

Regional Audit of HIV Diagnosis and Management in Northern Ireland

Report 2007





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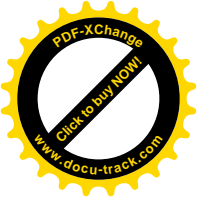




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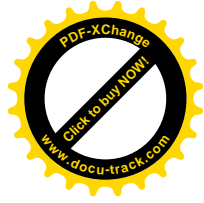
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Executive Summary

Background

HIV continues to be one of the most important communicable diseases in Northern Ireland. It is an infection associated with serious morbidity, high costs of treatment and care, significant mortality and high number of potential years of life lost. The infection is still frequently regarded as stigmatising and has a prolonged 'silent' period during which it often remains undiagnosed.

There has been an ongoing increase in HIV prevalence in Northern Ireland over the past four years. In 2005, a total of 63 new first-UK cases of HIV were diagnosed locally. Annual new diagnoses have increased year on year since 2001, almost doubling between 2003 and 2004.

Since April 2003, when the routine antenatal HIV screening programme was introduced in Northern Ireland, there have been 15 antenatal cases of HIV. This significant increase in cases had not been anticipated or planned for in terms of resource implications. The number of HIV infected individuals regularly attending the GUM clinic (as defined when last seen for care in the year) have increased to 322 in 2006, compared with 143 in 2002.

While highly active antiretroviral therapies (HAART) have resulted in substantial reductions in AIDS incidence and deaths in the UK, it is well recognised the ongoing management is particularly complex and a multidisciplinary approach is essential. The direct medical management of the condition is further complicated by emotional and psychological factors. This in turn presents health care professionals with an onerous task when trying to provide a holistic approach to patient care.

Project Rationale

Given the recent large increase in HIV prevalence locally, this regional audit has been carried out at a particular opportune time to assess current practice against national and international standards and determine where action needs to be taken for the future. The information and recommendations from the audit will make a major contribution to informing the current and future provision of multidisciplinary services for HIV positive patients in Northern Ireland.

Project Terms of Reference

- To establish evidence of the strengths and weaknesses of various aspects of the current regional approach to HIV in Northern Ireland.
- To allow coherent, evidence based, standards of care to be developed that best meets the needs of this vulnerable group of patients.
- To be in a position to define the multi-professional needs of the HIV positive people that access healthcare.
- To assemble a series of data sets that can be used to re-audit key aspects of HIV service provision in the future.



Project Management

- Funding for this regional audit was provided by the Regional Multi-professional Audit Group (RMAG)
- A project steering group was established (comprising of the project nurse, Clinical Effectiveness & Evaluation Unit audit staff, clinical leads and healthcare staff from the various professions) and responsible for the monitoring & planning of the project. The clinical leads were supported by expert sub-groups. The members of these groups are listed in appendix one.
- The Clinical Effectiveness & Evaluation Unit (The Royal Hospitals Site, Belfast HSC Trust) supported this project.
- The project was split into three strands – (1) HIV positive pregnancies (2) Management of HIV positive patients in GUM clinics and (3) HIV testing of GUM attendees.
- Consent to participate was sought from all Chief Executives of the Hospitals who participated in each particular strand. A letter was also sent to each Trust's Clinical Director, Lead Midwife and Clinical Audit Manager.
- Given the large and varied number of professionals involved in the audit project team a core group was agreed, and sub-speciality groups aligned to the three separate strands were set up.

Conclusions

This was a wide reaching and extensive audit covering many key areas of the HIV service. Overall the findings demonstrated that key services were on the whole compliant with national standards/ guidelines. However significant gaps were identified which may have the potential to impact negatively on the service provided. Given that the aim of HIV work is not simply about providing care for those affected but also in health protection and health promotion for the general public it would be counter productive to ignore the gaps and unmet needs.

Investment is required in HIV services to bring the service up to all the recognised standards. In so doing patients living with HIV can continue to receive a high quality of holistic care from the current service – this will in turn lead to improvement in patients' quality of life, improving treatment adherence, averting antiretroviral treatment failure, avoiding costly treatment of HIV complications and reducing the need of expensive salvage therapy.

GUM attendees are actively offered HIV testing. New cases of HIV are both diagnosed within and outside GUM clinics. For these cases, their need should be timely addressed including contact tracing, targeted sexual health advice, support to reduce high-risk behaviours and minimising mother to child transmission. It has been estimated that every case of HIV averted potentially saves the NHS £0.5 to £1 million. These interventions may limit the spread of the infection thus having the potential to save £ millions for the NHS

A number of areas identified in the audit findings will prove useful in future as baseline comparators. In particular, these include the multi-professional team (MPT) approach in delivering patients care, with a focus on comprehensive care being delivered and communicated; patients' satisfaction level of these services; standard



of laboratory service such as turn-around time of investigations; appropriate and inappropriate utilisation of investigations and HIV testing uptake rate among GUM attendees. Continuous audit process should form part of our service performance monitoring internally – it is hoped that this process could continue to be supported in the future.

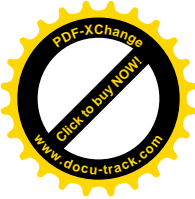
Recommendations

There are four key elements of recommendations to come out of this audit. They encompass all areas of service audited. These recommendations may require support in terms of funding and commissioning of services; the support and direction from Trust directors and managers; and modification of practice and care management by health care professionals (HCP's) within HIV services. These are presented in order of the audit strands rather than clinical priority or ease of implementation.

Key Element One – Investment in Service Development

The audit findings identified a number of gaps in the service where standards of clinical care failed to meet nationally recommended standards supported by evidence of patients' needs being compromised. Stakeholders should address these recommendations in future service development.

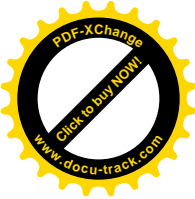
RECOMMENDATION	BENEFIT	REF.
Development of a specialist coordinator for management of pregnant women with HIV and their infants	Coordination of multi-professional management to include clinical and emotional support for women and their families, follow up of infant, updating and training of staff on changes to practice, auditing and maintenance of standard	1A.5 1B.1 1B.2
Development of a specialist pharmacist and multidisciplinary adherence clinic	This will improve the patients' adherence to antiretroviral therapy, addressing each of the barrier to adherence identified in the audit finding	2C.4 2C.6
Development of a specialist clinical psychology services	This will provide a high quality services to patients including direct therapy and indirect functions such as training, teaching, consultation & supervisions of other MPT members, research and audit.	2C.12 2C.14 2C.16
Development of a multidisciplinary cardiovascular risk clinic	A basic cardiovascular risk assessment clinic will identify those at risk, and promptly address basic risk modification including smoking cessation, dietary modification, exercise and management of uncomplicated hypertension and diabetes. This requires support in staffing, clinical space, equipments and drug expenses.	2B.1 2B.2 2B.3



Key Element Two – Education and Training

The audit findings identified a number of gaps in the skills and knowledge of the MPT in the management of HIV positive individuals, including pregnant women and their infants. In particular, gaps were evident in the understanding of roles and responsibilities of various disciplines. HCP's should develop their own competency frameworks; education programmes and when appropriate, attend courses and training to address identified needs. It is hoped that Trust directors and managers would continue to support these activities with resources, equipments, funding and staff time.

RECOMMENDATION	BENEFIT	REF.
The Obstetric, Neonatal and GUM HIV MPT members should conduct a joint education programme, hold regular case reviews, and incorporate feedback from patients and voluntary organisations	This will improve and maintain the overall skills and knowledge in this complex specialist area for all members of the MPT, raising the standard of care for patients. Both hospital and community staff should be included.	1A.3 1A.4 1C.1 1C.2 1C.3 1C.5 1D.1 1D.2 1D.3
Essential induction and ongoing education should be mandatory for all HCP's working in HIV services	This should consist of both generic and specific training, appropriate to areas of practice (e.g. GUM clinic, antenatal clinic, paediatric infectious disease service).	
(i) Generic training	This will raise understanding of HIV awareness, confidentiality, stigma, infection control, roles and responsibilities of members of the MPT in the HIV services	1A.5 1C.3 1D.1
(ii) Specific training	This will address the needs of patients while bridging the gap between specialist interventions. - Cardiovascular risk and non specialist intervention - Identification of psychological distress and non specialist intervention	1D.2 1D.3 2C.2 2C.8 2C.11 2C.12 2C.21 2C.22
(iii) Competency based and continuous development	All members of the MPT must be supported with supervision, a formalised induction programme, regular appraisal, assessment and resources to maintain their professional standards. This is essential for quality assurance of the service	
MPT members within the GUM clinics should regularly conduct joint education programmes and audits	This will continue to promote the involvement of skill mix and promote understanding of roles and responsibilities within the GUM service.	2C.23



Key Element Three – Care pathways / Protocols & Policies / Patient’s Information

The audit findings identified recurrent gaps in interdisciplinary communication, misunderstanding, duplications, as well as gaps within roles & responsibilities, unstructured approach to documentation, management and information provision. Many of these can be formalised and structured using care pathways, protocols, and policies for HCP’s and written information for patients. This will enable HCP’s to improve their effectiveness and efficiency in service delivery. Trust directors and managers should facilitate the development of these by appropriate resources i.e. equipment, funding and protected staff training time.

RECOMMENDATION	BENEFIT	REF.
Development of a MPT care pathway for the management of pregnant women with HIV and their infants	This will improve interdisciplinary communication; improve essential documentation in the management plan, thus reducing risk of mismanagement of the patients and their infants. This should include the development and utilisation of IT facilities	1A.1 1A.2 1B.2 1B.3
Development of clinical policies on the utilisation of, and pathway for, reporting of HIV related laboratory assays	This will identify the indications for and limitations of tests such as HIV resistance assay, HIV viral load assays (NASBA and Roche) - this will in turn reduce inappropriate utilisation and increase appropriate requests. Re-development of the reporting pathway may further improve on the turn around time for results.	2A.1 2A.2 2A.3 2A.4 2A.5 2A.6
Development of cardiovascular risk assessments proforma and basic management protocols for modifiable risk factors	This will improve on the current scarcity in risk assessment and documentation. A nurse led multidisciplinary clinic could be explored to improve risk identification and subsequent risk modification	2B.1 2B.2 2B.3
Development of a treatment adherence protocol using a standardised tool	This will improve on the current measurement of patients’ adherence and documentation. In turn, it will facilitate identification of adherence difficulties for further management, and increase patient participation in choice of treatment	2C.5 2C.6 2C.7
Development of a basic protocol to triage psychological distress with stepped care approach and non specialist intervention	This will improve patient support, reduce patient distress and improve adherence. Early intervention may reduce the need for major specialist intervention.	2C.13 2C.14 2C.15



Development of a comprehensive patient information leaflet.	This will promote patient's choice of care and should include: Patients' journey through the clinic, including roles of each member of the MPT, the ranges of services provided and how to access them. (To include contact tracing, sexual health advice, sexual health screen, psychological distress assessment, social work services, adherence support and cardiovascular risk assessment)	2C.3 2C.10 2C.15 2C.16 2C.18
Development of a comprehensive MPT care pathway for HIV positive patients attending the GUM clinic	This pathway is will improve patients' journey through the clinic with prompt participation of various disciplines of the MPT, improving documentation and clinical communication. This should be integrated to include consultation with doctors, CNS, named nurse, named social worker and health advisers	2C.9 2C.10 2C.17 2C.19 2C.20 2C.21

Key Element Four – Delivering a High Quality Service

The audit findings indicated that the regional uptake rate of HIV testing among new GUM attendees is 88.6%, well above the recommended target from BASSH guidelines. The findings however identified there are gaps between HCP's and patients' perception of reason for test refusal.

RECOMMENDATION	BENEFIT	REF.
Development of strategies to address reason of test refusal, including focused education for both HCP's and patients	Potential to improve uptake of HIV testing by increasing HCP's awareness of what is important for patients, and enhance focused information of asymptomatic carriage of HIV infection	3.1 3.2
Consider alternative methods of testing for selective groups of patients	Offer non-blood testing method to patients with fear of venesampling.	3.3



Strand 1 – HIV Positive Pregnancies

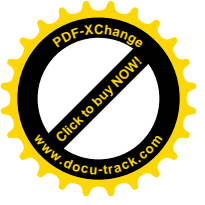
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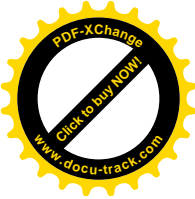
Highly active antiretroviral therapy (HAART) has transformed the treatment of HIV infection, improving the quality of life for women living with HIV and also reducing the risk of mother-to-child transmission (MTCT) from 25-40% to less than 2% during pregnancy and birth. Consequently an ever increasing number of HIV positive women are choosing to become pregnant. In addition, since the reduction of MTCT is dependant on knowing the woman's status prior to delivery, routine antenatal testing for HIV was introduced into Northern Ireland in April 2003, resulting in an increase in the proportion of women who are made aware of their diagnosis prior to delivery.

The increase of HIV positive pregnant women was not anticipated or planned for and has required coordination of a multi-professional team (MPT) for the management of both the mother during pregnancy and delivery, and her new born baby. The antenatal screening programme has been in place for over 3 years and it was considered an opportune time to audit the quality of service and to consider the findings against the existing standards for practice and care.

The management of HIV in pregnancy requires a collaborative approach from a MPT including staff from Genito-urinary/HIV medicine, obstetric, midwifery, neonatology and paediatric services. This strand aims to audit 4 different elements of the woman's journey. The four elements are as follows:

- A. Diagnosis, referral and management of pregnant women
- B. Follow up of neonate for HIV transmission assessment
- C. Patient perception of care
- D. Health care professionals' perception of care





Part 1A - Diagnosis, referral and management of pregnant women from initial reactive test to delivery

Standards

Standards for this strand were based on:

- Department of Health (2003): *Screening for Infectious Diseases in Pregnancy: Standards to support the UK Antenatal Screening Programme.*
- British HIV Association (BHIVA) 2005: *Guidelines for the management of HIV infection in pregnant women and the prevention of mother-to-child transmission of HIV.*
- Royal College of Obstetrics and Gynaecology (RCOG) 2004: *Management of HIV in pregnancy guidelines.*

Main points of management are:

- Management by multi-professional team (MPT)
- Screening for sexually transmitted infections (STI) and other blood borne viruses (BBV)
- Monitoring of HIV viral load (VL) and HIV resistance assay.
- Commencement of antiretroviral (ARV) therapy between 28 and 32 weeks of gestation
- Recommended and eventual mode of delivery
- Commencing zidovudine infusion if indicated, > 4 hours before Caesarean Section or at onset of labour
- Umbilical cord clamped as soon as possible following delivery
- Baby bathed immediately after delivery
- Amniotic membranes left intact for as long as possible
- Fetal Scalp Electrode and Fetal Blood Sampling should be avoided
- Advised not to breast feed
- Infants treated with ARV prophylaxis

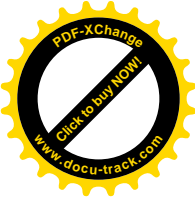
Audit Objectives

HIV positive pregnant women should be informed that interventions, such as ARV therapy, caesarean section and avoidance of breastfeeding, can reduce the risk of mother to child transmission (MTCT).

The BHIVA guidelines state that the risk of MTCT is related to maternal health, obstetric factors and infant pre-maturity. The principal risks of transmission are related to maternal plasma VL, obstetric factors and infant feeding. In addition they suggest that the only obstetric factors that consistently show an association with risk of transmission are mode of delivery and duration of membrane rupture. This audit therefore aims to measure adherence to recommended standards of practice in the BHIVA & RCOG guidelines as outlined above.

Audit Design

A retrospective and prospective case note review of both Genitor-urinary medicine (GUM) and Maternity case notes was carried out for all affected pregnancies in Northern Ireland from 2000 to the end of 2006. The proforma for case note review was agreed by the project team and reflected the standards as outlined above.



Audit Results

A total of twenty-two HIV positive pregnant women were identified up to the end of the audit period in 2006. Six of these women knew their diagnosis before pregnancy while the remaining sixteen discovered their HIV diagnosis during pregnancy as a result of routine antenatal testing. Approximately 50% of this population were from Northern Ireland and 50% were from countries with a high HIV prevalence.

Fourteen had complete antenatal care and delivery in Northern Ireland while the remaining eight attended for partial care. The results of this audit are based on the care received by the fourteen completed care cases. Three of these fourteen were aware of their diagnosis prior to conception, two of whom were already receiving ARV therapy for clinical indication prior to their pregnancies. One woman's diagnosis was discovered when she presented for delivery and therefore accounts for one case not meeting many of the standards.

Management by MPT

BHIVA and RCOG guidelines recognise this as important for holistic care

Of the fourteen women attending for complete care, all but one was managed by the appropriate MPT and received counselling from an appropriately trained member of staff.

Screening for sexually transmitted infections and other blood borne viruses

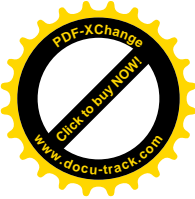
BHIVA and RCOG guidelines state coexisting infections can increase risk of transmission to the baby and recommend screening at point of HIV diagnosis and in the third trimester.

All fourteen women were screened for Hepatitis B and none were found to be hepatitis B surface antigen positive, however four had evidence of past infection. Of the fourteen women screened for Hepatitis C, one was positive. Screening for syphilis took place at the booking visit for all women, two of whom booked in the third trimester, and all were negative. There was no record of repeat syphilis screening in the third trimester with the other twelve women. Eleven women were screened for Chlamydia, one of whom was positive. Eight women were screened for Gonococcus, seven for Trichomonas and thirteen for Cytomegalovirus, all of whom were negative. One woman was found to be sero-positive for Herpes Simplex Virus (HSV) type 2 when she was tested retrospectively using an ante-partum serum sample, following the death of her infant with disseminated HSV-2 infection. Since this case, the clinic implemented routine screening of HSV-2 serology for all women. Since this recommendation, three other women were checked for type-specific serology for Herpes Simplex Virus (HSV) antenatally, of which one was found to be HSV-2 sero-positive.

Monitoring of HIV VL and resistance assay

BHIVA and RCOG guidelines state this is important in determining treatment, both what and when, and in deciding mode of delivery.

Except for one woman, whose diagnosis was discovered when she presented for delivery, all of the women had appropriate monitoring of their VL. Eleven women achieved an undetectable VL before delivery whilst three women had low VLs. The women who did not achieve undetectable VLs included one woman whose positive diagnosis at booking was missed until admission for delivery and two other women who presented at weeks 33 and 38 respectively.



Eleven of the women had a resistance assay performed. A resistance assay was not indicated on a further two women as they had been taking treatment prior to pregnancy. There was no evidence of resistance assay taken in one mother.

During 2005, it was recommended that maternal HIV VL testing should be performed at delivery. Of the six women who delivered since 2005, four had a VL taken at delivery and two did not.

Commence ARV therapy between 28 and 32 weeks of gestation

BHIVA and RCOG guidelines state this is necessary to reduce and/or maintain VL at an undetectable level or should be commenced earlier if the woman's health requires it.

Two women were already on treatment prior to pregnancy. One woman commenced treatment at 19 weeks gestation whilst a further eight women commenced treatment between 28-32 weeks gestation. A further woman, who presented for booking at 33 weeks, commenced treatment at 35 weeks gestation. One woman, who presented for booking at 38 weeks gestation, commenced ARV therapy at 39 weeks gestation. One woman whose booking diagnosis was missed until a few hours prior to delivery did not receive oral antenatal ARV therapy (but she did receive peripartum intravenous zidovudine).

Recommended and eventual mode of delivery

BHIVA and RCOG guidelines state this should be decided on an individual case basis and must be discussed with the woman and a joint decision made. Planned caesarean section should be undertaken at 38 weeks gestation. Women with an increased risk of emergency caesarean section should be offered a planned caesarean section as long labours; particularly those with prolonged rupture of membranes carry a higher risk of transmission.

Eleven babies were delivered by caesarean section and three by vaginal delivery. It was planned that ten of the women should be delivered by caesarean section; however one of these delivered vaginally. Four women had planned vaginal deliveries, two of whom had emergency caesarean sections due to complications. In total eleven of the fourteen women who delivered did so by their planned mode of delivery.

Commencing zidovudine infusion if indicated, of > 4 hours before caesarean section or at onset of labour.

BHIVA and RCOG guidelines state that if required zidovudine should be commenced 4 hours prior to planned caesarean section or as soon as labour commences and continued until the umbilical cord is clamped or later if indicated.

Eleven out of twelve women for whom intravenous zidovudine was indicated received therapy.

Of the nine planned caesarean sections for which zidovudine was indicated, seven had the infusion commenced at the recommended 4 hours or more before delivery; while one woman received less than 4 hours of infusion. The other woman who had a planned caesarean section was admitted in second stage of labour, quickly progressing to a vaginal delivery and therefore did not receive the indicated zidovudine.

Of the three planned vaginal deliveries, one woman who was already an in-patient received zidovudine at onset of labour. However it took up to 4 hours from admission for the other two women who presented in labour for zidovudine to be commenced.



Umbilical cord clamped as early as possible
BHIVA and RCOG guidelines state this helps to prevent micro-transfusion

This information was not recorded in the case notes.

Baby bathed immediately after delivery
RCOG guidelines state the baby should be bathed immediately following birth.

It was recorded that four of the fourteen babies were bathed immediately after delivery.

Amniotic membranes left intact for as long as possible if vaginal delivery
BHIVA and RCOG guidelines state that amniotic membranes should be left intact as long as possible. Risk of transmission increases after 4 hours by 2% for every hour membranes are ruptured up to 24 hours.

Of the four women who had planned vaginal deliveries the length of time membranes were ruptured was: at emergency caesarean section; 3 hours 15 minutes; 10 hours 24 minutes; and 25 hours 54 minutes respectively.

Of the ten planned caesarean sections, seven had membranes ruptured at delivery. One case had no information recorded in the notes. Of the other two cases, one woman who delivered spontaneously on arrival at hospital, had membranes ruptured 31 hours and the other woman's membranes ruptured 14 hours 37 minutes prior to her planned caesarean section.

Fetal scalp Electrode and Fetal Blood sampling should be avoided

In all fourteen cases, fetal scalp electrodes were not used and no fetal blood sampling was taken.

Advised not to breast feed

All fourteen women were advised not to breast feed.

Infants treated with ARV prophylaxis
BHIVA and RCOG guidelines state that all babies born to HIV positive mothers should receive ARV prophylaxis from birth.

All fourteen babies were commenced on ARV prophylaxis from birth. All but two of the fourteen babies received ARV prophylaxis within the recommended time of 8 hours after birth. The delays in commencement of ARV medications were recorded in both cases as a result of needing to wait for an available paediatrician to prescribe treatment.

Conclusions

The overall management of HIV positive pregnant women fulfilled most of the recommended guidelines. There was evidence of a MPT approach to management of HIV positive pregnant women. Some aspects of HIV monitoring and STI screening (STS) were good, whilst in other areas there is room for improvement. While screening for syphilis at the booking visit was good (100%), this was not consistently followed up with repeat screening in the third trimester.



Screening for other infections was more comprehensive in some instances than others. It was noted however that STS improved during the audit period.

It was noted that monitoring of VL and ARV resistance assay continued to improve throughout the audit period. The recommendation to monitor plasma VL at delivery was introduced in 2005, and four out of six women after that time had tests completed which indicated change in practice in keeping with new recommendations.

Reducing the mother's VL is an important factor in preventing MTCT and all women for whom it was appropriate were commenced on treatment during pregnancy to achieve this.

For many women zidovudine infusion is part of treatment and should be commenced 4 hours prior to caesarean section or at the commencement of labour. In this audit 66% of women for whom zidovudine was recommended received zidovudine in a timely manner.

The guidelines state that the greatest risk for MTCT is around the mode of delivery and length of rupture of membranes. There is still debate about the safest mode of delivery and many factors feed into the decision for mode of delivery, not least the mother's own wishes. The guidelines state that with the right conditions a vaginal normal delivery is an option. However instrumental and emergency caesarean section deliveries, especially in the presence of ruptured membranes, increases risk of MTCT. In the audit 70% of women had caesarean section as their planned mode of delivery and 63% achieved this. In total three women had an emergency caesarean section, two of whom had vaginal delivery as their original planned mode.

The length of rupture of membranes varied from 50% having rupture at caesarean section to 30% having over 4 hours rupture with two of those women having prolonged rupture of 26 and 31 hours.

No babies were put at higher risk by the use of fetal scalp electrodes or fetal blood sampling.

The cord clamping was not recorded in the notes and babies bathed immediately post delivery was recorded in 28% of cases.

Discussion

As a consequence of the multidisciplinary nature of the management of HIV positive mothers, it was often difficult to collate the information from the various subspecialties involved. This could potentially create an increased risk of patient mismanagement.

Given that prolonged rupture of membranes and emergency caesarean section are known to increase risk of MTCT the audit highlighted a need for careful active management of these women at the time of delivery to ensure that risk of MTCT is kept to an absolute minimum. There was lack of detail in the notes that indicated careful consideration of all the factors impinging on care and decision-making.

The management of HIV is constantly evolving in light of new evidence and treatment, which necessitates the need for staff to remain up to date and for those in charge of management of the woman to communicate the changes recommended. The audit highlighted a greater need for effective and regular communication of changes.



Recommendations

- 1A.1 Antenatal MPT comprising key staff from HIV, obstetric, paediatric and pharmacy services should continue to improve communication and sharing of information between services.
- 1A.2 Development of a shared care pathway accessible to all HCP's involved in the woman's and neonate's care. This would ensure that key investigations are performed, followed through and effectively communicated to everyone.
- 1A.3 MPT members should receive regular ongoing training and updates in line with changing guidelines. A joint education programme would encourage sharing of skill mixed.
- 1A.4 Case reviews should be regularly conducted in MPT meetings to identify learning points for incorporation into staff training that would help in the knowledge and understanding of these complex cases.
- 1A.5 Given that there are many disciplines in the MPT involved in many areas there should be a dedicated lead for the care of women who would take responsibility to coordinate management, communication, staff training, audit, and support for women across all hospitals and community areas.



Part 1B – Follow-up of neonate for transmission assessment

Standards

Standard for this strand were based on:

- British HIV Association (BHIVA), 2005: *Guidelines for the management of HIV infection in pregnant women and the prevention of mother-to-child transmission of HIV.*

Key areas of management are

- Multi-professional team (MPT) approach
- Good communication with mother
- Screening and follow-up of other sexually transmitted infections (STI)
- Neonatal antiretroviral (ARV) prophylaxis
- Monitoring side effects of ARV prophylaxis
- Developmental milestones
- MTCT outcome

Audit Objectives

We aim to assess compliance with current BHIVA guidelines for the prevention of MTCT of HIV, focusing on the neonatal care with respect to these key areas.

Audit Design

The charts of sixteen infants born to fifteen HIV positive mothers were audited retrospectively against these key areas.

Audit Results

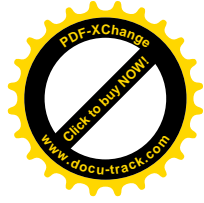
The charts of sixteen infants born between June 1999 and May 2006 were audited. During the study period, fourteen mothers gave birth to one child, and one mother had two children.

One mother had antenatal and postnatal care within, but delivered outside, Northern Ireland and although her baby is included in the neonatal audit, she is not included in the pregnancy audit. The first pregnancy of the mother who had two babies was outside the pregnancy audit time period of 2000 to 2006.

Thirteen infants were delivered by caesarean section (four emergencies, nine electives). One of these mothers, who had received antenatal care locally, delivered prematurely at 34 weeks by emergency caesarean section outside Northern Ireland but returned following delivery. Three infants were born by normal vaginal delivery. There was no evidence of instrumental delivery in any of the cases audited.

There was a history of prolonged rupture of membranes greater than twenty four hours in two instances. There was no evidence of chorioamnionitis in any of the cases audited.

The infants' charts were checked for documentation of maternal screening for STI and blood borne viruses. All fifteen mothers were documented as being negative for Hepatitis B surface antigen while five had evidence of past infection with Hepatitis B.



One mother was known to be Hepatitis C positive while fourteen were known to be Hepatitis C negative. Treponemal serology was negative in all fifteen mothers. One mother whose missed diagnosis was identified at delivery was positive for Chlamydia infection at delivery.

Four infants were preterm (less than 37 weeks gestation), while twelve were born between 37 and 41 weeks.

The therapy the baby receives is dependent upon the therapy the mother receives prior to delivery. Fourteen of the mothers had ARV therapy. In six of the pregnancies, combivir and kaletra were given; combivir and nelfinavir were given in four pregnancies; while five pregnancies had other combination therapies. Intrapartum zidovudine was given in fourteen of the cases audited. In one delivery zidovudine was not indicated. In one further case, where elective caesarean section was the planned mode of delivery, the mother presented in second stage of labour with prolonged rupture of membranes and zidovudine could not be given.

The management of the infant after delivery was documented as having been discussed by the paediatrician with the mother during the antenatal period in fourteen of the infant charts. However, two women received counselling in labour (one was a missed booking diagnosis, and one was not referred to the paediatrician prior to onset of labour). Eight infants were given zidovudine monotherapy following delivery for four weeks. Seven had zidovudine in combination with lamivudine and nevirapine. One child had zidovudine and nevirapine. The treatments given were relevant.

Fifteen infants tolerated ARV prophylaxis well. However, in one infant zidovudine was discontinued at 3 weeks 4 days because of anaemia.

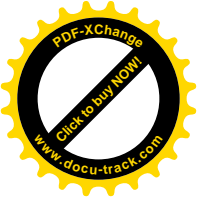
Co-trimoxazole prophylaxis was recommended for seven infants and was recorded in their notes as being commenced.

All sixteen infants were found to be HIV Proviral DNA negative at birth. One infant died at age ten days as a result of disseminated Herpes Simplex Virus type 2. The remaining fifteen infants were HIV Proviral DNA negative at one month. One infant moved out of Northern Ireland at one month and was referred to local paediatric services in the new country. The HIV Proviral DNA was negative in the remaining fourteen at three months. Subsequently, two infants were not followed up after three months as one moved to the south of Ireland and was referred to Dublin paediatric services and one failed to attend the clinic and was followed up by the GP and Health Visitor. The twelve remaining infants followed up were HIV Proviral DNA negative at one year and HIV antibody negative by eighteen months.

During the course of the audit period the recommendations for BCG vaccination in the UK changed (now targeted towards specific 'at risk' groups). There were four infants to whom this recommendation applied, and when they were known to be HIV Proviral DNA negative, BCG was given to two infants whilst the GP was asked to perform BCG vaccination in the other two.

All infants were developmentally normal at each of their follow up.

The British Paediatric Surveillance Unit (BPSU) was notified of all sixteen infants.



Conclusions

Overall there was evidence of a MPT approach to the perinatal care and follow-up of infants born to HIV positive mothers and this was noted to improve over the audit period.

All infants had ARV prophylaxis and this was generally well tolerated.

All 12 infants born to HIV positive mothers and followed up until 18 months were found to be uninfected. All infants were developmentally normal at clinic review.

All fifteen mothers were screened for Hepatitis B and C; and syphilis. One mother was Chlamydia positive and this result had not been conveyed to the paediatrician.

Discussion

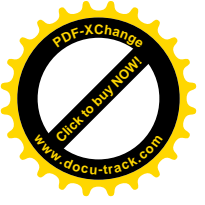
The audit highlighted the need to involve the paediatrician at an earlier stage in the management of care of the mother. It is essential that ongoing support is provided for the mother following diagnosis and that they have an opportunity to discuss the care and management of their baby following birth.

It was found that clinical investigations and results performed in different departments were difficult to access and not always recorded in the notes. Significant results at times were not effectively communicated between the genitourinary medicine physicians, obstetricians and paediatricians and this could have an impact on the standard of care.

At the start of the audit period children in Northern Ireland were only followed up until it was found that they were uninfected with HIV. The current BHIVA guidelines recommend that children born to HIV positive mothers should be followed up long term to ensure that there are no, as yet unrecognised sequelae, as a result of antiretroviral therapy given to mothers during pregnancy and in early infancy by the Children's HIV Antiretroviral Therapy (CHART) study. Ideally, children would be reviewed annually and their growth and developmental progress evaluated. During the audit period, from early 2006, all children born to HIV positive mothers commenced annual review by the paediatric infectious disease team.

Recommendations

- 1B.1 A dedicated lead for the care of women who would take responsibility to coordinate management, communication, staff training, audit and support for women and their infants, from pregnancy through to post natal follow up, across all hospitals and community areas is further supported (see recommendation 1A.5).
- 1B.2 Improvement in IT access for all members of the MPT to ensure all results of relevant investigations are readily accessible.
- 1B.3 Development of a shared care pathway for MPT is further supported (see recommendation 1A.2), to ensure continuing liaison with the neonatal team and the paediatric infectious disease physicians regarding long term follow up (CHART study) of infants born to HIV positive mothers.





Part 1C – Antenatal Patients’ Perception Questionnaire

Standards

Standards for this strand were based on:

- Medical Foundation and Sexual Health (MedFASH), 2002: *Recommended Standards for NHS HIV services.*
- British HIV Association (BHIVA), 2005: *Guidelines for the management of HIV infection in pregnant women and the prevention of mother-to-child transmission of HIV.*
- General Medical Council, 2006: *Good Practice Guidelines*
- Nursing & Midwifery Council, 2006: *Code of Conduct for members*

HIV positive women are entitled to a uniformly high standard of medical and maternity care in an atmosphere that respects the particular features of HIV, including the importance of confidentiality and the perception of stigma that can be associated with the condition.

Audit Objectives

We aim to assess the service users’ perceptions of care as provided by the health care professionals (HCP’s) in the multi-professional team (MPT) and the services provided with a particular focus on respect, confidentiality, stigma and communication.

Audit Design

The questionnaire was constructed with the assistance of a service user representative – an HIV positive woman who had given birth at the regional centre.

HIV positive women were contacted and asked to complete an anonymous questionnaire relating to the care they received in different clinical settings including antenatal, labour, postnatal, and community maternity services as well as care received in Genito-urinary medicine (GUM) services and baby and paediatric clinics.

The questionnaire consisted of two sections – in section one, each question was answered with a tick box, using a Likert scale, follow by opportunity to provide comments; in section two, women were prompted to provide further comments to specific questions.

Fifteen questionnaires were distributed personally to women and fifteen completed questionnaires were posted back.

Audit Results

NOTE: FOR PURPOSE OF PROTECTION OF CONFIDENTIALITY, SOME SPECIFIC NAMES HAVE BEEN REPLACED IN THE FORMAT OF <MY XXX>.

SECTION ONE

Q1.1 Did you feel you were treated with respect?

There was an answer rate of 91%, of which 93% selected “all of the time”.



Comments:

- They were all very helpful and kind
- Overall good-despite poor English, feel supported.
- What should have been the happiest day of my life, was one of the worst. The first team in the labour ward were lovely and understanding, especially as I had only found out. A nurse after my baby's birth made me feel my daughter was a leper.
- I found the help I received was fantastic.

Q1.2 Did you feel your confidentiality was considered important?

There was an answer rate of 91%, of which 93% selected "all of the time". However, one respondent selected "not at all" for one clinical setting

Comments:

- In **<my home town>** the health visitors were told after I said I didn't want them to be, because they wouldn't be treating me. The head of midwifery blamed another midwife for telling colleagues. Very upsetting.
- They were very good
- I found it a bit off putting the hazard stickers on the outside of my medical notes for antenatal.

Q1.3 Did you feel stigmatised in any way because you are HIV positive?

There was an answer rate of 91%, of which 70% selected "not at all". One respondent selected "all of the time" for every clinical setting.

Comments:

- I think everyone was great
- **<My community midwife>** was excellent and well informed about HIV offering me great support.

Q1.4 Did you feel there was good communication with health care workers?

There was an answer rate of 91%, of which 95% selected "all of the time". One respondent however selected "not at all" in one specific setting.

Comments:

- I found the labour ward was really positive. The woman who delivered my baby was really supportive

SECTION TWO

2.1 Did you feel that other patients knew you were HIV positive? YES/NO

3 women said YES; 12 women said NO

Those that said YES were asked in which area:

- GP, but not certain
- Johnston House/ green stickers everywhere and I felt like I was locked in the room
- **<My local hospital>** – not the patients but most of the nurses

2.2 How do you feel your experience could be made better?

- In Johnston House feel nursing team's approach could be more respectful and appreciate her anxiety.



- Maybe if I had have been aware that I was HIV positive early in my pregnancy then maybe I would have been prepared and informed about other peoples reaction
- My experience was really great
- Staff could have been a little more considerate
- I feel that in some areas some people made me feel more positive than others
- More confidential
- I feel that in some areas some people made me feel more positive than others

2.3 Do you feel that the health care workers that were in contact with you were sufficiently trained to meet your needs? YES/NO

12 women said YES, 2 women said NO, 1 woman did not answer

If NO in what way:

- Some!! Again GUM Clinic, midwife, doctors were excellent, it was a small group that made me feel small and dirty
- But they went out of their way to educate themselves. My midwife back home and my health visitor...but they were extremely helpful and could not do enough for me
- Every other area except Antenatal Clinic

2.4 Have you any advice for the health care workers who are involved in caring for patients who are HIV positive?

- They must keep up doing their job because they are very good at it. They are very helpful and they don't treat you any different to other people
- No
- To treat each HIV patient as an individual and not assume that I was some sort of drug user, as I was asked a couple of times had I injected myself with drugs. If they are ignorant and think they catch HIV by touch of the hand then they should not have been doing the job.
- Was very happy how I was treated, felt comfortable with all healthcare workers.
- To be understanding of HIV
- Yes

Conclusions

With section one, the majority of responses and comments were positive in relation to respect and confidentiality. While most women did not feel stigmatised due to their HIV diagnosis, occasionally some women did. One individual said she felt stigmatised all of the time throughout her care. Overall the opinion was that communication with clinical staff was very good. Comments provided highlighted a positive experience in labour ward due to the support of the midwife delivering the baby.

Section two managed to capture a significant number of open comments, which included a mixture of negative and positive feedback for both overall care and specific clinical setting.



Discussion

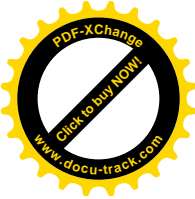
The one respondent who felt stigmatised irrespective of clinical setting highlights the stigmatising effect of being HIV positive can have. It is therefore most worrying that there was an implication from one individual that her confidentiality was not maintained.

Interestingly when the respondents were asked if they felt other patients knew about their HIV status, all the comments were related to concern about the hospital staff and GP, as well as the usage of hazard labels.

Although overall responses were mostly positive – the negative feedbacks highlights that there are still significant ground for improvement to be made.

Recommendations

- 1C.1 Continuous training and updates for members of the MPT via a joint education programme to encourage skill sharing is further supported (see recommendation 1A.3).
- 1C.2 Regular MPT case reviews to identify learning points for incorporation into staff training is further supported (see recommendation 1A.4).
- 1C.3 Training and education need should be extended to include both hospital and community staff.
- 1C.4 Ongoing process of patient and voluntary organisation participation and feedback to HCP's to ensure a service that is sensitive to, and meets the needs of, HIV positive women.



Part 1D – Healthcare Worker Perception Questionnaire

Standards

Standards for this strand were based on:

- British HIV Association (BHIVA), 2005: *Guidelines for the management of HIV infection in pregnant women and the prevention of mother-to-child transmission of HIV.*
- General Medical Council, 2006: *Good Practice Guidelines*
- Royal College of Midwifery, 1999: *Position paper 16a - HIV and AIDS*

Health care professionals (HCP's) caring for HIV positive women should have sufficient training to have gained the knowledge, skills and attitudes required to provide a uniformly high standard of medical, nursing and psychosocial care.

Audit Objectives

We aim to assess HCP's knowledge and understanding in relation to caring for a HIV positive woman, particularly in relation to:

- how prepared they feel for providing care,
- education and training needs,
- communication issues
- attitudes towards HIV positive women.

Audit Design

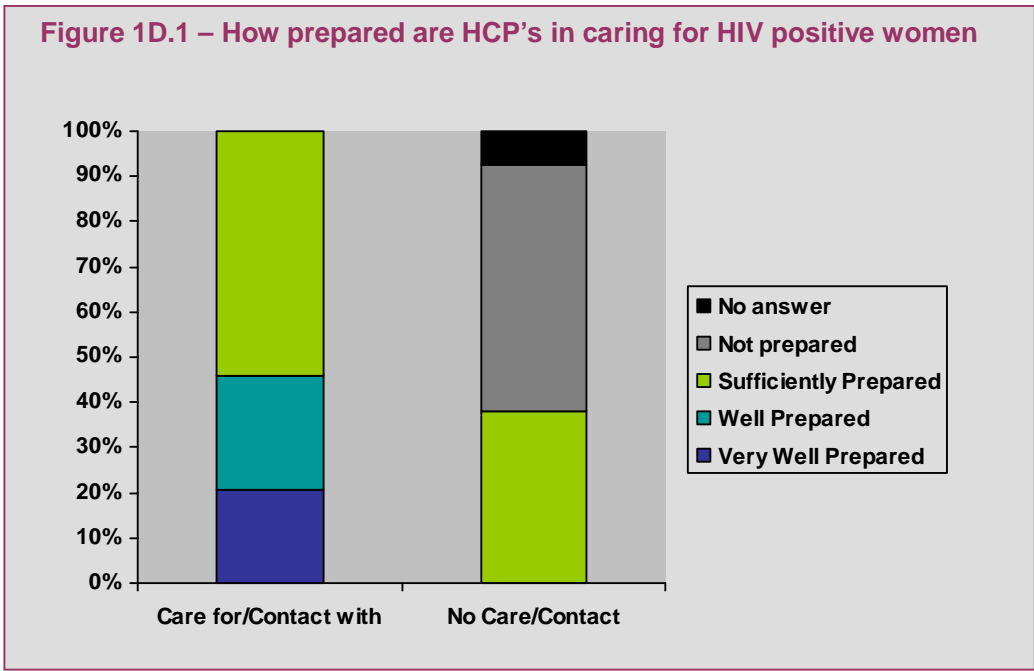
A HCP questionnaire was developed, including questions from a previously validated questionnaire used by Sigma Research "What so you need? 2001" and agreed by the project team. Questions focused on the preparation and training staff received to enable them to meet the needs of women and babies in their care; on attitudes of HCPs towards HIV positive women and any communication issues that arose when providing that care. It was circulated to health care staff within Maternity Services who were involved either in providing care for HIV positive pregnant mothers or in the initial recognition/diagnosis and referral of HIV positive pregnant women through the antenatal screening programme.

The questionnaire was completed anonymously by HCP's with a multi-professional spread across maternity services throughout Northern Ireland.

Audit Results

Of 110 questionnaires circulated, 80 (73%) were completed and returned from the eleven Trusts who provide maternity services and these were included in the final analysis.

30% (24) of respondents had cared for or had contact with an HIV positive patient while 55 (69%) hadn't. Figure 1D.1 illustrates HCP's who had cared for or contact with HIV positive felt more sufficiently prepared.



Only 42% (34) had received HIV training, of which the majority (29) were from the midwifery profession. Although some staff had received multiple training the majority had attended one session in either HIV/AIDS awareness or in-house HIV training. Only 25% (20) indicated they received HIV training within the last 4 years while 17% (14) had training within the last 5 to 12 years. 35% (28) had never received HIV training.

88% (70) felt that they would benefit from specific training in HIV related matters. Many commented that regular updates would be essential. Issues/areas staff felt would need to be addressed in HIV training included care of the HIV positive mother (throughout pregnancy to post-delivery), risks of infection to the baby, special clean up requirements (such as disposal of linen, cleaning agents, etc), blood letting training and confidentiality.

89% (71) stated that they feel that HCP's should not be allowed to refuse care for someone who is HIV positive, with six respondents commenting that they have 'a duty to care' with one noting 'I thought that stigma was gone'. In contrast, seventeen respondents commented if they had the choice they would prefer not to care for HIV positive patients. 47% (38) felt that extra precautions, over universal infection controls, are required when caring for a patient who is HIV positive.

50% (40) of respondents felt that HCPs should have the right to tell colleagues about a patient's HIV status without the patient's permission. There is a uniform agreement that disclosure should be based on concern about staff and patient safety. 50% (32) felt the baby's father has the right to be told why the baby needs medication, which is an indirect disclosure.

The majority of respondents recognised breast feeding, viral load and vaginal delivery as key factors contributing to MTCT. Respondents were less clear about indication of caesarean section and usage of antiretroviral prophylaxis for the neonate.



Conclusions

Less than 50% of the staff completing the questionnaire had received specific HIV training in the recent past, with only 25% having received training within the last 4 years.

There was variance of knowledge and understanding of certain issues such as confidentiality, infection control and aspects of management of care.

All (100%) healthcare staff completing this questionnaire wanted to have regular updates.

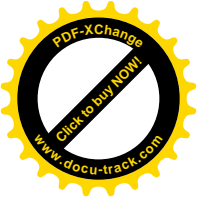
Discussion

Overall there seemed to be no standardised approach to training type or timescale. This is of concern given that antenatal testing and therefore a rolling HIV training programme was introduced in 2002-2003. This has an impact on the standard of service provided to women, which may put both the health of the mother and the neonate at significant risk. It may also affect the patients' ability to cope with their disease.

The variations in answers relating to questions on confidentiality, mode of delivery, transmission risks and infection control demonstrate a lack of knowledge and a need to include these issues in a regular training programme.

Recommendations

- 1D.1 Continuous training and updates for MPT's via a joint education programme to encourage skill sharing is further supported (see recommendation 1A.3). Training should include confidentiality, recommendations for care, transmission risks and infection control.
- 1D.2 Regular MPT case reviews to identify learning points and direct patient feedback to HCP's to ensure a service that is sensitive to the needs of this particular group of women should be further supported (see recommendation 1A.4 and 1C.4).
- 1D.3 HIV training should be mandatory as part of induction for new staff to Maternity Units including medical staff rotating into the Units.





Strand 2 – Management of HIV positive patients in GUM clinics

Introduction

Northern Ireland continues to have a rising epidemiological trend in HIV prevalence and this has major implications for planning health care services to support the need of these patients. In recent years, the lack of additional resources is stretching all the disciplines across the all multi-professional team (MPT) involved in the care of HIV infected patients.

Antiretroviral (ARV) therapy has transformed the treatment of HIV infection; dramatically reducing HIV associated morbidity and mortality, and significantly improving the quality of life of patients. However, the management of HIV represent an ongoing complex and growing problem. Successful management continues to require an ongoing holistic approach to the clinical need of HIV positive individuals.

In the publication – “*Recommended Standards for NHS HIV services*”, it is stated that services for ongoing HIV care should include the following required provision:

- Case management for HIV as a long-term medical condition, with a focus on self-management and enabling adherence.
- Assessment and routine management of HIV patients and initiation and management of ARV therapy in accordance with relevant national and local guidelines.
- Appropriate laboratory services to support access to all relevant tests recommended in guidelines produced by British HIV Association (BHIVA) for monitoring patients on and off ARV therapy.
- Access to health advisor/counsellor as required.
- Access to peer support.
- Treatment support including patient education, delivered in partnership with community or voluntary providers.
- Personalised information and discussion to support and enable patients in sharing decisions about their individual care.
- Facilities for partner notification.
- Genito-urinary/Sexual health screening and services.
- Access to contraception and pre-conception care.
- Clearly defined arrangements for 24 hour advice.
- Health promotion services.
- Good links with mental health services.
- Access to specialist nursing.
- Specialist Pharmacist support.

Non-clinical aspects of some of these services may be delivered outside clinical settings and in partnership with a range of NHS and non-NHS providers.

In this strand, we aim to audit different elements in the management of HIV positive patients in the Genito-urinary medicine (GUM) clinic. They are as follows:



- A. (i) Clinical use of HIV resistance assays.
(ii) Turn around time for HIV viral load assays.
- B. Cardiovascular risk assessments.
- C. (i) Multi-professional support – Patients' perspective.
(ii) Pharmacy support.
(iii) Health advisor support.
(iv) Clinical psychology support.
(v) Social services support.
(vi) Multi-professional support – Staff's perspective.

The clinical utilisation of HIV resistance assay is now a recognised cornerstone for selection of an effective combination of ARV therapy. Measuring HIV viral load (VL) remains a key part of essential monitoring of patients, in particular those on ARV therapy. Adherence to ARV therapy has been shown to be highly dependant on a MPT approach. With HIV patients surviving for longer period, cardiovascular disease is becoming an important cause of morbidity and mortality in HIV infected populations – leading to guidelines recommending regular assessment of cardiovascular risk.

This comprehensive HIV care model which addresses the physical / medical (including specialist nursing, and dedicated pharmacist support), emotional / psychological, social, relational and sexual health need of HIV infected patients is endorsed by Medical Foundation for AIDS and Sexual Health (MedFASH), Department of Health (England & Wales), British HIV Association (BHIVA), British Association of Sexual Health & HIV (BASHH), Royal College of Physicians (RCP) and British Infection Society (BIS).



Part 2A(i) – Clinical Use of HIV Resistance Assay

Standards

Standards for this strand were based on:

- British HIV Association (BHIVA), 2006: *Guidelines on the treatment of HIV-infected adults with antiretroviral therapy*

The guidelines recommend the clinical use of resistance testing for all newly diagnosed patients as a screen for primary or transmitted resistance guiding the selection antiretroviral (ARV) therapy.

Audit Objectives

We aim to analyse the appropriateness of clinical requests for resistance testing, excluding baseline testing.

We also aim to further analyse if there might be clinical situations whereby resistance assays might be indicated but requests were not made.

Audit Design

The BHIVA guidelines 2006 did not specify on clinical situations or timing of when resistance assays are best taken. Therefore local HIV specialists, based on clinical experience and expert opinion, constructed a list of clinical situations in which virological rebound or failure might be expected, and resistant viruses may emerge.

During the audit period, HIV resistance assays were conducted in the Public Health Laboratory Service Antiviral Susceptibility Reference Unit in University of Birmingham. Characteristically, only specimens with viral load (VL) of at least 1000 will reliably provide a genotypic resistance result.

The appropriateness of requests was to be classified as clinically appropriate (as per situations listed) and virologically appropriate if corresponding VL was over 1000 copies.

SECTION ONE

An analysis of 40 consecutive resistance assays from January 2005 for the appropriateness of requests clinically and virologically; excluding those taken for baseline purpose.

SECTION TWO

Consecutive VLs between January 2004 and December 2006 were examined to identify points of viral re-emergence of > 1000 copies/ml from previous suppression, where there is no corresponding resistance testing made, as possible points for HIV resistance requests. Ten of these were randomly selected and analysed against the list of clinical indications.



Audit Results

SECTION ONE

37/40 (92.5%) resistance tests requested were clinically appropriate – indications included: following planned discontinuation (25.5%), assessing poor adherent patient for possible resistance (23.4%), assessing new virological failure (21.2%), optimising new ARV regime in multi-resistance background (10.6%), assessing incomplete suppression on new ARV regime (6.4%) and others (12.9%). 3 (7.5%) requests had no identifiable clinical indication for resistance assay.

However only 29/39 requests (74.4%) were virologically appropriate. Ten (25.6%) of which were requested where the last or corresponding VL was <1000 copies/ml. Four could be re-classified as virologically appropriate requests as clinician instructed to “HOLD SAMPLE UNTIL VIRAL LOAD AVAILABLE” but assays were performed by laboratory despite this instruction - leaving six (15.4%) virologically inappropriate requests.

Combining these, 30/40 (75%) were appropriate resistance testing and 10/40 (25%) were inappropriate – of which all ten were inappropriate virologically, and three of these had no clinical indication.

Of interest, 16/40 (40%) of the resistance assays requested failed to amplify in Birmingham. Of these, seven had corresponding VLs <1000 copies/ml, and nine had VLs > 1000 copies/ml when analysed at the Regional Virology Laboratory in Belfast

SECTION TWO

Between January 2004 and December 2006, viral re-emergences of > 1000 copies/ml were considerably rare compared to viral blips (rebound with VL <1000 copies/ml). The majority of these re-emergences had a corresponding request for resistance assay.

When the ten randomly selected points were analysed, one had a resistance assay performed via research arrangement which was not based in Birmingham. The remaining nine had clinical indication(s) that warranted resistance testing. The ranges of VLs of these selected points were 4200 to 580000, with a median of 27000.

Conclusions

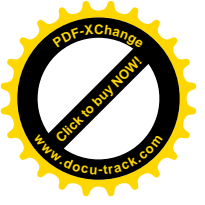
Most of the requests for resistance assay were clinically indicated; the inappropriate utilisations of resistance assays (in about a quarter of all requests) were mainly related to inappropriate virological levels at point of request. More than half of resistance assays which failed to amplify in the reference laboratory in Birmingham had a corresponding viral load > 1000 when tested in the Regional Virus Laboratory in Belfast.

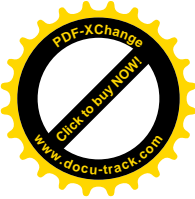
Resistance assays were not always requested despite appropriate clinical indication.



Recommendations

- 2A.1 Inappropriate utilisation of assays can be minimised by introducing practice policy at the clinic and laboratory that restrict resistance testing only when the last VL or corresponding VL is sufficient to generate a reliable resistance assay.
- 2A.2 Development of a clinic policy for resistance assay utilisation, to include a list of clinical indications for resistance assays. This should be disseminated to enhance the recognition of indication for resistance testing.
- 2A.3 Laboratory reports that list sequential viral loads could prompt clinicians of indication of resistance testing.





Part 2A(ii) – Turn around time for viral load assays

Standards

Monitoring of HIV viral load (VL) is an essential component in the assessment of patients infected with HIV. VL assays are performed routinely on a 3-4 monthly basis in most stable patients, and more frequently when there is clinical indication for closer monitoring.

There are many different methodologies for HIV VL assay. Nucleic Acid Sequence Based Amplification (NASBA) is the methodology adopted locally in the Regional Virus Laboratory (RVL) in Belfast. Studies have suggested NASBA may give quicker results and may be more sensitive than Polymerase Chain Reaction (PCR) Based Assay provided by Roche Diagnostics. However this does not apply uniformly for all cases of HIV infection where a different methodology may be selectively required – locally PCR-based Roche assay for HIV VL is conducted in Dublin.

We could find no clear published guideline regarding turn around time (TAT) for HIV viral load (VL) assays. In 2000, Royal Victoria Hospital (RVH) conducted an audit which indicated that more than 67% of patients expect their VL result to be available within 2 weeks. The same audit indicated that local VL TAT was 2-26 days, with a mean TAT of 8.9 days.

In practice, patients are recalled 2 weeks after the VL specimen is taken. A reasonable locally agreed standard would be that Laboratory TAT for HIV VL assays should always be less than 14 days (and ideally less than 10 days) to facilitate recall of patients

Audit Objectives

We aim to assess the TAT performance for VL assays for the Genito-urinary medicine (GUM) clinic in RVH and compare this to the data available from the audit findings in 2000.

Audit Design

Specimen details were retrieved from the current result management system known as Labcentre for all NASBA VL tests done for the calendar years 2004 and 2005.

Due to the problematic database structure in Labcentre, the only report date retrievable is the print date. This is overwritten if results are reprinted for example if a copy report is generated or a second assay performed on the same specimen.

For purposes of this audit the TAT was calculated using the calculation:

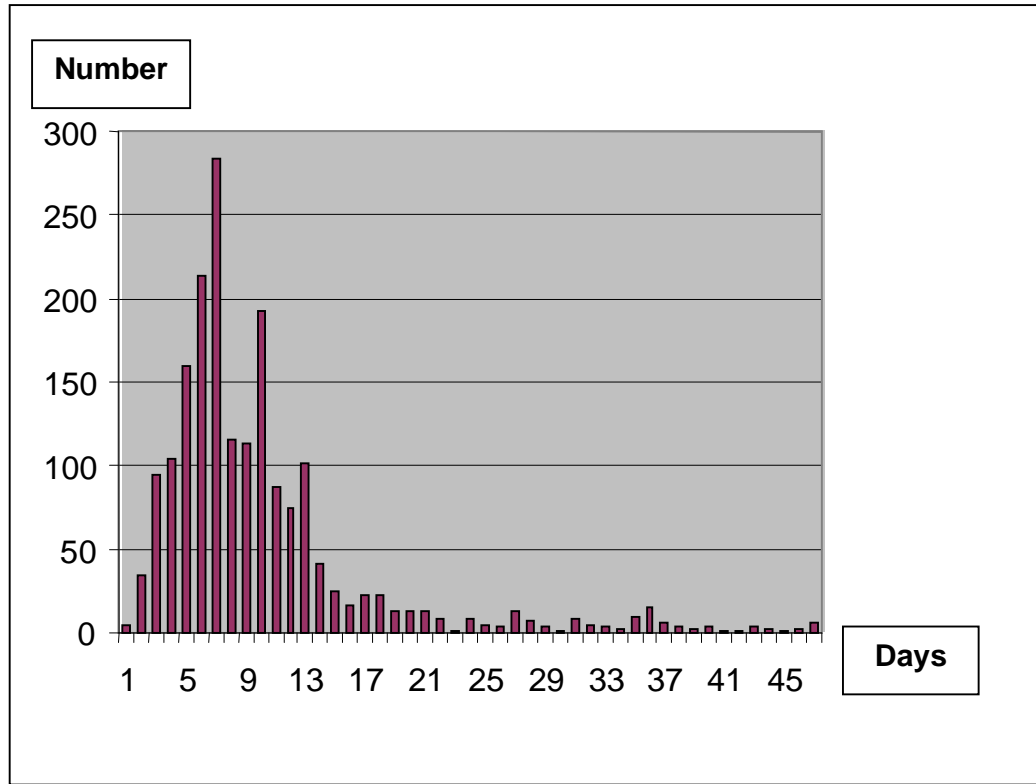
TAT= duration between [result print date] and [sample receipt date]

Audit Results

1870 specimen records were retrieved. The Modal TAT was 7 days and mean TAT was 10.05 days.



Figure 2A.ii.1 Distribution of TAT in the audit period



The long tail was investigated by examining the transaction trail for individual specimen numbers using the “Audit” utility in Labcentre. Of these, six samples had TAT >50 days, which were copy reports printed long after the original report date or were Roche assay print dates (i.e. artifactual report date) where actual TAT was less than 8 days. There were eight samples with TAT=22 days. The transaction trail of these indicated they were retests using Roche assays with artifactual TAT. Six of the eight specimens, the true TAT was 1 to 8 days (TAT=1,3,3,4,4,8 days). Remaining two were recodes (i.e. same specimen re-assayed) for VL (one related to a query HIV sero-conversion case & one was an HIV resistance test where there was amplification failure and therefore it was being investigated to see if the reason was an insufficient viral load). Therefore again all eight samples with TATs of 22 days were artifactual and only one has a TAT of greater than 7 days.

There were 25 samples with TAT=15 days. Eight of these were randomly chosen – of these, seven were valid TATs and one was a recode.

Conclusions

The situation is currently satisfactory. In general (97%) VL TATs are within 2 weeks. Our audit revealed that TAT in 2004/2005 was essentially the same as our previous result in 2000.

The finding indicates that selected patients requiring Roche assay had considerably longer TATs. Significant skewing towards longer TAT is related to recodes, which has no clinical implication.



Discussion

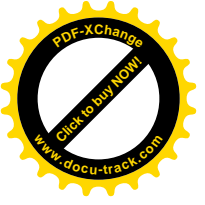
It is clear that HIV VL TAT varies according to pressures in the laboratory related to staff annual leave, sick leave, winter pressure and occasional assay problems. This will be an issue in all elective laboratory investigations where emergency investigations sometimes need to take precedence.

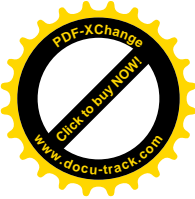
Based on the data from 2004 and 2005 we would like to change to a more flexible platform, which could be economically run with a wider range of run size to try to optimise TAT.

RVL has recently (2006) upgraded the assay to a more flexible platform with variable run size (8, 16 or 24 samples). This will be important in tackling peaks in specimen numbers, in keeping assay frequency up at times when specimen volume is lower (e.g. July). The reduction in hands on time means that it is more practicable to do a HIV load assay at times when the laboratory is busier than it was previously. This change should improve the TAT measurements further. This will be audited in December 2007.

Recommendations

- 2A.4 Any change to VL assay methodology in future due to quality issues should aim to at least maintain the TAT documented in this audit.
- 2A.5 VL assays by Roche are only indicated for selected patients where local assay is not compatible with the detection of their viruses. Vigilance in adhering to GUM policy in patient selection for Roche assays should be reminded to minimise inappropriate requests.
- 2A.6 The longer TAT for Roche should be further explored in term of transportation time from Belfast to Dublin, actual TAT in Dublin, and communication time between the two laboratories.





Part 2B – Cardiovascular Risk Assessment

Standards

HIV infection is associated with higher cardiovascular risk, independent of other factors, and recent studies suggest that the increased risk may be greater in younger patients than in older patients. Hypercholesterolemia, smoking, diabetes mellitus, male sex, and a prior history of cardiovascular disease are also associated with an increased risk of myocardial infarction.

In our practice, many of our patients rely on the Genito-urinary medicine (GUM) service more so than their own GP and we have an obligation towards general health promotion and management. Current guidelines recommend cardiovascular risk assessment at baseline, and regularly throughout long term care, with treatment offered where appropriate.

Evidences used to support the standard in this strand include:

- Currier JS, Taylor A, Boyd F, et al. *Coronary heart disease in HIV-infected individuals*. J Acquir Immune Defic Syndr 2003; 33:506-512
- The Data Collection on Adverse Events of Anti-HIV Drugs (DAD) Study Group. *Combination antiretroviral therapy and the risk of myocardial infarction*. N Engl J Med 2003; 349:1993-2003

Audit Objectives

We aim to assess how often we documented cardiovascular risk factors and whether we were taking measures to modify them.

Audit Design

Thirty charts were pulled at random and were assessed using a standard proforma designed by the project group. Patients were excluded if they had been under our care for less than one year. We recorded whether the notes documented age, weight, smoking status, cardiovascular history, family history, presence of diabetes, blood pressure (BP), and recent glucose and lipid results. We also recorded if treatment for hypertension, hypercholesterolemia, and nicotine dependence had been offered or given.

Audit Results

Twenty male and ten female patients' charts were examined and the results collated. 60% of the selected cohort was aged between 30 and 40 years, with the remainder above this range. The main results are summarised below:

Table 2B.1 Documentation of cardiovascular risk factors & offer of intervention

	% of Male	% of Female	% of Both
Weight documented	70	30	57
Smoking status documented	95	20	70
Appropriate cessation offered	20	0	14
Appropriate history documented	85	40	70
BP recorded at baseline	25	0	17



BP recorded since	55	30	47
Hypertension treated	100	n/a	100
Glucose recorded at baseline	0	10	3
Glucose recorded since	75	90	80
Lipids recorded at baseline	35	60	43
Lipids recorded since	90	100	93

Conclusions

We performed poorly when documenting smoking status, and worse when offering help with smoking cessation. Our BP recording was infrequent, but when hypertension was present, it was treated. While our recording of historical cardiovascular risk factors appears good, the majority of this history was recorded in nursing notes on a once only basis as part of a drive for better documentation in 2005 by motivated nursing staff. This was not referred to in the medical notes at any subsequent stage. Our recording of glucose and lipids is better, with almost all patients having lipids and glucose monitored and treated when necessary.

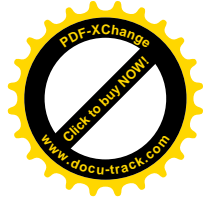
Discussion

Generally we do well in documenting and treating risk factors when they are measured with blood results. However, we do not actively seek out modifiable risk factors in the rest of the history and examination, and we are not identifying high-risk patients for targeted management.

The audit showed that patients do not routinely have BP and weight measured when they attend the GUM clinic. These observations should be carried out routinely and documented when patients attend the clinic. These measurements would prompt discussion about these and other risk factors when medically reviewed. Assistance should then be given to modify any risk factors identified. This may include smoking cessation services e.g. nicotine replacement therapy.

Recommendations

- 2B.1 The clinic should explore the role of nurse led service in providing patients with basic cardiovascular risk assessments and education on modifiable risk factors.
- 2B.2 Capital investment to ensure the clinic is appropriately equipped in assessing basic cardiovascular risk (BP monitoring and weight) is essential.
- 2B.3 Clinical care should include smoking cessation services and management of other clinical risk factors such as uncomplicated hypertension, diabetes and dyslipidaemia using written protocols. These services should be funded accordingly in terms of staffing, goods & services, and drugs expenditure.



Part 2c(i) – Multi-professional Support (Patients' Perspective)

Standards

Standards for this strand were based on:

- Medical Foundation and Sexual Health (MedFASH), 2002: *Recommended Standards for NHS HIV services.*

In this document, it is stated that ongoing clinical care for adults with diagnosed HIV infection should include a comprehensive range of services provided by a multi-professional team (MPT), under the direction of a consultant qualified to provide such care.

Audit Objectives

We aim to evaluate the patient satisfaction on the range of services provided by the MPT.

Audit Design

A self-completion satisfaction questionnaire evaluating the standard of care of HIV out-patients services was developed after input from a member of each discipline of the MPT involved in patient care.

The questionnaire was designed to cover a number of aspects of the patient journey through the clinic. The areas covered were access to the clinic, access to advice, waiting times, doctors availability, opportunities to talk with staff, interruptions during consultations, explanations of laboratory results, information given regarding medications, adherence support, access to social workers, referrals to other departments, access to clinical nurse specialist, the named nurse role and where the nurses equipped to answer queries on aspects of HIV care and treatments.

The questionnaire was given to patients attending the clinic from November 2006 to January 2007, they were completed anonymously and returned to a member of staff or left in a box provided within the clinic, they were completed by both long-term attendee's and relatively new patients.

Audit Results

70% of respondents found reception staff to be always helpful.

94% replied that they infrequently had to wait more than 30 minutes for their consultation, while 30% replied they rarely and 70% replied they never experience clinic cancellation. Majority of patients replied they were usually seen by the same doctor at each visit and 68% replied they always saw their consultant.

94% replied they felt they get enough time to talk with clinical staff about their concerns, although 12% noted their consultations would sometimes be interrupted. 88% replied they were always or often given clear explanation about their laboratory results, and 92% acknowledged clinicians also take patients' opinion into the account in term of management decisions.



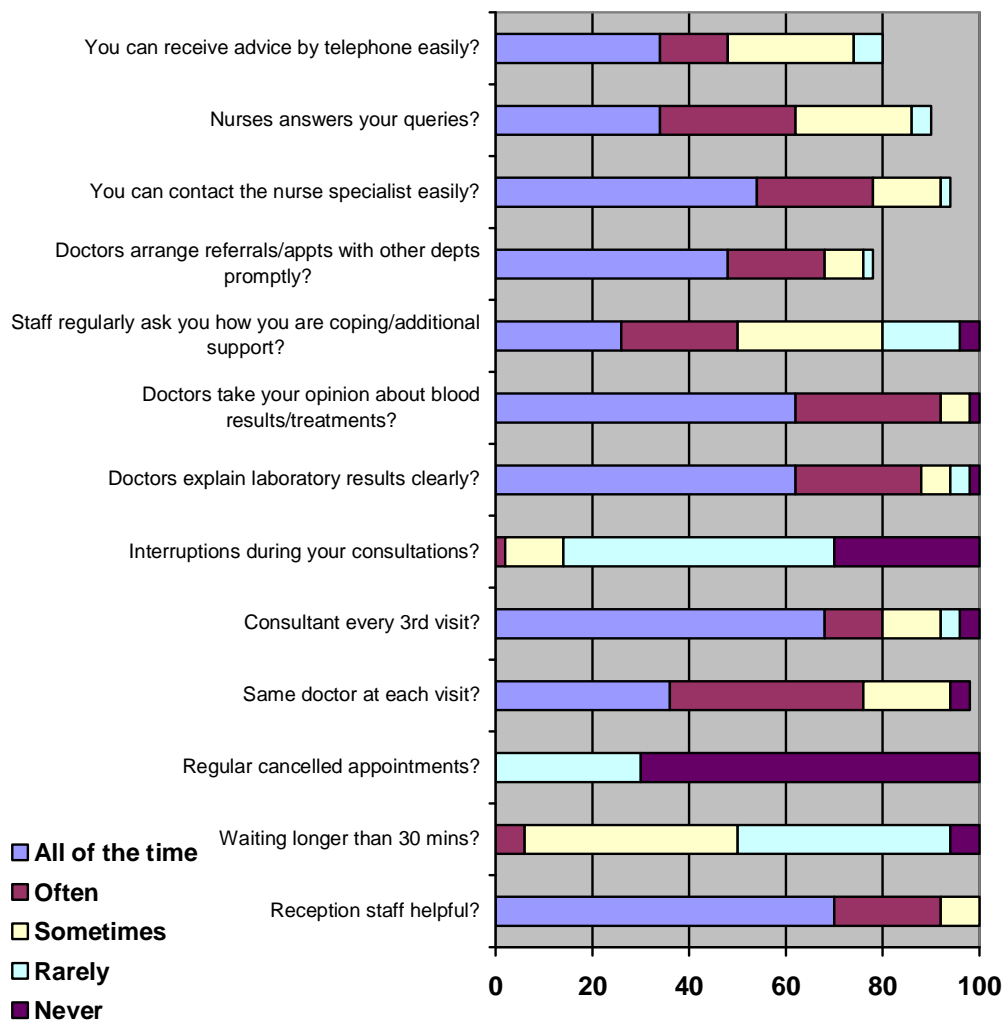
86% replied that they received clear information about the pros and cons, and side effects of their treatment from either doctors or pharmacist. 78% replied that they received such information in writing. 54% were aware of our direct telephone line to pharmacist for ordering repeat script but 34% were not. 82% replied that they felt they received enough support in taking their treatment regime.

90% were satisfied with the level of confidentiality they experienced at the clinic.

Only 54% replied that staff always or often asked how they were coping and whether they needed any additional support from another member of the team e.g. Social Worker, Health Advisor or Clinical Psychologist. 68% replied that their doctors always or often organised referrals/appointments with other departments promptly.

78% of respondents felt that they could contact the Clinical Nurse Specialist easily. 90% replied they would like to have a 'named nurse' – only 54% replied they knew who their named nurse was. 62% felt that the nurses could generally answer their queries regarding their condition/treatment. 48% replied that they could always or often receive advice by telephone easily.

Figure 2C.i.1 - Patient Satisfaction Questionnaire.





Conclusions

On a whole the feedback was very positive with the majority of patients feeling satisfied with the level of care they have been receiving from the clinic with exception to a few issues.

Discussion

While most aspects of our service received positive feedback, there remain areas for improvement and this must be acted on. One such is the concept of a 'named nurse'. In recent years, due to the change in staffing, many patients have not been consistently allocated a dedicated nurse. It seems that patients are very keen to have a named nurse. It is an area that needs to be developed within the clinic.

However new nursing staff must receive adequate training and be assessed in terms of competency, so that a high standard of care can be assured. Since the audit we are currently developing nurse based competency frameworks and in-house training. Such development is highly desirable but takes time and resources.

The audit also identified that a comprehensive information leaflet on the full range of services with instruction on how to access them is highly desirable to reduce the gap of accessibility to care which they need.

It was no surprise to the audit group that patients were less ready to identify their access with services provided by pharmacist, health advisors, clinical psychologists and social workers. It is with this anticipation that this audit strand has further explored the roles of these disciplines of the MPT in Part 2(ii), (iii), (iv) and (v).

Recommendations

- 2C.1 Patient satisfaction level of the service remains high and this must be maintained in future with service development that matches the increasing number of patients.
- 2C.2 Patients indicated "named nurse" is desirable. To facilitate this – nursing staff must be supported in time and resources to develop quality assured competency.
- 2C.3 Comprehensive information leaflet for patients should be developed, about the full range of services we provide and how to access them.



Part 2C(ii) – Pharmacy Support

Standards

Standards for this strand were based on:

- Medical Foundation and Sexual Health (MedFASH), 2002: *Recommended Standards for NHS HIV services.*
- *the British HIV Association (BHIVA) / British Association for Sexual Health & HIV (BASHH) guidelines on provision of adherence support to individuals receiving antiretroviral therapy, 2003*

Key areas of recommendation in these documents include:

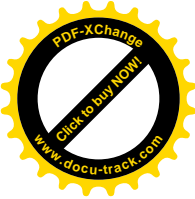
- Clinical networks should develop protocols for initiation of antiretroviral (ARV) therapy, including patient education and support and the appropriate choice of drugs.
- Case management for HIV as a long-term medical condition, with a focus on self-management and supporting shared decision-making about their individual care should start from the post-diagnosis assessment onwards and continue throughout the course of their HIV infection.
- Treatment support is essential in enabling patients to cope with their condition and its therapy, including adherence to ARV therapy.
- Assessment and routine monitoring of HIV patients and initiation and monitoring of ARV therapy in accordance with BHIVA and other relevant national and local guidelines.
- There should be Specialist pharmacy support (including pharmacists and pharmacy technicians).

Audit Objectives

The introduction of highly active anti-retroviral therapy (HAART) has revolutionised the treatment of HIV by dramatically reducing HIV-associated morbidity and mortality. HIV care is now a chronic manageable medical condition where treatment is available but it is also one of the most complex areas of prescribing in contemporary medicine.

We aim to:

- Obtain a baseline measure of patient's knowledge of their ARV regimen including self-reported adherence rate to ARV therapy.
- Evaluate patient's perceptions of their involvement in self-management, shared-care decision-making and whether duration of time on ARV therapy has an impact on these factors.
- Evaluate the contribution of various members of the clinical team to adherence support, the resources / aids used by patients to support adherence to ARV therapy and the extent to which patients report factors that impede adherence to ARV therapy.



Audit Design

SECTION ONE

A questionnaire was designed using standard validated questions used in HIV drug trial protocols and appended to the patient questionnaire. Consultation on the questionnaire design was also sought from other members of the audit group and a pharmacist with experience in HIV clinical trials. The questionnaires were self-reported and anonymous. The questionnaires were distributed to patients attending routine appointments within the HIV clinic. They were returned to a member of staff or posted into a sealed box in the waiting area.

SECTION TWO

A separate case note audit was also undertaken using 50 medical charts of individuals attending the HIV clinic to assess the documentation on adherence enquiry. .

Audit Results

SECTION ONE

40 questionnaires were returned however not all the participants had completed all the sections of the questionnaire. Results are reported from participants who filled in the relevant sections. 79% had been on treatment for over 1 year (see Table 2C.ii.1) and approximately a third of participants (32%) were on their first ARV regimen. All those on treatment less than 3 months were on their first regimen, this however reduced over the period of time on ARV therapy with only 17% on treatment over 2 years remaining on their first regimen (see Table 2C.ii.2).

Table 2C.ii.1 – Distribution by duration on ARV therapy

Duration on ARV therapy	< 3 Months	3-12 Months	1-2 Years	> 2 Years
Percentage	5%	16%	21%	58%

Table 2C.ii.2 – Percentage on first regimen of ARV therapy by duration on medication

Duration on ARV therapy	< 3 Months	3-12 Months	1-2 Years	> 2 Years
Percentage	100%	50%	63%	17%

Participants were asked, using a rating scale of 1 to 5 (i.e. from no input to personally selecting their regimen) in their perception of their input for deciding their current option of ARV therapy. Approximately a third of participants expressed they played no role in the decision process (see figure 2C.ii.1). Participants were asked using the same rating scale for their perception of the clinical team’s role in selecting the current option of ARV regimen. Over half of participants stated that their ARV regimen was chosen exclusively by the clinical team (see figure 2C.ii.2). Table 2C.ii.3 and 2C.ii.4 summarises the score for the patients’ and clinical team’s role in selecting the ARV regimen.



Figure 2C.ii.1- Participant's role in selecting their current ARV regimen

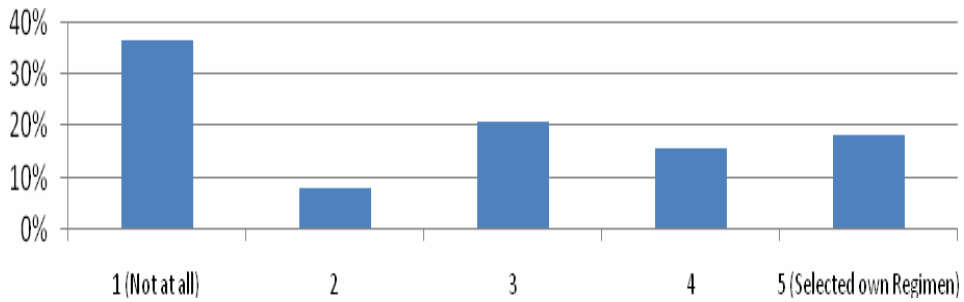


Figure 2C.ii.2 - Clinical Teams' role in the decision process for selecting current ARV regimen

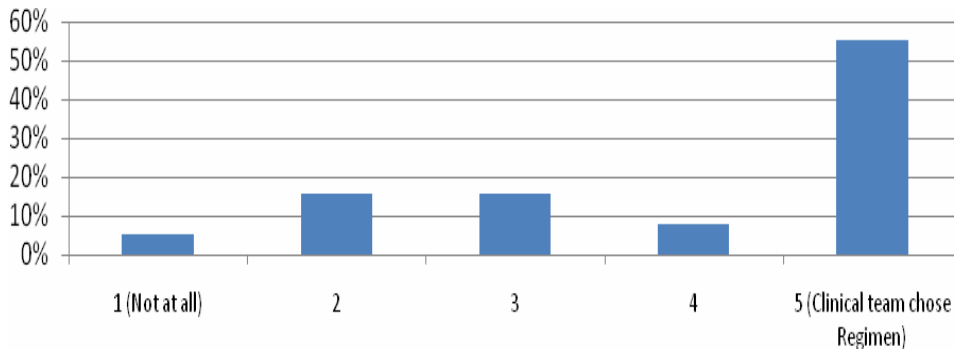


Table 2C.ii.3 – Average Score for Patient's role in selecting their current ARV regimen

Duration on ARV therapy	< 3 Months	3-12 Months	1-2 Years	Over 2 years
Average score	4	1.7	3	2.6

Table 2C.ii.4 – Average Score for Clinical Team role in selecting current ARV regimen

Duration on ARV therapy	< 3 Months	3-12 months	1-2 Years	Over 2 Years
Average score	3.5	4.7	3.5	4

The majority of participants were taking 8 or less tablets / capsules per day and the median number of tablets taken per day increased with the duration of therapy (see table 2C.ii.5). 84% of the participants were taking their medication once / twice daily (21% and 63% respectively).

Table 2C.ii.5 – Median number of tablets / capsules taken per day.

Duration on ARV therapy	< 3 months	3-12 Months	1-2 Years	> 2 Years
Median	3 or less	3 or less	4 to 8	9 to 15

The three most beneficial professions involved in supporting their ability to take ARV therapy were HIV doctors, HIV nurses and the HIV pharmacist. 59% of participants stated the HIV pharmacist contributed to supporting their ability to take medication. Only the HIV nurses (72%) and HIV doctors (90%) contributed more than the HIV pharmacist (see figure 2C.ii.3).

Over two thirds of participants would support the development of a dedicated clinic to support ARV therapy led by a HIV specialist nurse and pharmacist.

80% of the participants stated that they could name the medication that they were currently taking, however when asked to list the medication only 36% listed a recognised regimen according to current BHIVA guidance, whilst 22% of participants listed a questionable ARV regimen and 22% did not list any medication (see table 2C.ii.6). All the participants who listed a regimen were taking them once or twice daily, 36% and 64% respectively.

Figure 2C.ii.3 - Contribution of Clinical and Non-Clinical Staff at any stage in supporting the participants' ability in taking ARV therapy

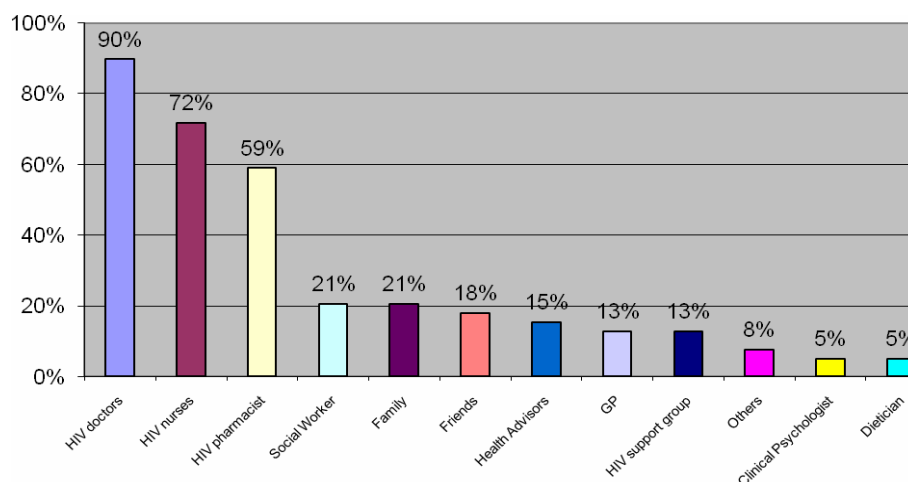


Table 2C.ii.6 – Results of participants able to name and list their ARV medication

Can you name your Current regimen	Recognised ARV regimen listed	Questionable ARV combination	No ARV medication listed	Unable to name
Percentage	36%	22%	22%	20%

The overall adherence rate in the participants was 77% (Cumulative distribution shown in figure 2C.ii.4). Adherence appeared to decrease with duration on ARV therapy (see table 2C.ii.7).



Figure 2C.ii.4 - Distribution of self-reported adherence to ARV regimen

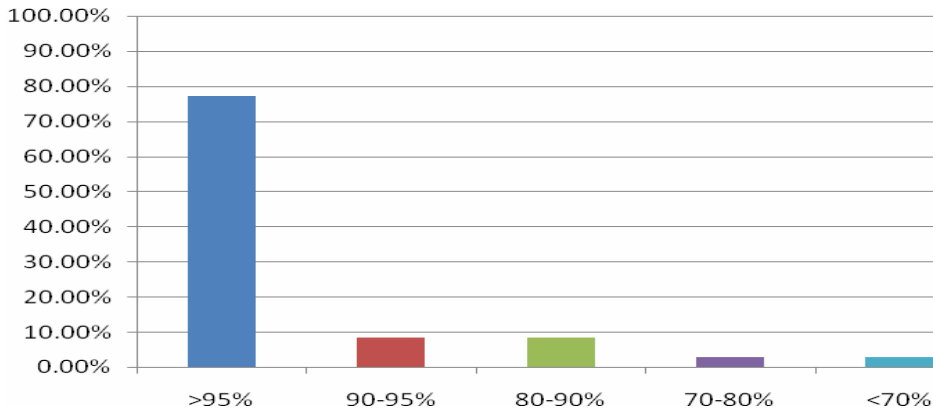


Table 2C.ii.7 – Percentage of self – reported adherence over 95%

Duration on ARV therapy	< 3 Months	3-12 Months	1-2 Years	> 2 Years
Self reported adherence	100%	50%	75%	74%

55% of participants indicated that they took their medication exactly as instructed all the time. The other 45% indicated they took their medication as directed most of the time. There were no responses to sometimes, rarely or never. Two patients listed that they did not take the correct number of medication however no reason was given. A quarter of participants stated that they missed medication at the weekend at some stage whilst being on ARV therapy.

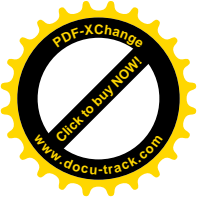
A fifth of participants also stated that they did not always take their medication within 30 minutes of their usual time and that a fifth of participants did not follow the special dietary requirements for taking their ARV medication (see table 2C.ii.8). 24% of participants reported that they had missed some ARV medication over the preceding 4 weeks. The reasons given included forgotten/away from home (62%) and sickness (25%). These generally occurred on one or two occasions in the preceding 4 weeks. Two patients reported an interruption of ARV therapy for more than 2 days in the previous year however only one patient discussed with the clinical team prior to the interruption but no reason for either interruption was given.

Table 2C.ii.8 - Percentage always following the appropriate dietary restrictions for ARV medication

Follow dietary restrictions	Yes	No	Not Applicable
Percentage	50%	21%	29%

Participants reported to use a variety of aids to support their taking of ARV therapy, with most using a combination (see figure 2C.ii.5). Participants reported various issues, which currently make it difficult for patients taking their ARV regimen (see figure 2C.ii.6).

Adverse events were the only one that showed a discernable difference over the groups with 50% of those on ARV medication for less than 1 year reporting problems.



This reduced to approximately a quarter of patients on ARV medication over 2 years (see table 2C.ii.9).

Figure 2C.ii.5 - Aids used by patients to support taking of ARV therapy

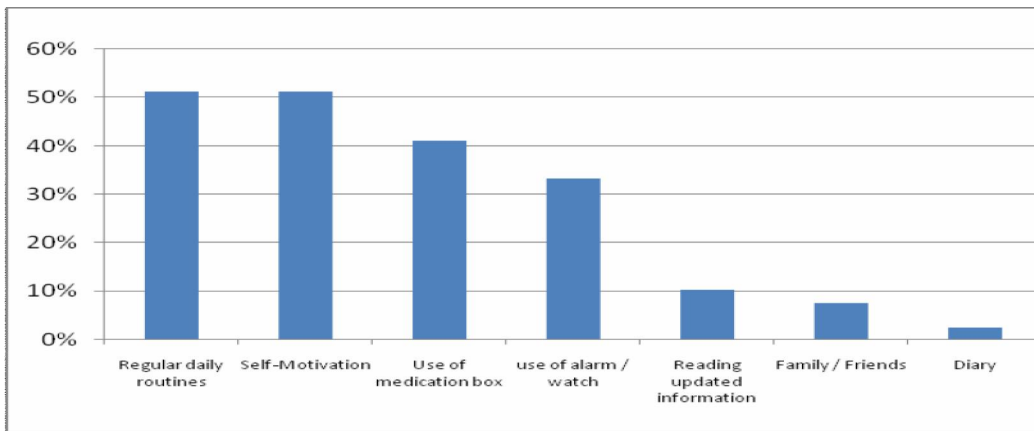


Figure 2C.ii.6 - Factor impeding adherence to HAART

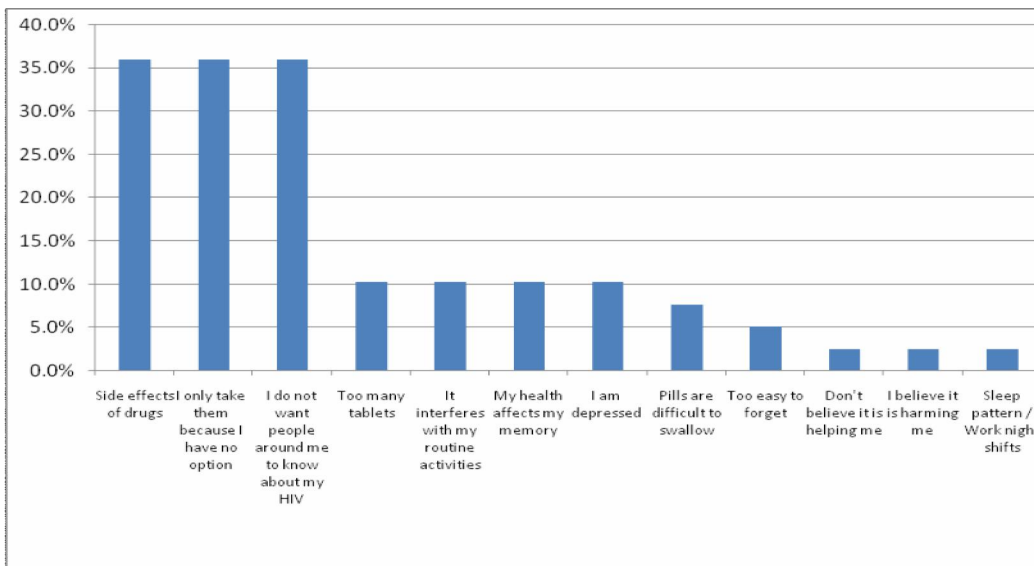


Table 2C.ii.9 – Percentage of participants reporting problems with adverse events currently

Duration on ARV therapy	< 3 Months	3-12 Months	1-2 Years	> 2 Years
Percentage	50%	50%	38%	28%

SECTION TWO

In this separate review of fifty case-notes, all had documentation that patients had been asked about their adherence to their ARV regimen. 88% had been asked every 3 months regarding adherence and the remainder every 6 months. 68% of patients' noted had documentation that pharmacist had spoken to them about adherence.



Discussion

Moyle et al reported successful therapy of HIV requires a high level of adherence ($\geq 95\%$) to be effective. Many centres in the UK report adherence rate of 75 – 80% based on self-reporting. The overall estimated self-reported adherence in this patient group was 77%, which is comparable to other centres. However in practice, it is not uncommon for patients to tell their doctors they are taking a 100% of their medication but then to admit to another member of the clinical team that they are having difficulties.

There may be a difference between self-reported adherence and the actual adherence of the patient to exact instructions. In the audit numerous patients reported various issues that would suggest a lower overall adherence rate compared to patients self-reporting of adherence.

Adherence is not a one off phenomenon and individuals are likely to be more or less adherent at different points in their ARV therapy, this is true of this patient group with varying responses to the questionnaire. Non-adherence can be related to a number of factors such as cognitive, personality, emotional, clinical and regimen factors. In addition there may be important issues for specific patient groups including issues about body weight, disclosure and drug interactions. There is no definitive predictive tool or method to identify who are going to have difficulties adhering to therapy either at the time of initiating therapy or on an ongoing basis. Therefore it is essential to continuously provide support and education to individuals for the duration of their therapy, rather than a one-off exercise at the initialisation of therapy.

The reasons for switching therapy can be complex which may involve drug toxicities, previous suboptimal therapy, tolerability issues or responding to changes in evidence for recommended drug combinations. Two thirds of the participants had been switched from their first-line combination. Generally the major reasons why patients discontinue therapy are mainly due to toxicities and tolerability issues. 35% of patients reported side-effects being their current issue making it difficult to take ARV therapy. All patients who had been on therapy for less than 3 months were experiencing problems with side-effects. A high proportion of patients starting ARV therapy will experience adverse effects, although not medically serious (e.g. nausea & vomiting), may undermine adherence. If initial side-effects and tolerability issues can be explained and controlled, individuals are more likely to adhere to therapy in the longer term. Patients can also experience chronic side effects from ARV therapy (e.g. metabolic complications) protocols should be devised that allow for appropriate choice of therapy in such circumstances.

In the audit a third of patients reported having no participation on their current regimen also patients that may initially agree with the doctor during the consultation but may subsequently disagree are more likely not to adhere. The process of involving patients and supporting shared decision-making about their individual care should start from the post-diagnosis assessment onwards and continue throughout the course of their HIV infection. It therefore requires patient education and personalised information provision to be integrated as part of the HIV services, including delivery in partnership with community or voluntary providers. Improving patient's empowerment with individual care and decision-making will increase concordance with their regimens.

Medication adherence support is an array of strategies and services to assist individuals in taking medications as prescribed. The type and level of adherence support needed varies with individuals and by life circumstances. Adherence is often



about blending a complex life with a complex medication regimen and an important aspect in this endeavour is spending time. Often appointments with doctors are limited to 20 minutes every three months therefore these complex issues may be overlooked. Effective adherence support requires an in-depth understanding of patient's lives, which can take a significant time, number of encounters and patience to develop. The majority of patients in the audit supported the development of a dedicated adherence clinic and commented on perceived benefits to their individual care.

Patients who are less adherent to therapy have a greater possibility of virological failure, greater chance of disease progression and development of resistance to available drugs. The subsequent regimens would probably be more complex and more expensive. Therefore from an economic perspective investing in an adherence support clinics to maintain patients on possibly the most cost-effective and most simple regimens would be advantageous to patients and services providers. Many centres in the UK now have these in place and a pharmacist and specialist nurse lead many.

The BHIVA / BASHH guidelines recommend that HIV centres should have a documented adherence strategy and recommends that adherence support and / or assessment should be an integral part of the patient's follow-up at each visit. The clinic does not have a documented adherence strategy or a formalised approach to assess adherence at each follow-up visit. Development of an adherence strategy would need multidisciplinary involvement. With the aim of continuing to build strong partnerships with patients and have a positive impact on promoting and improving adherence for all concerned

The recently published joint report on "*Standard of HIV clinical care*" from BHIVA, BASHH, Royal College of Physicians and British Infection Society (March 2007) has set the recommended ratio of HIV consultant and HIV pharmacist to patients number (0.2 WTE for every 50 patients). All prescriptions for ARV medications (including paediatrics, antenatal and those for haemophiliacs) in Northern Ireland originate from the Royal Victoria Hospital. The current provision of pharmacy support is provided by a single pharmacist (0.7 WTE) and no dedicated technician support for dealing with dispensing of prescriptions – this falls significant short of the recommended standard despite an ongoing increasing number of patients.

Despite these limited resources the impact of the HIV pharmacist is extremely significant with 59% of patients reporting that the HIV pharmacist contributed to supporting their ability to take ARV therapy and a fifth reporting that the HIV pharmacist was the most helpful. In addition in the case-note review two-thirds of patients had spoken to the pharmacist regarding adherence.

However with the rapidly increased workload, the current severe deficiency in pharmacy support for the HIV service means that the service is struggling to provide a basic service. This threatens the quality of care to patients, putting patients' health at risk if the pharmacist is unable to fulfil their duties. Additional pharmacy investment would have the benefit of improving and maintain the current standard of care delivered by this clinic and bring it up to par with other centres in the UK in meeting national standards.



Recommendations

- 2C.4 Investment in service development should include improvement in pharmacy support (specialist HIV pharmacists and technicians) to bring it in line with other centres in the UK and current recommended national standards.
- 2C.5 Clinical protocol on addressing adherence should be developed, incorporating the use of standardised tool for measuring and documenting local adherence.
- 2C.6 Establishment of a dedicated multi-disciplinary adherence clinic to ensure that adherence is optimised and maintained over time, including a holistic approach to delivering individual patient care.
- 2C.7 Development of a standardised tool for measuring patient's satisfaction with their understanding of and involvement in the clinical decision-making.
- 2C.8 Continuous development of the HIV pharmacist must be supported to include financial assistance for attendance at courses or establishments that are of benefit to the service.



Part 2C(iii) – Health Advisor Support

Standards

Standards for this strand were based on:

- Medical Foundation and Sexual Health (MedFASH), 2002: *Recommended Standards for NHS HIV services*.
- Society of Sexual Health Advisers (SSHA), 2004: *The Manual for Sexual Health Advisers*

Audit Objectives

We aim to look at:

- the number of new diagnoses referred to the Health Advisors
- the proportion of positive patients with contactable at risk partners
- the proportion of contactable partners notified and screened within 6 months of source diagnosis
- documentation of information provision on sexually transmitted infections (STI), STI screening (STS), cervical smear screening (CSS) for females and HIV post-exposure prophylaxis (PEP)

Audit Design

An audit proforma was designed based on the above objectives. Information was gathered by case note reviews of 50 most recent newly diagnosed patients with HIV infection attending the clinic

Audit Results

66% of newly diagnosed patients audited were seen by health advisors following a positive HIV result at first consultation. When patients were not seen, frequently there was a lack of documentation to indicate the reason of this variance of practice. Follow-up of newly diagnosed patients was less, with 42% being seen at second visit. 30% of those audited had never seen a health adviser. There is a trend of delayed or non-referral if these patients had their diagnoses made outside genito-urinary medicine (GUM) clinic.

78% of those patients audited indicated that they had partners that were at risk. 18% of these patients mentioned between 2 and 6 partners had been at risk. 66% of at risk partners were contacted within 6 months (48% notified and screened within one month, 12% at 2 months and 6% at 3 months). Inconsistent documentation revealed gaps in information about partners not followed up.

For all patients seen by health advisors, it was documented that information was given on STIs, STS, CSS, and PEP. 68% of these patients received this information within one month.

Conclusions

Almost one third of patients in the audit had not been seen by a health advisor since diagnosis. However, of those who were seen, all received essential information



related to sexual health needs. Two thirds of at risk partners were successfully contacted in a timely manner.

Discussion

The Manual for Sexual Health Advisers, published by SSHA recommends that every newly diagnosed HIV positive patient be referred to the health adviser. This also refers to patients transferring care from other clinics. It recommends partner notification be addressed at first “post-test” visit. In this audit, up to one third of patients weren’t seen by health advisers following diagnosis – in part, this reflects confusion of the working relationship of the members of the multi-professional team (MPT). With unclear responsibilities for each of the disciplines of the MPT, many specific roles were being duplicated

The role of the Sexual Health Adviser is pivotal for HIV positive patients receiving their diagnosis with regard to their physical, emotional, relational and sexual health and safety. Poor psychological adjustment can create barriers to effective disease management. The continuing stigma and poor public understanding of HIV can increase isolation and fear of disclosure, leading to failure to access appropriate medical and social support services.

Partner notification is an essential component of patient care, which can be a pivotal role in breaking the chain of infection. It has been estimated the each new HIV case averted may save between £0.5 to 1 million of NHS money. Factors that impact on the success or failure of this role are identifying HIV positive individuals through uptake of tests, notifying patients as soon as possible, early discussions with patients re partner notification, and establishing a protocol for managing the index case and contacts, with or without the involvement of provider referral.

Recommendations

- 2C.9 Agreed patient care pathway should be developed by the MPTs. This must reflect the patient’s journey through the HIV service and outline both the health advisers input as well as the roles & responsibilities of the other multi-professional teams.
- 2C.10 Patients who are diagnosed with HIV infection outside the GUM clinics should have input from health advisers integrated early so that their involvement can be timely introduced.
- 2C.11 Continuous development of the health advisers must be supported to include financial assistance for attendance at courses or establishments that are of benefit to the service.



Part 2C(iv) – Clinical Psychology

Standards

Standards for this strand were based on:

- Medical Foundation and Sexual Health (MedFASH), 2002: *Recommended Standards for NHS HIV services*.
- British Psychological Society, Division of Clinical Psychology, 2002: *Briefing Paper 17, Clinical Psychology Services in HIV and Sexual Health*

There are three relevant recommended areas:

- All HIV positive patients should have easy and timely access to a consultant clinical psychologist led clinical psychology service with staffing and training levels that match the service demand, which conforms to professional and governance standards, located in convenient and comfortable setting
- Core services to be provided by clinical psychologists should include assessment, treatment and intervention; services to health care professionals (HCPs) working in HIV services (teaching, training, supervision, research collaboration); and services for purchasers and planners.
- Clinical psychology services should be located close to or based within HIV services and work as part of a multi-professional team (MPT) and in partnership with other health psychology departments.

Audit Objectives

Currently there is very little (a total of 2 sessions per month or 0.05 WTE) clinical psychology service for patients with HIV. Due to the limited resources it is not possible to provide the range of psychological services recommended. Assessment from a service user and service provider perspective is required to identify the effects of the current service provision and the associated unmet psychological needs.

Audit Design

SECTION ONE

Psychologists who have experience of working in the HIV service in the Royal Victoria Hospital (RVH) designed two questionnaires. Consultation on the questionnaire design was also sought from a clinical psychologist with substantial experience in research and audit.

The first questionnaire aimed to assess psychological need from the service user perspective and the second from the HCPs' perspective. The questionnaires were self-reported and anonymous. Each questionnaire was piloted on one appropriate individual i.e. an individual attending the HIV service and a HCP. No problems were noted during the pilot administrations.

The questionnaires were distributed to 40 consecutive service users attending routine appointments within the HIV clinic. They were returned to a member of staff or posted into a sealed box in the waiting area. Twenty five HCPs were sampled, 20 questionnaires were completed and returned using the internal mail.



SECTION TWO

A case note audit was also undertaken using 50 randomly selected clinical notes of individuals attending the HIV clinic.

Audit Results

SECTION ONE

(1) HIV infected patients' perspective

75% of the respondents identified psychological difficulties arising from their diagnosis of HIV and 64% rated that their psychological difficulties would interfere with their day-to-day life either 'often' or 'all of the time'. Nearly half of those who indicated difficulties had not discussed their psychological problems within the HIV clinic. The majority of those individuals indicating problems were not receiving any form of psychological intervention from a mental health worker (counsellor/therapist/psychologist).

An equal proportion of individuals wished to receive psychological services (28%) to those who did not wish to receive services (28%) however a significant number of individuals were undecided (44%).

Where individuals had received psychological interventions the majority had been organised by the HIV clinic. Clinical psychologists or multidisciplinary community mental health teams provided the majority of the psychological interventions organised.

The majority (80%) of the respondents believed that access to specialised psychological support is very important to individuals with HIV, that professional psychological support should be offered to all individuals with HIV (92%), and the offer should be made within weeks of the diagnosis (97%).

The majority of the respondents wanted psychological services to be located within a physical health setting, either an acute hospital or genito-urinary medicine (GUM) clinic. Flexibility is required as some individuals find at various times that the clinic is very difficult for them to attend.

The majority of the respondents would want to be able to self refer to psychological services or obtain referral via a member of the HIV clinic staff. It was noted that attending during work hours is difficult if a patient wishes to keep attendance confidential therefore some flexibility in appointment times would be helpful.

(2) HCPs' perspective

The majority of HCPs (85%) reported that they routinely ask patients about their psychological wellbeing. HCPs indicated that on average at any time 65% of the patients on their caseload would have psychological difficulties that affect their quality of life or their ability to manage their condition.

The most frequent psychological difficulties encountered by HCPs include low mood/depression, health anxiety, general anxiety, relationship problems, sexual risk taking behaviour, and treatment adherence difficulties. HCPs indicated that the likelihood of patients developing psychological difficulties increases at the point of diagnosis and at other significant events in the course of treatment.



The majority of HCP's (90%) believed access to specialist psychological services for patients with HIV is very important and that specialist services should be located within the HIV service or on the hospital site. HCPs identified that psychological needs in over 50% of patients are not met. The inadequate amount of psychological support available for patients is repeatedly cited by HCPs e.g. 'totally inadequate clinical psychology care'

HCPs indicated that 34% of patients with psychological problems had contact with a specialist psychological service such as hospital or community psychiatry. Other statutory or voluntary services e.g. a family centre, befriending service or HIV centre were also identified as providing psychological support or interventions.

In addition to the needs identified in respect to patients, HCPs identified their own needs for training and supervision in relation to the general psychological support they provide within the HIV clinic.

SECTION TWO

100% of charts sampled in the case-note audit had documented that patients were asked about their current coping with their HIV diagnosis. In 76% of cases this took place on a three monthly basis.

38% of the sample was receiving some form of psychological support from services outside of the RVH. 20% were identified as requiring a referral to clinical psychology.

Conclusions

The current British Psychological Society standards are not met – there is little or no specialist psychologist service.

Both the questionnaire audits identified that there is a significant burden of psychological morbidities among the HIV infected patients. The HCPs' and case note audits confirmed that individuals with HIV are frequently asked about the psychological issues relating to living with HIV and its affect on their psychological health, however for the majority there is no identified intervention available. All the sections confirmed that there is a very limited service accessible to patients.

HCPs identified a broad range of psychological difficulties, including those that can include serious risk of harm to self or others and those, which require specialist psychological therapy.

Both individuals with HIV infection and HCPs believe specialised psychological support/intervention is a necessary part of overall care and should be available from early on following diagnosis and remain flexibly accessible throughout the management of patients' condition.

The HIV clinic is the most acceptable location to patients for psychological services to be located as they feel 'safe' in this environment and have built trust with professionals around important issues such as confidentiality. This confirms the need for psychological services to be embedded into the HIV service.

Discussion

Psychological care is an integral and essential part of the health care given to individuals with HIV – this is clearly endorsed by both HCPs and service users in this



audit. There is clear evidence that both groups believe access to psychological care is inadequate despite the need being high.

There is evidence to suggest that a significant group of individuals exist with unrecognised and unmet psychological distress. The general effect on the individual is likely to be one of reduced quality of life but at worst could increase the risk of harm to self or others (e.g. sexual risk taking behaviours) and potentially have negative effects on the efficacy of any current treatment and health outcomes (e.g. poor adherence).

Results suggest that in the absence of sufficient specialist psychological services, HCPs are trying to provide complex physical health care as well as non-specialist emotional support to patients with potentially complex psychological problems that require specialist intervention. The amounts of training, supervision and time HCPs have available to provide emotional support to individuals with these types of difficulties is neither sufficient nor appropriate to address their difficulties. The psychological care offered in this inappropriate model is by necessity non specific and its effectiveness uncertain. It could also potentially put patients at risk of further deterioration and may result in long-term harm to patients' mental and physical health status.

Recommendations

- 2C.12 Investment in service development should include establishment of a specialised clinical psychology service providing a high quality service to individuals with HIV in line with current recommended standard. The service would provide direct therapy and indirect functions such as training, teaching, consultation, & supervision of HCPs, in addition to research and audit functions.
- 2C.13 HCPs should have clear and agreed functions and ring fenced time allotted where they are involved in routine screening by developing a routine simple protocol for recognition and triaging of psychological distress.
- 2C.14 In order to provide the right service to the right individuals at the right time, a stepped care approach should be developed designed to fit individual need including provision of any type of non specialised psychological interventions with appropriate specialist supervision for quality, effectiveness and governance.
- 2C.15 Range of non specialised interventions should be specified – this may include non specialist emotional or informational support, individual, couple or family intervention. Self help material could be developed aimed at prevention and self management of initial/mild symptoms of psychological distress in the context of living with a chronic illness.
- 2C.16 The development of specific information about common psychological difficulties and range of specialised intervention via specialist clinical psychology service and formalised links to a range of statutory and voluntary organisations province wide.



Part 2C(v) – Social Services Support

Standards

Standards for this strand were based on:

- Medical Foundation and Sexual Health (MedFASH), 2002: *Recommended Standards for NHS HIV services.*
- Northern Ireland Social Care Council, 2002: *Code of Practice for Social Care Workers*
- British Association of Social Workers, 2002: *Code of Ethics*

The aims of the HIV Social Work Service should include:

- To be person-centred: empowering the individual to make health choices and to manage their own HIV, through education and support which recognises the importance of lifestyle, culture and religion, and which, where necessary, tackles the adverse impact of material disadvantage, social exclusion and stigma.
- To develop in partnership: so that goals and the respective responsibilities of the individual and the medical and social support services are agreed and clearly set out in a regularly reviewed plan.
- To be equitable: so that services are planned to meet the needs of the local population, including specific groups e.g. ethnic minorities and gay population, and are appropriate to people's needs.
- To be integrated: drawing on the knowledge and skills of the multi-professional team (MPT) including primary care and social care as well as specialist services.
- To uphold social work standards – promoting and protecting the rights of service users and carers while upholding users, carers and public trust and confidence, promoting user independence while protecting them from harm, maintaining and improving professional quality in skills and knowledge

Audit Objectives

We aim to audit

- MPTs co-ordination and referral to available services for people with HIV disease attending the clinic – i.e. time delay from diagnosis to access of appropriate Social Services support.
- the spectrum of Social Services accessed by patients with HIV disease attending the genito-urinary medicine (GUM) clinic.
- patient satisfaction within the HIV social work service.

Audit Design

SECTION ONE

An extended questionnaire section related to social services was included in the questionnaire given out to patient in the patients' perspective audit on multi-professional support (audit strand 2C(i)).



SECTION TWO

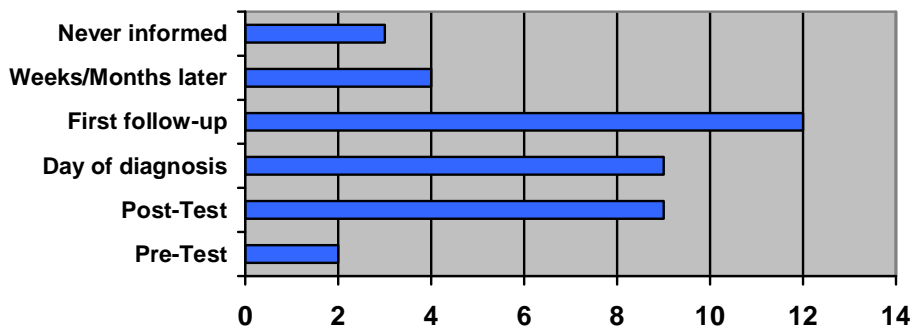
We conducted a case note review of 50 current cases, randomly selected from all caseloads under all 4 members of social workers.

Audit Results

SECTION ONE

In this sample, the length of time patients had been diagnosed as HIV positive ranges from eight weeks to twenty years (median of six years). The lengths of time they have been attending the GUM clinic ranges from one year at to 14 years (median of 5 years). All but three respondents were informed that a social worker was available to offer themselves, their partners, family and friend's emotional and practical support and advice. Of these, 91% were informed by the first follow up visit (see figure 2C.v.1)

Figure 2C.v.1: When were you made aware that a social worker was part of the multi-professional teams?



Within the sample, only 15% of respondents had current regular contact with a clinic social worker. 25% had current but infrequent contact whilst 55% had previous involvement but not current. Of the 39 respondents who had any previous or current contact with the clinic social worker 72% were aware of the name of the social worker whilst 28% were not.

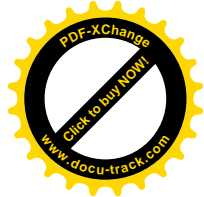
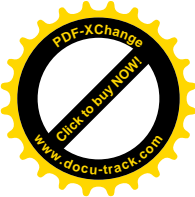
Table 2C.v.1 summarised the awareness of range of service provided by the social workers. Open comment feedbacks from patients on social workers were largely positive. Examples included:

‘The staff in this department could not be more helpful or caring’

‘I am totally satisfied with the help I receive from my Social Worker and all the staff at the clinic’

Table 2C.v.1 Are you aware the Social Worker can assist you with:

	Yes	No	Not Answered
Emotional support & counselling for self, partner or family.	83%	12%	5%
Help with emotional issues.	69%	24%	7%
Information regarding access to benefits	75%	20%	5%
Support with housing issues.	71%	22%	7%



Financial help / Grant applications.	71%	24%	5%
Provision of community care support.	66%	29%	5%
Provision of volunteer visiting services.	54%	39%	7%
Advocacy within the clinic & outside agencies.	66%	27%	7%
Respite / Convalescence.	59%	29%	12%

Improvements that were mentioned in the comments were as follows:

- More organised involvement from the clinic Social workers.
- More regular contact between patients and the clinic Social Worker.
- Spiritual comfort and Christian fellowship amongst other HIV positive people.

SECTION TWO

Basic demographic characteristics of the selected cases in this case note audit are summarised in table 2C.v.2. Of the sample, 80% were ethnically Anglo-Irish Caucasians (see figure 2C.v.2)

Table 2C.v.2 - Demographic characteristics:

	Male	Female
	32	18
AGE		
Under 18 Years	-	2
18 – 25 Years	-	3
26 – 35 Years	7	5
35 – 45 Years	13	7
45 – 55 Years	5	2
55 – 65 Years	7	-
MARITAL STATUS		
Single	18	5
Married/Civil Partnership	5	4
With Partner	5	2
Lone Parent	-	4
Divorced/Separated	4	3
SEXUAL ORIENTATION		
Gay	65%	-
Straight	31%	100%
Bisexual	3%	-

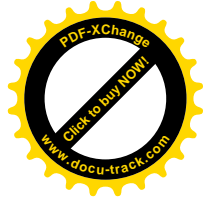
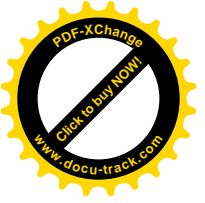
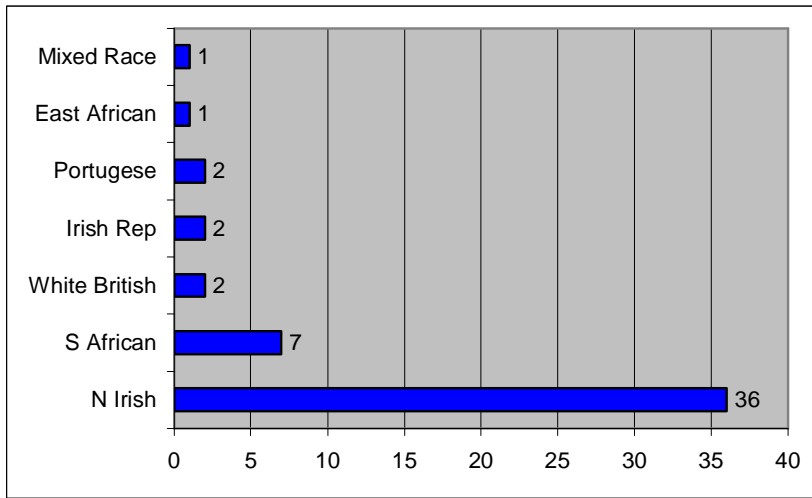


Figure 2C.v.2 – Ethnic Group of Audit Sample Cohort



68% of sample was diagnosed in Northern Ireland, with the remaining 32% diagnosed outside Northern Ireland. Date of diagnosis of sample surveyed ranged from 1987 – August 2006.

The immigration status of the sample were 80% UK nationals, 8% had indefinite or limited leave to remain, 6% were other EU nationals, 4% had working visas, 2% asylum status, and 2% over-stayers. 84% uses English as their first spoken language.

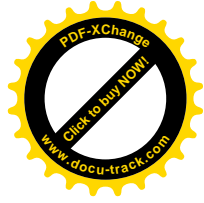
Only 32% were waged – of these 68% held full time employment while remaining were working part time or had temporary work. 44% resided in Greater Belfast Area, 46% in provisional town and 10% in rural area.

The time delay from a patient receiving a positive diagnosis to referral to the social work service in this sample ranged from within 4 weeks to 6 years, with 76% referred within first year (see Table 2C.v.3). The lengthier delays could be accountable due to the fact that a significant number of this group were diagnosed outside the province. 86% of referral was made by GUM staffs (doctors, nurses and health advisors) and 6% were self-referred.

Table 2C.v.3 – Percentage of patients referred to social work service by time from diagnosis

Within 1 month	56%
1 - 6 months	12%
6 - 12 months	8%
1 - 2 years	12%
2 - 4 years	8%
4 - 6 years	4%

With the exception of one case – all patients referred to the social work service were seen immediately or within a 2-week period. In the single case mentioned above, the senior social worker delayed allocation for 2 months due to staff shortages and unacceptably high caseloads of existing social workers.



Initial contact in 66% was a “face to face” meeting with the patient either in GUM clinic or after a clinic appointment in the social services offices in Royal Victoria Hospital. The remaining 34% of cases initial contact was made by telephone and subsequent arrangements made for initial meeting with patient at home or in social services. . In addition to “face to face” meetings, regular social work contact was maintained by telephone in all cases; 28% e-mail contact; 14% text message contact and 58% contact by letter. Many of the survey samples were contacted by several different mediums.

32% of patients restricted/limited who the social worker could liaise with and offer professional support due to their perceived fear of discriminatory response. Social work meetings with patents took place in a range of venues, mainly in response to patient choice

36% of cases had intensive contact with complex issues, while a further 44% had regular contact of at least once a month.

In 98% of cases, the social worker offered counselling and emotional support to the patient. This level of support was extended to include partner, family and others in 34%, 30% and 6% of the cases respectively.

Practical assistance provided were related to employment issues (52%), welfare rights (96%), housing matters (78%), and immigration issues (18%), grant aid (78%) and provision of community care services (18%). In 38% of cases there was evidence of co-working and liaison with other Health and Social Services Agencies (see table 2C.v.4).

Table 2C.v.4 Referral to other health and social services

12%	Referred to Mental Health Services
6%	Referred to Addiction Services
8%	Referred to Family & child Care
22%	Referred to Physical Health & Disability
16%	Referred to more than 1 of the above mentioned Agencies

18% of patients were in receipt of the HIV Volunteer Visiting Service. 78% of patients used the social work service in an advocacy capacity and 68% of patients actively sought Information regarding HIV Disease from the social worker to make informed choices about the future. 44% of patients has availed respite care organised through the HIV social workers (include 16% received respite at home while children attend Baretstown Children’s Camp in Co. Wicklow). 6% has ever used residential or nursing Homes and 4% ever used Benedictine Monastery Retreat House. 16% ever used Positive Voices Weekends or HIV Centre Weekends

66% of patients in this sample study had links with other voluntary agencies predominantly the HIV Support Centre, but also Cruse Northern Ireland, Northern Ireland Community Addiction Service (NICAS) and other Addiction Services

Conclusions

The basic demographic characteristics of the random sample of patients are similar to those of our current total cohort of patients.



There is inconsistent practice regarding both informing patient of the avail the social services and referral for social services assessment.

It is evident that there is a high prevalence of social difficulties among the cohort of patients - 66% were unwaged and consequently more likely to be suffering from social/economic deprivation and poverty. This is also evidenced by survey results regarding wide variety of practical assistance accessed by patients.

14% of sample patients were of Non-UK, Non EU – for them, immigration issues and communication difficulties can become a major barrier in accessibility of social and medical care.

Almost all of the patients who were referred for social work support availed of practical and emotional support for themselves, their partners and family members.

There is evidence of an integrated community support service, liaison and co-working with statutory and voluntary agencies in the community.

Discussion

A diagnosis of HIV can lead to poor social and emotional adjustment, including self blame, denial and fear of disclosure that create barriers to managing HIV. The continuing stigma and poor public understanding of HIV can create or reinforce a sense of low self-esteem and increase isolation and feelings of depression. Fear of social exclusion can lead to non-disclosure and failure to access appropriate social support services. Along with this sick role is a high burden of poverty as seen in our sample. National research HIV Poverty Report, presented to House of Commons December 2006 further substantiated the link between HIV and poverty in the UK.

In this audit sample, there was a high uptake 78% of the social work advocacy role thus adhering to principles of Human Rights and government White Paper – “Our Health, Our Care, Our Say”, in which government wants to improve health and emotional well-being, freedom of choice and control.

The definition of social work is

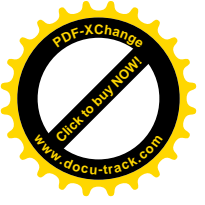
***“The profession which promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being. Utilising theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments.*”**

Principles of human rights and social justice are fundamental to social work”. The holistic approach in provision of information, emotional and practical support that encourages self-management, including dealing with stigma is very much a cornerstone of HIV care.



Recommendations

- 2C.17 The development of an agreed patient care pathway for MPTs is further supported (see recommendation 2C.9). Involvement of social work services must be integrated as an essential component of patients care pathway for all patients following a HIV diagnosis and future follow up.
- 2C.18 The development of comprehensive information leaflet is further supported (see recommendation 2C.3). This should include range of service provision and how to access social work support.
- 2C.19 In similar fashion to the concept of named nurse, each patient should be allocated with a named social worker. Individualised contractual agreement should be formulated between patient and social worker tailored to their need, regarding frequency of contact, mode of contact and review of purpose and outcome of intervention.





Part 2C(vi) – Multi-professional Support – Staff Perspective

Standards

The following documents endorsed the importance of a comprehensive HIV service provided by a multi-professional team (MPT):

- Medical Foundation and Sexual Health (MedFASH), 2002: *Recommended Standards for NHS HIV services*.

There is no set standard for this strand of audit. Using a qualitative approach, we aim to audit the current collaborative working relationship between the members of the MPT.

Audit Objectives

We aim to gather the opinions of the MPT working in the HIV clinic on aspects of the HIV service. Areas discussed include: - clarity of roles/remits within the team, how to meet professional development/ training needs, medical chart management, increasing efficiency/ effectiveness within current available resources, the presence of forthcoming changes locally and nationally that could affect the service and identification of strengths of the service.

Audit Design

Focus group methodology was employed to gather qualitative information. Four focus groups of professionals were formed following an invitation to all members of staff to participate. Each group had an independent facilitator and all groups met at the same time. Each group's responses were recorded. Common themes arising out of the opinions expressed by staff during discussions were constructed and suggestions made for areas for further examination / development by the service.

Audit Results

It is clearly evident throughout the opinions gathered within the focus groups that there was a strong commitment to the HIV service among the current staff. Staff recognised and valued their commitment to this service. This high level of commitment is a significant asset to the service.

It is speculated that where dissatisfactions were expressed by staff about aspects of the service, some may be connected to the effects of a high level of commitment encouraging staff to take on roles and provide more service than both time and resources realistically could allow. Staff beliefs about the service illustrated this; they believed it is important for the HIV service to be 'holistic', to be offering a comprehensive range of services, to be a life long service to patients and their families, to be able to provide flexible and easily accessible clinics and access to staff advice. Trying to achieve these values in the present circumstances of rising patient numbers and static personnel could contribute to the dissatisfaction surrounding the effects of increasing work loads and the presence of unclear duplicated roles and responsibilities. In addition, opinions also reflect insufficient time for team communication, training, review and reorganisation of the service in response to changes in demands/environment.



When groups were asked to look at the service from the perspective of increasing efficiency to cope with increased demand, staff acknowledged that changes may need to be considered in the amount and breadth of service offered, how patients will access the services and who will provide aspects of the service. Important issues surrounding the priorities for the service were highlighted.

Conclusions

Roles and responsibilities was a recurring theme that emerged throughout the audit. It would seem that many staff were seeking clarification as individuals and as part of a team, on the roles and responsibilities each performs. They saw clarity and agreement in this area as fundamental to a successful working relationship between different disciplines of the MPT. The issue of who is responsible for aspects of medical charts upkeep is a specific example of this type of issue.

Discussion

Staff discussion generated many interesting and useful suggestions to solve some of the challenges and difficulties identified. This demonstrates further strengths of the HIV service that of openness and willingness to consider changes.

Future discussion and action arising from the focus groups might focus on:

- The nature and the breadth of the service
- Who will do what and when, perhaps considering the possible use of induction programmed/ competency frameworks/ protocols/ patient care pathways

It would be hoped that staff will take up some of their creative solutions, pilot them and measure outcomes to the service.

Recommendations

2C.20 The development of an agreed patient care pathway is further supported. In particular, this should define the roles and responsibilities of each discipline of the MPT, around actions and documentations, which in turn aid communication and efficient working.

2C.21 An agreed clinical policy should be developed to defined the nature and the breadth of the service.

2C.22 Specific staff induction should be developed, within a competency framework. Staff roles and competencies should be matched within a context of ongoing assessment.

2C.23 A joint MPT educational and audit programme will promote sharing of skill mix, and an ongoing understanding of roles and responsibilities.



Strand 3 – HIV Testing of Genito-urinary Medicine Clinic Attendees

Introduction

The Health Protection Agency Press Release in November 2006 announced that there is an estimate of 61500 people living with HIV infection in the UK, of who 20100 remain undiagnosed.

The National Strategy for Sexual Health and HIV has set the national target for HIV testing for Genito-urinary medicine (GUM) services: to offer HIV testing to all GUM clinic attendees. The aim is to reduce the number of undiagnosed HIV infections in patients visiting GUM clinics.

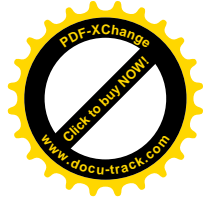
Prompt diagnosis of HIV infection allows the opportunity for improvement in the health and well being of individuals through access to medicines; improvement in the public health from the expected reduction in onward transmission; and patient empowerment in knowing their status.

A variety of methods have been studied and published which could be used to increase the uptake of HIV testing by GUM attendees. Among these include staff training, provision of information leaflet to GUM attendees, inclusion of HIV prompts in clinical notes as a reminder and the adoption of HIV testing as a routine on an “opt-out” basis. All these methods are currently employed by all four GUM clinics in Northern Ireland.

In seeking further improvement, it is desirable for us to audit our present uptake rate of HIV testing, and to explore the reasons which patients may decline the offer of HIV testing and correlating with those perceived by our health care professionals (HCPs). This may better inform our strategies in promoting a higher uptake of testing within the clinics.

In this strand, we aim to audit the following:

- Uptake rate of HIV testing in the four GUM clinics
- Reasons of test refusal – Patient perspective and HCP perspective



Part 3 – Patient HIV Test Refusal Questionnaire and Healthcare Worker Questionnaire

Standards

Standards for this strand were based on:

- Sexual health and HIV Strategy Integrated Steering Group, Department of Health, 2001: *The national strategy for sexual health and HIV*.
- British Association of Sexual Health and HIV (BASHH), 2006: *UK National Screening and Testing Guidelines*.

It is recommended that all patients presenting to a genito-urinary medicine (GUM) clinic should be offered an HIV test regardless of signs or symptoms of disease or risk factors for infection. A system whereby patients would actively have to opt out of HIV testing has been implemented for all GUM attendees in Northern Ireland.

Audit Objectives

We aim to determine the number of patients who attend the clinic and are not tested for HIV infection, and assess reasons for this. In addition, we aim to audit the reasons for test refusal from patients and health care professionals' (HCPs) perceived reasons for test refusal. This would better inform strategies to improve uptake of testing within the GUM clinics.

Audit Design

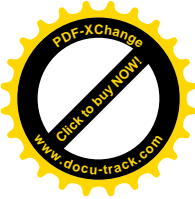
SECTION ONE

A retrospective analysis was used to estimate uptake of HIV test of new patients attending all four GUM clinics (Royal Victoria Hospital (RVH), Causeway Hospital (CAU), Altnagelvin Hospital (AH) and Daisy Hill Hospital (DHH)) from 1st August 2006 to 31st December 2006. The number of HIV tests performed on these patients was obtained from Regional Virus Laboratory.

SECTION TWO

An anonymous questionnaire was designed for patients to capture the actual reasons of test refusal. Clinicians were actively encouraged to give the questionnaire to all patients who declined testing in this corresponding period at each of the four GUM clinics offering HIV testing

A separate anonymous questionnaire was designed and issued to HCPs of all grades in each of the clinics to determine what they are the most important factors that influenced patient's decision in declining HIV testing. The design of the questionnaire allowed selection from a list of reasons with room for free text. More than one reason could be selected by the patients but for the HCPs, respondents were asked to select which two reasons were most important to allow for better comparison.



Audit Results

SECTION ONE

During the audit period, 88.6% of new patients attending GUM clinics in Northern Ireland accepted HIV testing. 71.9% of all HIV tests performed in the four clinics were in new patients. Table 3.1 summarises the finding in each clinics. It is not possible to determine the number of patients who were not offered HIV testing. It is not possible to determine the number of patients that refused HIV testing.

Table 3.1 - HIV testing in all four GUM clinics in Northern Ireland from 1st August 2006 to 31st December 2006

	Total HIV tests in all patients	Total HIV tests in new patients only	Total new patients	% of tests in new patient	% of new patients who accepted HIV testing
RVH	3449	2316	2611	67.1	88.7
CAU	326	291	376	80.8	91.3
AH	666	538	589	89.3	77.4
DHH	484	395	419	81.6	94.3
REGIONAL	4925	3540	3995	71.9	88.6

SECTION TWO

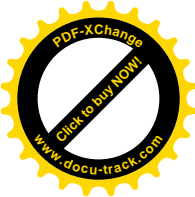
A total of 114 questionnaires were returned from the patient group. All relevant HCPs were continually encouraged to actively identify individuals who declined HIV testing for recruitment. It is not possible to determine the total number of patients who eventually received the questionnaire.

All HCPs who has active roles in obtaining consent from patients for HIV testing during the recruitment period were asked to participate in the HCP group. A total of 40 HCPs were asked to participate and 27 (68%) of them replied.

Both groups gave a number of varied reasons. A comparison of responses from each group is displayed below in Table 3.1. Reasons with a low frequency have been omitted from this summary.

Table 3.1 – Most important factors perceived by HCP's and Actual reason given by patient for refusal of HIV testing

Reason	HCPs	Patients
Fears test would be positive	70%	0%
Potential reaction of partner	22%	4%
Worries about confidentiality	22%	6%
Fear of Needles	33%	52%
Little or no chance of being positive	22%	60%
Intends to get test done later	0%	7%
Fears life insurance difficulties in future	11%	1%



Conclusions

HIV testing was accepted by 88.6% of new patients attending GUM clinics in Northern Ireland. This was well above the audit target set by BASHH of 60% by the end of 2007.

Patients gave a very different set of reasons to the ones the HCPs felt were important. The most common patient cited reasons were 'fear of needles' (52%) or 'little or no chance of being positive' (60%). Few patients expressed 'worries about confidentiality' (6%) at the clinic. No patient identified 'fears test would be positive' as a reason which was perceived by HCPs to be the most important (70%).

Discussion

From the analysis of HIV test uptake in section one; there were at least 455 new patients who declined HIV testing. These patients were only part of the potential recruitable patients for the questionnaire, which could also include review patients who declined HIV testing on subsequent attendances. Only 114 patients' responded from an unknown number of questionnaires given out. This significant gap may limit the interpretation and conclusion that can be drawn from the audit findings.

During the audit, recruitment of patients for the questionnaire was dependant on active participation of HCPs – this unfortunately, despite continual encouragement, was not guaranteed. It was observed during the audit period that a low number of questionnaires were given to patients, although few incomplete questionnaires were returned. These observations suggest the low number of completed questionnaires was mainly due to non-participation of HCPs, rather than patients' unwillingness to participate.

There are a number of possible explanations for low recruitment rate by HCPs – HCPs may be too busy; HCPs may be selectively not offering HIV testing to all patients, including those who recently tested in other settings (e.g. antenatal patients, blood donors), patients perceived to be at no risk (e.g. individuals who have never had a sexual relationship); HCPs may be selectively not recruiting patients who have declined HIV testing on what the clinician perceived to be a less clinically important reason.

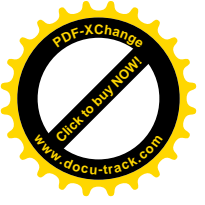
Despite this, the audit findings managed to illustrate a significant difference in the most important factors perceived by HCPs for test refusal, and the actual reasons given by patients opted against HIV testing.

The two most frequent reasons for test refusal from patients were fear of needles and self-perceived low risk of infection. While HIV testing using a non-blood specimen is generally discouraged due to concern with sensitivity/accuracy – for those with fear of venepuncture, an alternative such as oral fluid testing should be considered. Patients who considered themselves to be at low risk may require more information about their risk, with emphasis on the chronic asymptomatic carrier state of HIV infection. Although not identified in this audit, there may also be situations where point-of-care testing may have roles for patients who felt they had low risk, who may also be refusing test due to reluctance in waiting.



Recommendations

- 3.1 HCPs need to be educated in the reasons why patients refuse testing, and develop strategies to improve uptake accordingly. HCPs should avoid influencing patients' decision based on their own perception of risk.
- 3.2 HCPs should focus more discussion with patients on the asymptomatic carrier state of HIV infection, which may improve uptake of HIV testing.
- 3.3 Alternative methods of testing should be considered for patients who declined HIV testing due to fear of venesampling. This may include point-of-care testing.





Appendix One – Contributors and Acknowledgements

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Hospital Participation

Thank you to all the various clinical staff from each of the hospital sites listed below who took part in this regional audit – the project team very much appreciated your support – without your help this regional audit could not have taken place.

Altnagelvin Hospital

Antrim Area Hospital

Causeway Hospital

Craigavon Area Hospital

Daisy Hill Hospital

Erne Hospital

Lagan Valley Hospital

Mater Hospital

Mid-Ulster Hospital

Royal Jubilee Maternity Hospital

Royal Victoria Hospital

Ulster Hospital

Patient Participation

Thank you to all the patients who provided their support for this audit. Your views and opinions were extremely valuable to the project team in assisting making recommendations for improvements for future care.





Appendix Two

Glossary

AH	Altnagelvin Hospital
AIDS	Acquired immune deficiency syndrome
ARV	Anti-retroviral
BASHH	British Association of Sexual Health & HIV
BBV	Blood borne viruses
BHIVA	British HIV Association
BIS	British Infection Society
BP	Blood pressure
BPSU	British Paediatric Surveillance Unit
CAU	Causeway Hospital
CHART	Children's HIV Antiretroviral Study
CHIVA	Children's HIV Association
DAD	The Data Collection on Adverse Events of Anti-HIV Drugs Study
DHH	Daisy Hill Hospital
DNA	Deoxyribonucleic acid
GP	General Practitioner
GUM	Genito-urinary medicine
HAART	Highly active antiretroviral therapy
HCP	Health care professional
HIV	Human immunodeficiency virus
HSV	Herpes simplex virus
MedFASH	Medical Foundation of AIDS and Sexual Health
MPT	Multi-professional team
MTCT	Mother to child transmission
NHS	National Health Service
NICAS	Northern Ireland Community Addiction Service
PCR	Polymerase chain reaction
RCOG	Royal College of Obstetricians and Gynaecologists
RCP	Royal College of Physicians
RVH	Royal Victoria Hospital
RVL	Regional Virus Laboratory
SSHA	Society of Sexual Health Advisers
STI	Sexually transmitted infection
STS	Sexually transmitted infection screening
TAT	Turn around time
VL	Viral load