

Phase 1 Research Report on the IMPRESS Health 2 (Interreg IVA Channel Programme) Project 4282

Understanding factors behind the late testing and diagnosis of HIV



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1.0 Background to the study

By the end of 2012, an estimated 98,400 people were living with HIV in the UK (Public Health England, 2013). Approximately 20% of this number are likely to be unaware of their infection and about half (47%) of the 6,360 people newly diagnosed with HIV in 2012 were identified at a late stage, defined as having a CD4 count <350 cells/mm³ within three months of diagnosis. New diagnoses among men who have sex with men (MSM) also reached an all-time high in the same year (Public Health England, 2013). In the same year, more than 131,000 new HIV infections were reported in Europe and Central Asia, with 29,000 of these being diagnosed in the European Union and European Economic Area (http://ec.europa.eu/health/sti_prevention/hiv_aids/index_en.htm accessed 6th June 2014). Effective treatment of the virus exists, but there is still no cure, nor a preventive vaccine. Current public health policy in relation to HIV is therefore focused on prevention and support for people living with HIV/AIDS.

Although men who have sex with men continue to be at higher risk of HIV infection overall, individuals from other groups are more likely to present later than men who have sex with men for HIV testing and subsequent diagnosis (Johnson et al, 2010). As a consequence, heterosexual men are almost twice more likely to be diagnosed later with HIV than men who have sex with men (65% versus 34%), and the corresponding figure for heterosexual women is also higher at 57% (Public Health England, 2013). The figures for late diagnosis are also higher in comparison to men who have sex with men amongst black African men (66%), black African women (61%), black Caribbean women (66%), black Caribbean men (47%), white women (44%) and white men (47%) in 2012 (Public Health England, 2013).

Older age has also been associated with late presentation in a number of studies reviewed by Mukolo et al (2012) as borne out by the latest figures from Public Health England (2013). These demonstrate that 63% of adults diagnosed with HIV in 2012 were over 50 years of age in comparison to 44% of those diagnosed aged 49 or less. Low socio-economic status, immigration status, poor literacy and lower educational attainment have also been correlated with a higher risk of late diagnosis. These suggest that stigma, lack of knowledge and poor understanding of HIV risk factors continue to impact upon early testing in many sectors of society, and a greater understanding of these issues is crucial to the development of effective public health strategies and testing programmes aimed at increasing the early uptake of HIV testing amongst each of these groups as well as men who have sex with men (Mukolo et al, 2012).

Individuals who are diagnosed early can gain greater benefit from active antiretroviral therapy (ART) and as a consequence, early testing can contribute to a near-normal lifespan for most HIV positive patients (Castilla et al, 2002). Late presentation and diagnosis are clearly detrimental to long-term health status however, and are associated with increased morbidity and mortality as well as the potential for those affected by the virus to transmit it to others (Public Health England, 2013). In addition, it has been demonstrated that individuals diagnosed late with HIV also incur significantly higher medical costs during the course of their lives than those diagnosed and subsequently treated earlier (Krentz et al, 2004). Public Health England (2013) found that over a quarter (28%) of people diagnosed with HIV in 2012 were already severely immunocompromised, defined as having a CD4 cell count <200 cells/mm³ at diagnosis, and likely to require longer and more frequent admissions to hospital than those diagnosed earlier.

The reasons for late presentation, testing and diagnosis are many and varied however (Yazdanpanah et al, 2010). Studies suggest that barriers exist at individual, societal, medical, and public policy levels, and each of these must be better understood if rates for early detection are to be improved (Mukolo et al, 2012). Mukolo et al's (2012) review of the literature suggests that living in a region with a lower known prevalence of HIV increases the risk of late diagnosis, possibly because the risk of infection is perceived to be lower or there is a greater stigma associated with the condition in such areas (Adler et al, 2010). Cognitive appraisal of actual or potential risk factors also tend to influence presentation and diagnosis timelines, with denial or cognitive dissonance being identified as exacerbating factors in a number of studies (Yazdanpanah et al, 2010; Hanf et al, 2011; Dowson et al, 2012). Similarly, fear of the consequences of a positive HIV test, including anticipation of pain, illness, premature death, stigma, discrimination and diminished economic and wage-earning capacity may all contribute to an individual's prevarication with regard to HIV testing (Hanf et al, 2011; Mukolo et al, 2012; Dowson et al, 2012). These assume that the individual is aware that they have been exposed to HIV risk whereas many may not in fact be aware of this at all.

Mukolo et al's (2012) review highlighted that presentation decisions were sometimes made within social contexts characterised by hostility towards people living with HIV and AIDS, the stigma associated with stereotypical assumptions about those most at risk of infection, knowledge deficits regarding relative risk, as well as unusual or unhelpful beliefs about the causes of HIV, individual responsibility for infection, and attitudes about human sexuality and behaviour. Fear of disclosure and subsequent ostracisation within close-knit social communities was a common reason for not being tested in some migrant populations, as was fear of economic, legal or immigration sanctions (Yazdanpanah et al, 2010). This later study showed that specific barriers exist for many migrant populations, including the stigma associated with HIV positive status within African communities in the UK, the prevailing belief that it is a life-threatening condition, anxiety that the results of an HIV test may not remain confidential, and that diagnosis of HIV infection would either reduce an individual's chance of success when applying for permanent residence or bring them to the attention of immigration services for questioning or deportation (Yazdanpanah et al, 2010).

Evidence suggests that many opportunities to identify and test those at risk in health facilities are being missed (Sullivan et al, 2005; Sudarshi et al, 2008). Potential barriers include lack of time and uncertainty about consenting and pre-test counselling requirements, logistical barriers such as competing priorities, lack of knowledge and language barriers. Deficits in the knowledge, education and training of physicians for this task have also been identified, and they may therefore be unaware of which groups and behaviours indicate a high risk for HIV infection and lack confidence to suggest that a test may be necessary. Wohlgemut et al (2012) warn against stereotyping 'at risk' patients however, as 20% of diagnoses in their study occurred in those without a clear transmission risk, suggesting that early diagnosis is complicated by rapidly changing socio-demographic factors and subtle shifts in at risk HIV populations in the UK. In particular, opportunities to identify HIV infection in those who are older, white British, and those from socially deprived communities are often missed.

Current policies in the UK tend to target individuals who are deemed to be at 'high risk' of being infected. For example, the Terrence Higgins Trust only provides postal HIV test kits to African people or gay or bisexual men who live in England (Terrence Higgins Trust, 2013). Mukolo et al

(2012) point out that most targeted HIV prevention and testing interventions do not specifically target heterosexual males, meaning that they are provided with fewer opportunities for HIV testing and diagnosis than men who have sex with men, injecting drug users and women attending antenatal care where HIV testing is routinely undertaken.

Many studies have suggested that there is a need to develop interventions that increase HIV testing and facilitate earlier entry into care, such as routine screening in healthcare and non-clinical settings for those at risk of HIV (Girardi et al, 2007; Yazdanpanah et al, 2010; Garcia de Olalla et al, 2011; Camoni et al, 2013). Branson et al (2006) suggest that it might be feasible to include HIV testing as a routine part of healthcare practice for all adults and adolescents aged 13-64 years as proposed by the United States Centers for Disease Control and Prevention, whilst guidance from the World Health Organisation (2007) recommends the use of an 'opt-out' approach; including the provision of health care provider-initiated testing aided by simplified pre-test information and improved health counselling facilities. In this model, individuals attending healthcare settings would routinely be offered a recommended HIV test although they would be free to decline such a test.

It is clear from the evidence that further work needs to be done to raise awareness of HIV risk and transmission together with the benefits of early testing and diagnosis both for the general public and healthcare professionals. Current examples of health promotion interventions include National HIV Testing Week (which takes place annually in the UK) and World AIDS Day. Evidence also supports the use of mass media campaigns to raise awareness and increase the uptake of testing and signpost concerned individuals to appropriate services. There is an emerging evidence base for the delivery of targeted HIV prevention messages using the internet and social media since these technologies offer the potential to reach far deeper into certain target populations (Rashbrook, 2013), and may also be used to de-stigmatise HIV/AIDS by emphasising the positive benefits of testing and portray HIV as a chronic rather than a life threatening or debilitating condition (Mukolo et al, 2012).

Dowson et al (2012) suggest that a more proactive approach by healthcare professionals, including general practice, may result in earlier testing by making it more convenient and accessible. Other suggestions include improving recognition of potential indicators of infection amongst physicians and other healthcare providers (Yazdanpanah et al, 2010), continuing education and the use of financial incentives to motivate them to discuss HIV risk with their patients (Lo et al, 2011; Dowson et al, 2012). Pereira et al (2011) suggest that since nurses are in the frontline in 'the war against the HIV pandemic', they too must improve their knowledge and intensify their efforts to support and encourage people to have an HIV test. Schwarz et al (2011) meanwhile, asserts that public health messages to increase HIV testing should include up-to-date information about the ways in which HIV can be transmitted, the fact that effective, tolerable and low cost medication is readily available for HIV; and that early diagnosis significantly improves an infected individual's health outcomes.

2.0 Project aim(s) and objectives

The overall aim of the IMPRESS Health 2 Project is to identify the reasons behind late testing and diagnosis of HIV in Kent and Medway (UK), and Picardy (France), and subsequently design and test new interventions to improve rates of earlier diagnosis in these areas. The two regions have been paired because despite differences between the two regions in the methods used to test patients for HIV, there is a similar prevalence in the levels of new HIV diagnoses and the percentage of these that are classified as 'late' i.e. with a CD4 count <350 cells/mm³ within three months of diagnosis.

The aim of the first research phase of the project, on which this report is based, was to investigate and set out the reasons behind late diagnosis in Kent and Medway (UK). Consequently, following a review of the literature, the research team identified some of the barriers and challenges known to exist in the literature, both from the perspective of patients and healthcare professionals, although these had not been studied locally within the context of care delivered in Kent and/or Medway.

Having ascertained the main theoretical barriers to early HIV testing and diagnosis, it was then important to contextualise these within the local health economy and consider how applicable these reasons were to the local setting. The following objectives were therefore set for the project which was designed to:

- Recruit and interview a target number of HIV positive patients who had been diagnosed in the previous five years (from the end of 2008 to the end of 2013) to elicit their personal experiences and any potential barriers around the testing and diagnosis of their HIV infection
- Recruit and interview a target number of healthcare professionals from four local trusts (Medway NHS Foundation Trust, Maidstone and Tunbridge Wells NHS Trust, Kent Community Health NHS Trust and East Kent Hospitals University NHS Foundation Trust) to elicit their views and experiences and any challenges and barriers regarding testing for and diagnosing HIV infection
- Review clinical data of patients diagnosed as HIV positive within the last five years in Kent and Medway to establish demographic data and patterns relating to certain criteria, such as gender, age, etc.
- Analyse the data gathered from both sets of participants (patients and healthcare professionals) to elicit key themes and patterns that will provide the basis of discussion for the next stage intervention phase of the IMPRESS Health 2 project in phase 2 of the project.

3.0 Findings from clinical review of patient data

3.1 Clinical settings in which data were collected

As part of the first phase in the project, health professionals working in participating centres in Kent and Medway were asked to provide data on patients diagnosed with HIV for the preceding five years. A standard EXCEL format was developed for this purpose and data were collected from the following areas, consisting of the HIV clinics in two acute hospitals and the HIV services provided across the region by a community health trust:

- Maidstone and Tunbridge Wells NHS Trust - Rubin Clinic, GUM Services
- Medway NHS Foundation Trust - GUM Department, Green Zone
- Kent Community Health NHS Trust - The Gate Clinic, Kent and Canterbury, Canterbury
- Kent Community Health NHS Trust – William Harvey Hospital, Ashford
- Kent Community Health NHS Trust – Royal Victoria Hospital, Folkestone
- Kent Community Health NHS Trust – The Riverside Clinic, Gravesend Community Hospital
- Kent Community Health NHS Trust – Queen Elizabeth the Queen Mother Hospital, Margate

3.2 Data collected for the review

The following data were elicited as a result of discussion with clinicians from each of the participating centres and staff from the University. Data collection was carried out by staff in each clinical centre under the coordination of Sharon Manship and the project administrator Sarah Keeling-Smith. Data were analysed by Stephen Clift.

- Sex of patient (male/female)
- Ethnic origin (white British, white Irish, Asian/Asian British, Black African/Caribbean or Black British, mixed ethnicity, other)
- Highest level of education attained (compulsory secondary, further education, higher education)
- Occupational status (employed full-time, employed part-time, unemployed, in education or training, retired, self-employed)
- Current or most recent employment (unskilled manual including service and retail, skilled manual, office/routine administrative work, managerial/supervisory, professional)
- Country or region of birth (UK, EU, other i.e. rest of world), likely mode of transmission (men who have sex with men, intravenous drug users, heterosexual, other)
- Circumstances/place of first test (GUM clinic, on hospital admission due to illness, antenatal screening, other)
- Relationship status at time of infection (single, married, civil partnership, cohabiting, separated, divorced, widowed)
- Whether or not the patient was registered with a GP.

Details were requested on HIV/AIDS defining illnesses recorded at the time of diagnosis, together with any other non-HIV defining illnesses. Few data were available on the details of current or most recent employment and in some cases the categorisation provided of occupational status appeared inconsistent with the job descriptions and educational level. For this reason, data on employment and educational status were judged to be unreliable and were therefore excluded from this part of the analysis.

3.3 Patient CD4 counts across and within study settings

Data were provided from each of the centres involved in the study for a total of 242 patients, with information on CD4 counts at first diagnosis provided for 240 individuals and missing/unknown for 2 individuals. The histogram below shows the distribution of CD4 levels. The cut-off criterion for late diagnosis is included. One hundred and forty-five patients (60.4%) had CD4 counts on diagnosis of 350 or less, and 95 (39.6%) had CD4 counts greater than 350. No significant differences in the levels of late diagnosis were found across the health trusts involved in the project.

Figure 1: HIV positive patients' CD4 counts at initial diagnosis in Kent and Medway centres

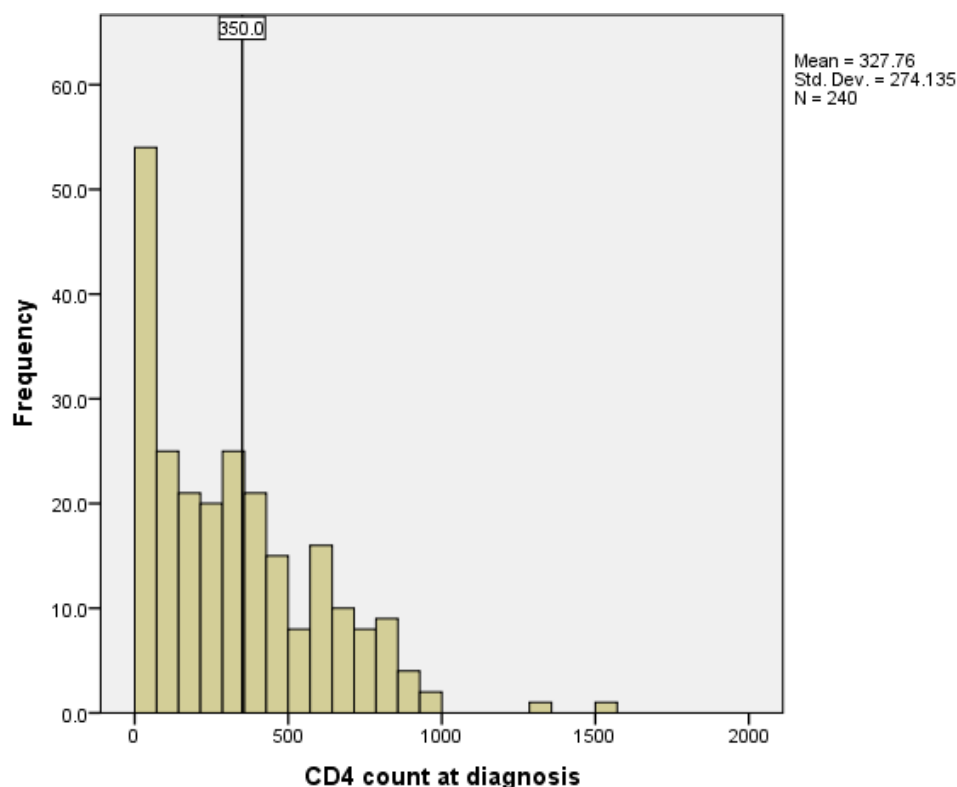


Table 1: CD4 status on diagnosis by participating centre

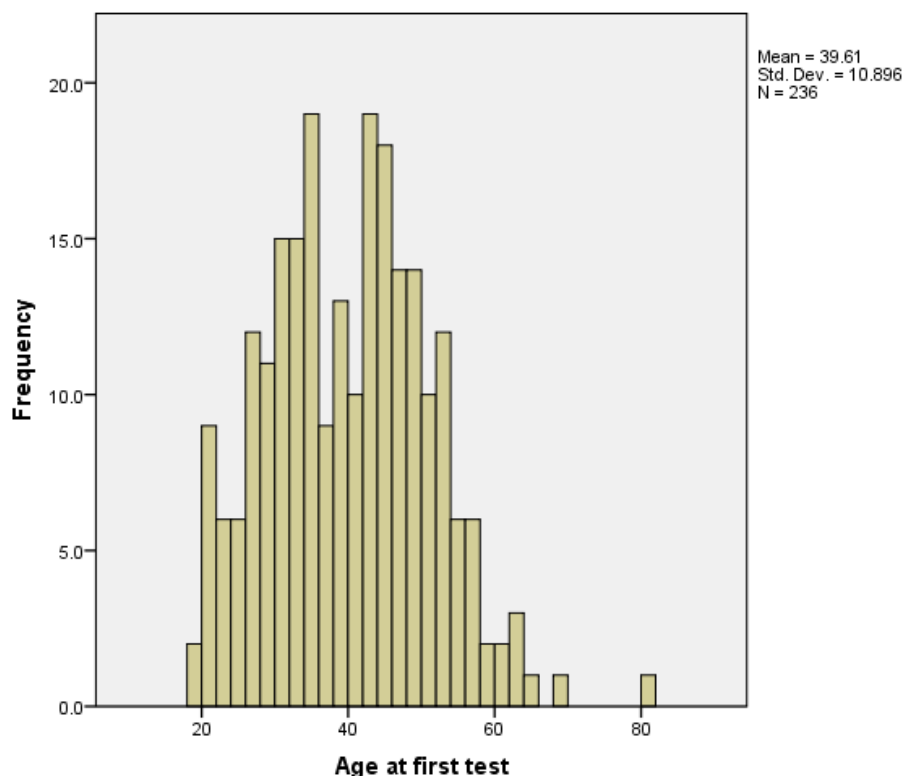
Participating Centre		CD4 count 350 or less	CD4 count 351 or more	Total
Maidstone and Tunbridge Wells	Number	42	23	65
	Percentage	64.6%	35.4%	100.0%
Medway	Number	37	19	56
	Percentage	66.1%	33.9%	100.0%
Kent Community Health NHS Trust	Number	66	53	119
	Percentage	55.5%	44.5%	100.0%
Total	Number	145	95	240
	Percentage	60.4%	39.6%	100.0%

3.4 Investigation of factors associated with late diagnosis

3.4.1 Age

It is clear that HIV infection is no respecter of age. The mean age of the sample at first test was 40, with a wide range from 19 to 81 years (N=236). The following histogram shows the distribution of age at first diagnosis. The distribution appears to be bi-modal with peaks at 38 and 43 years, but this is likely to be a reflection of the moderate sample size and the units on the x-axis. Those diagnosed late are a little over four years older than patients diagnosed early (independent t = 2.89, $p < 0.005$).

Figure 2: Age at first test and diagnosis of HIV infection



Those diagnosed late were just over four years older than patients diagnosed early (independent t = 2.89, $p < 0.005$).

Table 2: Age at first test CD4 >350 versus CD4 349 or less

	N	Mean	Standard Deviation	Std. Error Mean
CD4 350 or less	141	41.24	10.922	0.920
CD4 351 or more	94	37.11	10.475	1.080

The following sections present comparisons of the late and early diagnosed patient groups in relation to further patient characteristics with the exception of occupational status. Multiple categories are condensed as appropriate given the frequency of cases. Simple comparisons were made using the chi-squared test.

3.4.2 Relationship status at time of infection

Seven relationship status categories occur in the data, with 'single', 'cohabiting' and 'married' the most frequent categories. A small number of patients were described as 'civil partnership', 'separated', 'divorced' or 'widowed'. There was no indication in the data that relationship status had any bearing on late or early diagnosis.

3.4.3 Sex of patients

There was approximately twice the number of men (162) in the sample as women (79). Women are more likely to be diagnosed late when compared with men. This difference is marginally significant (chi-squared 2.74, df1, $p < 0.10$).

Table 3: Sex of patients CD4 >350 versus CD4 of 349 or less

Sex of patient		CD4 count 350 or less	CD4 count 351 or more	Total
Male	Number	92	70	162
	Percentage	56.8%	43.2%	100.0%
Female	Number	53	25	78
	Percentage	67.9%	32.1%	100.0%
Total	Number	145	95	240
	Percentage	60.4%	39.6%	100.0%

3.4.4 Ethnic origin of patients

Most patients in the sample fell into two ethnic groups: White British or Black African, Caribbean or British; with a small number of patients in the remaining categories provided. The sample was therefore divided into White British and 'Other'. It is clear that ethnic background does have a bearing on late diagnosis with 70.2% in the minority ethnic groups having CD4 counts of 350 or less at diagnosis compared with 53.0% in the white group (chi-squared 7.26, df1, $p < 0.01$).

Table 4: Ethnicity of patients CD4 >350 versus CD4 of 349 or less

		CD4 count 350 or less	CD4 count 351 or more	Total
White	Number	71	63	134
	Percentage	53.0%	47.0%	100.0%
Other	Number	73	31	104
	Percentage	70.2%	29.8%	100.0%
Total	Number	144	94	238
	Percentage	60.5%	39.5%	100.0%

3.4.5 Educational level of patients

No information was available in just over 40% of cases of the patient's educational level. In those for whom data were available, just over half (56%) had not progressed beyond compulsory secondary education. Similar proportions of the remainder had completed further (21%) and higher education (23%). Interestingly, those with only a secondary education had the lowest level of late diagnosis. The differences in the table below are marginally (chi-squared 5.01, df2, $p < 0.10$).

Table 5: Educational level of patients with CD4 >350 versus CD4 of 349 or less

		CD4 count 350 or less	CD4 count 351 or more	Total
Compulsory secondary education	Number	40	38	78
	Percentage	51.3%	48.7%	100.0%
Further education	Number	22	8	30
	Percentage	73.3%	26.7%	100.0%
Higher education	Number	21	11	32
	Percentage	65.6%	34.4%	100%
Total	Number	83	57	140
	Percentage	59.3%	40.7%	100.0%

3.4.6 Occupational status of patients

Six categories of occupational status were used. Almost half of the sample was classified as 'employed full-time' and just over a quarter as 'unemployed'. The categories are difficult to condense meaningfully so Table 6 shows the breakdown of late and early diagnosis for each group. There is no clear indication that employment status has any bearing on levels of CD4 at diagnosis.

Table 6: Occupational status of patients with CD4 >350 versus CD4 of 349 or less

		CD4 count 350 or less	CD4 count >351	Total
Full-time employment	Number	73	55	128
	Percentage	57.0%	43.0%	100.0%
Part-time employment	Number	11	5	16
	Percentage	68.8%	31.3%	100.0%
Unemployed	Number	35	22	57
	Percentage	61.4%	38.6%	100%
In education or training	Number	5	2	7
	Percentage	71.4%	28.6%	100%
Retired	Number	6	1	7
	Percentage	85.7%	14.3%	100%
Self-employed	Number	0	1	1
	Percentage	0.0%	100%	100%
Total	Number	130	86	216
	Percentage	60.2%	39.8%	100.0%

3.4.7 Place of birth of patients

Just over half of the sample (56%) was born in the UK with 39% born outside the UK and European Union. A small minority (5%) originated from within the European Union. The percentage of late diagnosis for patients born in the UK are lower than for those born elsewhere in the world (chi-squared 6.67, df2, p=0.10).

Table 7: Place of birth of patients with CD4 >350 versus CD4 of 349 or less

		CD4 count 350 or less	CD4 count >351	Total
UK born	Number	71	62	133
	Percentage	53.4%	46.6%	100.0%
Rest of world	Number	74	32	106
	Percentage	69.8%	30.2%	100.0%
Total	Number	145	94	239
	Percentage	60.7%	39.3%	100.0%

3.4.8 Likely transmission route for patients

The percentage of late diagnosis varies by transmission group. Men who have sex with men show the lowest proportion of late diagnoses compared with other groups. The differences in the table are statistically significant although several cells have expected values below zero and this result should be treated with caution (Chi-squared 8.15, df3, p<0.05).

Table 8: Likely transmission route for patients with CD4 >350 versus CD4 of 349 or less

		CD4 count 350 or less	CD4 count >351	Total
Men who have sex with men	Number	44	44	88
	Percentage	50.0%	50.0%	100.0%
Intravenous drug users	Number	4	1	5
	Percentage	80.0%	20.0%	100.0%
Heterosexual	Number	87	48	135
	Percentage	64.4%	35.6%	100%
Other	Number	7	1	8
	Percentage	87.5%	12.5%	100%
Total	Number	142	94	236
	Percentage	60.2%	39.8%	100.0%

3.4.9 Circumstances or place of first test

Four options for the circumstances or place of first test were identified in the coding scheme. The most common place of testing was the GUM clinic, following by hospital following admission due to illness. Limited testing also took place in the context of ante-natal screening, and in 41 cases, initial

test took place elsewhere (in some cases GP administered tests were referred to). The full data are reported in the table below. The chi-squared value for this table is high (26.22) and statistically significant ($p < 0.001$). It is clear, and not surprising, that the large majority of patients tested following admission to hospital had low CD4 counts (89.1%). It is also interesting to see more than half of the women identified as HIV during ante-natal screening, where late.

Table 8: Circumstance or place of first HIV test of patients with CD4 >350 versus CD4 of 349 or less

		CD4 count 350 or less	CD4 count >351	Total
GUM clinic	Number	61	62	123
	Percentage	49.6%	50.4%	100.0%
Hospital admission due to illness	Number	49	6	55
	Percentage	89.1%	10.9%	100.0%
Antenatal screening	Number	8	6	14
	Percentage	57.1%	42.9%	100%
Other	Number	21	20	41
	Percentage	51.2%	48.8%	100%
Total	Number	139	94	233
	Percentage	59.7%	40.3%	100.0%

3.5 Summary of findings and statistical significance of clinical data

Findings from our analysis of the clinical data on HIV positive patients in Kent and Medway clinical areas can be summarised as follows:

- Late diagnosis of HIV infection is substantial across Kent and Medway
- Two hundred and forty patient records were examined, and of these one hundred and twenty-eight (53.3%) had CD4 counts on diagnosis of 350 or less, and one hundred and twelve (46.7%) had CD4 counts over 350
- No significant difference in the levels of late diagnosis was found across the health trusts involved in this survey
- HIV is no respecter of age. Patients at first diagnosis ranged in age from 19 to 81, with a mean age of 40
- Patients diagnosed late were four years older on average than those diagnosed early. This difference is statistically significant
- Approximately two thirds of the patients were men, but no gender difference is apparent in levels of late diagnosis between males and females
- The sample is ethnically diverse, with 56% of the sample being White British/Irish, 30% Black, 4% Asian, 1% of Mixed race and 8% other
- Late diagnosis was more common in ethnic minority groups (70.2%) compared with the white group (53.0%). This difference is statistically significant
- Patients born outside the UK were more likely to be diagnosed late, although this difference was only marginally statistically significant

- Four transmission groups were distinguished. However, it is clear that the most frequent categories of people infected are heterosexuals and men who have sex with men, with small numbers of people in the IDU and 'other' categories
- The percentage of late diagnosis varies by transmission group, but there is no clear association
- The most common place of testing was the GUM clinic, followed by hospital after admission due to illness. Limited testing also took place in the context of ante-natal screening, and in 41 cases, the initial test took place elsewhere e.g. a GP clinic
- Very high levels of late diagnosis for HIV infection were found for patients admitted to hospital on account of illness (89.1%) compared with other settings (range from 49.6% - 50.1%).

4.0 Methodology and sample for qualitative interviews with patients and staff

Fifty-three semi-structured interviews were conducted as part of the study with 37 patients and 16 health or social care professionals. The interview topic lists for patients and healthcare professionals are provided in Appendices 1 and 2. Recruitment to the study was lower than anticipated, especially amongst healthcare professionals, although data saturation does appear to have been achieved in both sets of interviews and it is unlikely that any more useful information would have been gained by continuing any further with these. Data collected from patient interviews tend to corroborate the views of the regrettably small number of healthcare respondents interviewed and vice versa. This in itself is interesting and demonstrates the relatively high level of convergence in opinion about the interview topics between both groups.

4.1 Timeline for collection of interview data

Interviews were conducted to an extremely tight schedule due to research and governance changes made necessary by an unavoidable change due to the retirement of the principal investigator at the University in November 2013. The timeline for collection of the qualitative data was thus governed by an extremely short data collection period for the reasons summarised below:

- 25th September 2013: Applications for R&D approvals sent to Medway, Maidstone and Tunbridge Wells and Kent Community Health NHS Trusts and the RM&G Consortium (for GP interviews) on the basis of the former NRES approval letter subject to approval of new Chief Investigator by NRES Committee North East (Newcastle and North Tyneside).
- 6th November 2013: Informed at project meeting that Kent Community Health NHS Trust (KCHT) approvals would not cover interviewing of KCHT patients on East Kent Hospitals University NHS Foundation Trust (EKHUT) sites as previously believed.
- 11th November 2013: Approval of the substantial amendment documentation relating to the change of Chief Investigator sent to the NRES Committee North East (Newcastle and North Tyneside) by Professor Ruston on the 22nd October 2013 received.
- 11th November 2013: notification of NRES approval sent to the R&D departments at Kent Community Health NHS Trust, Maidstone and Tunbridge Wells NHS Trust, Medway NHS Foundation Trust and the University's Research and Governance Office.
- 11th November 2014: Permission and letters of access received from Kent Community Health NHS Trust and the RM&G Consortium (for GP interviews)
- 14th November 2013: Ethical approval to interview trainee GPs received from the University's Research and Governance Office.
- 27th November: clarification sought from NRES Committee North East (Newcastle and North Tyneside) about the need for a further substantial amendment in order to add East Kent Hospitals University NHS Foundation Trust to the protocol following clarification that they were not covered by KCHT application. Meeting with Medway Hospital staff to discuss patient and HCP recruitment.
- 2nd December 2013: Permissions and letters of access received from Medway NHS Foundation Trust.
- 5th December 2013: Permissions and letters of access received from Maidstone and Tunbridge Wells NHS Trust.

- 5th December 2013: Permissions and letters of access received from Maidstone and Tunbridge Wells NHS Trust.
- 6th December 2013: offered 8th January 2014 for first meeting with Maidstone and Tunbridge Wells NHS Trust staff to discuss patient/staff recruitment for project.
- 3rd January 2014: confirmation received from NRES Committee North East – Newcastle and North Tyneside that a second substantial amendment to add East Kent Hospitals University NHS Foundation Trust to the protocol was not required.
- 8th January 2014: Meeting with Maidstone and Tunbridge Wells NHS Trust staff to discuss patient and staff recruitment. Emails sent to HCPs and arrangements made for the university's research staff to attend clinic Monday and Tuesdays weekly.
- 17th January 2014: Final local R&D access letters granted by East Kent Hospitals University NHS Foundation Trust
- 21st January 2014: Last of the research passports received from East Kent Hospitals University NHS Foundation Trust granting access to KCHT patients in the GUM clinics.
- 30th January 2014: First patient interview of KCHT patients at EKHUT.

4.2 Details of the qualitative data collection team

All of the interviews were conducted by one of the following: Sharon Manship, Matt Hart and Stephen O'Connor from Canterbury Christ Church University. Matt Hart conducted most of the patient interviews in Maidstone and Tunbridge Wells, Sharon Manship conducted the majority of patient interviews in Medway, and Stephen O'Connor and Sharon Manship conducted the nine interviews for Kent Community Health NHS Trust (including those carried out at premises owned by the East Kent Hospitals University NHS Foundation Trust). The small size of the interview team had no bearing on recruitment to the study and may be regarded as a strength of the study since it provided greater consistency in the approach taken by each interviewer and increased inter-rater reliability. Data were transcribed by Fiona Tudor who also assisted with data analysis in partnership with the three interviewers. Another member of the research team, Agatha Benyera, an experienced qualified HIV counsellor working at Canterbury Christ Church University and volunteer for the Health Action Charity Organisation was also available to provide psychological and emotional support to patients should they require it, and facilitated two meetings of the research team to discuss the emotional impact which interviews of this nature inevitably cause in research of this nature.

4.3 Issues of reliability, validity and rigour in the interview process

Pilot interviews carried out by Sharon Manship and Matt Hart were reviewed by Stephen O'Connor to assess their face validity, i.e. the degree to which semi-structured interviews carried out by different interviewers unambiguously and reliably access the information and constructs they were designed to investigate. All three are experienced qualitative researchers and the face validity of the interviews was good since there was a high level of convergence in the information derived from different respondents by different interviewers, even when differences in personal circumstances and experience were taken into account. The intrusion of social desirability variance seemed low with respondents giving open, candid, and at times, very explicit accounts of their knowledge about HIV risk factors, their experiences of HIV testing, and the social, psychological and physical sequelae of a positive test result. They were also forthcoming in their advice and opinions as to how screening and the uptake of HIV testing could be improved.

A high degree of data saturation was observed by the time that patient interviews had been concluded at Maidstone and Tunbridge Wells and Medway hospitals, but interviews had not yet commenced with patients cared for by Kent Community Health NHS Trust at this time due to delays in obtaining consent from EKHUT to access patients on their premises. It was important therefore, to continue data collection in the event that new or divergent information would emerge unexpectedly from this setting in order to ensure that the data set was complete. It quickly became apparent that this was not the case however, and in the light of no new data emerging, data collection ended at the end of March 2014. We are confident with regard to the reliability of the data set therefore, that patient experiences across all three participating centres (and the units associated with them) are similar and broadly therefore, to be representative of the majority of patients cared for in each of these settings. As such, they provide a sound basis on which theoretical generalisations about the required changes to service provision in these (and perhaps) other settings can be made.

4.4 Actual versus target recruitment numbers by centre

Table 9 indicates the number of early and late presenters recruited within each of the participating centres. With the exception of Maidstone and Tunbridge Wells NHS Trust which met and on one case exceeded its target for early and late presenters, and Medway which exceeded the target for late presenters, overall recruitment in each of the Trusts and particularly Kent and Community Health NHS Trust fell below target in spite of patients and healthcare professionals being sent three reminder emails by the project administrator once they had initially expressed an interest in being interviewed. Patient recruitment at Kent Community Health NHS Trust was delayed by the need to obtain additional research clearance from East Kent Hospitals University NHS Trust where their patients were care for. This was not granted until 21st January 2014. Notwithstanding this, we are confident that data saturation has been achieved across the 37 patient interviews as a whole. Moreover, the observations of patients were frequently reiterated by interviews with healthcare professionals so this convergence of views leads us to believe that data saturation was already reached by this point in the study.

Table 9: Target recruitment versus actual recruitment by participating centre

Name of Trust	Early presentation		Late presentation*	
	Target	Actual	Target	Actual
Kent Community Health NHS Trust	15	5	15	4
Medway NHS Foundation Trust	10	6	10	11
Maidstone and Tunbridge Wells NHS Trust	5	5	5	6
Total	30	16	30	21

** Late presentation defined as CD4 count <350 cells/mm³ and early as a count of 351 cells/mm³ or more*

4.5 Demographic and clinical details of the patient interview sample

All HIV positive patients diagnosed within the participating centres within the last 5 years on commencement of the study were eligible for interview. Table 9 shows the recruitment of patients from each participating Trust and their HIV status defined by a CD4 count over or below 350 as follows:

Table 10: Patient HIV status at presentation

Name of Trust	Early	Late*	Total
Kent Community Health NHS Trust	5	4	9
Medway NHS Foundation Trust	6	11	17
Maidstone and Tunbridge Wells NHS Trust	5	6	11
Total	16	21	37

* *Late presentation defined as CD4 count <350 cells/mm³ and early as a count of 351 cells/mm³ or more*

4.6 Number and significance of male to female respondents in the patient interview sample

Twenty-nine respondents were male and 8 were female, suggesting in comparison to the clinical demographic data presented earlier in this report that women were underrepresented in our qualitative sample of patients in comparison to the known population of HIV patients in the Kent and Medway region. The reasons for this underrepresentation are not known, but four (exactly half) of the women were of African or Caribbean descent, and the interview data suggest that issues of stigma and isolation are particularly powerful in this group which often faces religious as well as social censure in response to an HIV diagnosis. For the most part, these women regarded themselves as innocent victims of others' risk-taking behaviours (predominantly infidelity on the part of male husbands or partners) although one wondered about a blood transfusion she had received in West Africa some 20 years ago as a young teenager.

However, it should be noted that white British female respondents also reported feeling a keen sense of stigma connected to their HIV status. One such woman (aged 63) reported that her HIV diagnosis had made her feel '*dirty*' and '*unclean*'. This particular lady had not been allowed to have contact with her grandchildren since diagnosis by her daughter who had erroneously been informed by a nurse at the time of her mother's diagnosis that it might be possible for them to become infected with the HIV virus through social contact such as kissing. She was also a regular churchgoer who, on informing her parish priest of her diagnosis was instructed to intinct the Eucharistic host rather than drink from the chalice at communion in case she passed the virus on to other members of the congregation through the drinking vessel. There may be good reasons therefore, why heterosexual women in particular may be less willing to come forward for interview than some males, although there is no direct evidence for this.

4.7 Likely route of transmission of HIV in the patient interview sample

All of the eight women in the sample declared themselves to be heterosexual and most attributed their infection to partner infidelity although there was no difference in early and late presentation between the white British and ethnic minority females in the sample interviewed, there being two early and two late presentations for both white and ethnic minority women in the study.

Seventeen males were diagnosed as late presenters. These included 7 of the 11 men who identified themselves as heterosexual. The proportion of heterosexual men diagnosed early or late in the disease process is broadly comparable with the population mean identified by our survey of clinical patient data highlighted in table 8. Similarly, six of the 13 men who identified themselves as 'gay' were late presenters. This too bears a close resemblance to the population mean identified for this group in the survey data. All of the 3 men who identified themselves as bisexual at interview were late presenters. Two males did not specify their sexuality at interview. One of these was a late

presenter and the other an early presenter. Overall, the ratio of men who have sex with men to heterosexual men in the interview sample is relatively representative of the population means identified in the larger survey of patient records. It was particularly helpful to hear the experiences of three bisexual men whose voices are seldom heard in the literature, and may feel themselves ostracised by other men (whether homosexual or heterosexual) on account of their bisexuality as well as the stigma associated with their HIV status.

4.8 Details of the healthcare professional interview sample

Interviews with healthcare professionals were conducted face to face or by telephone if preferred. Notwithstanding this flexibility and offers to interview staff at a time of their choosing, the recruitment of professional respondents was disappointingly low in all three settings. The greatest representation from a single professional group came from General Practitioners (5), followed by specialist HIV social workers (3), and GUM consultants (2), with single respondents from other areas and specialities. Many practitioners known to care for HIV positive patients in acute clinical areas identified via a 'snowballing' recruitment strategy whereby HIV specialists emailed clinicians they regularly referred patients onto. Many of these simply failed to respond to email requests to take part in the study whilst others failed to respond to a maximum of three reminder emails sent by the project administrator after an initial expression of interest was received. Others indicated that they could only be available for interview after the 30th March when letters of access allowing entry to the research centres expired. One potential respondent wished to be interviewed whilst driving in his car which the team refused to do on the basis of legal and road safety issues. It is also disappointing that high levels of interest shown by a group of GP trainees during one of their training days at the University failed to result in a single interview with someone from this group in spite of the three reminder emails sent by the project administrator to those who initially expressed an interest in being interviewed.

As a consequence, 11 healthcare practitioners only were interviewed for the study. This number consisted of 5 General Practitioners, 3 Specialist Social Workers, 2 Genitourinary Consultants, 1 Clinical Nurse Specialist, 1 Sexual Health Nurse, 1 Specialist HIV Pharmacist, 1 Obstetrics and Gynaecology Consultant, 1 Nephrology Consultant, and 1 Gastroenterologist. The initial target for interviews with GP 'specialists' was met in full (5 interviews) although it proved difficult to identify 'poorly performing' practices directly. Those GPs who did come forward for interview were exceptionally well-informed, enthusiastic and committed to the testing, diagnosis and care of HIV patients, so were clearly in the vanguard of their profession group and not representative of the somewhat negative feedback about GP involvement in HIV testing, diagnosis and management made by other healthcare professionals and patients. Surprisingly, there was a high degree of convergence between healthcare professional and patient opinion regarding HIV testing, so for the most part, the discussion and recommendations are based upon the patients' experience and opinions supplemented by those of healthcare professionals.

5.0 Findings from interview data

Several common themes quickly emerged from the qualitative data as to how early testing and diagnosis of HIV could be encouraged. It is first necessary however, to consider patients' historical experience of their own diagnosis and how they felt about the settings in which these occurred.

5.1 Patient satisfaction with GUM services

Patients were extremely positive about the care received from staff in all of the genitourinary medicine (GUM) clinics involved in the study. This satisfaction ranged from the point of first referral, through the testing, diagnostic and treatment phases. No negative feedback was received in relation to single members of staff or the clinics as a whole. On the contrary, several individuals were named on more than one occasion as offering exceptionally high standards of care and going beyond the remit of the professional responsibility to provide excellent care. One patient for instance said:

"They assisted me...beyond probably their remit...The fact is that there is always someone I can call. I mean [name of clinician] has given me her number and has said you can call me at any time. And she has even replied back out of hours."

Patients felt that their needs were attended to in these settings and that they were listened to and cared about as individuals. They felt that they received high levels of emotional and psychological as well as medical care from their clinicians, another patient saying of some of their carers:

"[Name] and [name] were fantastic. Absolutely fantastic, I have to say. Great support...[Name] has become a friend really to be honest."

A high degree of person-centredness with a commensurate level of emotional, social and psychological support was highly appreciated by patients at the GUM clinics, all of whom seemed to have developed strong, trusting, long-term professional relationships with their clinicians. There is no doubt that frequency of visits and continuity of care are important factors, in some cases, making a very desolate situation at the point of diagnosis more bearable in the longer term:

"[Names] are just wonderful. They are. I think had it not been for them it would have been a whole different situation and it would have been just horrible. They were so supportive right from the very start."

Many patients expressed regret that they could not receive all of their health and medical care from these services rather than having other aspects managed by their GPs. It was generally felt that there was little which could be improved in the GUM clinics themselves, other than making access to these easier and less stigmatising. It was notable in relation to this that older and in particular, older female patients found these visits more stigmatising, especially when they might be seen in waiting rooms etc. by people they knew.

5.2 Patient satisfaction with GP services

Patients were, on the whole, very critical of the care received by GPs in the time leading up to their diagnosis and in many cases afterwards. Many felt that their needs were not listened to and that GPs did not view them holistically or seek to know them better. Most felt that the GPs they came into contact with knew very little at all about HIV or the needs of those who might be HIV positive, one patient saying:

"I don't think their [GPs] knowledge of HIV and the way it's transmitted, and the symptoms, and how also how they deal with someone when they've contracted it is particularly good at this point in time."

In some cases their knowledge was considered to be little better than a lay person, and many patients gave examples of occasions when signs which should have indicated that an HIV test might be necessary were not picked up by their GP as the following two quotations demonstrate:

"[I'd been to the doctor] a few times. They just thought it was a throat infection and bit of bad flu. They didn't even test for HIV or anything. It didn't cross their mind. I had thrush in the mouth, I was being sick...I couldn't stomach food, I couldn't even look at it."

"There are probably five or six main symptoms [for HIV] that as soon as the GP sees them, they should make that suggestion or they should send them for a test and they can pick it up so much quicker."

Sadly, even once diagnosed, some patients felt that their GPs lacked sufficient interest to address these knowledge deficits or find out more about the condition they were now treating the patient for:

"I think that GPs need to understand a bit more about it because there is lots of stigma around it and even the GPs aren't too fussed to understand much about it all."

The stigma and embarrassment associated with an HIV test or positive diagnoses often made for difficult encounters with a patient's GP even after the initial subject of an HIV test had been broached, as illustrated by the following excerpt from the data:

"My GP who I had been seeing all the time...he's a very nice guy... but he seemed like... quite shy. And even when I got the call to go back to the GP I sat down, and he was sat there, and asked 'how are you?' 'As good as I can be' [I replied] and he just sat there looking at me. And I said 'so was the test positive?' and he said 'Yes'. I mean, and this is not being derogatory of people with cancer, but if someone had cancer, would he sit there in exactly the same way? I don't think he would."

There were many examples of GPs making assumptions about a person's HIV risk based on age, appearance or presumptions about a person's sexuality. Interestingly, this appeared to put older

heterosexuals and particularly women at risk of not having their concerns about HIV infection acted upon. Several patients recounted discussing concerns that their symptoms might be HIV related only to be told that it was highly unlikely given that they were in a stable heterosexual relationship and did not belong to any 'at risk groups'. The notion that HIV was a condition affecting gay men and certain ethnic minority groups was still prevalent amongst many GPs according to some patients. These attitudes and the stereotypes which underpin them must be addressed as a matter of urgency as in some cases patients felt demeaned or ridiculed by their GPs for asking about having an HIV test.

Some examples were given of occasions on which GPs (and other healthcare professionals) failed to spot obvious indications that the patient might be immunocompromised and at times, the more marked signs that they were experiencing a seroconversion illness. Many more reported receiving numerous sequential misdiagnoses before an HIV test was finally suggested, and in some cases, patients had endured prolonged periods of treatment (including hospitalisation) for conditions which they were subsequently found not to have, as the following long but detailed quote from a 54 year old heterosexual male clearly demonstrates:

"I had been very ill for about nine months. I was getting diarrhoea, weight loss, candidiasis in the mouth and what I later found out was molluscum on my face. I was backwards and forwards to my GP for nine months, I saw two gastroenterologists, I lost 4 stone, could barely walk and no one really seemed to understand what it was. When you consider the amount of professionals I actually saw. I had an endoscopy, I had a colonoscopy twice, and to not even get it [i.e. the diagnosis] from that was unbelievable. I was sat down in front of about ten or twelve people, professionals, and not one of them come up with it... I wouldn't want anyone going through my experience of all those months of going downhill and down, your family in tears, because they think you're dying."

In at least one other case, a GP disregarded a letter provided to him by an occupational health physician recommending that he investigate a patient's HIV status and drawing attention to the fact that he might have been misdiagnosed with a stomach bug for which the GP had recommended yoghurt, when his own suspicions were that it might have been pneumocystis carinii pneumonia:

"And the Occupational Health guy when I went to see him took one look at me and said I'll tell you what's wrong with you. You've got pneumonia'.... So he phoned my GP up and said you must see this guy quickly. And I went to see my GP on the Monday... by which time I couldn't actually get there under my own steam so I got a taxi there, and again he said 'you've just got a stomach infection. I've told you once'."

In this case, the patient was known by the GP to be a homosexual, but assumptions that he was not, or had not recently been sexually active because of his age had led him to conclude that it could not be an HIV related condition. The patient subsequently became extremely unwell but requests by his family and friends to review him urgently were ignored with the GP insisting that his original diagnosis was correct and the patient made to feel like a hypochondriac. As a result, this previously healthy man was admitted to an acute hospital unable to walk or stand without assistance by ambulance within 24 hours, and was subsequently transferred to a specialist unit in London where he remained for several weeks in a critically ill condition.

This is clearly an extreme case, but similar instances were recounted by patients who felt that they had to work hard to convince their GPs that they might need an HIV test. For many, HIV simply did not seem to be *'on the radar'* of their GP and many only considered it as a possibility as a last resort. Patients often commented however, that GPs were quick to suggest that a diabetes or cholesterol test might be beneficial without any clinical indication for such a test being present. In a small number of cases, patients felt that requests for an HIV test were declined or evaded because of a perceived lack of time or fears about the emotional response to a positive result in a necessarily brief GP consultation. This is particularly worrying however, where patients are reluctant to attend a GUM clinic for testing as one older heterosexual women accompanied first time by her daughter suggested:

"My daughter said to me... 'Oh my God. I've got to sit there'... because there was a sign saying GUM on the desk... I just said, just because you are sitting there, it doesn't mean to say you are not going to go there, or go upstairs or something. But it is. The label is bigger than the word itself".

Observations made by patients about GP services seem to accord with the observations made by the five GPs interviewed for our study. These individuals seem to be in the vanguard of the profession and were regarded as HIV specialists in their practices for the most part, but their critique of fellow GPs reluctance to discuss issues of a sensitive or sexual nature for fear of opening a *'Pandora's box'* of concerns within a ten minute consultation seem to accord with the observations of many patients. They were critical too at times about the lack of knowledge demonstrated by fellow GPs in this area, and of outdated assumptions about those likely to be at risk of HIV based on assumptions regarding the age, marital status or sexuality of their patients or indeed, the communities they loved and worked in. These respondents also felt that some GPs are fearful of offending patients by asking difficult though necessary questions at times and said nothing which would contradict the views and experiences reported by several patients in the study.

5.3 Patient satisfaction with acute hospital services

Patients reported having mixed experiences of acute hospital care. In some cases, the care described was excellent, particularly in some of the specialist centres:

"I was extraordinarily impressed by the treatment from the NHS. Most particularly the standard of care at consultant level and in particular up in London. Flawless really".

They were often the place in which patients were initially diagnosed, although not always quickly, and in some cases, patients might have received long periods of treatment without having the actual cause of their illness recognised as the following demonstrate:

"I know you have to ask if people about being tested... but surely it's better to just ask and get it done sooner rather than later. I mean if they had done that...months earlier...I would have been nine months of not being the way I was which would have saved not just heartache for myself, but it would have saved a lot in terms of resources over that time."

"For about two years before I thought I had irritable bowel syndrome and you know the hospital did as well... it went on for ages and ages and then the penny dropped what it was... I even went through an operation to have a lump removed, and still nothing was detected. And nothing was said, nothing

was even mentioned, nothing was even suggested. I reckon that process probably went on, well getting on for a good nine months probably."

Similar to GP practices, diagnosis sometimes seemed to depend on the attending physician's perception of the patient's risk status. One homosexual patient was surprised that a hospital consultant had not considered HIV as a possibility after having had several opportunistic infections only to be told when saying to his consultant that that he was in a vulnerable group, *'well my radar is obviously not very good any more'*.

In at least one other case, an HIV test was only finally carried out as a result of the patient's insistence that she would like the possibility that her illness might be HIV related excluded. Once diagnosed and treated appropriately, she made a swift recovery after many months of intermittent hospital admissions and costly investigative procedures for a sequence of debilitating illnesses which kept her bed-bound at times.

"Interviewer: 'so you suggested having an HIV test yourself?' Patient: 'Yes because all the other checks that they were doing for me in the hospital were really good. My heart was perfect... my lungs was [too] thank God. And I couldn't believe it. Sixty-three isn't that old... and I couldn't... nobody could think what else could it be, and just in my head, I thought well let's eliminate that [HIV]. But it didn't. It came [back] positive'".

The problem of synecdoche seemed to be apparent in many such cases, and consideration of the patient's immune status was often missed amidst the search for more 'obvious' explanations for the patient's condition. Many patients could not understand why HIV status was not routinely assessed on admission to hospital as part of the gamut of tests and procedures undertaken. One felt that it should be no less routine than swabbing for MRSA or urinalysis at the point of entry into the system, a sentiment voiced in different ways by many others.

In at least one case, unhelpful and inaccurate information was given by a nurse to a patient's relative (who herself suffers from obsessive compulsive disorder) about 'contagion' risk which resulted in her refusing the patient access to her grandchildren which persists to this day. The distress caused by this healthcare professional's inappropriate actions was more than apparent during the interview, as were her feelings of anger and betrayal by those who should have had a duty of care towards her.

Other patients felt that the care they had received in acute settings was good once their status was known with those referred to HIV specialist centres in London voicing the highest opinion of acute care services. At least one patient with experience of both had been told by his London Consultant that the treatment he had been prescribed elsewhere was 'archaic' although this is an isolated case and may be anecdotal. What is clear from the data is that patients' experiences prior to diagnoses were many and varied. They were far more heterogeneous than might be anticipated by the relatively small number of categories used to elicit their information in the quantitative survey of patient data and each patient experience was rich in anecdote and experience with some particularly good examples of a lack of person-centredness which may be due to a lack of time or unwillingness to listen to a patient's concerns, particularly but not uniquely in the GP practice setting.

5.3.1 Access to information about HIV

Many patients acknowledged having only limited knowledge about HIV risk, transmission, its diagnosis, treatment, and long-term outcomes prior to diagnosis. Men who had sex with men appeared to have better knowledge about its transmission, diagnosis and treatment, often from their own or a friend's experience, or the many health promotion and education messages portrayed in the gay media or in places where they regularly associated (pubs, clubs, saunas etc.) This was by no means complete however, some respondents for instance failing to recognise the risks involved in oral sex and attributing their infection to this activity as the following demonstrates:

"I am certainly not engaging in anal sex in a flipping layby you know. People do, but it would probably be oral sex and swallowing sperm really. That is it. That is probably where it came from. I can think of nothing else. And even then I would have had to be quite unlucky... but clearly I was."

At least one bisexual male felt that men who have sex with men are 'more switched on' to the benefits of early testing and had easier access through the 'gay scene' and media to sources of information and support, although some older men who have sex with men would not concur with this view, and voiced concerns that older gay men are as unlikely as heterosexual men to access all of this information given the ageism that some felt to be present in the gay scene itself. They like others, made extensive use of online sources of information and support however, unlike some other groups prior to diagnosis.

Heterosexual respondents also concurred that there was probably greater exposure to targeted health promotion and education materials in the gay community, as did the bisexual respondents. This group in particular felt very isolated from mainstream HIV support services which they regarded as being predominantly targeted towards men who have sex with men and people of afro-Caribbean origin, especially in the Medway area, where the work of the Health Action Charity Organisation in particular is well publicised but only offers support to ethnic minority groups. The policy of other charities such as Terrence Higgins Trust in only offering postal HIV self-test kits to those deemed 'high risk' was also resented by some who were not within their target service user groups. Other services, such as those offered in Kent seemed to be more generic with the needs of HIV positive service users being less visible on their websites which appeared to be aimed at providing financial and employment help/support rather than emotional or psychosocial support, or indeed, health education to people affected by HIV. It should be noted however, that some heterosexual male respondents also made similar observations.

Clearly however, many of the men (of all sexual orientations) interviewed for the study had been shocked and surprised to find themselves diagnosed with HIV although it is clear that in line with the literature, men who have sex with men are more likely to be diagnosed early. Women (particularly older white women) were more likely to present later for testing, and this appears to be borne out in both the qualitative interviews and quantitative survey data in this study. Unlike most of the men interviewed, the majority of these women felt that they did not have cause to consider themselves to be at risk of infection, and most attributed this to partner infidelity, including one black African woman who had only ever had one sexual partner (her husband) prior to her diagnosis and he had died of an unspecified illness some years before.

Whilst internet use amongst young and predominantly homosexual males was high, the vast majority of respondents reported that most of their knowledge about HIV prior to their diagnosis

came from the popular media, predominantly newspapers and the television, but these were widely regarded as unreliable sources of information in the light of their subsequent experiences although some felt that the coverage of 'celebrity' deaths or infections with HIV might serve to increase others' decisions to get tested. One current storyline in a popular television programme about an older woman infected with HIV by an unfaithful partner was mentioned by several respondents as being realistic and thought provoking, and it transpired that this storyline had in fact been introduced into the programme as a result of one of the older female respondents writing to the television channel concerned to complain that many prominent HIV storylines were predicated on the experiences of younger and predominantly male characters, usually men who have sex with men.

Almost none of the respondents could recall seeing information about HIV/AIDS or HIV testing services displayed prominently in their GP surgeries, although they had all seen such materials in the GUM clinic or other acute hospital settings. Some concluded from this that HIV testing was not regarded as a core activity of primary healthcare professionals in the GP settings although most thought it should be and if true, this is particularly regrettable for those who feel uncomfortable accessing the more traditional GUM services for fear of recognition or stigma.

5.3.2 Patients' understanding and perceptions of HIV and HIV risk

All of the patients interviewed intimated that their understanding of the illness was better than when first diagnosed, and that their perception of HIV as a chronic rather than a terminal or life threatening condition had changed as a result of their diagnosis and treatment, largely thanks to those caring for them in the HIV units. Some, particularly those from black African and Caribbean backgrounds were still wary of divulging their diagnosis to others given the poor understanding of others about the condition and possible repercussions of this. They were not unique in this however, and many others could cite examples where others' knowledge was at best rudimentary and at other times completely erroneous including, but not restricted to some healthcare professionals. Once again, men who have sex with men were more likely to have a better understanding of the condition either as a result of others' experiences, or the internet and other health literature, although the knowledge of at least one older gay man was limited in some respects.

5.3.3 Patient's perceptions of HIV as a condition of relevance to them prior to diagnosis

Interestingly although perhaps not surprisingly, nearly all of the patients interviewed had been shocked and surprised to learn that their HIV test had proven positive – even amongst those in so called high risk groups. For some of the heterosexual women, this is not surprising, but even amongst younger men who have sex with men there was a sense of invulnerability and an assumption that the virus was something which affected other people. Evidence for the presence of cognitive dissonance is clear within the study population, with many actively engaged in risky behaviours refusing to believe that they might become infected. This included at least one highly educated, young, erudite and well-informed gay male who regularly, until his diagnosis, visited gay saunas in London for the purpose of engaging in 'bareback' sex with other men.

5.3.4 Length of awareness prior to HIV testing that the patient might be HIV positive

The length of time that a patient suspected themselves to be HIV positive prior to seeking testing varied enormously and broad generalisations cannot be made about any particular group in relation to this. What we know from the literature, and seems borne out by our data, is that men who have

sex with men are more likely to present for testing earlier, and hence have a shorter 'lead in' time to diagnosis. It is not entirely clear on the basis of so small a sample however, whether this is because they are more likely to have regular HIV tests as recommended for sexually active men in this client group, or because they or their physicians are more attuned to the clinical signs of possible HIV infection. In some cases, this seems definitely not to have been the case, and diagnosis was as a result of surreptitious screening or hospitalisation for other causes (such as non-HIV sexually transmitted diseases, hepatitis etc.), but in some cases, even very experienced and knowledgeable individuals still did not anticipate a positive result to such a test. Moreover, as we have seen, others had to overcome significant barriers to get their GPs to acknowledge the need for such a test although most were more likely to access this through a local GUM clinic or voluntary agency such as the Terrence Higgins Trust. Other patients, particularly those diagnosed as a result of routine screening in antenatal clinics or as a result of negative investigations into other causes of their ill health had little time to prepare themselves for either the test or its outcome.

5.3.5 Likely cause of transmission

Unsurprisingly, respondents tended to attribute their HIV infection to the most likely known cause for transmission, predominantly unprotected sexual intercourse or other sexual activity, intravenous drug use, or in one case, a potentially infected blood transfusion received by a black African female respondent in her home country, although her first husband and only sexual partner until that point had also died of an unspecified wasting disease back in Africa prior to her coming to the UK. All of the patients understood the risks of unprotected sexual intercourse and intravenous drug use, some wondered whether barrier protection methods had failed them in the past, but many of the heterosexual men and women had not thought that they faced any significant risk by engaging in unprotected sex with an established partner of the opposite sex or another sexual partner they presumed to be exclusively heterosexual.

5.3.6 Decisions leading to an HIV test being taken

Unsurprisingly, apart from routine antenatal screening, generalised illness, malaise or specific symptoms indicative of an HIV infection or some other illness were the main reasons for patients seeking an HIV test. Less common reasons were exposure to a known risk such as intravenous drug use or the diagnosis of a current or previous partner with HIV. Relatively few patients subjected themselves to regular testing even when in an at risk group or engaging in risky behaviours, and it would seem that even when the risks are known, positive symptomatology is the main reason for patients seeking a test of their own volition. Where patients were tested at the suggestion of a medical practitioner, this was primarily within the context of other medical tests. Tests were sometimes initiated by patients and at others, by healthcare staff, but it is difficult with so small a group to identify any definitive pattern which would indicate how the uptake of early screening could be increased other than better education and training for healthcare practitioners (GPs being a priority it would seem), or generic health promotion for all members of the general public.

Where patients had time to reflect and make the decision for themselves, anxiety about the impact of a positive result, fear of stigma, worries about employment, relationship issues including how to break the news to a partner, friends or other family members, financial, and insurance concerns were prevalent in causing them to delay seeking an immediate test. It is also interesting to note that many patients cited anxiety about their medical records not remaining confidential, especially in small GP practices or communities where healthcare staff and patients were likely to see and meet

each other socially, or where other members of the family might also be registered. These latter concerns were also voiced by most of the GP respondents in the study who also identified poor soundproofing of waiting rooms and reception areas in small practices and the possibility of clinic staff knowing patients socially as possible causes of embarrassment. GP clinics were not alone in this however, some patients reporting that they preferred to attend GUM clinics in towns many miles distant from their home, or even in London rather than those in their own towns or cities for fear of being seen entering or leaving the premises.

Family members' opinions did not seem to feature highly in a patient's decision to get tested, although testing had been suggested by close friends in some circumstances. Few patients on taking actually expected a positive result, but a small number reported feeling relieved as it made sense of signs or symptoms they had been experiencing for a long time:

"As soon as I got that medication it was miraculous... and I thank God for [name of clinician] and for them [indicating to the nurses and doctors] out there... they have stopped one of my medications because they said, the viral one, I don't need that now, because my counts are really good... but the other ones I will be on for life.... but who knows what is going to come through tomorrow".

5.3.7 Reasons for continued poor uptake of early testing

Most patients and some healthcare professionals interviewed were surprised that routine testing and screening for HIV is not more common. Many said that misunderstandings about HIV and the stigma associated with it will only be improved when HIV testing becomes as routine as having a cholesterol test. One patient said that early testing would only be achieved by:

"...making it normalised and accessible. So you don't have to go to a certain place which is, may have a stigma, it could be available anywhere. And you can get access to support at other places other than a GUM clinic perhaps."

Whilst regarded as places where excellent HIV care was provided, many still felt the stigma attached to visiting the clinics and this might preclude people from visiting them for regular testing, particularly when they share reception areas or waiting rooms with other services as the following two quotes demonstrate:

"I don't think it is still seen as a healthy thing to do. You must be going to a GUM clinic because you think you have caught something."

"I went to the main blood test section, phlebotomy, which is fine because everyone is there. No-one knows why you are there, do they? But then I obviously came straight here [GUM], which I thought was a little bit daunting. When you walk in and there're rows of people, you know."

This view was also shared by healthcare professionals, particularly the GPs interviewed for the study. There is a strong view that HIV needs to be demystified and de-stigmatised, and that public health messages about the risk of HIV infection in non-typical groups be better understood by healthcare professionals and the lay public alike, some arguing that it should be possible to undertake an HIV test in a private booth in church or school halls, libraries or workplaces in much the same way as others might go there to donate blood and have it seen in as positive a light as this.

5.3.7 Reasons for continued poor uptake of early testing

All of the older respondents, both patients and healthcare professionals could recall the graphic public health campaigns of the 1980s and 1990s in relation to HIV/AIDS and had vivid memories of these. Many remembered them as depressing and anxiety inducing;

"I remember a TV campaign around about mid-80s. It was quite a hard hitting campaign on the television and it went by certain names which I don't think is very nice to talk about...But it was all, if you've got it, that's it. You're going to be dead within so many months or whatever, and I think that was the stigma with it."

They felt that these had also contributed to HIV being seen as a 'gay disease' and felt that it was time for outdated ideas such as this to be challenged:

"I think because it is a virus that can affect anybody, I don't think it matters. You haven't got to be a gay man. It's affecting straight ladies as well. Even post-50 [year old] people are getting infected so I think more people need to be aware of that it is not a stereotypical illness."

Once again, many thought that health messages were reaching too narrow a population and needed to stress that anyone could become infected as the following two quotes demonstrate:

"There is lots of adverts in gay magazines ...but should they have those in heterosexual magazines?.. Because then it doesn't become a gay man's illness does it? It is everyone's problem."

"Another advert would be normal people. Not looking ill...And maybe the fact that you can't tell by looking at someone. I mean it is a hidden disease, right? So you've got to be careful. No matter what really."

The rationale for a new public health campaign was widely accepted therefore, but it was felt that this should accentuate the positive benefits of early HIV testing rather than the consequences of not doing so. There was also great concern about the sexual health of younger generations in the light of increasing STD rates and a perception of greater sexual tolerance and engagement of older children and adolescents incapable of making truly informed choices about sexual and indeed, emotional health. Many therefore thought that greater efforts should be made to increase health promotion and screening programmes for younger people who were just beginning to embark upon their sexual careers as follows:

"I think with a lot of youngsters it is out there that they are very careless... I think they should go into schools"

"Maybe in schools it [sex education] needs to be you know, at a younger age, so that they really are aware as to the hows and wherefores as to what you know. From chlamydia to this to that. It's everything isn't it? Are you aware of what could happen?"

5.4 Observations from health professional interviews

Without exception however, each of the five GPs who were interviewed for the study highlighted areas of poor practice and a general lack of HIV awareness and training amongst the profession including at times, specific individuals in their own practices. One of the aims of the project was to

identify poorly performing practices, but it is perhaps not surprising known or suspected 'poor performers' did not come forward for interview whether knowledgeable of this status or not. Those GPs who came forward were clearly at the vanguard of the profession and many said that they had come forward because they were concerned about current deficits in most if not all of the GP practices they were aware of. These respondents tended to have a negative view of their peers willingness and ability to confront problems with patients which should have altered them to the patient's sometimes advanced HIV status. Several intimated that HIV is simply '*not on the radar*' of their colleagues, an observation noted by many patients; either because they consider it to be primarily the remit of GUM clinics, or are too constrained by other policy objectives to pay it much attention. One GP respondent suggested that GPs don't get paid to think about HIV as they are other chronic conditions such as diabetes and obesity. Another suggested that financial remuneration for HIV screening and uptake would significantly increase their interest in the condition, but without it, this was unlikely to occur. Most also suggested that misunderstandings and confusion about the need for 'pre-test counselling' constrained GPs from raising the topic as they considered a maximum ten minute consultation too short to deal with such issues. Sadly however, in not raising the topic at all, many subsequently were felt not to refer patients in need of an HIV test to a GUM clinic either and felt that it was better not to raise it as the patient would make their own decision in the end.

Recruitment of medical specialists from the acute hospitals was disappointingly low with little representation from consultants or other physicians working for example in dermatology, oncology, haematology units etc. However, the recruitment of 3 HIV specialist social workers, a specialist pharmacist, a clinical nurse specialist and a sexual health nurse helps to provide a better sense perhaps of the multi-professional management of HIV now that it is recognised as a chronic health problem rather than a terminal condition. Their views are surprisingly similar to those provided by the patients however. Healthcare professionals were selected for interview using a purposive sampling method – predominantly at the suggestion of those working in GUM clinics, but the unresponsiveness of many to the invitation to be interviewed may owe more to competing clinical pressures in these areas as research fatigue or ennui. Some who were interviewed (e.g. a gastroenterologist) did not regard the management of HIV patients as the fulcrum of their work and had a more site specific focus preferring instead to refer HIV patients back to the GUM specialists where these were unconnected to the task in hand and would refer HIV patients to a specialist HIV unit had they known their diagnosis in advance. The majority of other healthcare respondents were either working in or connected to the centres involved in the study and since they are adequately represented in the discussions of the project management team, it is probably not necessary to go into any further detail of their observations in this document although they have of course informed the discussion which follows.

6.0 Conclusions and recommendations

The project report has been prepared in the aftermath of the recent publication of a new EU Commission staff working document designed to support the implementation of a new action plan on HIV/AIDS in the EU and neighbouring countries (SWD(2014)106 final). The document is complemented by an operational action plan that contains 50 actions structured in the following areas: (1) Politics, policies and involvement of civil society, wider society and stakeholders, (2) Prevention, (3) Priority regions, (4) Priority groups, (5) Improving knowledge, (6) Monitoring and evaluation (for more details see http://ec.europa.eu/health/sti_prevention/hiv_aids/index_en.htm).

Chief amongst the healthcare outcomes identified in the action plan is the need to 'improve the capacities and knowledge of medical staff and community based organisations with regard to HIV infection/co-infection (such as viral hepatitis and vital tuberculosis), prevention, testing, treatment and care, including the dissemination of best clinical practice'. In relation to priority groups, the action plan stressed the need to intensify the promotion of safer sex amongst men who have sex with men, improve information on HIV prevention, and better integration of sexual and reproductive health systems. It is envisaged that this will be achieved by intensifying voluntary counselling and testing programmes among men who have sex with men and similar at risk groups, including the encouragement of innovative testing strategies such as outreach and peer support mechanisms to promote early testing. More risk and harm reduction measures are posited for injecting drug users, whilst efforts to improve the health of migrant populations include targeted health promotion measures and improved access and treatment to services for this group of people. There is little mention however, how burgeoning rates of HIV infection in heterosexual patients who make up over half of the HIV positive population (both male and female) in Kent and Medway are to be addressed. Nevertheless, there is some mileage in taking a similar approach to highlighting the conclusions and recommendations that can be drawn from our data, so these will be presented under the following headings:

- Politics, improving policies, community and stakeholder engagement
- HIV Prevention strategies
- Priority areas for intervention
- Improving knowledge
- Monitoring and evaluation

Given that time for the second intervention phase of this project is short, it is proposed that any interventions developed should not address lengthy research objectives which require prolonged application periods for ethical approval. Rather, it is proposed that efforts should be focused on pragmatic initiatives in these five areas which can be achieved quickly and whose outcomes can also be evaluated effectively as the basis for any scaled-up research projects in the future. It is recognised that priorities may be different in each centre, so the following are not intended to be prescriptive. Rather, they are designed to stimulate discussion and debate at the project partner meeting to be held in June.

6.1 Politics, improving policies, community and stakeholder engagement

HIV is a political issue. It is clear from our data that Kent and Medway have not been immune from the many changes in its prevalence within the region. Surprising perhaps, is the fact that heterosexuals form the majority of the HIV positive population in both areas. They are also more

likely, together with injecting drug users, to present late and thus incur additional substantive costs for health and social care providers. Hence the importance of using a cost-benefits approach when seeking to get buy-in to these initiatives from NHS managers and external stakeholders is crucial. Any increase in early testing and diagnosis will have benefits for the healthcare system and not just the individual.

6.1.1 Political action to raise public/professional awareness and support active HIV surveillance

Given the apparent lack of engagement in HIV surveillance, testing and diagnosis within primary healthcare indicated in our data, it is essential that new efforts are made to raise the need for these in this group of stakeholders. This may involve militating for financial reimbursement for this work at local and national levels and where necessary, involving national and local community groups and the media in this process. Given that media exposure alone can raise awareness of the need for early HIV testing, it is suggested that the partners in the project consider how its findings can be made available and accessible to as many people as possible via these means. It will be interesting to see with regard to this, how our project partners in France have fared in the past given the greater level of involvement (or so it would seem) in the project of charitable organisations which have HIV testing and diagnosis, and the support of such individuals as their remit. If there are such charities in the Kent and Medway area patients are clearly unaware of them. With the exception of HACO and national HIV charities such as Terrence Higgins Trust, no one interviewed for the study, including healthcare professionals, mentioned one.

6.1.2 Policies and procedures to support active HIV surveillance and early testing

Every clinical area should also be encouraged to have policies and procedures in place to identify those in need of an HIV test and the means to refer them for further support to recognised agencies. Apart from the support of nurses, medical staff and social workers, patients in particular had little idea where to turn for support in some cases other than their GUM clinic, and few appeared to know that local authorities now have a duty of care to them since changes in the delivery of public health in England. There needs to be more integration between the NHS, charitable and local authority services in all areas and if they do not exist already, opportunity for regular meetings to discuss how better cross-organisational working can be achieved. A similar forum is held regularly between local authorities, healthcare providers and the charitable sector (namely hospices and care home providers) in respect of end of life and dementia care in Kent and Medway, and a forum of this kind should be considered as an urgent priority apart from any interventions designed for the clinical areas. The inclusion of staff from Kent County Council in the project to date has been commendable and it would be good to build upon these relationships to further expand this cooperation including perhaps, the development of interventions which would benefit both sectors.

6.1.3 Changing the culture of NHS services towards HIV

It is essential to change cultural attitudes towards discussion of sexual health and HIV risk. Frank open discussions about sexual health and risk behaviours should be a feature of healthcare consultations for all adults and indeed, adolescents notwithstanding their chronological age, presumed sexuality or outward appearance. We heard on many occasions (from both patients and healthcare professionals) that too many assumptions are made about people's sexual relationships and behaviours on conjecture or mere appearance alone. Healthcare providers must take a lead in changing social attitudes and mores in society which continue to stigmatise and force into the shadows those who are risk of HIV infection irrespective of their 'risk group'. Managers and senior

clinicians in all settings should be exhorted to review their policies and procedures immediately, and if necessary, develop new ones in order to ensure that assessment of sexual health risk is as normal as asking someone about their familial cancer or diabetes risk. Medical practitioners should take a lead in this but the cultural change needs to span the remit of all professionals engaged in patient care. GP practices in particular need reminding that older people in particular would rather discuss such issues with their GP than go to a GUM clinic, but unless they provide an invitation and opportunity to have these conversations without embarrassment or feeling themselves to be a nuisance, this vulnerable cohort will continue to be diagnosed late and fail to benefit from treatment which may necessitate greater cost to the GP practice as well as the NHS in general. A healthy, happy sex life should be portrayed as a positive life-enhancing experience for everyone, including the elderly, and attempts to minimise embarrassment by inviting discussion about this should be positively encouraged in such settings, especially amongst older people who feel a greater affinity for GP than GUM services.

6.1.4 Review of testing and referral documentation, policies and procedures

We were surprised to learn during the course of the study that many areas still do not have policies or practices in place to identify those who might benefit from an early or expedited HIV test. These examples ranged from GP practices which lacked policies or procedures aimed at promoting conversations about a patients' sexual or reproductive health concerns and possible HIV risk factors on a regular basis (such as new patient consultations or where patients present with multiple opportunistic or viral infections) to acute hospitals and GUM clinics which do not routinely ask for an HIV test to be conducted when testing blood for chlamydia or other sexually transmitted diseases when the route of transmission for each is the same. It would appear that better HIV surveillance and improved rates of early testing could be achieved by relatively simple changes to clinical documentation such as blood testing forms which are pre-checked or contain an aide memoire to this effect should any sexually transmitted or blood borne infection be suspected. It would be relatively easy to evaluate the impact of such a change now that a 5 year database of new diagnoses has been established as part of this phase one study both in terms of the number of diagnoses, but also the number of infections identified earlier.

Attention should also be paid to the ways in which services are delivered in some areas. Walking into a busy GUM clinic may be difficult for many individuals, particularly the elderly or those who are socially inhibited by virtue of fear of recognition or stigma. They may however, be more inclined to attend for a 'closed' appointment at certain times of the day when other groups or clinics are not running on the same premises. They may also value a confidential helpline or clinic telephone number which can be displayed in non-GUM settings around the hospital in leaflet, poster or sticker form so that their first encounter with the service can be via a more anonymous and less threatening route. Stakeholder engagement could also include contact with local youth or LGBTQ organisations, churches, workplaces, sixth form colleges and employers to highlight the work of local screening centres and reiterate the confidentiality of the services they offer.

It had been suggested that the development of a 'red flag' software programme to identify those likely to be at risk of contracting HIV or experiencing frequent unexplained illnesses could be developed, but these are costly and unlikely to work within different parts of the same organisation let alone between many organisations in the NHS. They also run the risk of perpetuating the idea that HIV is a condition which only affects certain groups of people. In contrast, it seems necessary

that a whole systems approach should be taken whereby everyone coming for an appointment for such reasons is asked about their sexual health and automatically offered information on HIV testing. These efforts could be piloted around World Aids Day but would require considerable support and in some respects, a top-down approach for the present in order to make this happen. In the meantime, an audit of all clinical areas including those in primary care should be undertaken to ascertain whether posters, leaflets and other sources of information are available and prominently displayed. Consideration might also be made to the development of a simple video or PowerPoint display which could be shown on a waiting room television or appointment screen. Similarly, a simple screen saver application reminding staff to be alert to those patients whose presentation history is indicative of possible HIV infection might be more effective than complex integrated systems – especially in primary care settings and voluntary agencies or charities may be willing and able to help develop these.

6.2 HIV prevention strategies

Attempts to encourage early testing and diagnoses are laudable, but testing has no preventative value. Closely aligned to, but separate from the above therefore, would be the development of a pilot outreach project which identifies target groups or areas of local concern and provides free condoms, lubrication etc. as well as information about safer sex and HIV testing to targeted groups of individuals in places where they associate such as shopping malls, supermarkets, pubs, clubs, bars, schools, universities etc. We were impressed by the use of a converted double decker bus for such purposes by Kent Community Health NHS Trust on World Aids Day although marginalised somewhat in a very large supermarket car park. We regard it as essential however, that projects such as this are continued and extended, with particular emphasis on targeting those accessing the night-time economies of our main towns and cities together with high profile events such as University Fresher's weeks or Summer Balls. These are more likely to reach younger sexually active adults who might be engaging in multiple sexual encounters for the first time and less inhibited in doing so as a result of alcohol consumption or peer pressure.

Activities of this nature could be used to promote HIV prevention and promote awareness of the benefits of early testing by visiting local schools, youth clubs and sports centres/events as part of a targeted health promotion project for young people in the region. They could of course be used as well to promote HIV testing, but the health promotion message should also be an integral part of such outreach attempts. One patient mentioned a very successful initiative at Leyton Orient Football Club which was run precisely on these lines and helped to de-stigmatise HIV and using peer pressure/support in a very positive and encouraging way. Centres could also look at joining together to fund advertisements on local radio about the benefits of early testing which might also be used in local cinemas, theatres etc. which would also attract an older cohort of people if shown during matinees.

It would be relatively easy to evaluate the outcome of these interventions both in terms of recording the number of people accessing these units, but also by asking all new attendees at a GUM or other HIV testing areas how they had learned about the service and correlate these with the number of early and late diagnoses subsequently identified in comparison to the five year database which has now been established.

6.3 Priority areas for intervention

All respondents felt that HIV testing should be more easily accessible in non-stigmatising locations. For many this precludes their being tested at a GUM clinic. Many patients said that they would much have preferred having this made more easily available to them in the GP clinic although others had concerns about confidentiality and the issue of their HIV status being on their official medical record if this were the case. Common assumptions that HIV is a condition affecting young people (predominantly men who have sex with men or immigrants from African, Caribbean, some Asian or eastern-European countries) must be challenged. Many of the respondents in the study were in their late 40s, 50s and 60s and some HIV patients locally are known to be in their 70s or 80s. Furthermore, contrary to popular myth, the majority of those diagnosed with HIV in the Kent and Medway during the last five years are heterosexual. Consideration must be given therefore, to ways in which the positive benefits of early HIV testing (and of HIV risk in this group) can be conveyed to the majority heterosexual population of Kent and Medway, and in particular women and older adults who are particularly likely to be diagnosed later than others.

There is perhaps a role for greater intervention using voluntary agencies including churches and faith groups, social clubs and other sources of peer support to eradicate the stigma associated with HIV in older cohorts and promote the benefits of testing, particularly for those engaging in new sexual relationships following a divorce or the death of a lifelong sexual partner. The very positive and supportive help provided by an occupational health physician in at least one instance should also alert us to the fact that other opportunities for intervention in this population exist, and occupational health practitioners should definitely be encouraged to see a greater role for themselves in this regard although anxiety about employee confidentiality are bound to arise.

Consideration also needs to be given to other options for testing, including making self-test kits freely available in pharmacies and other locations such as fitness centres, bars, clubs, university health centres etc. The availability of self-testing kits is currently very limited. Terence Higgins Trust for instance, only make them available to men who have sex with men and ethnic minority groups perceived to be at greater risk, but these attitudes and the easy availability of such kits (from whatever source) must be increased for those who would prefer to undertake an initial test in the privacy of their own homes. Consideration should be given perhaps, to making these available via a confidential postal service from the GUM or GP clinic prior to a subsequent consultation if necessary with the requisite level of awareness-raising about such a service using local authority agencies perhaps as well given their responsibility for public health services.

6.3 Improving knowledge

All of the respondents old enough to remember the public health campaigns of the 1980s and 1990s have vivid memories of these and whilst most would not want to see a return of the very negative and sometimes stigmatising messages conveyed then, most feel that there is a dearth of accurate information in the media about HIV at present. All of them said they would like to see clear public health messages targeted at the general population as well as those perceived to be at risk and there was a strong feeling that the a national health education campaigns is long overdue given what they now know about the condition and the positive impact which early diagnosis can have on their health chances. Other opportunities to improve the knowledge of the general population have already been addressed in the above sections in relation to prevention and screening.

The vast majority also identified a need for the better education and training of healthcare professionals (particularly GPs) about HIV and the indicators which suggest a test might be necessary. They also felt that communication skills training and improved insight into the needs of patients affected by HIV should also be provided. Many, including our GP respondents, felt that all patients should be tested at least once when signing on with a new GP as part of a general health consultation and at other key moments in their health journey as (for example) when being admitted to hospital with any acute and unexplained condition. This requires the up-skilling of a large proportion of the workforce, initially through continuing professional development but ideally prior to entry to the profession as part of their regulatory training and registration. IN the first case, it may be advisable to consult with external stakeholders such as Medical Deaneries and funding bodies such as Health England Kent, Surrey and Sussex about funding for short courses which can be developed, delivered and evaluated relatively easily - and potentially within the timescale for the second phase of the project. These should be aimed primarily at GPs and those working in acute areas as they seem to be the areas of greatest need. It is acknowledged that gaining 'buy-in' from practitioners who are extremely busy may be challenging, hence the need to consult with local professional bodies/agencies. There is a clear policy emphasis for this though, both in terms of the EU documents which were considered at the start of this section, but also in relation to the delivery of the core NHS values with their emphasis on compassion or the Chief Nursing Officer's 'Six C's of nursing' which may be entirely relevant in relation to practice nurses, school nurses etc. who may come into contact with patients likely to become or have been infected with the virus.

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Appendix 1: Patient Interview Topic List

Can you tell me what you knew about HIV before discovering that you were HIV positive?

What was your understanding of the disease
Where did you get your knowledge about it
Did you feel that HIV was relevant to you?

How long have you known that you were HIV positive?

*How long before taking the HIV test were you worried you might be HIV+?
(if they did not think they would be ask if they had previously heard of HIV testing before their test)
Do you have any idea what circumstances or situation would have put you at risk of being infected with HIV?*

Who made the decision that about having an HIV test?

*What happened in the lead up to you deciding to take an HIV test?
What triggered you to have a test?
What happened in between deciding to go and going for the test?
What was going through your mind?
Did you decide on your own to take the test?
Did anyone convince you to do it? If yes, who (a relative, friend, acquaintance, professional) and how did it come about?
Did anything prevent you from having/asking for a test earlier?*

Following the decision to have the test how long did you wait to actually take it?

*What were you feeling at this time?
What factors influenced the timing of going for a test?
Did you talk about going for a test with anyone?*

Did you know who or where to ask for an HIV test?

*How did you know where you could get an HIV screening test?
Had you seen any advertising about HIV testing in the community or in the media?*

If you could turn back the clock is there anything about the process leading up to your test that you would change?

What advice would you give to others in the same situation as you?

Is there anything about the HIV testing process that you would change If so, how?

If you were asked, to come up with three main suggestions about how the NHS could persuade people to seek HIV testing earlier, what would they be?

Is there anything that you would like to add?

Appendix 2: Health Professional Interview Topic List

Could you tell me briefly what you know about HIV infection?

Is it something you come across with your patients?

What sort of patients do you feel may be at risk of HIV infection?

What kind of factors or symptoms would trigger/lead you to think about HIV testing?

Have you ever had to refer a patient for HIV testing or offered them a test?

If yes what symptoms or other factors triggered the referral and how did you go about it?

If no what do you think might be your course of action if you came across a patient who you felt might have HIV

How did the patient react and what effect did this have on your actions?

Do you consider you have a role to play in the detection of HIV?

If yes what would it be and if no what are your reasons

Is there a policy/process in your surgery or clinic that covers HIV testing?

How would you feel about broaching the issue of HIV testing with your patients?

Have you ever had a patient who has voluntarily ask you for an HIV test?

What have you done following this request

What sort of obstacles/barriers do you think might prevent a patient from asking you for a test?

What sort of obstacles could prevent you from offering a test?

In your professional experience, do you think that patients are adequately informed about the possibility of undergoing an HIV test as part of their clinical care?

Do you feel you have enough the skills and knowledge and understanding of HIV to be able to respond to patients who need a HIV test?

Additional topics for General Practitioners only

For the HIV patients registered in your practice, do you think there were opportunities where HIV infection could have been diagnosed earlier?

What suggestions do you have in terms of earlier diagnosis?

To what extent are you involved in the prevention of HIV?

Are you aware of any regional or national initiatives regarding your HIV prevention?

Do you have any posters or literature on HIV or HIV testing in your waiting/consulting room?

Does your surgery provide condoms to patients if available or requested?

Is there anything that you would like to add?

Demographic data on respondent

Speciality

Year qualified from medical school

Age

Gender



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