Improving knowledge and understanding of HIV not only by medical professions and but also by general public
- By mandatory training for all employers
- By availability of better quality of information
- By re-evaluation of risks for dentists treating HIV+ people
- By providing better media coverage (more information on TV)
- By providing education in schools
- By having better access to safer sex information
- By educating people working for insurance companies

QUESTION 38

If you are happy to do so, please state your immigration status

Status	Male	Female	Total
Not applicable (UK passport)	37 90%	7 26.9%	44 65.7%
EU National	0 0%	1 3.8%	1 1.5%
On a student visa	0 0%	2 7.7%	2 3.0%
On a work permit	0 0%	2 7.7%	2 3.0%
Seeking asylum	1 2.4%	5 19.2%	6 8.9%
Indefinite leave to remain	0 0%	5 19.2%	5 7.5%
Receiving support from NASS	0 0%	1 3.8%	1 1.5%
Other	3 7.3%	3 11.5%	6 8.9%
TOTAL	41 ticks	26 ticks	67 ticks

NB: 12 people did not answer this question.
5 people ticked 2 different boxes:
1. seeking asylum + other (article 3. No support from NASS)
2. seeking asylum + support from NASS
3. UK passport + other (dual national, 2 passports)
4. on a student visa + other (I don't know, my passport is with Home Office since (...) [date])
5. on a student visa + other (holiday visa)

*For **other** people specified:*
Article 3. No support from NASS (M);
Compassionate leave to remain, residence permit (F);
Dual nationality (2 passports) (M);
Had visa as work permit holder spouse (M);
Holiday visa (F);
Don't know, my passport is with Home Office since (...) [date] up to now (F).

Majority of people (65.7%) who answered this question had British passports.

ADDITIONAL COMMENTS

Satisfaction with services:

- (…) [*name*] Health Care worker from (…) [*location*] Clinic is fantastic. We (my husband and I) were first told we had HIV, (…) [*this person*] gave us a number we could call 24 hours a day. (…) [*that person*] would phone us to make sure we were all right. There are hopefully people like (…) [*this person*] all over the country. Actually all the staff at (…) [*that clinic*] were fantastic.
- The clinic I use – (…) [*location*] is a good reliable clinic. The staff are friendly, but I feel they need to organise more meetings/focus groups about all areas of HIV just to make us all happy plus it would be cool to meet people with HIV so we can help each other. Its good that everyday more and more people are beginning to realise the risks of HIV. I think you should go to Channel 3 with my advert idea. Seriously though this is what the public need while Coronation Street goes to adverts while they are sipping tea. A shocking HIV advert comes on - it will make everyone stop what they're doing and re-think their future sex experiences.
- I am very grateful for the help I get at the clinic and at Ribbons. If I didn't know about my HIV I would be dead.
- Thank you for having a GUM Clinic and wonderful doctors and nurses, which attend to us so wonderful, God Bless them.
- I like going to the Ribbons Centre and I can find other people to talk to. Groundswell helps with transport or when I feel lonely and when I am stuck with bills or

food. Groundswell helps me with housing and reading letters.

Problems with the services:

- I have used many services in different areas over the years. (…) [*location*] is a bit behind the times with medication. They don't always have enough time at the clinic. I find it useful to get information (…) [*name*] at (…) [*voluntary organisation*] about my HIV drugs. (…) [*this person*] is well informed.
- I felt bad at (…) [*location*] - these professionals telling me that no-one was trained/or rather appointed to do that kind of test.

Suggestions for the services:

- It would be very helpful to me in Basingstoke to be able to get to a local support centre. The closest is Aldershot or Southampton. I attend already but closer to me would help me financially. HIV support through GUM clinic in (…) [*location*] is excellent and I consider that I am very fortunate to have such an amazing hospital to support.
- In a city the size of Southampton and indeed within Hampshire, the needs for an HIV counsellor that is easily available is paramount!! Also a local HIV social worker to replace the post lost a few years ago would be a great asset. To have a specific HIV nutritionist considering lypodistrophy and increased cholesterol levels caused by drugs would be beneficial. Also what would be a great help is a place where one can exercise without feeling self-conscious of weight or muscle loss. Some where someone knowledgeable in relevant exercising to improve body image due to loss through medication would help the mental aspect as well.
- GUM could be more user-friendly/informative. They "refuse" to email blood results out - other GUMs do so...? They seem to have an HIV specific waiting room with HIV related info/condoms in say 12 visits I've been in it once. Would have thought good place to put condoms/hiv related info. My main reason for going to Ribbons is social/to get an HIV+ partner. The various "social" groups don't seem to mix much - so number of people you meet is limited. I would say there's a need for HIV+ dating site. Ones that exist seem American. Guys don't usually disclose status - safe sex always could mean hiv- or hiv+ and that why safe sex always. Initial diagnosis/counselling - why don't GUM hand out a list of "all" local/web hiv-related sites/resources? Even recent diagnosed aren't told about local resources
- To have more therapy when we need it. To be helped in both difficulties and emotional situations.
- More support groups for straight people as a lot of groups seem to be condom specific.

Immigration related issues:

- I think if I was not knowing about Ribbons Centre I think my life was going to be bad. Because even if I need money they help me and they give me food vouchers. Sometimes I just feel pity for myself. Am I not troubling this people? But at the end I will say even if I am shy where am I going to get support. My last support was in (...) [date] to get money from NASS. I am not getting anything and I am still waiting for my papers to come.
- Had my visa application refused as my ex-wife divorced me. I appealed to (…) [*solicitor*] on the fact that I have children attending school here who are living with my ex-wife. Appeal was held on (…) [*date*] before Immigration Judge who ruled that I should be allowed to live in this country because of my daughters. However, the Home Office successfully appealed against that decision. I am waiting for the date of the new trial.
- In this north Hampshire Area we live, as for my own experiences, there is an increase in lack of support services within the Black Ethnic Minority Group. These people have no where to live. They live in poverty. Some can't even get medical treatment. Some have children. Because of their Immigration Status these people have got no where to turn to. The Services are there for those who have their Immigration Status sorted. Where do we send these people for help. It is affecting their mental health. Please help!

Other:

- Due to lack of post-diagnosis counselling received, I still feel the service has failed me. Being a (…) [*service provider*] and service user, what is there for me? I still feel I cannot come in the open to declare my status for I have 2 young children who do not know. How will my teenager feel about me. HIV is considered to be a shameful disease. Employer wants to know whether you are or have suffered from it to discriminate you. I can not even tell my colleagues because of the stigma attached to it. To help myself I have done a (…) course to help myself, but would not even wish anyone to go through what I have gone through. I am happy to help others, but those that do not know me I can discuss and share my situations. But not to those I know, for the fear of just people knowing. It is frightening. I hope the research will meet the needs of people like me especially from minorities.
- Not enough emphasis on network of friends as vital support system - i.e. I wish to move to (…) [*location*] to be near my friends, but this is not considered a health issue. I am very isolated in (…) [*location*], not a well developed Support Group. Isolation has a knock on effect. It is not just a health issue but affects empowerment. The status quo is never changed – it is as hard for me to disclose my status now as it was 16 years ago.
- You ask some questions about organisations I haven't heard of - how can I comment. If you'd outlined their services/objectives, that would be helpful.
- Even though I have given top rates for some services this does not mean that say (….) [*support organisation*]) funding is adequate - along with other services. Also the fact that I use two centres for services/support and some of the questions do not account for this. I hope that information received via the questionnaire is not going to result in cuts in services. *Note* Don't cut our services. Improve. I hope no hidden agenda in here.
- It appears that the questionnaire is leading the person towards using statutory services for counselling etc. I am not aware of any services available in Hants and when I have tried to access services and have been told by GUM staff that they are not able to provide or, the waiting list is so long. I work full-time so I cannot travel to London or Brighton to access specialist services. All my support from the beginning has been from GU Consultant/Health Adviser, but most noticeably from Voluntary/Charity Sector who have ensured that if they can organise support they do. I have no evidence of this from the statutory sector. My GP just asks if I wish to give up work.
- Too many fit, healthy people with HIV use HIV as an excuse not to work and claim benefits they are not entitled to. Some people need to ditch their victim mentality and get on with life instead of living it up on benefits.

- There is much emphasis on legal matters involving HIV at the moment. I think the burden of disclosure rests heavily on HIV+ people. Why similar emphasis on other serious STIs like HEP is not there? The hardest thing I have had to deal with so far is the stigma. It is a barrier to accessing services. It took much courage to go to Ribbons, but I'm so glad I did. I shared the issue with 2 line managers at work. I told them I had been diagnosed with a long-term illness and that the most likely symptoms would be tiredness and fatigue. How right I was! This project is essential - particularly with the growing threat of funding cuts in the NHS as a whole and some HIV services.
- To me HIV is just another illness and needs to be de-stigmatized by the media and general public. The biggest issues I have had are with Insurance and Financial Institutes who shut up shop at the mention of HIV. Try getting Private Health or Life Insurance. The media and publicity as an illness of drug addicts and gay community is wrong. I am a working executive who contacted HIV by accident but who would believe me?

Some respondents made very positive comments about voluntary support organisations and about GUM clinics. It is becoming clear from the comments that for many people disclosure and stigma are still big problems. The results showed that there was a clear need for support groups for heterosexual people

The results also showed that immigration status affected possibility of accessing services.

Somebody suggested importance of shocking HIV advert on TV. One respondent asked a question which could be interpreted as a useful suggestion for a better signposting: “Why don’t GUM hand out a list of “all” local/web HIV-related sites/ resources?” It was suggested that it would be good to have dating site for HIV+ people.

A number of people stated that HIV counsellor and HIV nutritionist would be very helpful. Some clinics were described as being a bit behind times with medication. Some people believed that network of friends were very important part of support system. A number of respondents stated that it would be helpful to meet other people with HIV. One respondent suggested that people working in Private Health and Life Insurance companies should be better informed about HIV/AIDS. It was also suggested that it would be useful to know how and what to tell to employer and work colleagues.

3.2 Qualitative Survey Analysis

It is notoriously difficult to amalgamate the results from a series of qualitative surveys such as interviews and focus groups, and indeed purists might argue that such results should not be aggregated as they are meaningful only at the level of the individual. Nevertheless, in order to sense overall trends and build a picture of the “agenda” of certain groups, there is value in combining these individual responses. The social science research software package NVivo has proved particularly successful at characterising qualitative responses, and at aggregating these characterisations. The approach is based on a process of “coding” whereas every significant element of a response (including topics, opinions and moods) is assigned a code, which is then applied to every other instance of the same topic. Thus a topic such as “dentistry” can be coded and then identified in every response in the survey that mentioned it.

NVivo lists these references so that it can build aggregated lists of all the different views that have been expressed. Sections 4 and 5 of this report have largely been constructed on the basis of these lists, and the quotations used have been drawn from them. This is an excellent way of ensuring that every voice has indeed been heard and considered – one of the key elements of the ethical brief for the project. At the same time, NVivo records three quantitative measures of coded responses:

- Number of documents coded with a particular topic. This identifies the number of survey elements (interviews; focus groups) that mentioned the topic, and is a crude indicator of the overall “*breadth* of interest” in the topic. This a vulnerable measure, in that some topics were raised by the interviewers/facilitators, and therefore the number is indicative of their interest.
- Number of paragraphs coded. A topic may be mentioned once in a document or more often. This number is a crude indicator of the overall “*depth* of interest” in the topic.
- Number of characters coded. Regardless of the number of mentions, complex and high-priority topics will attract more protracted discussion.

The qualitative results are tabulated separately for service users and service providers, thus making it possible to compare and contrast their perspectives. Despite the inevitable imprecision of a coding analysis, and the subjectivity inherent in the choice of codes, this comparison is instructive. The codes were defined inductively, emerging from the documents themselves rather than being determined externally by the researchers.

In order to highlight trends in the report, the analysis is presented through a set of arbitrary conventions:

- All codes with a “Number of paragraphs coded” of 1 have been eliminated, as these occurrences represent topics raised by only one person and are thus inappropriate in an aggregate review.
- For the service user survey, an arbitrary threshold priority of 10 paragraphs coded has been chosen to identify the major priorities, and these are displayed in bold type.
- For the service provider survey, since there was a larger number of respondents, an arbitrary threshold of 20 paragraphs coded has been used to select topics for highlighting.

3.2.1 Interview and focus group discussions with service users: results

The following table displays the magnitude of NVivo code scores for service users. Frequencies of 10 or more paragraphs coded have been highlighted in bold text.

NVivo Codes	**Characters coded**	**Paragraphs coded**	**Documents coded**
access to medication	1333	5	5
access to services	430	3	2
anti-depressants	305	2	1
appointments	982	4	2
asylum seekers	575	3	3
awareness	844	4	4
baby	737	2	1
benefits	1056	4	3
care or support	78	2	1
centre of excellence v. local centre	**4373**	**22**	**12**
changes	387	3	1
changing situation	374	2	1
coded approach	257	2	1
condoms	436	5	1
feeling confident	191	1	1
confidentiality	898	8	1
consultant	624	3	3
continuity of care	380	2	2
counselor/ counselling	3508	22	8
dedicated HIV social worker	**1255**	**11**	**6**
dentist/ dentistry	**3193**	**22**	**11**
depression	942	4	3
disability	581	2	1
disclosure	**3899**	**20**	**10**
discrimination	304	2	1
drop in centre	2655	11	7
education	451	2	2
emotional support	218	3	2
facilitator of a group/ centre	1055	4	1
far away	1968	9	6
file/ medical record	188	2	1
friendship	1132	5	4
funding	273	5	3
gay men	1537	5	4
gay people/ community	388	3	2
GMHP	1029	2	1
GP	**5924**	**30**	**16**
group for heterosexual people	490	2	1
GUM	**6013**	**35**	**13**
health advisor	1174	6	2
heterosexual people	1098	4	3
need to hide everything (mail, etc)	294	2	1
HIV network	790	4	1
HIV status	1422	9	6
housing situation	609	10	3
housing advice	373	2	1
ignorance	374	2	1
immigration status	**3818**	**19**	**5**
independent forum	**4747**	**20**	**13**
information	**4653**	**26**	**9**
Internet	729	3	2
involvement of service users	**2059**	**10**	**6**
IoW	1308	9	2
isolation	**2090**	**10**	**6**

employment and related issues	**6988**	**37**	**14**
knowledge	2565	11	6
London	**3672**	**22**	**6**
medication	**2629**	**14**	**7**
mental health	1714	9	4
misunderstanding	694	2	2
money	1362	7	2
needs	996	7	3
network of friends	1237	9	6
nice place to go	498	3	2
numbers	332	4	1
nurses	475	3	3
nutrition advice	462	4	4
opportunistic infections	210	2	1
outreach	599	6	4
PA	**3469**	**17**	**7**
patronizing	1091	4	1
peer support	580	5	2
personalities	683	4	2
pharmacist	755	7	6
prevention	**5355**	**31**	**12**
privacy	294	2	1
being proactive	906	3	2
problems	**10766**	**56**	**15**
general public	926	2	2
PV	397	3	3
quality	1256	3	3
RC	**5022**	**28**	**10**
religion	787	2	1
rights	611	2	1
satisfaction with services	**3647**	**28**	**7**
secrecy	913	3	3
segregation	753	3	1
shared accommodation	859	4	2
sickness benefit	650	2	1
side effects	1535	5	3
signposting	335	2	2
smoking	210	2	1
social services	**1724**	**23**	**11**
social support	1074	4	3
social worker	1794	10	5
specialist solicitor	181	2	1
specialist VS generalist	897	7	4
stigma	478	3	2
stress	570	2	2
support groups	2340	12	6
supportive	571	9	4
sympathetic	550	2	2
test results	771	5	4
training	340	2	2
transmission of HIV	374	2	1
travel	**2786**	**13**	**8**
treatment	622	4	2
trust	87	2	1
understanding	**2008**	**14**	**7**
voluntary sector	**1914**	**12**	**4**
voluntary workers	796	5	3
vulnerable	192	2	1
working people	134	2	1

Based on this analysis, it is possible to identify 15 topics as achieving “number of paragraphs coded” scores of 20 or more (selected as being twice the arbitrary threshold of 10):

• Problems	56
• Job/employment issues	37
• GUM clinics	35
• Prevention	31
• GP services	30
• Satisfaction with services	28
• Ribbons Centre	28
• Information	26
• Social Services	23
• Dentistry	22
• Centre of Excellence v Local	22
• London	22
• Counselling/ counsellor	22
• Independent forum	20
• Disclosure	20

Despite all the cautions surrounding NVivo analysis, this is the best available indication of the priority list of issues that are of concern to service users.

3.2.1 Interview and focus group discussions with service providers: results

The following table displays the magnitude of NVivo code scores for service providers. Frequencies of 20 or more paragraphs coded have been highlighted in bold text.

NVivo Codes	Characters coded	Paragraphs coded	Documents coded
access	1059	20	11
accessibility	549	7	4
accommodation	535	5	3
add-in benefits	114	1	1
adherence	248	4	1
advertising	275	5	2
anonymity	165	5	4
ante-natal care	121	2	1
ante-natal screening	206	5	3
aromatherapy	198	2	1
ARV	182	3	2
Asian community	772	19	5
asylum seekers	**3073**	**33**	**12**
attitudes	917	17	8
awareness	993	18	11
barriers	137	4	3
benefits	1448	15	8
big centres	494	6	1
bisexual men	102	4	2
black african men	1126	14	6
black african women	**1780**	**24**	**12**
Black Africans	**2989**	**44**	**15**
BME	869	9	3
Brighton	548	12	7
budget	640	6	3
building-based service	861	5	2
CAB	319	5	4
care-packages	672	10	5

centre of excellence	286	5	3
children	1119	12	8
Chinese community	195	4	2
choices	**2209**	**22**	**8**
chronic disease	439	7	4
clash of cultures	170	2	1
clinical nurse	602	10	4
committed people	234	4	3
communication	500	9	4
communities	295	2	1
community worker	31	2	1
competition	256	2	2
complains	324	5	3
condoms	526	7	1
confidentiality	**4109**	**61**	**21**
conflicts	113	2	1
consultants	129	2	2
continuity of care	533	6	3
cooperation	456	9	3
counselling	**2242**	**32**	**13**
counsellor	390	5	4
criteria for social care	654	7	4
cultural diversity	93	2	1
cultural issues	433	5	2
denial	168	3	2
dentist/ dentistry	1237	9	6
depression	80	3	1
deprivation	144	3	1
decision making	363	5	3
dietician advice	188	2	1
dietician	704	7	4
different groups	**1482**	**30**	**11**
disclosure	1552	16	8
discrimination	1146	16	7
diversity	285	7	4
drop-in service	495	10	6
drugs	694	13	5
duplication of services	409	7	2
East Europeans	613	9	4
educated people	790	16	6
education	**1377**	**22**	**9**
elderly population	77	2	1
emotional support	**1220**	**23**	**9**
equality	922	7	3
exclusion	164	3	1
expertise	908	13	9
family	356	7	5
Feedback and feedback mechanism	227	6	3
flexibility	**1673**	**25**	**14**
forum	**1625**	**23**	**8**
friendliness towards different group of people (Black Africans, gay people, etc.)	229	9	4
front-line services	317	4	2
funding	**3998**	**60**	**14**
gatekeepers	96	2	2
gay men	**3450**	**57**	**21**
gay venues	366	8	3
generalist model	1258	16	7
generalist+specialist mixture	**1749**	**43**	**9**
good will	23	2	1

GP	**3008**	**39**	**20**
grant	683	15	2
Groundswell	**1679**	**29**	**10**
hemophiliacs	398	3	2
hard-to-reach groups	587	9	4
harm reduction	100	2	1
health advisor	285	5	3
health promotion	**1489**	**26**	**10**
heterosexual people	334	7	2
HIV status	670	11	7
HIV testing	**2172**	**31**	**11**
holistic approach	759	11	5
home-based service	902	6	4
housing	**2251**	**23**	**10**
ignorance	130	6	2
Illegal immigrants	1328	11	5
immigrants	1251	17	8
immigration service	634	10	7
immigration status	634	8	5
inclusion	548	8	4
independence	96	2	1
individual approach	479	15	7
information	**3457**	**51**	**20**
informed consent	208	3	1
Inscape	516	13	5
integrated services	989	15	5
internet information	884	12	5
interpreter	974	13	3
IoW	417	10	6
isolation	1038	16	7
knowledge	**1948**	**22**	**8**
language	1225	14	5
live longer with HIV	478	9	5
local clinics	217	5	2
London	**2258**	**34**	**13**
long-term diagnosed	657	10	3
long-term health condition	216	4	2
marginalised	276	2	1
massage	198	2	1
maternity	114	3	2
medical approach	717	16	7
medical model	345	5	4
meetings for service providers	539	9	4
mental health	898	11	5
mental health specialist	110	2	1
mentality	87	3	2
messages	363	9	3
migrant workers	123	2	1
migration	231	3	1
military	594	8	3
minority groups	645	10	6
money	**2584**	**43**	**17**
MSM	727	8	6
named specialist	796	7	4
navy	385	12	3
needs	466	8	4
negative discrimination	115	2	1
negotiating skills	89	2	1
network	**913**	**24**	**12**

newly diagnosed	790	13	3
normalisation of HIV	513	11	3
numbers	**4229**	**77**	**23**
nurses	1969	31	14
nutrition	276	2	1
nutritionist	369	3	2
objectives	504	11	1
open-door policy	50	2	1
opening hours	479	7	5
outreach service	308	4	4
outreach worker	900	19	9
PA	**4855**	**57**	**13**
paediatric staff	31	2	1
paediatrics	237	2	2
partnership	551	14	6
patients do talk	411	11	4
peer support	211	3	1
perception	466	7	5
personal perception	494	12	3
personalities	336	7	5
pharmacist	**1696**	**22**	**8**
place to come for treatment	1229	18	7
police	176	8	4
policy person	67	2	1
positive discrimination	159	3	1
pregnancy	438	5	4
prejudice	581	9	5
prevention	532	8	5
prison	669	13	5
proactive	453	7	5
problems	**7943**	**102**	**31**
professionalism	215	6	3
public	311	4	4
PV	**1297**	**27**	**9**
quality	949	15	6
rape	276	6	3
RC	**4691**	**76**	**24**
receptionist	536	5	4
records	426	2	2
refugees	700	11	3
relationships with other organisations	**8897**	**193**	**30**
resources	78	2	2
responsible	74	2	1
routes	286	6	3
rural	493	8	6
safe environment	54	2	1
Seeds of Africa	78	2	1
segregation	319	4	2
self esteem	72	2	1
sensitivity	68	2	2
service user involvement	751	14	5
sexual health	**951**	**22**	**4**
sexuality	192	3	2
signposting	622	9	6
smoking	228	3	2
social approach	842	8	4
social model	101	4	2
Social Services	**4266**	**63**	**21**
social support	169	3	2

SOPHID data	123	4	2
specialist care	1266	11	8
specialist clinic	1275	19	7
specialist model	**2209**	**27**	**12**
specialist social worker	**4095**	**67**	**16**
statutory sector	596	10	4
stigma	**2006**	**46**	**16**
strengths in the current system	**8912**	**191**	**32**
team work	972	12	6
to know their patients	701	9	6
training	**3068**	**54**	**14**
transmission of HIV	1003	9	5
trends	1795	30	6
trials	713	10	4
trust	470	6	5
understanding	1765	18	7
urban	142	4	2
virtual network	441	5	3
vulnerability	666	8	5
voluntary sector	**2680**	**48**	**15**
voluntary support groups	**2512**	**29**	**11**
waiting room	470	9	5
weaknesses in the current system	**8495**	**146**	**24**
women	982	18	11
workload	565	5	3
wrong advice	690	5	2
young people	132	4	2

Based on this analysis, it is possible to identify 17 topics as achieving “number of paragraphs coded” scores of 40 or more (selected as being twice the arbitrary threshold of 20):

• Relationships with other organisations	193
• Strengths of the system	191
• Weaknesses of the system	146

[The above three issues absolutely dominate the concerns of the providers]

• Funding + Money	103
• Problems	102
• Numbers	77
• Ribbons Centre	76
• Specialist social worker	67
• Social Services	63
• Confidentiality	61
• Positive Action	57
• Training	54
• Information	51
• Voluntary sector	48
• Stigma	46
• Black Africans	44
• Generalist versus Specialist provision	43

It is apparent that the providers have a notably different set of priorities, more focused on the organisation of care delivery than is the case with service users. These topics are picked up in Section 4 and 5, in which they are linked together to identify a set of core issues which dominate the debate and set the challenge.

4: Implications - the priorities

4.1 The Big Issue(s)

The project surveys (questionnaires; service provide interviews; service user focus groups; service user interviews) reviewed in Section 3 identified a wide range of views on an equally wide range of topics. In part, the agenda for the questionnaire survey was set by the selection of questions, but even here the respondents were able to introduce other issues of concern through the open-ended answers. In the other components of the survey, respondents were always encouraged to introduce topics of their choice and to determine the allocation of time spent discussing various topics. No debate was guillotined: no topic was embargoed.

In order for attention and action to be focused where they are most needed, it is necessary to make value judgements about the questions that are of greatest concern to the providers and users. In this respect it is helpful that a small number of issues emerged time and time again. They may be articulated in different ways, but they both permeate and dominate the debate. Above all else, these are the unavoidable challenges that flow from this project. In every case, they involve a fundamental concern surrounded by a host of associated implications: it is this grouping of topics that makes it possible to converge on just six core issues:

- 4.2.1 specialist versus generalist models of care and support delivery
- 4.2.2 the relationship between medical and social care and support
- 4.2.3 organisational options for equitable access to care and support
- 4.3.1 the challenge of delivery within spatial diversity
- 4.3.2 responding to diversity of personal circumstance and need
- 4.3.3 immigration – the long term challenge of transient needs.

Three of these issues can be seen as key contentions in which there is a spectrum of opinion, often polarised into strongly and significantly contrasted viewpoints. Fascinatingly, these opinions do not split neatly along any conventional or stereotypical line. It is not a matter of providers against users, professionals against volunteers, medics against social providers, men

Diversity rules, and the real challenge is that management, resource and logistic constraints, particularly in the formal sectors, make it difficult to respond by offering diverse services that are made available as a matter of personal choice.

against women, or locals against immigrants. The simple fact is that opinions differ, significantly. Diversity rules, and the real challenge is that management, resource and logistic constraints, particularly in the formal sectors, make it difficult to respond by offering diverse services that are made available as a matter of personal choice.

The remaining three issues can best be viewed as underlying dimensions which colour and constrain the needs of the users and the delivery capacity of the providers. They are complex issues, often buried deeper than the key contentions, but they tend to attract consensus rather than contention. While this convergence should in principle be a spur to action, it can have the opposite effect – with a sense that the issue is known, respected but to an extent taken for granted as a given. We attempt to indicate that even with these externalities, it is possible to devise interventions which address needs more effectively than is currently the case. To do less is to risk failing in the mission to provide equitable access to care and support.

4.2 The key contentions

4.2.1 Specialist versus generalist models of care and support delivery

No other issue comes close to this in engaging the passions of the local community of service providers and users. It seems to be impossible to talk to anyone about HIV/AIDS without the conversation drifting towards the contention between specialist and generalist provision. Indeed, the debate seems almost to have assumed iconic status. The loss of a dedicated post or function is seen either as indicative of a downgrading of the importance of PLWHA in a cynical withdrawal of support for financial reasons, or as a stride forward in according them the mantle of normality and integrating them fully into the community of those living with manageable health and social problems. Both viewpoints serve as flagships around which other issues tend to cluster, and the two models are coming to serve as rallying points for opposing philosophies.

> *"The loss of specialist post? They use the argument that other illnesses don't have them so why should HIV, rather than saying, we have a gold standard lets raise all others to the level of the HIV care given. We have lost many people. Maybe we don't need as many hours but they are still needed, so the voluntary organisations end up picking up the issues/problems instead. They are often having to deal with very complicated issues that a case worker should be dealing with. [NHS provider]"*

> *"A generalist approach is more appropriate. Years ago there were more issues about HIV, now with treatment available, it is a chronic condition. It should not be different from other chronic conditions. It is manageable condition. It should not be specialist. [NHS provider]"*

As has been mentioned above, at first sight the centre ground appears largely empty, and viewpoints have polarised to the two extremes: either a fully specialist set of services geared for PLWHA and delivered specifically to them, or a wholly general service in which PLWHA seek to satisfy their needs alongside all of those other groups who require care or support. However it was also suggested more than a few times that at the time of diagnosis, specialism is needed, then over time, the users can tap into the generalist services they require. Moreover, the suggestion is definitely towards having a person who is specialist and can signpost through the complexities of services currently available. And the supporters of the two models are drawn from across the whole community: there are providers in both camps and there are users in both camps. Clearly, whichever way the issue is resolved, there will be a sense of winners and losers unless great care is taken in promoting stakeholder engagement in any changes take place. At the same time, the breadth of support for each of the two models is such as to suggest that each has real merit, in which case a composite provision of some sort might be seen as an appealing way forward. The starting point is to consider in a little more detail what each model represents.

The specialist HIV service: unique provision for a unique condition

This approach is based on the premise that HIV/AIDS is still a unique medical and social condition, with significantly different implications to other more-mainstream illnesses such as cancer or diabetes. On this argument, HIV care should be given in specialist centres by people who are specialists in the field. Because absolute numbers of PLWHA are low in the county, it is difficult for individual GPs and other providers to maintain this level of expertise in HIV, so specialists are required. Both social and medical care should be provided by people with special skills and knowledge. For social care, the specialist model is better because clients can contact one person who is an HIV specialist worker and will not need to disclose to number of people. There will also be a continuity of care which will reduce the need for repeated disclosure and, at the same time, build confidence and thus adherence in what are often marginalised groups of people. For health promotion, it remains important to treat HIV as a special issue and avoid allowing it to slip down the agenda on the basis that improved drug therapies are now life-maintaining. Even if there is no specialist worker available, it is still very important to have a named/dedicated HIV person. These people should have more HIV-related training and it should be easier to access these people for clients (without need to disclose to many people).

It is important to appreciate that this "special status" is in part a legacy of a past in which HIV/AIDS was a precursor to a premature death, or to a precarious and difficult survival on a very challenging therapeutic régime. It can also be recognised that the loss of a "special" designation and provision can be interpreted by both participating providers and users as a painful and potentially damaging downgrading of status.

> *"Previously clients did not want to be singled out as being different, but now they are not, people say why don't we*

have specialist services. Patients are feeling uncomfortable in non-specialist settings. [NHS provider]"

If this was all that was involved, then there would be solid grounds for suggesting that with strong stakeholder engagement, it would be possible to migrate towards a more generalist/holistic pattern of provision adjusted to the different circumstances of the twenty-first Century. But this is not all that is involved: two of the underpinning arguments in favour of specialist provision cannot so easily be dismissed.

First, the desire to be dealt with by medical experts (whether consultants or nurse specialists) is high amongst PLWHA, and there is some logic in their wish. In an ideal world, everyone would receive care and support in a context of expertise and excellence, but such a world is unrealistic. The norm in most contexts is to deliver services through personnel at a range of skill and experience levels, with the highest levels being reserved for cases of exceptional challenge or complexity. This graded model works well in most cases, but HIV/AIDS has particular medical requirements relating to the pace of development of new drugs and regimes, and to the relatively small number of patients (which means that many of them will have little chance of accessing an expert without long-distance travel, and the locally-available "general" providers will have little experience of their condition and the appropriate responses. One outcome of the gradual shift of care from consultants to GPs is that almost any illness of PLWHA may be diagnosed as AIDS-related, even when it is not. It is probably the problem of low numbers of PLWHA that fuels the widespread (though in absolute terms, limited) response of turning to specialist London clinics for what is seen as "cutting edge" knowledge and service. This perception that there may be better care available elsewhere (London and Brighton being most often cited) is a characteristic of the gay community, particularly those diagnosed many years ago. The immigrant community has demonstrated a much greater tendency to be satisfied or very pleased with locally-available services. The associated debate about the possibility of establishing a Centre of Excellence in Hampshire is considered separately below.

The survey has revealed shocking tales of a casual and dismissive approach adopted in communicating diagnosis and in handling patient confidentiality which are too widespread and personalised to be cast simply as urban myths.

The second residual challenge countering the move towards mainstreaming HIV/AIDS care and support is much more likely to concern immigrant PLWHA, and involves the ongoing trauma of stigma and disclosure. Here, there is a stark disagreement between a growing number of providers who assume that stigma (and associated demands for absolute confidentiality) is becoming less of an issue, and a still-substantial number of PLWHA who argue the exact opposite. The survey has revealed shocking tales of a casual and dismissive approach adopted in communicating diagnosis and in handling patient confidentiality which are too widespread and personalised to be cast simply as urban myths. While the gay HIV+ community in the main urban centres does appear to be experiencing a slowly-reducing level of stigma, this is absolutely not the case for many of the immigrant groups, and remains more problematic in the rural areas (including the whole of the Isle of Wight) where "everyone knows everyone else". It is difficult to conclude other than that the move towards mainstreaming HIV/AIDS care and support will involve an escalation of confidentiality breaches as patients are forced to disclose to increasing numbers of generalist providers. And it is clear that in some cases these breaches will create catastrophic negative impact for extremely vulnerable individuals, particularly in the immigrant community.

The generalist HIV service: mainstreaming and normalising

This approach is based on the notion that in the UK, HIV+ status is now a chronic but manageable condition and thus should not require highly specialist facilities in order to provide routine treatment. (It is, of course, recognised that there may be extreme or complex cases that will always benefit from referral to specialists.) This suggests that PLWHA should not be treated differently from people with other long-term (chronic) conditions. For service users, this mainstreaming approach is beneficial because it avoids labelling and marginalising them into an "AIDS ghetto" mentality. In principle, they should increasingly find that they are being treated equally, and it should be easier for them to find employment and win a full integration into society. Thus, mainstreaming of AIDS should help to reduce stigma, which is currently exacerbated by the fact that PLWHA are seen as different because they are given specialist care in specialist clinics. Mainstreaming will also help to reduce the isolation that is fuelled by specialist services. HIV-related symptoms cannot be predicted easily: they may arise suddenly, and access to general medical services (rather than periodic HIV clinics) should reduce delays for patients seeking treatment. There are also arguments of operational efficiency and cost-effectiveness for providers if they can reduce the need to run HIV-specific services. This does not need to imply withdrawal of resources from PLWHA (though the loss of ear-marked funding promotes such a perception), but rather that resources can be used more effectively and thus develop more effective services.

The role of the GP is a particular case in the consideration of specialisation and the mainstreaming of HIV. There is support for the notion that, in principle, GPs could assume routine care once diagnosis had taken place and the appropriate therapy had been established. However, there is also real concern that the handling of records in local surgeries is a challenge to personal confidentiality – and a worry that GPs might not have contact with the most recent therapeutic trends.

"I changed my GP for the one who was interested in

> *HIV, and it was a good move. My friend told me about this GP. Negativity comes from those GPs who are not informed." [PLWHA]*

> *"My new GP is supportive, I changed GP, went to another practice which was recommended by GUM. My current GP is interested in HIV." [PLWHA]*

> *"None of the GPs had proper HIV training .... I went to see my GP for side effects, the GP did not have a clue about what was going on, was not well-informed about HIV." [PLWHA]*

> *"I went to see GP because of side effects, because I was vomiting everywhere. GP told that I should stop taking all the medication. However, I knew I should not do that, I should take my drugs, so went from the GP without any help, not knowing what to do." [PLWHA]*

The philosophy of normalisation is very broad based. At its heart, it challenges the value of using the "provocative/evocative" label of AIDS, since increasingly the patient's HIV+ will be managed to avoid the development of AIDS. Normalisation starts at the level of testing, which are becoming increasingly routine in the case of HIV – particularly in the context of pregnancy and ante-natal care. Tests are also increasingly being offered as a package, with other tests being added to HIV, and the concept of opt-out is gradually replacing the conventional notion of opt-in (ultimately challenging the value of the "voluntary testing" notion). Nevertheless, there is support for the notion that a mainstreaming of HIV/AIDS does not necessarily imply downgrading the role of specialists, nor suggest that core social services are no longer required.

> *"There is clear value in dedicated HIV specialist people. When they had an HIV social worker, it took a lot of work load from consultants (letters to solicitors, housing, etc.). Now it is down to doctors. It would probably be good to have designated social worker for voluntary groups. Better to have a social worker who would cover bigger geographic area, than to wait until critical number will be accumulated. [Consultant]"*

Quite apart from the entirely valid and proper arguments in favour of economic and operational efficiency, mainstreaming of HIV has a strong moral foundation in the desire to allow PLWHA to move forwards into full integration. But such a move will not be without its stresses, and a successful transition that minimises user backlash will require stakeholder engagement in organisational strategy design at a level that is not currently available. Not only do the users need to buy into the advantages of change, but the providers need to confront the potential negative impacts of the major residual issues. In addition, there will need to be a substantive and sustained programme of curriculum and professional development if general providers are to acquire the knowledge and skills required to address the needs of PLWHA – which will remain "special" in important respects.

The hybrid HIV service: towards a hierarchical organisation of HIV support: The point has been strongly made that stakeholder views on the specialist/generalist debate polarise starkly into two largely exclusive camps, but perhaps even this perception of a polarisation is little more than an unfortunate illusion. While the adherents of the two models support their respective views stridently, each group actually acknowledges that in practice a hybrid model is inevitable. Those who promote a specialist service with specialist posts also welcome the idea of access to the full range of "normal" services" without the stigma of an HIV/AIDS label. Those who cherish the progression to mainstreaming fully support the notion that there will remain cases that require specialist/consultant attention (as there are with every condition).

The hybrid HIV service implies enhancing specialist services for those in greatest need but increasingly delegating routine aspects of care and support to well-informed general providers within a framework of meticulous observance of confidentiality. It must not be allowed to be introduced simply as a corner-cutting withdrawal of named posts and specialist services without associated development and resourcing of alternative arrangements, and it cannot be effectively implemented without a programme of professional training. The still-massive implications of stigma will require formal and monitored response, as will the need greatly to improve communication to PLWHA about the range of services available. There is currently a major deficiency in this area: no-one appears to have knowledge of the range of requirement and provision. This is of particular importance at the stage of communicating the initial diagnosis: in some areas this is handled sensitively and well, but in other areas it is not and there are signs that some providers are slipping into the unjustified notion that HIV+ status is no longer "a big deal". It is, and it will remain so, and the people involved remain vulnerable, confused and ill-placed to take control of the complex process of building an effective response to their illness and its social implications. To relegate this need to the level of "You'll find a leaflet on the rack outside" is cruelly insensitive, and does not meet the required standard of care – especially since there often isn't a leaflet!

Despite the inherent threats, the hybrid model retains some significant logic and is a realistic option for consideration. It involves responses such as:

- Reviewing the relationship between Health Advisor and Nurse Specialist posts in order to identify the optimum balance between maintaining a separation between the roles and accepting that this may reduce the number of posts or imply a reduction from full-time to part-time.
- Reviewing the value of using either part-time or part-allocation (such as two days per week) posts to retain named "specialisms" which would retain personal experience and commitment, enhance continuity of care and reduce the need for repeated disclosure.

The broader implications of specialist care:

The debate about specialist versus mainstreamed HIV+ response have tended to focus on the provision of medical care, but the survey of providers and users has highlighted a set of important related roles.

Dentistry is a case in point. User experience varies wildly, with some reporting outstanding support (which includes those who simply find dentists who take disclosure in their stride and handle the information discreetly) while others continue to be confronted by dentists who decline to treat them after disclosure or who handle HIV status with scant regard to confidentiality.

> *"I have a very good dentist and did not have problem with the dentist after disclosure. I needed to have an abscess surgery and went to a facial clinic. They said that I would have the last appointment on the day because of my HIV status. I do not think it was right, they should sterilise everything anyway and it should not matter when my appointment is." [PLWHA]*
>
> *"I had a miserable experience with dentistry originally. I was recommended a specialist one ... and it felt awful in there. Everything was covered in plastic, it made you feel unclean or something. I would rather pay and go to a normal dentist and I feel comfortable with this as I was told that dentists treat everyone as though they could have a contagious disease. The HIV dentist was just so obvious – nothing like a normal dentist experience. It would be good to have a practical advice when you are diagnosed that you can go to a normal dentist. It is a constant battle to know where to go and who can treat me and what my rights are." [PLWHA]*

The overall sense is that there is little force behind any move to designate HIV-specialist dentists, but PLWHA still benefit enormously from an informal grapevine that leads them towards sympathetic dentists, and it may be that this informal street knowledge could be captured and communicated more effectively. The voluntary sector may play a key role in this informing. This is apparently one sector where there is little professional appetite for mainstreaming HIV, and where PLWHA suffer significant burdens in accessing care and in avoiding latent discrimination.

Pharmacists play a disproportionately important role. A well-informed and HIV-experienced pharmacist clearly provides exceptional support to both the Specialist and Hybrid care models, and they are frequently mentioned by consultants, nurses and users as one of the real strengths of the system. The training needed to reach the "well-informed" level may represent a resource burden, but the outcomes are clearly highly beneficial to service provision.

Nutritionists and dieticians occupy a somewhat more ambiguous position, possibly because the provision of formal services is now so restricted that few users or providers have sufficient experience to comment on value. In reality, one of the responses is that some pharmacists are taking on this role. This should be regarded as a real opportunity for service enhancement, as nutrition remains an important backdrop to most anti-retroviral therapy regimes, and it cannot simply be assumed that people accessing these therapies will make and sustain the right decisions on the basis of a leaflet or poster (sometimes not even in their own language). This deficiency is particularly marked in the case of the immigrant group of PLWHA, which includes many individuals whole economic status and lifestyle preclude easy access to good nutrition.

In the case of **Counsellors**, there are strongly contrasted views. Some consultants feel that as HIV+ status and ARV therapy are mainstreamed, there is ever less need for counselling. Pre-test counselling is becoming the exception rather than the rule, except for notably high-risk individuals, and post-test/diagnosis counselling is increasingly downgraded or delegated (amazingly, it appears that some positive diagnoses may still be given by phone!). The logic behind the reduction in counselling is understandable, especially in a resource-limited organisation where other priorities take precedence, but it is important to recognise the counter arguments. Interviews with PLWHA have repeatedly revealed the personal trauma of diagnosis, and the shattering experience of confronting it with little more that the "pick up a leaflet on the way out" approach. In part, the unfulfilled need could be (and is being) met by the voluntary sector, but this has real drawbacks. First, it is commonplace for newly-diagnosed individuals to go into retreat for months or even years before they access voluntary organisations, and many (for a variety of reasons) never make that contact. Second, the consultants who feel that formal counselling is a decreasing priority frequently also feel that the voluntary sector cannot be relied upon to provide balanced and up-to-date advice on medical aspects. There is a closed loop here that does not work to the advantage of PLWHA. However, it may be that a traditional counsellor role is not essential, but rather someone who can talk through the emotional practicalities with users, particularly those newly-diagnosed, and help to signpost appropriate responses.

Finally, it is helpful to consider **HIV Specialist Social Workers** since these posts seem to be amongst the most vulnerable to closure or reduction. This is a flagship issue, with passionately-held views on both sides. The arguments about specialist versus generalist care all apply here, as does the suggestion that hybrid structures may offer a way forward in which designated posts remain, but with either a reduced time per week or an increased spatial responsibility. It is also worth mentioning that the proponents of the two models sometimes overlook inconsistencies in their arguments. Thus, withdrawal of a post does not save resources if it merely diverts demand within the same service, and can easily increase costs since decisions are repeatedly researched by different operatives and decisions are made slowly and ineffectively simply because experience does not build up. At the same time, users who bemoan the loss of a dedicated post often reveal entirely satisfactory experiences in accessing general provision: the loss is sometimes more in name than in function.

The scope for a Hampshire Centre of Excellence:

This question has arisen repeatedly throughout the survey. Excellence is an intoxicating target, and the sense of excellence (both “the best” and also “cutting edge”) lies behind the continuing real and mythical attraction of London to PLWHA: but are the streets really paved with gold? At least in part, the answer is clearly yes. Unfortunately, the alchemy necessary to turn a service into gold is embedded inextricably in scale. Where London is “best”, it is largely because it is biggest – and big attracts resources, people, efficiencies and positive interactions. A centre that has a sufficiently large user base to sustain 15 consultants will inevitably be able to draw advantage from the professional interactions between these specialists, thereby accelerating the accumulation of experience. Users, too, have a wider network with whom to interact. And for research investment (the trials which are seen by consultants and PLWHA as a key to a better future) the attractions of these large centres in cohort recruitment and research management will inevitably be irresistible. Opinions derived from interviews vary:

Centre for Excellence	**Middle Ground**	**Local Centre**
Participant 1 would rather travel to the Centre for Excellence (even if it is far away) where he could trust.	*Participant 3 does not mind a centre of excellence or a local centre, the most important thing is that the person can access services he/she needs.*	*Participant 2 prefers access services locally. First two years it was difficult, needed specialist care, but now GP and ordinary dentist can come, no need in the Centre of excellence*
Participant 6: A specialist centre could be useful as it could help people who get diagnosed to come to terms with the diagnosis. I wouldn’t have a problem in travelling to the mainland, but at the moment everything I need is here.		*Participant 4: local services are not a problem. I would not mind whether it was a centre of excellence or something less but locally, the main issue is getting there. I have problems travelling too far due to a disability and because I do not have money for transport*
Participant 8: Having lived in London for 6 year, he got used to being in HIV specialist clinic. But he does not know if it could be possible for Hampshire because of money. There is also no guarantee that if the service is established, it will be demand for it. You can always go to London.		*Participant 5: Accessing services locally is good. I need help with my baby so I can not travel far away. It would be a problem if I had to travel to London for everything.*
		Participant 7: I would rather have local services than a Centre of excellence, as long as there is always openness for one place to learn from another. I would rather have local treatment from people I know. I don’t want to drive too far or have to meet with different people each time.
		Participant 9: is happy with a local clinic, no need for the centre of excellence. *Participant 10: I think people are less likely to go miles away to visit a centre for excellence. I feel I have a very good service from my own consultant, they are up-to-date, but still small enough to be a personal service.*

Clearly, some people think that it would be very good to have a centre of excellence (they trust more to experts and they are happy to travel far away), others say that they are happy with the services provided locally (distance is a problem for some people; local services are small enough to be personal which is good; continuity of care is important - do not want to meet new doctor every time when you are accessing a service).

So, would H&IOW benefit from an HIV/AIDS Centre of Excellence? The question has been put to a wide range of users and providers, and the answer is universally positive – but it is almost universally associated with a sense that this is a dream rather than a realistic proposition. Size really does matter.

But this sadly-dismissive caution may not be the end of the debate. Indeed, in many senses it merely opens the debate with a greater sense of urgency: if so many people see advantages, we cannot simply reject the target as too difficult without considering itself seriously. This report is not an appropriate framework for such a review, but it can point up some of the core issues that have emerged from the survey interviews and focus groups.

- Hampshire cannot escape from the scale demands of a Centre of Excellence, so the inevitable implication of a move in that direction would be a significantly greater fusion of H&IOW-wide medical services than is currently operational through the GUM clinics in Southampton, Portsmouth, Winchester and Basingstoke, together with the offshoot clinics in Andover and Newport and with Frimley Park GUM clinic which is funded by Hampshire to provide care to residents of Blackwater Valley and Hart PCT.

- Merger of service provision in an administrative and human resources sense does not necessarily imply a merger on one site, since the Centre might to a degree be virtual. Nevertheless, there is a widespread sense that a Centre of Excellence might on average be more remote from the individual user.
- The current reorganisation of the NHS in H&IOW might actually provide a rather easier operational framework within which to consider cross-County co-ordination.
- It is clear that a Centre of Excellence would be unrealistic if the stakeholders opted for a wholly generalist model of care delivery, but it might be feasible with either the specialist or hybrid models.
- A Centre of Excellence would imply cross-unit and possibly cross-sector co-operation, whereas respondents have acknowledged a prevailing sense of competitiveness at present.

4.2.2 The relationship between medical and social care and support

Alongside the pivotal debate about the overall strategy of care and support delivery (Section 4.2.1), probably the most important question in most people's minds is the relationship between the medical and social components of the service. This issue may be framed in some cases as a contention between the formal and voluntary sectors, but that question is best kept separate. Again, there is a wide range of opinion, spread across the provider/user spectrum, but the polarisation is rather less stark than in the case of the "specialist post" debate. There is room for both doubt and caution here, which suggests that there is plenty of scope for convergence and consensus. But before looking at that centre ground it is helpful to characterise the viewpoints at the two ends of the spectrum.

The medically-driven perspective is promoted primarily by the formal health sector, but has significant support in the user community. There is a compelling logic behind the notion that HIV response is and must be medically driven. Diagnosis itself comes from medics, so the process of interaction with the individual client inevitably starts within a health context. The personal prognosis is also medically-derived: because of advances in ARV therapy, HIV+ status need no longer be life threatening (though it remains utterly destructive of lifestyle and life prospects in some cases). Medical advances in the development of a vaccine, even if it were not retrospectively applicable, would trigger another revolution in the epidemiology and progress of the pandemic. The management of individual symptoms and side-effects will lean heavily on medical intervention, though at this level other forms of support (social, nutritional) become significant. Prevention advice and guidance on specific procedures for working with PLWHA will necessarily have a strong medical background, but the social context is mission critical. There is clearly a range of circumstance, but overall there is a marked trend by which medics are more likely to be dismissive of the importance of the social role than social providers are to be dismissive of the importance of medical treatment.

The NHS has traditionally worked through a strongly-hierarchical professional structure, with consultants in general and at individual level playing a major role in setting the agenda and determining the approach. This will not change to suit the needs of HIV response, and is an element in creating spatial contrasts in the detail of care delivery across H&IOW. It is, moreover, a potential constraint on inter-sector integration and on the evolution of an integrated Centre of Excellence. The use of the term "constraint" is not implicitly derogatory, since it is this constraining of service transformation that is necessary in order to maintain the integrity and quality of medical care. But it certainly is implicit that moves towards a more holistic approach, blending medical and social needs more effectively, will happen only if the consultants want it to happen, and they will want it to happen only if it poses no threat to the integrity and quality of medical provision. This is the challenge: integrity versus integration.

The socially-driven perspective is substantially different in kind, since it is almost always acknowledged that a strong medical element will be vital, for those on monitoring or therapy regimes, and that the target is to blend it, not replace it, with social provision. There is almost no suggestion that medical care is unnecessary, and where this does emerge it is almost always against the backdrop of an extreme religious or cultural mantra, or extreme constraint of family or group circumstances.

Social support takes many forms, from advice on employment and benefits issues to personal counselling and support through depression. Each element plays its part in a genuinely holistic approach, and it is important to be cautious with value judgements about their relative significance. There is little doubt that this form of support ranges far beyond matters that are strictly driven by HIV+ status, yet that status can be seen as magnifying the need, increasing the sense of vulnerability and helplessness, and obstructing the process of problem solving. Immigration issues loom large, but they are all the more crushing for PLWHA for whom diagnosis creates huge problems of stigma in the UK and even greater

> *Alongside the pivotal debate about the overall strategy of care and support delivery, probably the most important question in most people's minds is the relationship between the medical and social components of the service.*

problems should they be required to return to countries with inferior therapeutic backup or particularly serious stigma and discrimination. Unemployment is a burden, but doubly so if job seeking has to be associated with HIV disclosure.

Although the individual with HIV+ status is an indivisible person, this does not mean that HIV/AIDS needs to colour their whole existence and dominate their life decisions. The argument for integrated services with good links (or, at least, good awareness and mutual respect) across sectors is powerful. But at the same time there is a substantial range of opinion about the extent to which basic social services such as benefits and housing advice need to be regarded as a part of the holistic HIV/AIDS response. It is difficult to isolate this fundamental debate from familiar closely-associated questions about disclosure and continuity of care and support. PLWHA want informed access to the full range of social services, and almost without exception they want that access to be sensitive to their medical condition. However, it is far from easy to establish the extent to which this demand represents a genuine requirement for a quality provision of service as opposed to a personal preference. There are elements here of the "moving on" discussion that lies behind the desire to mainstream HIV/AIDS (or just HIV). Real benefits might emerge, but the transition from a health system and a personal value system focused in on HIV status will be difficult and will require sustained stakeholder engagement.

Although social provision is generally interpreted in quite a broad-brush fashion, three individual functions have emerged repeatedly in the surveys, interviews and focus groups. Counselling is an ever-contentious issue, with polarised views either promoting its continued pivotal role in the overall service, particularly at the time of diagnosis, or relegating it to a subsidiary role on the assumption that ARV therapy has relieved much of the trauma associated with diagnosis and coping. Both views are strongly held, and the progressive downgrading of the service is seen as deeply negative in some quarters.

> *"Counsellors at the (support centre) are very useful. It is helpful that they are specialists as they can understand what you are going through. When you discuss with them what you are feeling, they can understand." [PLWHA]*

An associated issue is **Mental Health support**. This has never been particularly strong in the context of HIV/AIDS, and is now highlighted as a pressing deficiency of service.

> *"Mental health support is so important. I haven't got anyone, so it would be good to talk about things with someone. I have been on anti-depressants for a while but I have never heard about other help. The doctor just prescribes things. It is really affecting me at the moment. I need someone to talk to." [PLWHA]*

There is no implicit suggestion that HIV status must always cause mental health problems, though both stress and depression are widely experienced and both may develop to a degree that might be classified as mental illness. It is also relevant to note that some of the groups who are vulnerable to acquiring HIV are marginalised in other ways and may also be vulnerable to mental illness.

Public Health and Preventative Services pose a particular challenge, often relating to sexual and reproductive health in general. There are very mixed views about the efficacy of awareness programmes underpinning preventative efforts. It is notable that the great majority of questionnaire respondents and interviewees acknowledged that they had sufficient information to make informed decisions about safer sex, but admitted taking risks – often under the influence of alcohol or drugs, or because they were not in a position to negotiate safe practices. Nevertheless, there is a very widespread view in the user community that informing needs to be proactive, high profile and sustained, and this viewpoint usually involves reference to the absence of hard-hitting TV messages about safer sex.

> *"Prevention information is not one-off service, it should be dripped in all the time. All of us are stupid idiots sometimes. I would like to tell people that I am positive, how I became infected that they should not do that. Prevention is not out there! It is too late for prevention at (the support centre) because people are already infected. I am talking about HIV to people around me. People are ignorant. They are worried about pregnancies but this is the last thing they should worry about." [PLWHA]*

> *"Prevention advice needs to be out there. It's too late to get it in voluntary sector. People using "morning after" pills several times a month! Schools and colleges bases are ideal for prevention." [PLWHA]*

> *"People think HIV is not here, it is in Africa. I remember the 80s. But you could die from AIDS then, people think that you can not die from AIDS any more, so they got rather lazy. Also, when I was young, although I knew about the risks, there was a buzz attached to this." [PLWHA]*

There is an apparent contradiction in the demand for prevention messages and the acceptance that they are often ignored. The gay community specifically expresses widespread support for proactive preventative services which include free condoms and lubricants in gay meeting places and cruising or cottaging sites. The service providers are less strident but more polarised. Whilst those involved in preventative services demonstrate commitment and resilience in the face of a very difficult task, they are often denigrated by their professional peers in the health and social services. The result is that the broad public health role appears likely to come under increasing pressure as management structures change and earmarked funds are lost. Also, the general approach to sexual health currently promoted by government is seen by some service users as too broad-based to give a really strong message about prevention, and this imbalance needs to be addressed.

The challenge of cross-sector integration remains massive, both because of barriers to funding and administrative crossover and equally because of professional and cultural defensiveness. If this latter point appears unduly critical, then it may be helpful to consider that while the user community (PLWHA) align themselves equally with both the medical and the social professions, these two professions themselves are each very tightly concerned with promotion of their own role. Support for a holistic approach is more likely to come from the social and voluntary sectors and the users, and less likely to be a priority for the health sector. Where it has worked well, it has been reliant on particularly committed and influential individuals: the system itself does not appear to be well geared towards integration, and there are few signs that it is getting better. This is in no way a problem specific to HIV/AIDS, which may be comforting in principle but does nothing to help those seeking a more joined-up future in practice.

4.2.3 Organisational options for equitable access to care and support

Without doubt, the degree to which HIV services should be specialist and the way in which they are balanced between medical and social elements are the two dominant issues emerging from the survey. However, there are other debates which attract less attention but which could nevertheless impact significantly on service users seeking equitable access. The matters concerned are diverse, but all impinge on the organisational approaches to, and constraints on, the delivery of care and support within what might be deemed to be an equitable framework.

Building-based versus home-based service delivery Health sector HIV/AIDS service delivery has always been primarily building-based, with the GUM clinics and associated specialist nursing services all having fixed locations (albeit with a few peripatetic outposts). The Social Services and the voluntary sector have traditionally functioned within a more mixed framework involving both location-based provision and a home-visit component. The concept of the drop-in centre is quintessentially building-based, and assumes (with much supporting evidence) that PLWHA derive social benefit as well as formal services through contact with centre staff and other visitors. There is a widespread view that the very best social support and counselling is that received from other people in like situations, and many PLWHA derive great satisfaction from providing formal or informal counselling and mentoring to those who are less fortunate, less informed or simply more-recently diagnosed. Such mutual support is the heart of a community, and many PLWHA gain great advantage from it.

Most organisations in the formal sector operate open-door policies, usually with an associated appointment system. The door is accessible to anyone who is economically and physically able to reach it. But some doors are regarded as daunting by some users, and this may deter them from using the service.

Some parts of the Social Services provision, some voluntary organisations and a few of the NHS HIV/AIDS services are offered on a home-visit basis. This approach is of value to those PLWHA whose mobility is impaired physically or economically, and it has the merit of being potentially highly personalised and discrete. Staff involved in home visits frequently stress the great care (sometimes the extreme caution) that they have to exercise in order to maintain the confidentiality of those that they are visiting. This perceived need, and the fact that it is apparently successful and well-received, demonstrates that there are groups of PLWHA for whom the use of a "public" drop-in centre is unthinkable or impracticable.

The perceived success of home-based services, the fact that many of the easy-to-reach PLWHA (particularly those in the gay community) have access to other social provision, and the cost of maintaining expensive building space in accessible locations for very small numbers of users is leading some organisers of traditional drop-in centres to reconsider their strategies. There is no simple outcome, and the continuing diversity of potential users suggests that a range of provision (some home-based and some building-based) is ideal. Whether the ideal can be afforded and staffed is a question that will doubtless come under periodic review.

Open-door versus closed-door approaches

Most organisations in the formal sector operate open-door policies, usually with an associated appointment system. The door is accessible to anyone who is economically and physically able to reach it. But some doors are regarded as daunting by some users, and this may deter them from using the service. The usual context within which this constraint is met is in the use of physical signage or clinic session labelling that refers specifically to HIV/AIDS.

Some organisations in the voluntary sector place limitations on the use of their facilities, and on occasion this takes the form of a closed door, in the physical sense as well as organisational. The door will then often require unlocking via a speaker phone system. This approach is usually employed when exclusion of non-concerned visitors is necessary in order to preserve the safety or confidentiality of bona fide visitors.

It is often the case that doors are unlabelled, or carry organisational names that cannot readily be associated with HIV/AIDS. The ultimate stage in this process is to restrict availability of information on the location of a centre, thereby maintaining a high level of control on access. Each of these measures reflects a different thinking on the needs of individuals visiting a centre, and different perceptions of the threat to their confidentiality. In a world devoid of stigma, such measures would not be necessary. In practice, the differing strategies offer choice to individuals with needs.

Virtual frameworks of support delivery

For those with the skills and facilities to access the internet, it is clear from the survey that web resources are becoming a standard method of acquiring information and are used by both providers and users. There is an immediacy that is compelling, but there is also the well-known problem of quality controlling many of the data and opinions identified. This is an admirable way of keeping up to date, and is now becoming a familiar addition to the patient-doctor relationship (not always unambiguously welcomed by doctors!) regardless of HIV status.

However, the web goes far beyond providing information. It offers an apparently safe haven for those who feel threatened by physical networking, and builds a virtual community, enlivened by email, voice-over-internet phones, chat rooms and blogs. Regardless of one's opinion of web sources overall, the internet now fills three niches in HIV/AIDS support:

- For many people, it is the best or only way to keep up to date on therapy.
- It offers a cloak of anonymity which is hugely attractive to some people, and is in any case also the method-of-choice for communication for professional PLWHA
- By widening the accessible community of fellow-travellers to national and international level, it permits some of the most isolated groups (including white heterosexuals) to make and maintain contact with peer support.

Given the strong and growing role of virtual support mechanisms, it would be beneficial for both the voluntary and formal sectors to pay much greater attention to embodying this technology into their service delivery. At the same time, however, it must be stressed that such an approach excludes those people for whom the internet is not a practical or acceptable mode of communication. Care needs to be exercised, but virtual HIV/AIDS communities cannot be ignored.

Reaching the unreachable

It is trite but pertinent to note that the unreachable have not been reached by this survey. Their voices are unheard, and the best that we can do is to attempt to represent what we think might be their best interests. This lack of communication and thus of engagement extends, of course, to many aspects of contact between individuals and "the system" – and in extreme cases contact ceases altogether after diagnosis. More usually, the minimum routine of attending GUM clinic appointments will be maintained so as to ensure access to therapy, but all other links will be unused. There are three wholly distinct groups in this unreachable or hard to reach category, with manifestly different needs.

- Affluent, fluent and professional PLWHA often require (or assume that they require) no support other than strict medical intervention. They will attend GUM clinic appointments but are unlikely to draw upon any other HIV-related service.
- Marginalised groups who do not readily fit into any of the conventional user categories may fall through the system and abandon it in the feeling that their needs and interests are neither understood nor met. This group is further considered in Section 4.3.2, and includes white heterosexuals and to an extent bisexual PLWHA and gay men who are not part of the 'gay scene'.
- The more conventional usage of the "unreachable" label is in application to the group that is marginalised by its immigrant status, particularly illegal immigrants. It also applies to some who are excluded by abject poverty coupled with communication or social networking difficulties that may be related to mental health problems.

In crafting models of care and support delivery, it is important to maximise the opportunities to promote contact with those marginal groups that need support but have difficulty in accessing it. It is possible to envisage progress through a greater use of personalised home-based services, but at any scale this would involve an additional cost burden. As is noted in Section 4.3.3, some immigrants may be easier to reach through the voluntary sector, but the fact remains that there will be some who for one reason or another are unreached regardless of the system adopted.

Stakeholder engagement and the HIV Forum

Apart from the group that classifies as difficult to reach, PLWHA do have powerful, varied and relevant views – but at other than the individual level these are not frequently heard because there is no obvious context within which to listen. Time and again, those involved in the provider and user interviews for this survey have expressed satisfaction at having the opportunity to give their opinions and share their experiences. Often, they have regretted that no-one had asked before, and almost universally they have expressed the hope that the process will not stop with a survey and a set of reported results. Stakeholder engagement implies very much more than just "consultation" – a process that is increasingly met with cynicism derived from negative experience in the past. There is little satisfaction in the realisation that this mismatch between the rhetoric of stakeholder involvement and the actual experience spreads across the whole of public life and is no way related specifically to HIV/AIDS.

> *"Service providers should be facilitated by people with HIV in order to set priorities. I am not suggesting that one person with HIV knows all the issues, but at the moment, either you join a group run by people with HIV and they tend to be segregated (e.g. gay men), or the services are being provided by people who are not HIV+ and it can feel quite patronising. I think a lot of people would like to be involved." [PLWHA]*

> *"I am not sure how it would work. Why people would need a feel for that? Individuals would think about individual needs but services have their own approaches. So forum would not work. At the beginning of the epidemic users were driving services, now I do not think*

> *that they should go back to that circle. In the past people did not get anything so they were demanding services. Now there is no need for this." [PLWHA]*

It does not have to be like this. Occasionally, it is possible to point to practice that appears to work and to succeed in bringing satisfaction right across the provider-user spectrum. The survey suggests that for several years the HIV Network on the Isle of Wight met this ideal, though it has since fallen into abeyance. At its best, it provided a framework for monthly meetings between representatives of social services, NHS staff, voluntary sector and PLWHA. It focused on understanding how the pieces of an individual's care and support jigsaw might fit together, and it won allegiance by fast-tracking solutions to problems. Even in the particularly sensitive context of the Isle of Wight, with its very small absolute number of PLWHA, it appears to have engendered a "quality" of care that is missing today in most areas. And it did all of this without any large and costly infrastructure – mainly because it was fed and guided by the energies of a group of especially committed people determined not to adopt inflexible positions.

This very positive experience on the Isle of Wight, albeit rather short-lived and vulnerable to change of personnel, gives support to the notion that there might be a role for a broader regional HIV Forum. The survey was asked to assess opinion on this possibility, and revealed a general sense that there would be much to gain from a genuine meeting of minds, not least in debating issues concerned with the organisation of care and support. Some respondents expressed an enthusiasm to be personally involved, but many supported the principle without suggesting that they would personally participate in the practice. Not surprisingly, there was a resigned undercurrent of assumption that it would just become a talk shop with little practical outcome – or that the debate would be dominated by the largest groups, notably gay men and black heterosexuals. Some of the service providers expressed a big concern about the idea of the users' involvement saying that their experience suggested that whilst service users had indicated a desire to be involved, very few actually did when had asked to do so.

The service received once access has been achieved is in principle the same for all (though in practice there are marked contrasts in delivery culture), but access itself is not. This is not a matter of service failure, but of geography.

Despite these doubts, there is an overall positive response to the notion of an HIV Forum. What form it might take has not been discussed, but the need is clear. In assessing the major contentious issues surrounding HIV+ care and support, this report has stressed that major transformation of service delivery will be implemented most successfully if they are rooted in genuine stakeholder engagement (that is, playing a role in planning, decision-making and monitoring), not just token stakeholder consultation.

4.3 The underlying dimensions

It has been stressed that while some of the major issues raised by the Needs Assessment Survey are inherently contentious, others serve more as a backdrop against which the design of care and support delivery must be devised, implemented and reviewed. They are management externalities, but no less complex or important for that.

4.3.1 The challenge of delivery within spatial diversity

Fundamental to the challenge of providing equitable access to care and support is the fact that Hampshire and the Isle of Wight do not present a level playing field. Whether in terms of distance, cost or time, access to care and support is very far from equal for people living in different parts of H&IOW. The service received once access has been achieved is in principle the same for all (though in practice there are marked contrasts in delivery culture), but access itself is not. This is not a matter of service failure, but of geography. Within-county variations in HIV/AIDS prevalence rates are not available to the public, but they would not in any case help in responding to variations in the geography of the condition. The real challenge lies not in varying proportions of the population but in absolute numbers, and thus in the density distribution of PLWHA. It is self evident that a service geared to support 300 people within a 10-mile radius may well be non-viable in areas where demand is from only 30 people within the same radius. The result is that the urban areas and the rural areas present a very different challenge to service providers, promote a very different response and receive a very different experience. As so often, this is not unique to HIV/AIDS, but is exacerbated by the small absolute numbers in H&IOW.

Quite separately to the matter of client density distribution, there are apparently significant socio-economic gradients in H&IOW that would affect demand and access. Clinics report that areas outside the main urban centres (Southampton and Portsmouth) are more likely to receive clients who are affluent, well-housed and professionally employed, and who are therefore less likely to require services outside the medical sector. Conversely, the urban centres themselves are more likely to yield clients with substantial socio-economic problems, and more likely to involve immigrant status. These are tendencies rather than absolute distinctions, but they colour the reported experience of providers significantly. Stigma may thus tend to be focused on the urban centres, but this simplification may be flawed since some rural areas (including the Isle of Wight) emerge as particularly sensitive and culturally inflexible. There is a deep-rooted and widespread feeling in the region that "the Island is different", and this certainly arises in the responses of PLWHA.

The reported trends are relevant to the design of provision strategies regardless of their causation. Indeed, the lack of clear and consistent causation is apparent in the fact that the two major urban centres reveal very different patterns of response to demand for HIV/AIDS care and support. This is revealed in the GUM clinics, social services provision and the voluntary sector (or, in the case of Portsmouth, the lack of a home-grown voluntary sector). These significant contrasts in outcome suggest that corporate culture, the role of influential individuals and simple historical accident all contribute meaningfully to the development of service structures, relegating geographic gradients to a background role – though an important one.

In discussing models of care and support delivery (Section 4.2) the point was made that variety and choice would be an ideal, but that scale factors would probably render it unachievable. This was emphasised in the discussion of a Hampshire Centre of Excellence, which would imply and increased degree of service and sector fusion rather than a promotion of diversity. On the other hand, the review of County spatial diversity indicates that varied models may indeed be necessary if equitable access is to be offered across areas of contrasted client density and needs profile. There is an element of conflicting argument here that is not easily resolved.

4.3.2 Responding to diversity of personal circumstance and need

Just as it is clear that the great diversity of the economic and demographic landscape in H&IOW makes it difficult to devise a general model of care delivery that works everywhere, so it is apparent that the social profile of PLWHA is also so varied and so much in flux that strategic planning is difficult. The survey has made no attempt to create a comprehensive typology of client profiles, but the responses to the questionnaires and the content of the interviews have highlighted a series of key elements that deserve attention from providers.

The diagnosis timeline It is the universal experience of PLWHA that diagnosis is the beginning of a timeline of coping and adjustment that will last from a few months to a few years. There are no signs in the survey that the availability of ARV therapy has removed, or even substantially reduced, this adjustment process. This is where counselling may be most valuable in principle, but where making meaningful contact with those afflicted may be at its most difficult. Service provision needs to be sensitive to the substantially-changing needs of individuals through this period, but inherent mainstreaming is tending to downgrade the attention that is paid to adjusting provision in this way. Efforts should continue to identify the spectrum of need, including giving consideration to the roles of peer mentoring and virtual networks of support if conventional provision is downgraded by healthcare strategy or by funding restriction.

Layers of discrimination The point has been made repeatedly that most of the core groups of PLWHA face discrimination in contexts other than their HIV status – whether by sexual orientation, race or immigrant status. Small advances have been made in reducing racial and sexual discrimination, but the practice is often less than the principles and the rhetoric might suggest. Service providers have generally been well geared to recognising the need to customise responses appropriately, but there are fears that moving from specialist to generalist service provision might lead to the additional burden represented by an HIV+ diagnosis being underestimated.

Ante-natal and Paediatric HIV The number of pregnant women with HIV+ status is increasing steadily, though from a very small base. The ante-natal context has been seen as an appropriate framework for routine testing, and there is a broad feeling amongst providers that this group is well catered for.

> *"The clinics are seeing more diagnosis in women because of ante-natal care. We have a female consultant who is dealing with HIV and pregnancies" [NHS provider]*

> *"We are starting to have more families and more women in general and children in here which is predominantly adult environment." [Voluntary Organisation]*

At present, this group is dominated by black African women, and the difficulty of establishing effective contact with their partners makes it unrealistic in many cases to consider adopting a family-based approach to HIV response. In other countries, however, there is experience of using the ante-natal regime as a context within which to communicate with potentially or diagnosed HIV+ men, and this potential could be acknowledged and exploited in H&IOW. Nevertheless, while antenatal services can be provided locally, there are concerns about specialist HIV paediatric care:

> *"People with children need to go to London because children need specialist care which is not available locally. The big issue is paediatrics – prescribing locally. There are a very small number of people and we have a link with London so we are kept updated but children are overlooked." [NHS provider]*

This viewpoint mirrors the wider experience of HIV paediatrics world-wide. Prescribing is highly specialised, especially given the lack of paediatric-specific drugs. It will be necessary in time to address the issue of local provision, but this may well have to be delayed until the absolute number of HIV+ children in H&IOW has increased.

The real minorities and margins A strong message emerging from the programme of interviews has been that there is an under-class of PLWHA marginalised by their failure to fit within the conventional classification of the marginal groups. Notable examples are men who have sex with men, but who do not regard themselves as gay, and gay men who have not disclosed

There is great scope for service providers to explore the growing potential of the web to stand alongside other forms of service delivery in a holistic package that is better suited to responding to diversity and flux.

their sexual preference. Such individuals find no place for their interests and needs within the active gay groups who have classically dominated the voluntary sector, nor in the emergent provision for immigrant populations. Perversely, white heterosexuals are also highly marginalised in the same way.

For such people, the sense of isolation is profound and the absence of like-minded peers is as challenging as the lack of formal or voluntary services. These individuals may turn inwards and abandon the attempt to network. They may find some satisfaction through using national services (such as the Terrence Higgins Trust) to identify peers, though socialising may require travel to London where absolute numbers are high enough to allow even small sub sets to reach a sufficient scale to form an active community. Alternatively and increasingly, they may find (or give) support through the internet. Web communities transcend spatial boundaries, and their very anonymity can compensate from their physical remoteness. The survey confirms that they fill a real need that would otherwise not be met. It is comforting to know that individuals have found a viable level of support in this way, and disappointing that the survey did not reveal any case in which "the system" alerted them to this possibility rather than leaving them to discover it through their own efforts. There is great scope for service providers to explore the growing potential of the web to stand alongside other forms of service delivery in a holistic package that is better suited to responding to diversity and flux.

Special mention must be made of the situation of haemophiliacs in H&IOW. The first HIV+ diagnosis was made in 1983, so this is a long-established cohort and is served by a mix of specialist haemophiliac clinics and provision for haemophiliacs within the general HIV clinics run by GUM. The relationship between GUM and Haemophilia clinics varies across H&IOW and has varied through time. There have been examples of close co-operation, but this has in some cases been based on individual provider enthusiasm and has lapsed on the loss of a particular post. It is difficult to highlight best practice on the basis of this survey, but the provider and user interviews suggest that haemophiliacs are often highly protective of their confidentiality and highly defensive about being regarded as part of the HIV community. There is also an element of bitterness about the plight of haemophiliacs, and an indication that the context within which they are provided with services is sometimes deficient:

> *"Don't lie about knowledge to haemophiliacs in the UK." [Haemophiliac]*
> *"Haemophiliacs do not have anything to do with HIV community, they have a number of different issues. These people are marginalised even from minorities." [PLWHA]*

4.3.3 Immigration – the long-term challenge of transient needs

This is not a survey of the problems of immigrants in H&IOW, but there have been times when it has felt like it! So overwhelming are these problems to the individuals concerned, that they permeate every aspect of life including the experience of HIV/AIDS. Every challenge is viewed through the lens of immigrant status, and every attempted response is constrained by burdens of immigration. This is a widespread experience, and is hugely magnified in the case of illegal immigrants and those of unascertained immigrant status.

> *"With immigration status, everything is in limbo. You don't know where you are. Once you start treatment, you can't stop and if I have to go back home that is what will happen. This violates my human rights if they return me. The economic situation back home means I won't have access to medication there. I am doing very well on my medication at the moment - no side effects." [PLWHA]*

At the opposite extreme, there are professional and legal immigrants in the County who have a full range of rights but may well have a socio-economic status that means that they do not require any support other than medical intervention.

At the moment the problem is largely one of black African immigrants, a significant number of whom are from Zimbabwe. Black Caribbean immigrants are less numerous, but no less challenged. Such people find themselves facing life with burdens of race, poverty, immigrant status (which impinges on housing and access to employment and benefits), separation from extended family, in some cases language … and then there is AIDS. These are communities within which stigma may be a crucial issue, yet housing circumstances (shared property, and often shared rooms) make non-disclosure exceptionally difficult. The problems are thus multi-layer, each source of difficulty magnified by having simultaneously to confront the others. As yet, the region has not experienced a significant surge in Eastern European PLWHA, but given the focus of influx on the South Coast, this would be expected before long.

The medical system is essentially equitable in response (though it has real problems in handling illegal status), and in many respects has developed highly effective structures for providing care despite the constraints of limited disclosure. Sometimes, extreme precautions are necessary in order to maintain a façade of normality despite the need for clinic visits or home visits. But the effort tells on both providers and users. Still more difficult are the repercussions of the progressive loss of experienced personnel, and the fact that incoming staff are not only often less informed and less experienced, but they are also often less committed to constraining their activities to the needs of non-disclosure. Appointed in the post-ARV era, they may intuitively or formally adopt a mainstreaming approach that assumes that confidentiality is not an AIDS-specific concern and that it is basically a matter of handling paper records responsibly. The point has already been made that the valid arguments in favour of mainstreaming should not be allowed to fuel a drift towards assuming that normality is achievable by the most marginal groups.

In practice it may be rather more challenging for Social and related Services to provide truly equitable access to immigrants who do not have legal status. The limitation on rights to benefits and services are such that the system is highly constrained to act flexibly, and even if sensitive questions are avoided the range of available options is small. Service providers have commented that immigrants face major difficulties in seeking employment.

> *"I would like to work if I could, everything just stopped with the immigration thing. I used to work very hard." [PLWHA]*

> *"My employers haven't paid me yet as they don't know if I am employable, even though I provided all the information from my solicitor." [PLWHA]*

Some immigrants simply assume that they have no rights, and seek no support. In such cases, the voluntary sector is widely seen as playing a potentially-vital role using their greater flexibility to operate without asking questions. Significant success has been achieved in offering support to African women, but heterosexual HIV+ African men have proved to be a group that is very hard to reach – often for cultural reasons.

There is every sign that the immigration component of the H&IOW HIV/AIDS programme will increase and diversify, particularly as the Eastern European element begins to emerge in small numbers, both through IDU and through commercial sex work.

> *"If we look at sex industry (which is considered not to be in Hampshire at all), the newspapers are full of adverts from Eastern Europeans and Asian sex workers in Hampshire.... Eastern Europeans are not visible because of the colour of their skin. They are not registered anywhere so they are invisible" [Service Provider]*

> *"From the GU point of view (STIs), we are seeing lots of Eastern Europeans. Increase of clients from Eastern Europe (seasonal workers, etc)" [NHS provider]*

There is only a limited opportunity to solve the immigrant aspects of the challenge through HIV/AIDS-related services, but it is well worth taking proactive steps to ensure that HIV/AIDS support becomes a standard and high-profile element in the immigration service strategy of H&IOW. It would be misleading to characterise Eastern Europe as an HIV hot-spot at the present time, though prevalence rates are sometimes higher than the 0.1% UK average. UNAIDS estimates the prevalence rates in the 15-49 year age group as follows:

Poland	0.1%
Lithuania	0.2%
Latvia	0.8%
Estonia	1.3%
Bulgaria	<0.1%
Romania	<0.1%

Perhaps more significant is the fact that migrant populations are likely to be subject to higher than average HIV+ status both because of involvement in the sex trade and as a result of the increased sexual and IUD risks associated with dislocated and fragmented family structures. The demographic group originating in Asia is also very significant in H&IOW, but not yet identified as a particular at-risk group in the HIV clinics. Given the high and sometimes rapidly-rising prevalence rates in parts of Asia and the association with the sex trade, we may expect to see a rise in the profile of this group in terms of demand on HIV services:

> *"An Asian HIV epidemic? Around 2007!" [Service Provider]*

> *"There is a much bigger Asian and Chinese community than African one in this part of Hampshire, should these people be focused on more?" [NHS provider]*

Immigration is now tightly woven into the fabric of the HIV/AIDS challenge. Both problems show signs of worsening, and together they are a major burden for the individuals concerned and for those organisations who seek to support them.

There is only a limited opportunity to solve the immigrant aspects of the challenge through HIV/AIDS-related services, but it is well worth taking proactive steps to ensure that HIV/AIDS support becomes a standard and high-profile element in the immigration service strategy of H&IOW.

5: Options and opportunities

5.1 Context

If you don't ask, you won't know. So we did ask, and a lot of people told us: but at the end of the day, what do we actually know about the challenge of living with HIV/AIDS in H&IOW? What should we be doing next? One of the risks of the evidence-led approach is that information can be overwhelmed by data, and trends can disappear in a welter of detail. Issues that are mentioned many times by many people tend to catch the attention, but a point made once may be more important. No approach to report writing is a panacea that meets all of these challenges, but in order to maintain both focus and priority, Section 5.2 is organised in the form of a series of questions that have been found to be important to the project's Commissioning and Steering Group, the providers and the participant PLWHA.

In addressing these questions, material is drawn largely from survey responses to questions about notable strengths and weaknesses of present survey provision. These comments tie the report back to the voices of its participants, but they are placed in the context of a general commentary that is designed to identify balance and background, and to lead towards the planning of the next steps in Section 6.

5.2 Review and Perspective

5.2.1 An overview of service provision, access and use

The big question, of course, the extent to which people living with HIV/AIDS in H&IOW are well-served, and whether they are satisfied with that service. Great satisfaction can be taken from the generally positive response of participants from all the communities concerned (PLWHA and providers): the honesty and frankness of their responses was extremely impressive and there was very rarely any sense of reserve. Punches were not pulled, and verbal blows were struck when this was felt necessary, so the many generous comments that were made can be regarded as a genuine indication of satisfaction. At the same time, there were many points where respondents voiced real concerns and made pointed criticisms – with providers being every bit as likely as users to voice dissatisfaction with both the present system and the perceived trends. The standard survey health warning is appropriate here: for every view there is a counter view, and the most striking characteristic of the opinion expressed is its diversity. Some people (often immigrants and sometimes the newly-diagnosed) express almost pathetic gratitude for what they have received, whilst others (often the long-term diagnosed, particularly gay men and the most isolated groups such as heterosexuals and bisexuals) compare the present with an

Punches were not pulled, and verbal blows were struck when this was felt necessary, so the many generous comments that were made can be regarded as a genuine indication of satisfaction.

unachieved ideal or with almost nostalgic reference to times, systems and personnel past.

There is genuine appreciation of the general principle of open access for all, of the availability of free medical consultation and drugs, and of those many professionals in both the formal and voluntary sectors who have devised systems flexible enough to fit with the needs and capacities of PLWHA. Choice is widely appreciated – including choice of clinics and of consultants (including access to female consultants), clinical nurses and advisors. In many senses, choice sooths perceived lack of optimum service. Some individuals, sometimes well-informed and influential, have voted with their feet and sought care elsewhere, notably in London or Brighton. The great majority have not: in some cases, doubtless because of lack of opportunity, of resources or of confidence ("I'm just a town boy: going to London is a daunting thought"), but often because any dissatisfaction with what is available locally is small (see Section 4.2.1). The importance of choice is admirably illustrated by the fact that there is (limited) movement of clients in both directions between Southampton and Portsmouth GUM, showing that each of these cultures of service delivery has its fans and its detractors.

Not surprisingly, likes and dislikes are often tagged to a particular place, but are expounded in terms of a particular individual. Eulogies of committed, enthusiastic and sympathetic staff and volunteers emerge from our interviews in every sector of the HIV/AIDS response system. Key people make the system work and make the individual feel good: their loss is sensed as a threat, and often triggers retrenchment or downgrading of service. The best people make the system work for them and their clients, not vice versa – a truism that applies in all contexts at all times. Not only are key personnel critical to the design and delivery of individual services, but they are also widely seen as the catalysts and facilitators of inter-service integration. Despite a very widespread support for front-line workers, there are still reports of people who are insensitive and unsympathetic towards PLWHA. There is anecdotal evidence that some ward nursing staff are ill-informed about HIV/AIDS, and adopt inappropriate responses to PLWHA ("They panic: use double rubber gloves"). Surprisingly, this overall criticism is also sometimes applied to the voluntary sector, where those not conforming to the stereotypical client groups may feel unwelcome or misunderstood. The physical premises in which HIV-related services are delivered are sometimes criticised on the basis of quality or suitability (notably with respect to handling confidentiality), and physical location is a significant issue. Some sites are ill-served by public transport, and the time/cost of accessing services can be a barrier for some PLWHA.

To what extent can problems be attributed to lack of funding? The question is often asked, and answers inferred, but the situation defies simple characterisation. Budget pressures are very real across the sectors, and are doubtless cutting into services. But change would be taking place anyway, and much of this change would be promoting concern or dissatisfaction. There is a refreshing acceptance across all sectors that demands for service must be realistic in the face of budget cuts. Few people assume that service provision could be unrestrained. Yet there is a sense that some of the restructuring of services, supportive in a general way of strategic moves towards mainstreaming HIV/AIDS, may be based on misconceived ideas that general service provision is cheaper than the maintenance of specialist provision (albeit part-time or more geographically extensive) – an argument that is made in the context of specialist social workers in Section 4.2.1.

HIV is changing in its impacts and demands, but the support services appear slow to respond, yet when they do so (as with the promotion of mainstreaming/normalising HIV/AIDS) they are often criticised for doing so. This happens at a variety of scales, and at the most practical level may manifest itself in examples such as gay men having issues with parents and children attending 'their' drop-in centre. The diversity of people with HIV is not fully represented in the current support group provision. Or perhaps it is fairer to say that the perception is that they do not provide a rounded service. This affects smaller groups such as heterosexual white British PLWHA, but also the hardest to reach groups including black African men. Also, it must be remembered that the needs vary across the County. There appears to be less need for support groups in areas where the users are employed and in a stable family environment (e.g. Winchester and Basingstoke areas), but what about those who still crave involvement with others in the same situation as themselves? There can be extreme isolation for those who are perhaps single, or at least do not fit into the box, and on-line communities then become the only alternative.

The survey has also revealed the lack of co-ordination between the different service sectors, and even between components of the same service sector but across geographical divides. There are implications here for the concept of a regional centre, as services have not demonstrated any great success in developing a joined-up approach at present. This links into the "signposting" issue, the role of providing a gateway to the range of available services, and this appears to be where voluntary support groups are plugging the gap where they can. It is often these groups that guide users towards Social Services or counselling, or alert them to a particularly amenable dentist or GP. But such services should be universal rather than *ad hoc*, and they should not be reliant on an individual attending a particular voluntary group. There is a need for a virtual network that is understood by all service providers so that they are able to articulate it to their users. This network might most appropriately be at the level of the area (Southampton or Portsmouth) so as to match the needs of particular sets of users, but also at the regional level to support providers and cater for those many users who do not fit into the major urban groupings.

Problems have emerged with Social Services also, but these are probably generic rather than HIV-specific. The changes to Social Services (notably in the downgrading of dedicated posts) are contentious, and have been seen to run counter to some of the exciting trends across HIV service provision. The loss of dedicated case workers can disrupt continuity of care and exacerbate the stress of disclosure. Hampshire still has a specialist HIV Development Worker, though demand for their services has declined in recent years and it is no longer sustainable to maintain this as a full-time post. Those people receiving Social Services can opt to receive direct payments and as a result can employ their own dedicated carer, but this does not solve issues such as those relating to phoning for advice. It has also been noted that there is a widespread lack of knowledge about what Social Services do and what they can provide for PLWHA – partly because the signposting from the NHS is lacking, but also because they are not being sufficiently proactive in promoting their services.

5.2.2 Why do people turn away from services?

It is claimed that the number of people with HIV/AIDS in H&IOW is increasing, but the number of those accessing core services in the County is not. Regardless of the numerical substance and evidential base of this claim, it has a powerful effect in promoting the argument that people are turning away, or being turned away, from local services. The notion of barriers to service access is helpful in terms of an overall review of provision such as this. There are some criticisms of aspects of GUM clinics, but an overwhelming sense that the service works and that individuals can exercise choice.

The experience of the Social Services is more varied, with some real or perceived problems of access in cases where dedicated posts are absent. There is also an amazing lack of awareness of what services are available to PLWHA, what the conditions of access are and how to achieve access. Very few people indeed have any real idea what their rights are, and no-one tells them. This is a mind-boggling revelation in 2006, and one that urgently needs addressing. It is further discussed in the context of information services below.

Other services also present a confused face. Where specialist pharmacist services are available, they are hugely appreciated by medics and users alike. So why are they not found more frequently? Good dentists provide excellent service, and the informal grapevine leads many needy users to them. Disappointingly, access to dental services by PLWHA is patchy (in part reflecting a national problem), and many dentists either avoid taking on patients with HIV+ status, or treat them inappropriately in terms of confidentiality and misinformed restrictions on service. This again simply should not be the case in 2006. Greater controversy surrounds the role of specialist counsellors and nutritional advisers, but both roles are prioritised on many people's list of services to be preserved or enhanced.

Section 5.2.1 has raised the issue of people from Hampshire preferring to seek care in other centres, with London and Brighton being the most important. The scale of this "defection" is small in absolute terms, but it appears to play an important symbolic role in debates about the quality of local services. The pull factors include choice (centres with consultant lists in the double figures are available in London) and anonymity, but also the documented sense that the large Centres of Excellence are best-informed and have greatest access to cutting-edge trials. The push factors include the problems experienced beyond the two major urban centres, where HIV-related services feel remote and infrequent (the Isle of Wight and North-West Hampshire both have the challenge of providing services to a very small absolute number of people), and sometimes focus on a particular sensitivity to disclosure in these areas.

5.2.3 Local service or a Centre of Excellence?

The debate about the relative merits of local service provision versus the development of a County-based service from a Centre of Excellence has been introduced and fully reviewed in Section 4.2.1 above. This is the tip of an organisational iceberg whose submerged base concerns the much broader contention between a specialist and a generalist model of care delivery for PLWHA. It has been stressed that this argument has

> *Scale has been seen to play an all-pervading role. Excellence and specialism (which combine to offer the most up to date and highest quality service) require a client population that exceeds a given (but undefined) operational threshold. Whether or not the combined service provision of H&IOW reaches this threshold is a moot point . . .*

become highly polarised, and the point has been made that there is the alternative of a hybrid system in which the post-diagnosis routine services might become rather more general while the provision of advanced specialist services might be upgraded through a structure similar to a Centre of Excellence. Opinion is broadly spread across the options, and it sometimes appears that the passion of the argument is more based on its symbolic implications (are PLWHA being down-prioritised? Is HIV funding being diverted?) than on the operation detail or benefits of the various models.

Scale has been seen to play an all-pervading role. Excellence and specialism (which combine to offer the most up to date and highest quality service) require a client population that exceeds a given (but undefined) operational threshold. Whether or not the combined service provision of H&IOW reaches this threshold is a moot point, and there is only a point in trying to determine it if there is a genuine appetite for a hierarchical hybrid service delivery model. Integration would be required at a level far exceeding anything so far achieved or attempted. Competition (inter-sector and inter-site) would need to be replaced by co-operation. People in the non-urban areas might become more remote from specialist services (though closer to routine services). But the prize is very enticing. The prize is a unique model of service delivery with genuine excellence at its peak.

5.2.4 Service integration – joined-up working

One of the major issues that underlies the focussed debate about a Hampshire/IOW Centre of Excellence has been acknowledged to be the broad issue of the role of special/dedicated/named posts within the HIV-service. In the rhetoric of the street, this has come to be seen as the antithesis to the trend towards mainstreaming HIV/AIDS. But if mainstreaming is deconstructed and viewed in a hierarchical framework, there is actually no conflict between normalising HIV/AIDS but retaining dedicated posts. Part of the justification for such posts lies in the universally-strong support that they receive in the survey, not just from users and post-holders, but also from the wider professions including the consultants. Specialist HIV social workers have established a formidable reputation for effective service. Named posts overall, and the highly-committed individuals who usually (but not quite always) occupy them, have often been the key to empowering such inter-sector and inter-service integration as has been achieved. They breathe life into the concept of a holistic service – yet they appear to be undergoing a systematic dismantling. The point has been repeatedly made that, in some cases at least, this is a false economy – though structural, operational and cultural change is certainly not in itself disadvantageous. The lesson appears to be that strategic planning is proceeding in an *ad hoc* and rather non-strategic way, and that the principle of integration is being vaunted with scant respect for the practice of inter-sector consultation, let alone genuine joint participation.

The lesson appears to be that strategic planning is proceeding in an ad hoc and rather non-strategic way, and that the principle of integration is being vaunted with scant respect for the practice of inter-sector consultation, let alone genuine joint participation.

Related issues abound in the surveys, and one provoking thought is that integration of service might logically (but not necessarily operationally) suggest integrated location. Many services remain building-based, and the concept of the one-stop shop supports the notion of drawing the strands together to co-locate. This is, of course, happening at the moment – though sometimes in an ad hoc rather than planned way. The voluntary sector frequently invites in representatives to take advantage of its drop in facilities, and the health sector sometimes invites in representatives of social services or voluntary organisations to function in a clinic setting. This is a useful foundation, that might have merit both in service quality and in cost reduction. At the same time, however, it must be noted that there are demands for an increased component of home-based service delivery which might pull in a different direction.

Another manifestation of service integration is the proven scope for inter-sector and inter-service commissioning. This often builds on existing co-operative frameworks between organisations (joint committees, discussion groups, forums), but cements the relationships and co-ordinates their efforts by jointly commissioning and jointly funding activities, routine or one-off. The commissioning of this survey of the needs of PLWHA in H&IOW is a case in point. Some respondents have gone as far as to consider the merit of commissioning at a County level. This has particular interest in that it begins to confront the issues of co-operation that would be necessary if there was a move towards a Centre of Excellence, even if this was a largely virtual network. Both organisation and personal competitiveness have been raised as barriers to such a move, and joint commissioning is a tantalising counter-argument.

5.2.5 The Voluntary Sector – stop-gap, alternative or partner?

The voluntary sector has been taken for granted throughout this report. It has been variously praised and criticised, but no-one has questioned its role or importance. It, too, is undergoing change – and change almost always involves stress as new roles, responsibilities and hierarchies emerge. PLWHA do not always want access to voluntary services, either because they are in the fortunate position of having no unmet needs, or because there are cultural or social barriers to their seeking personal networking. But those who do want voluntary support are very pleased with the service they receive except in a very few cases (usually relating to the new marginal groups, white heterosexuals or bisexuals for example). Their commitment and flexibility, and their willingness to work around the system, are major assets. The survey responses spread praise widely, though the individual organisations are very different in mission and style and thus each attract their own supporters. Choice, again, is vital.

But what is the voluntary sector for? This is not a threatening question, but an invitation to move on – perhaps to mainstream the voluntary organisations. At one level, the early organisations were proudly functioning as stop gaps: their establishment and growth demonstrated the recognition of huge deficiencies in the state system, and the voluntary groups evolved to address them. They were so successful that they came to be seen as sufficiently integrated into the overall service provision that they could receive referrals from the state sector and could be given state funding for their activities. Nevertheless, there was and still is a sense that the voluntary sector is propping up rather than enhancing the more formal services, and a worry that they are not always ideally placed to do so, since their expertise is filtered through a set of eclectic sources and experiences. The suggestion has been made that closer two-way liaison between the health and voluntary sectors would assist in converging what can become conflicting medical advice.

But what is the voluntary sector for? This is not a threatening question, but an invitation to move on – perhaps to mainstream the voluntary organisations.

In addition, the voluntary sector (as with their formal sector colleagues) tends to focus is on the majority need – immigrants and gay men - leaving heterosexual British and MSM (not out gay men, or gay men but not part of the gay scene) neglected. The mission is always “everyone welcome”, but the fact is that everyone does not feel comfortable. This is a clear sense of tension. Those organising services may stress that services customised to each and every subgroup of PLWHA merely magnifies the sense of isolation and promotes a ghetto experience. However, those seeking social support want above all the support of “people like them”. This is one case where the politically-correct principle may yield an outcome which inadvertently excludes vulnerable individuals.

The survey responses demonstrate that 20 years on, the voluntary organisations are so much an established part of the scene that they tend to be thought of as alternative providers, not so much filling gaps as delivering services in a different way (perhaps at a more human level, perhaps more flexibly, perhaps needing to ask fewer questions where the answers might make service delivery difficult). This is success, of a sort. But it is not necessarily the future. It is not necessary to go as far as promoting a formal Public-Private Partnerships (PPP) in order to see the merit of a mixed but integrated set of service providers, mutually-respecting and respected, and providing a sustainable holistic approach through partnership. Probably the voluntary sector would remain the most under-funded and economically volatile, but it would also retain all the advantages of flexibility and rapid responsiveness, and its value would be lastingly recognised. This seems to be an attractive future, but it should be a strategic target rather than an accidental outcome.

5.2.6 Stakeholder engagement – listening to other voices

The debate concerning the merits of establishing County-wide or local forum structures to encourage stakeholder involvement in operational and strategic decision making has been addressed in Section 4.2.3, where a range of views was apparent. In general, there is support for the principle of a wider voice, particularly a user voice, but in practice there is significant assumption that it would be a talking shop with little real influence, and that those involved would be more likely to represent themselves than represent the needs of others. Behind this caution, there is substantial indication that such a framework could work, and a realist recognition that against the backdrop of today’s commitment to stakeholder participation it is an inevitable move. The functioning of the Isle of Wight HIV Network was cited as a widely-acknowledged example of successful practice.

There is little more to be said. The operational framework is in many ways less crucial than the principle. There appears to be merit in and broad support for a stakeholder forum, and the next step would be to assess various organisational models and (in the spirit of the exercise) develop them through stakeholder debate. It is important to stress that though a forum is strictly a place where debate takes place, the concept could well have a virtual manifestation today. There is much value in exploring the extent to which individual or joint service providers could develop on-line delivery of informing, group discussion and even voting facilities, whether text based or voice-over-internet.

At a broader level, it is worth mentioning that survey participants have welcomed opportunities for patients to be involved in deciding their therapeutic futures, though the great majority of patients are more concerned that they are dealt with the expert staff who can provide a firm lead based on the latest information.

5.2.7 Informing, educating, preventing

Though there are times when information overload appears to be a problem, the overwhelming evidence of the survey is that users both perceive and experience a lack of information. In the case of **preventative guidance** (essentially safer sex information), this deficiency frequently emerges as a complaint that HIV/AIDS has slipped out of the headlines (particularly, off the TV screens) and that preventative messages and supplies need to be widely and freely available at the point of need. It has not been within the scope of the survey to test this claim, but the point has been made that almost every HIV+ respondent admitted being aware of the safer sex message but chose to ignore it for one reason or another. There is, therefore, no immediate evidence that better communications would directly reduce the number of new diagnoses, though it is apparent that outreach distribution of condoms and lubricants does have a beneficial effect in the gay community. There is, however, a clear sense that a new generation of at-risk individuals is emerging because the safer-sex message is muted and focussed on avoidance of pregnancy or STDs rather than HIV.

General HIV awareness and education is a category of response in its own right, and requires concentrated effort. Despite all the many advances made, the survey has still revealed frequent cases of service providers (social services, nurses, GPs, dentists) and employers who are drastically misinformed with respect to HIV/AIDS, leading to inappropriate, offensive and even disruptive behaviour. The public at large also remains seriously under-informed. This lack of education/awareness can quickly turn to stigma, and lies behind many of the disclosure issues still experienced by PLWHA. Ironically, the extreme discretion inherent in the service delivery of some providers may be perpetuating the cycle of secrecy and misinformation, and this supports moves towards mainstreaming HIV/AIDS, at least in part. The severe lack of awareness amongst many GPs was also frequently raised by users and providers, and this clearly points to a need for proactive response through graduate and postgraduate medical training. There are attitudinal as well as knowledge challenges, and it may be that "informed" professionals in every sector could act as ambassadors to persuade their colleagues (including the mission-critical gate-keepers and receptionists) of the merits of a normalised approach to PLWHA.

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Health promotion and PCT involvement have been frequently referenced by users and providers, often in a context of frustration. Investment and personal skills are available, albeit in limited quantity, but the delivery and organisational context rarely empowers these services to yield notably beneficial outcomes There is a real conflict here: a near-universal feeling of sub-optimal delivery but a widespread sense of a potentially vital role. The interview responses identify a focus on health promotion messaging rather than action, and suggests that there is an element of duplicated effort – diluting rather than reinforcing the message. Health promotion is one of the most important issues, and education is key right across the board, but there is much scope for refocusing these services to greater effect. This would, of course, require concerted cross-sector cooperation coupled with meaningful stakeholder engagement.

The health promotion imbalance is seen in a current focus on testing and monitoring rather than prevention. This links to lack of awareness and education, but also relates to Government policy which concentrates on getting people to clinics for testing on a regular basis, rather than instilling and empowering the importance of adopting preventative behaviour. The approach is reactive rather than proactive. There is demonstrable yield from initiatives such as Gay Men's Health Project delivery of condoms in cruising spots, but also unaddressed need – for example non-out gay men or what about young people who don't seem to see an STD as a problem anymore.

Quite separately, this report has frequently referred to a drastic lack of awareness by PLWHA (particularly when newly diagnosed) of the **services available** to them. Indeed, we have not met one single person (user or provider) who could confidently be said to be aware of the full range of options. Under these circumstances it is literally impossible for PLWHA to make informed choices, and one of the basic tenets of care delivery is thus missed. It was very clear that most users were not aware of even the basic services that were available, who to ask or even what people's roles were supposed to be. There seems to be some confusion over some job descriptions: for example, a "counsellor" may in practice be more of an information service than a traditional counselling "listener". There is a strong and immediate need for greatly improved service signposting – making the services easier to understand and providing a one-stop shop of information rather than relying on individuals being proactive at a time when they least want to be. It is difficult to imagine a more productive use of short-term investment, or a more creative test of much-needed inter-sector integration.

The role of the internet in providing access to information about available services is significant, though it inevitably raises concerns in terms of exclusion of those individuals without the means, skills or inclination to access the web. The HIV site on Hantsweb (administered at http://www.hants.gov.uk/hiv/localsupport.html by Hampshire County Council and managed by the County HIV Development Worker) is the most comprehensive local service. It includes information on a range of voluntary organisations, County and NHS services, and Social Services (via a web portal). It is informative, supportive and non-judgemental, but not complete in its listings, and it relies on the browsing skills of the individual to track down the full range of services. Nevertheless, this is probably a platform upon which web services for PLWHA might be built, including "community" services that go beyond information listings (contact services, chat rooms, blogs, podcasting). It is interesting to note that an active volunteer-run service is already available to Haemophiliacs at national level: http://www.haemophiliachat.com/ is the URL.

Another possible channel for general advice might be the existing network of **Citizens' Advice Bureaux** (CAB).

A telephone/email survey established contact with 20 of the 28 listed in H&IOW, and addressed the following questions:

- Do you have contacts with members of public who are prepared to disclose that they are living with HIV/AIDS in relation to problems that they are addressing with you?
- How would you respond to such a disclosure?
- Do you have available contact points for specialist advice and/ or advisory materials (if so could you please list them)?

Only 6 responses were forthcoming. Four indicated that no HIV disclosure had been made to them in the last 3 years, and one acknowledged occasional disclosure and pointed to the wide range of standard CAB advice functions including benefits and immigrant status. Just one reported an active strategy on HIV, implemented through a fortnightly outreach post in one of the voluntary organisations' centres providing advice on an appointment basis to PLWHA or their carers. The situation revealed by the survey is one of a significant under-use of the CAB network, and a significant lack of CAB preparation for any interaction with PLWHA.

5.2.8 Back to work

The survey has revealed an extremely mixed experience of PLWHA with respect to employment. Some have been extremely fortunate, and are productively employed following disclosure. A disturbing number report that disclosure has been a barrier to new or retained employment, and it is clear that employers are effectively discriminating in practice despite the prevailing principles of human rights. Many PLWHA have been advised by consultants, advisers or friends against disclosure to their employer or work colleagues: there is a widespread tendency towards non-disclosure as the default risk-avoidance strategy for the individual. Some employers – notably the police service and to a lesser extent the NHS – have developed exemplary non-discriminatory systems, and could be used as examples of best practice.

This leaves us with a significant proportion of PLWHA who are not in employment and not actively seeking it. In most cases this situation appears to have generic rather than HIV/AIDS-specific roots – the familiar benefits trap, immigrant status or gender/cultural presumptions against paid employment. Some people are deterred from working by genuine health problems. But there are examples of PLWHA who would like to work but cannot, or think they cannot, because of their HIV status.

> *Some people are deterred from working by genuine health problems. But there are examples of PLWHA who would like to work but cannot, or think they cannot, because of their HIV status.*

6: What next?

6.1 Context

This HIV Needs Assessment project was undertaken within the framework of an operational Service Level contract with the commissioning authorities, and a series of professional procedure contracts with a number of Ethics Committees. But in many ways the most important guide and constraint on the study has been the moral contract between the researchers and the respondents to the questionnaire and interview surveys. This has taken the form of an implicit and explicit commitment that the many voices of the respondents would be heard and considered. In the terms of the “voice” analogy, ensuring that people are heard is relatively easy to achieve. The meticulous reporting and commentary of Sections 3, 4 and 5 have met this part of the commitment. Every single respondent has appeared in the tables and listings, and many are quoted direct, so the report itself is sufficient to see that the voices are heard. But how can we be sure that what is heard is seriously considered? And what is the chance that this consideration will lead to the development or maintenance of best practice, ensuring a good or better deal for service users and providers alike? Strictly, of course, we can’t be sure of anything – but we can certainly make every effort to take the next steps effectively, and that is the purpose of this final section of the report.

6.2 Options for promotion and implementation

There’s never a right time, but there’s unlikely to be any time that’s better than now. This may sound trite, but it’s worth saying nevertheless in order to ward off any temptation to argue for a delayed response. The NHS is, at the time of writing, emerging into a drastically reshaped organisational structure in which many roles and responsibilities are in flux. The Social Services at County and Local Authority level are undergoing reshaping as individual posts are redefined or removed. The voluntary sector is evolving, with some internal stress, in response to fundamental changes in the profile of PLWHA, external changes in the formal provider sectors, and internal rebalancing between old and new voluntary partners. Those with front-line experience will say that no time is better to achieve real progress than a time of instability and uncertainty. By this standard, there is currently an unparalleled opportunity to ensure that, as the new organisational and funding roles and partnerships clarify and firm up, they do say in a way that meets as many as possible of the needs revealed in this survey. To achieve this, however, will take flexibility, determination and energy on a grand scale. Cherished norms may have to be sacrificed, but in a spirit of co-operation it should be possible to create in H&IOW a genuine exemplar of innovative best practice for HIV support beyond the metropolis.

There's never a right time, but there's unlikely to be any time that's better than now.

6.2.1 Activate the partnership: a network for implementation

The key to planned action in response to the survey is the creation and empowerment of an operational structure through which to make choices, decide priorities and commission activity. Such a ***Network for HIV Care and Support*** would take on the responsibility for rolling out the tasks identified in this report as well as establishing an ongoing review of HIV needs. In principle one might envisage building a new cross-sector stakeholder organisation to take this work forward, but in practice an effective kick-start is readily available in terms of the commissioning body for this survey of PLWHA needs. It will certainly need refinement in membership, and may well feel that the tasks are best carried forward by a series of working groups, but any other launch pad for the follow up would involve formidable delays in negotiating the necessary co-operative structures. Some of the implementation tasks could well be actioned without high-level strategic implications or involvement, but if the work is really successful then it will soon reach the point where strategic buy-in will becomes essential. To lay a foundation for this, the group would be well advised to seek to establish its targets in the formal mission and business plan of each of the component sectors, and to identify strategic champions with whom to work to take the vision forward. The network will only work effectively if it establishes working two-way links with the existing provider groups and organisations.

At some point it will be advantageous for the group to consider metamorphosis into a full stakeholder forum, representing the many voices that this survey has identified. Alternatively, it might be felt that such a forum should be launched as a subgroup. In either case, the target is to avoid slipping away from tackling the need for genuine stakeholder engagement, and to ensure that the "operational" and "stakeholder" functions do not develop a separate existence.

One of the issues which attracts most attention (but in some ways least creative thinking) from service providers is the challenge of achieving adequate and reliable funding. In the state sector, this task is a familiar part of the annual management year - but with many specific nuances that relate to the peculiar and ever-changing status of HIV/AIDS in the corporate agenda. As the professional and political priorities drift, earmarked funding and high-profile targets may come and go. Earmarked HIV/AIDS funding lay the foundation for many of the services that are now taken for granted, and as this type of funding dwindles, the challenge of maintaining cashflows for those services is acute. Policy changes in relation to the dispersal and support of immigrants have also created particular tensions for HIV service providers over recent years. For the voluntary sector, all of these problems are magnified. Both the scale of funding and its long-term continuity are crucial to effective staffing and service provision, but with much of that funding being received from the state sector there is a real sense that a competition could develop for the same reduced earmarked funds. How best to ensure that the very creative partnership that exists between the state and voluntary sectors through a period of reduced and reconfigured funding (different headings; different channels; different bidding processes) is an important and urgent task for those charged with taking forward the agenda of this Needs Assessment.

It would, of course, be for the *Network for HIV Care and Support* to determine its own agenda and priorities – and, indeed, this is the very essence of stakeholder engagement. However, in order to provide an illustration of the kind of profile and task load that might emerge, a proposal has been developed for a 3-year mission which tackles the report's options in a sequential manner. The aim is to avoid overload and ensure that urgent and fundamental needs are addressed first. There is nothing rigid in the proposed timescale: it could be shortened or extended to reflect available time and resources. Two of the components are background tasks which need to established from the outset but would be expected to remain current throughout the work of the *Network*.

6.2.2 Establish and develop the governance and funding structures

If the *Network for HIV Care and Support* is to function effectively – whether in providing routine steer to existing programmes or lobbying for major strategic change – it will need a robust and resourced position in the newly-emerging organisational structures of the various sectors. Its work cannot wait for reorganisation to be completed (not least, because it is never completed), but the *Network* should prioritise identifying new opportunities to embed its role and targets in the new governance structures.

6.2.3 Address the spectrum of information and education needs

It has been made clear throughout this report that service users feel starved of information at all stages in the timeline of their care and support, and particularly in the immediate aftermath of diagnosis. This feeling is so universal that it cannot be dismissed as "wrong" by

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service providers. Either the information does not exist in an appropriate form, or it is not being made readily available, or it is available but for some reason it is not being accessed. Whatever the reason, an active response is required and this can serve as an early demonstration that the Needs Assessment outcomes are to be implemented. Moreover, information provision can achieve high service-user impact without requiring either high-level strategic buy-in or major long-term strategic funding.

The starting point is to focus on regenerating and expanding the existing "signposting" services which point users towards services that they might consider accessing. Such services may take the form of leaflets, posters, web-delivered materials or components of personal advice-giving – or, indeed, all of these simultaneously. The point has been made repeatedly that web-based services have a massive potential for expansion from their present base of information listing and portal functions (signposts/links). The use of the web to build high-efficiency low-cost contact networks is currently perhaps the single major trend of internet usage, but is not exploited at all by the H&IOW HIV services. Despite the inevitable exclusion of those at the economic, literacy and skills margins, such virtual networks would be effective in reaching some of the new isolated groups such as white heterosexuals, MSM or bisexuals.

The whole area of public health promotion and outreach requires serious and on-going attention. In a professional sense, staff involved in these activities are often marginalised from the heart of the HIV support mission, and there is sometimes a tangible sense of lost mutual respect. The *Network for HIV Care and Support* should proactively seek to engage with these staff and their functions, ensuring that they are properly placed within the spectrum of an integrated HIV support provision. There is no doubt at all that the service users widely feel that "HIV risk promotion" is slipping down the agenda – locally and nationally. They see this as threatening, despite the fact that few of them actually report not knowing what the risks are. More specifically, as the demographic profile of HIV+ status widens to include many more transient immigrant groups, it is essential to regard awareness and risk promotion as being permanent functions.

The Needs Assessment survey has revealed numerous examples of inappropriate professional behaviour stemming from lack of HIV/AIDS awareness, miscomprehension or (it has to be said) outright bigotry. It seems unavoidable that the *Network for HIV Care and Support* will have to take on the mantle of champion to promote changes to the initial training curriculum, postgraduate medical training, and in-post professional training curricula. This should not be just a voluntary "specialism" (which is well tackled by existing *ad hoc* short courses), but a required part of professional standards. The need is apparent in doctors, nurses, dentists and advisors – and in a range of Social Services roles. It magnifies rapidly as named posts and associated HIV experience are lost.

6.2.4 YEAR 1: Refine the cross-sector organisational structures for HIV care and support

If the *Network for HIV Care and Support* was to establish a Working Group tasked with taking forward the major strategic implications of the Needs assessment report, then one might suggest that its Year 1 priority would be to review and refine cross-sector organisational structures. The immediacy of this task is to catch the current wave of organisational change and ride it. Any delay in this vital task will mean that new structures and roles bed down without incorporating HIV/AIDS needs, and short-term tweaking will then be very difficult. Organisational strengthening for the HIV support and care services is also an essential basis for empowering the rest of the report's recommendations, and thus the *Network*'s agenda. Many of the aspects concerned are addressed in Section 4.2.3 (organisational options for equitable access to care and support). The current re-organisation may also offer scope for considering some of the implications of tackling demographic and spatial diversity of need.

Specifically, there is a priority requirement to acknowledge two important opportunities. First, an operationally effective structure and funding mechanism for inter-sector co-operation has to be established before more fundamental service integration could even be considered. And without effective integration, it is difficult to envisage a meaningful debate about establishing a H&IOW Centre of Excellence. Second, at a more pragmatic level, there is a high-priority need to tackle the loss of named posts and responsibilities, and this may involve inter-sector lobbying or compensatory adjustment to new patterns of service. It has been suggested that the removal of named posts may be a false economy and an ineffective service change, and that it is not necessarily a positive step towards mainstreaming HIV/AIDS. A coherent debate is required as a precursor to action.

6.2.5 YEAR 2: Tackle the challenge of immigration and of the unreached margins

If the aim of a Needs Assessment is to identify the most "needy" individuals, then the spotlight of isolation and lack of support falls strongly on the least privileged parts of the immigrant group and on some of the new margins such as those occupied by small numbers of white heterosexuals and bisexuals. It is mission critical that we should avoid setting up conflicts of interest because of this changing profile of need. The fact that there are new focuses of abject poverty and total lack of support does not imply that the "traditional" needy groups such as white gay men have suddenly become less important. They remain the biggest need group, but at least they are recognised and in general reachable: others are not.

Once the organisational foundations of the *Network for HIV Care and Support* have been established, it will be appropriate for the Year 2 agenda to focus on the margins, so that by the end of that year the service is comprehensive, the challenge of emergent new immigrant groups has been fully scoped, and the stakeholders (providers and users alike) have had an opportunity to assess the implications and consider the options.

6.2.6 YEAR 3: Re-evaluate the implications of HIV mainstreaming and assess the scope for a H&IOW Centre of Excellence

Year 3 of the operation of a new *Network for HIV Care and Support* is so far ahead that any agenda-setting is likely to be conjecture at best and pure speculation at worst. Nevertheless, if the development of strategy is to remain coherent and progressive, it is likely that the comprehensive overview of need (in total and in diversity) achieved in Year 2 will lay the foundation for a truly innovative phase of strategic review.

Two issues will probably dominate that process. First, the mainstreaming of HIV/AIDS (progressively normalising the lives of PLWHA and drawing their particular service needs into the general scope of service provision where appropriate) has been under way for some time. This is a complex process, and has provoked some controversy, and occasional high passion. Because it has both extremely valuable potential and very real threats, the process needs to be planned and prioritised rather than being achieved entirely on the back of other changes, such as post loss or redefinition. The *Network for HIV Care and Support* will be well placed to undertake this review.

Second, on the assumption that the mainstreaming process is not used to dismantle HIV/AIDS-specific services, it is possible to question whether a fully integrated H&IOW-wide inter-sector HIV support service might be able to seek recognition and funding as a Centre of Excellence. The notion of creating such a "centre" outside a major metropolis, with all of its scale advantages, is contentious but innovative. Whether or not it succeeded, the debate would be a fitting close of the chapter opened by this HIV Needs Assessment. It would allow the development of a genuine exemplar of best practice, and would breathe life into the commitment to listen to the voices of those who live with HIV/AIDS in Hampshire and the Isle of Wight.

Whether or not it succeeded, the debate would be a fitting close of the chapter opened by this HIV Needs Assessment. It would allow the development of a genuine exemplar of best practice, and would breathe life into the commitment to listen to the voices of those who live with HIV/AIDS in Hampshire and the Isle of Wight.

THE QUESTIONNAIRE

Location code:					

University
of Southampton

The Centre for AIDS Research
The University of Southampton

Centre for AIDS Research

ON BEHALF OF THE NHS / SOCIAL SERVICES
Needs Assessment Questionnaire

SECTION 1: ABOUT YOU

Please tell us about yourself by ticking the appropriate box(es), or stating details where asked.

1. Age
Please state: ________________________________

2. Which area do you live in?
Please tell us the nearest town or city to where to you live (eg. Winchester)
or give us the first part of your postcode (eg SO17): ________________________

3. Gender
☐ Male ☐ Female ☐ Transgender

4. Your preferred sexual partner would be:
☐ of the same sex
☐ of the opposite sex
☐ either sex

5. Relationship Status *(please tick all that apply)*
☐ Married
☐ Living with partner
☐ Single
☐ Divorced ☐ Widowed
☐ Other (please state ____)

6. Dependants

Number of children (under the age of 18)
☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more
Number of adults (above the age of 18)
☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more

7. Where do these dependents live?
☐ Live with you (please state how many dependents live with you _______)
☐ Live elsewhere (please state how many dependents live elsewhere _______)

8. Are any of your dependants HIV positive?
☐ Yes ☐ No ☐ Don't know.

9. Do you live alone?

☐ Yes ☐ No

9a. If No, do you live with

☐ Partner ☐ Relative ☐ Carer ☐ Friend
☐ Other (please state ______________________________)

10. Country of birth

Please state: ______________________________

11. Nationality

Please state: ______________________________

12. Ethnic Group

White
☐ British ☐ Irish
Any other White background. Please describe______________________________

Mixed
☐ White and Black Caribbean ☐ White and Black African ☐ White and Asian
Any other Mixed background. Please describe ______________________________

Asian or Asian British
☐ Indian ☐ Bangladeshi ☐ Pakistani
Any other Asian background. Please describe ______________________________

Black or Black British
☐ Caribbean ☐ African
Any other Black background. Please describe ______________________________

Chinese or Other Ethnic Group
☐ Chinese
Any other ethnic group. Please describe ______________________________

13. Employment Status

☐ Employed full time ☐ Employed part time ☐ Self-employed
☐ Retired ☐ Student ☐ Seeking employment
☐ Unable to work (please see question 13a)

13. a) If you are unable to work, please let us know why this is

☐ Due to immigration status ☐ Due to illness/regular medical appointments
☐ Would lose benefits ☐ Responsibility as a carer
☐ Lack of skills ☐ Lack of confidence
☐ Other (please state ______________________________)

Please give further information if appropriate: ______________________________

____

14. Housing status

☐ Own home ☐ Private Rented ☐ Housing Association
☐ Hostel ☐ Sharing accommodation with friends/others
☐ NASS accommodation ☐ Supported accommodation
☐ Other (please state ______________________________)

15. Is your current housing status affecting your ability to manage your HIV status?

☐ Yes ☐ No ☐ Don't know.

15a. If yes, please explain: ______________________________

SECTION 2: YOUR HEALTH

16. When were you diagnosed as HIV+
Please state year: ____________________________________

17. How did you become aware of your HIV status?
(Please tick appropriate box)
☐ Routine HIV test ☐ Testing during pregnancy
☐ Testing for unknown illness ☐ Partner diagnosed
☐ Other (please state ____)

18. In which country do you think you became infected?
Please state: ____________________________________

19. How did your infection probably occur?
(Please tick all appropriate boxes) ☐ Sexual intercourse (between woman and man)
☐ Sexual intercourse (between man and man) ☐ Needle use
☐ Blood transfusion/blood products ☐ Mother-to-child transmission
☐ Other (please state ____)

20. Were you first diagnosed in this country?
☐ Yes ☐ No (if no please state country where you were first diagnosed ___________________)

21. Before your diagnosis, were you informed of how to prevent HIV infection?
☐ Yes ☐ No ☐ Don't know

If yes, please state methods of prevention sources:

____

21. a) If Yes, which services gave you such information and in what form?
(please tick all that apply)

	Leaflet or printed materials	One to one discussion	Workshop or training	Other (Please state) _____________
GUM clinic	☐	☐	☐	☐
Family planning clinic	☐	☐	☐	☐
School/college/educational establishment	☐	☐	☐	☐
Family Doctor (GP)	☐	☐	☐	☐
Social services	☐	☐	☐	☐
Social group or interest group *(please state)* _____________________	☐	☐	☐	☐
Voluntary organisation/service	☐	☐	☐	☐
Television	☐	☐	☐	☐
Radio	☐	☐	☐	☐
Newspapers/magazines	☐	☐	☐	☐
Internet site or chat room	☐	☐	☐	☐
Sexual Partner(s)	☐	☐	☐	☐
Friends	☐	☐	☐	☐
Family	☐	☐	☐	☐
Youth Service	☐	☐	☐	☐
Religious organisation	☐	☐	☐	☐
Prison Service	☐	☐	☐	☐
Gay Community Health Service / Gay Men's Project	☐	☐	☐	☐
Gay pubs/clubs	☐	☐	☐	☐
Other *(please state)* _____________________	☐	☐	☐	☐

22. To what extent do you think the following factors may have contributed to you being infected with HIV?

	Greatly contributed to infection	May have contributed to infection	Did not contribute to infection	Not sure
Lack of information about sex at school/college	☐	☐	☐	☐
Lack of information about relationships at school/college	☐	☐	☐	☐
Lack of confidence in negotiating safer sex	☐	☐	☐	☐
Lack of information in the media	☐	☐	☐	☐
Lack of information from health settings (GP, family planning, GUM)	☐	☐	☐	☐
Use of alcohol	☐	☐	☐	☐
Use of recreational drugs	☐	☐	☐	☐
Drinks being spiked	☐	☐	☐	☐
Lack of access to condoms	☐	☐	☐	☐
Didn’t think it could ever happen to me	☐	☐	☐	☐
Took a risk	☐	☐	☐	☐
Other *(please state)* ____________________	☐	☐	☐	☐

23. Do you think any of these sources of information or awareness could be improved?

☐ Yes ☐ No ☐ Don’t know

23. a) If yes, how could these services have been improved?

____

SECTION 3: SERVICES YOU USE OR NEED

24. Which GUM clinic do you use? (Please tick all that apply)

☐ Andover
☐ Basingstoke
☐ Bournemouth
☐ Brighton
☐ Frimley
☐ Guildford
☐ Isle of Wight
☐ London: Chelsea and Westminster
☐ Portsmouth
☐ Southampton
☐ Winchester
☐ Other (please specify ____)

24.a) Which services do you access at this clinic? (Please tick all that apply)

☐ HIV monitoring or blood testing
☐ HIV drug treatment
☐ Nutrition advice for HIV related issues
☐ Treatment for other infections related to HIV status
☐ Medication advice and support
☐ Other (please specify ____)

24.b) When did you last visit a GUM clinic? (Please tick all that apply)

☐ within the last week
☐ within the last 4 weeks
☐ within the last 3 months
☐ within the last 6 months
☐ within the last year
☐ over a year ago

24.c) If you do not use a GUM clinic, please explain why: ________________________

25. Do you use the following health-related and emotional support services? (Please tick all that apply)

☐ HIV Health advisor
☐ HIV Counsellor
☐ Other Counsellor
☐ HIV Pharmacist
☐ Dental Care (HIV Dentist)
☐ HIV Clinical Nurse Specialist
☐ Mental Health Services
☐ GP for HIV Issues
☐ Other (please specify ____)

25a. What are you using those health-related and emotional support services for? (Please tick all that apply)

☐ HIV monitoring or blood testing
☐ Nutrition advice for HIV issues
☐ Medication advice and support
☐ HIV drug treatment
☐ Treatment for other infections related to HIV status
☐ Other (please specify ____)

25b. When did you last visit these health-related and emotional support services? (Please tick all that apply)

☐ within the last week
☐ within the last 3 months
☐ within the last year
☐ within the last 4 weeks
☐ within the last 6 months
☐ over a year ago

25c. If you do not use these health-related and emotional support services, please explain why:

____

26. Do you use the following social care and voluntary services? (Please tick all that apply)

☐ Gay community advice / support centre of project
☐ HIV Social Worker
☐ Positive Action – Aldershot
☐ Positive Voice
☐ Positively Caring
☐ Inscape
☐ Ribbons Centre
☐ Positive Action – Portsmouth
☐ Groundswell
☐ Body Positive Dorset

26a. Which services do you access at these social care and voluntary organisations? (Please tick all that apply)

☐ Nutrition advice for HIV related issues
☐ Help at home
☐ Financial/ benefits advice
☐ Safer sex information
☐ Social and emotional support
☐ Housing advice
☐ Access to immigration advice
☐ Other (please specify ____)

26b. When did you last visit these social care and voluntary support services? (Please tick all that apply)

☐ within the last week
☐ within the last 3 months
☐ within the last year
☐ within the last 4 weeks
☐ within the last 6 months
☐ over a year ago

26c. If you do not use these social care and voluntary support services, please explain why:

____

27. How important do you consider these service providers to be?

	Essential	**Important**	**Not important**	**Not needed now**
GUM Clinic				
HIV health advisor				
HIV counsellor				
Other counsellor				
HIV pharmacist				
Dental care (HIV dentist)				
HIV clinical nurse specialist				
Mental health services				
GP for HIV issues				
Gay community advice/support centre or				
Inscape				
HIV social worker				
Local social worker				
Ribbons Centre				
Positive Action - Aldershot				
Positive Action – Portsmouth				
Groundswell				
Positive Voice				

Positively Caring				
Body Positive Dorset				

28. Are you aware of the services available to you locally?
(please tick a response for all services)

Services	Aware and have used	Aware but have not used	Not aware
Drug therapy	☐	☐	☐
Treatment for other infections related to HIV status	☐	☐	☐
Nutrition advice	☐	☐	☐
Counselling	☐	☐	☐
Dental care	☐	☐	☐
Support/advice centre	☐	☐	☐
Family Doctor (GP)	☐	☐	☐
GUM/HIV Clinic	☐	☐	☐
Social Services / Support	☐	☐	☐
Voluntary HIV Services / Support	☐	☐	☐
Mental Health Services / Support	☐	☐	☐
Gay Community Health Projects / Services	☐	☐	☐
Other *(please state)* ___________________________	☐	☐	☐

29. Are you satisfied with the services you are receiving?
(please tick a response for all services)

Treatment	Very good	Adequate	Not adequate	Not available	Have not used
Drug therapy	☐	☐	☐	☐	☐
Treatment for other infections related to HIV status	☐	☐	☐	☐	☐
Nutrition advice	☐	☐	☐	☐	☐
Counselling	☐	☐	☐	☐	☐
Dental care	☐	☐	☐	☐	☐
Family Doctor (GP)	☐	☐	☐	☐	☐
GUM/HIV Clinic	☐	☐	☐	☐	☐
Social Services / Support	☐	☐	☐	☐	☐
Voluntary HIV Services / Support	☐	☐	☐	☐	☐
Mental Health Services/Support	☐	☐	☐	☐	☐
Gay Community Health Projects / Services	☐	☐	☐	☐	☐
Other *(please state)* _______________	☐	☐	☐	☐	☐

29a. If you have ticked 'have not used' for any service, please could you explain why

____

30. Do you travel outside Hampshire to access any of the services you receive?

☐ Yes ☐ No (if no, go to question 31)

If Yes, please list the services you travel to and where are they located:

Service: ___________________ Location: ______________________

30a. If you have answered yes to the previous question, why do you access these services away from your local area?

(Please tick all answers which apply)

Local services not adequate ☐
Location of drug trial ☐
Friends use the service ☐
Same location as job ☐
HIV specialist service ☐
Friendliness of staff ☐
Anonymity ☐
Other *(please state)* ☐

____

Please could you explain your reasons for using services outside of your local area in more detail:

____

SECTION 4: YOUR NEEDS

31. What information relating to HIV do you require? *(please tick appropriate boxes)*

	Yes, I need this	No, I don't need this	I don't know if I need this
Treatment/therapy support	☐	☐	☐
HIV and the effects on the body	☐	☐	☐
Safer sex	☐	☐	☐
Relationships	☐	☐	☐
Sexual problems	☐	☐	☐
Coping with a recent diagnosis	☐	☐	☐
How to live healthily with HIV	☐	☐	☐
Avoiding other infections	☐	☐	☐
Who to tell and how to tell	☐	☐	☐
Other *(please state)*	☐	☐	☐

____

32. What services do you require? *(please tick appropriate boxes)*

	Yes, I need this	No, I don't need this	I don't know if I need this
Emotional support	☐	☐	☐
Counselling	☐	☐	☐
Depression/Mental Health Support	☐	☐	☐
Health services	☐	☐	☐
Benefits, allowances and other financial support advice	☐	☐	☐
Housing and accommodation advice	☐	☐	☐
Employment opportunities	☐	☐	☐
Training and further education	☐	☐	☐
Street (recreational) drug support	☐	☐	☐
Alcohol support	☐	☐	☐
Support for children	☐	☐	☐
Immigration issues advice	☐	☐	☐
Legal services	☐	☐	☐
Support to live at home	☐	☐	☐
Support by others with HIV	☐	☐	☐
Other *(please state)*	☐	☐	☐

____

32. a) Please feel free to add any comments on why you need these services and what you hope to gain from them.

____

33. How important do you consider these services?
(please tick appropriate box)

	Essential	Important	Not important	Not needed now
HIV drug treatment	☐	☐	☐	☐
HIV monitoring/blood testing	☐	☐	☐	☐
Treatment for other infections related to HIV status	☐	☐	☐	☐
Nutrition advice for HIV related issues	☐	☐	☐	☐
Social and emotional support	☐	☐	☐	☐

Complementary therapies	☐	☐	☐	☐
Help at home	☐	☐	☐	☐
Housing advice	☐	☐	☐	☐
Financial/benefits advice	☐	☐	☐	☐
Immigration advice	☐	☐	☐	☐
Other *(please state)*	☐	☐	☐	☐

____

34. Who have you told about your HIV status?

	Yes, I have told	I have told some of this group	No, I have not told	Not applicable
Partner	☐	☐	☐	☐
Children	☐	☐	☐	☐
Parents	☐	☐	☐	☐
Wider family	☐	☐	☐	☐
Friends	☐	☐	☐	☐
Employer	☐	☐	☐	☐
Work colleagues	☐	☐	☐	☐
Family doctor (GP)	☐	☐	☐	☐
Dentist	☐	☐	☐	☐
Other *(please state)*	☐	☐	☐	☐

____

35. Of the people you have told, who have you received most support from?

Please state: ____

36. Have you experienced any negative responses/attitudes towards you because of your HIV status?

☐ Yes ☐ No

If yes, please explain : ____

37. If you answered yes to the previous question, how do you think this situation could be improved?

____

OPTIONAL QUESTION

If you are happy to do so, please state your immigration status:

☐ Not applicable (UK passport)
☐ on a work permit
☐ Receiving support from NASS (National Asylum Support Service)
☐ Other *(please state ____)*
☐ EU National
☐ Seeking asylum
☐ on a student VISA
☐ I have Indefinite leave to remain

ADDITIONAL COMMENTS

Please use this space if you have any further comments to make about the questionnaire or project as a whole.

(As this information is being used to improve support and services, any additional help you can give is very useful).

Thank you very much for your time

Appendix 2

Information about voluntary support organisations in Hampshire

Body Positive Dorset:
For those living in South West Hampshire, Body Positive Dorset, based in Bournemouth, provides an extensive range of complementary therapies, support, advice and information services.

Groundswell:
Groundswell is a registered charity founded in 1989 to provide support for people living with HIV, irrespective of race, religion, lifestyle or how they come to be infected. Over the last 17 years we have provided care and support to over 250 people living with HIV. Using a team of trained and experienced volunteers managed by a professional staff Groundswell provides home based support, befriending and care to those people living with HIV, particularly from marginalised groups, to relieve social isolation, to build self esteem and empower people and to enable people to access statutory medical and social services. Groundswell works in partnership with the health and social services and last year we supported 54 HIV positive individuals plus their carers, family and friends, providing 384 individual visits to clients and this represents 967 hours of care during the year and 6,500 miles travelled.

Ribbons Centre:
The centre is based in Southampton but the services are available to any Hampshire or Southampton resident, it is a voluntary organisation offering support, advice and information to people both infected and affected with HIV. The Centre is staffed during normal office hours. If you telephone the Centre outside its opening hours, leave a short message on the answer phone and we will return your call as soon as possible. You can be assured that any information you give will be kept in the strictest confidence.

Positive Action:
Positive Action (PA) provides a comprehensive range of information and support services to individuals and families affected by HIV/AIDS across North & Mid Hampshire, West Surrey and Portsmouth; and information and advice to the general public to help reduce further spread and discrimination of HIV. The team at PA is proud of the high quality support provided to its clients. It is committed to working in partnership with the statutory bodies and other voluntary organisations to support those affected by HIV. PA facilitates integration of social care and clinical treatment and is the only organisation to provide a drop-in facility within this catchment area which provides a safe haven and a central base for multi-disciplinary assessment, care planning and service provision. PA ensures that clients know what services are available from PA and other agencies and aims to provide culturally-appropriate services

Positively Caring:
Support for carers and family members across Hampshire is provided by Positively Caring which meets monthly in Winchester with telephone support available at other times.

Positive Voice:
Positive Voice (PV) is an independent and diverse group of HIV+ people. PV is intended for anyone who is HIV+ and only members may attend meetings. PV is an opportunity for all HIV+ people to have a stronger voice in the provision of relevant services to meet the current needs and requirements of HIV+ people who would otherwise be unheard. PV exists to empower people living with HIV/AIDS; to act as advocate for its members; to challenge stigma and ignorance; to give a voice to HIV+ people; to ensure their views are represented at all levels of planning, development, strategy and decision making processes; to provide a means of involving people in decision making processes; to identify areas of needs and liaise with relevant service providers to address those needs; to contribute to the strategic planning of HIV services and to influence planning and commissioning bodies for the benefit of all members; to address any sexual health issues for impact on HIV.

Seeds of Africa:
Seeds of Africa is a self-help support group for African people around sexual health. The aims of the group are to raise awareness about sexual health and HIV/AIDS; to raise awareness of African culture and identity, especially people who have been infected and affected by HIV/AIDS; to provide a save meeting place for Africans who live in North East Hampshire. Our objectives: to organise get-together in a community centre once

a month; to organise and share African food/ refreshments to combat social isolation; to invite guest speakers from health and social care professionals to raise awareness about sexual health and social care services; to advice and support especially individuals, families who are infected and affected by HIV/AIDS to improve their health and social conditions; to organise outings to London and other places of interest, and create links with other groups in the South East of England; to provide and create prevention, educational resources e.g. leaflets, posters, videos/ DVDs and live drama shows on safer sexual health messages; to create better understanding and awareness of African community need to the local authorities and voluntary organisations.

Appendix 3

Interviews with Service Providers

LOCATIONS	ROLES
Body Positive Dorset	Director
Groundswell	Project Manager
GUM Basingstoke	Health Advisor
GUM Basingstoke	HIV Consultant
GUM Isle of Wight	Clinical Lead GUM
GUM Isle of Wight	Senior Staff Nurse GUM, HIV lead
GUM Portsmouth	Clinical Nurse specialist HIV
GUM Portsmouth	HIV Consultant
GUM Southampton	HIV Consultant
GUM Southampton	HIV Counsellor
GUM Southampton	HIV Pharmacist
GUMs Winchester and Andover	Health Advisors
GUMs: Winchester, Andover and Isle of Wight	HIV Consultants
Hampshire County Council	Commissioning Officer
Hampshire County Council	HIV Social Worker
Hampshire Police	Diverse communities officer for the LGBT community
Inscape	Service Manager
Isle of Wight PCT	Head of Health Promotion
Isle of Wight PCT	Outreach Worker for MSM
Isle of Wight PCT	Safer Communities, Care Manager with a blood-borne viruses remit
Isle of Wight PCT	Senior Health Promotion Specialist
Mid Hampshire PCT	Head of Health Promotion
Newtown Health Clinic	Clinical Nurse Specialists HIV (2)
Newtown Health Clinic	HIV Specialist Dentist
North Hampshire PCT	HIV Prevention Project Manager
Portsmouth City Council	Assistant Head of Social Care for Adults
Portsmouth City Council	HIV Lead (Adult Social Care)
Portsmouth City Council	Regional Manager, South of England Refugee and Asylum Seeker Consortium
Positive Voice	Coordinator
Positive Action	Client Services Manager
Ribbons Centre	Coordinator
Southampton City Council	Locality Services Manager
Southampton City Council	New Communities Manger
Southampton City Council	Principal Planning Officer
Southampton City Council	Project Worker (Housing Equalities)
Southampton City PCT	Head of Health Promotion
Test Valley Borough	Health Strategy Coordinator