HIV-1 INFECTED WOMEN AND THEIR CHILDREN IN EUROPE: AN EPIDEMIOLOGICAL STUDY OF HEALTH AND SOCIAL CARE

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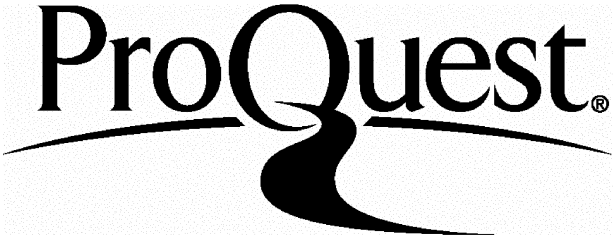

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Abstract

This thesis aims to describe the characteristics of HIV-infected women and their children in Europe and to investigate their clinical and psycho-social care. Socio-demographic, clinical and immunological characteristics of 2131 HIV-infected pregnant women, enrolled between 1985 and July 1997 in an on-going multi-centre prospective study, the European Collaborative Study (ECS) are described: two-thirds had a history of injecting drug use (IDU) and heterosexual acquisition of HIV infection had increased significantly over time. Five years after delivery, 14% of mothers will have died and 18% progressed to AIDS. Results from two surveys of 55 centres in 1994 and 1997 to identify obstetric policies for HIV-infected women showed that zidovudine use to reduce vertical transmission has increased significantly since 1994. Of the 1123 children enrolled in the ECS by September 1996, 70% had always been cared for by their parent(s) in the first four years of life, but by age eight, an estimated 60% will have lived in alternative care. Maternal IDU, clinical status and single parenthood were the main reasons necessitating alternative care. The hospitalisation experience of 1189 children is presented, showing that infected children were four times more likely to be admitted to hospital than uninfected children of the same age. The final part of the thesis presents the results of two surveys carried out in 1996/7. A survey of service-providers in 15 paediatric HIV centres was carried out to document the provision and organisation of clinical and psycho-social services for HIV-affected families. Service provision was similar, despite national differences in medical and social infrastructure. A survey of 182 parents and carers of children affected by HIV attending the same centres showed that satisfaction with services varied by centre and according to respondent characteristics. The thesis concludes with a discussion of the implications for service development and future research.

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Chapter 1 Women and HIV infection: an overview

1.1 Introduction

Acquired immunodeficiency syndrome (AIDS) was first described among homosexual men in the USA in 1981 (Gottlieb *et al,* 1981). AIDS is characterised by a range of opportunistic infections and neoplasms, resulting from progressive loss of immune function. The causative agent of the syndrome was identified in 1983 (Levy *et al,* 1984; Gallo *et al,* 1984; Barre Sinoussi *et al,* 1983) and subsequently named the human immunodeficiency virus (HIV) or HIV-1. Since HIV was first identified, the infection has spread to over 190 countries (Mertens and Low Beer, 1996) and has developed into arguably the most important and far-reaching pandemic of this century. In 1985, HIV-2 was isolated in a study of Senegalese women (Morlat *et al,* 1992) and subsequently found to be prevalent in West Africa and in areas of emigration from West Africa. This thesis is restricted to the more common HIV-1 infection.

By the end of 1996, nearly 30 million people world-wide had been infected with HIV, of whom about 500 000 were living in Western Europe (UNAIDS, 1997). The World Health Organization (WHO) estimates that by the year 2000, there will be 40 million adults infected with HIV world-wide, of whom 90% will be living in developing countries (Mertens *et al,* 1995). Globally, there are two HIV-infected women for every three infected men but it is expected that by 2000 the number of new infections among women will equal those among men (Quinn, 1996). However, the male-to-female ratio varies between countries: approximately equal numbers of male and female AIDS cases are reported from sub-Saharan Africa, with an excess of female cases reported from some areas such as Uganda (Mertens and Low Beer, 1996). Initially homosexual transmission was the main

mode of acquisition of HIV in the USA and most of Europe and the sex ratio among AIDS cases was skewed towards men. However, with the increasing importance of heterosexual transmission and the adherence to health education messages among homosexuals and injecting drug users (IDU), especially in urban populations, the proportion of AIDS cases in homosexual men and IDUs is levelling out or even declining in some countries (WHO-EC Collaborating Centre on AIDS, 1997; Franceschi *et al,* 1996). This shift has been accompanied by an increase in infections among women; in Europe, the proportion of female AIDS cases has risen from 12% of the total adult cases in 1986 to 21% in 1996, with nearly 30 500 cases reported by December 1996 (WHO-EC Collaborating Centre on AIDS, 1997). However, on a global scale HIV infections among women continue to be concentrated in the developing world, mainly in sub-Saharan Africa .

1.2 Biology and immunology of HIV infection

A detailed description of the molecular biology and immunology of HIV infection is beyond the scope of this thesis and therefore the following section only provides a brief summary (for an excellent review see Stevenson, 1997). HIV is a retrovirus belonging to the lentivirus family and was initially known as lymphadenopathy-associated virus (LAV) and human T-cell lymphotropic virus type III (HTLV-III). Cells expressing the surface antigen complex CD4, the main receptor for HIV, are the major targets of the virus, the most important being the central regulatory cells of the immune system, the T-helper lymphocytes (known henceforth as CD4 cells). HIV enters the target cells and integrates into the nucleus following reverse transcription of viral RNA to DNA. Viral replication may then take place, although some infected cells remain in a latent state of infection and continue to circulate the body as viral reservoirs.

Primary HIV infection is frequently characterised by high levels of plasma viraemia, with the initial immune response occurring six to 12 weeks after infection. During the next phase of infection, the "asymptomatic period", there is a very high turnover of virus and CD4 cells and a relatively constant level of cell-free HIV RNA (Ho *et al,* 1995; Wei *et al,* 1995). The average time from primary infection to development of AIDS in developed countries is in the region of 10 to 11 years (Mocroft *et al,* 1997; Enger *et al,* 1996; Brettle *et al,* 1996) but with the advent of combination antiretroviral therapy this is likely to increase (Hammer *et al,* 1996; Delta Co-ordinating Committee, 1996).

1.3 Transmission of HIV infection

Transmission of HIV infection takes place through three main routes: sexual contact with an infected person, parenteral exposure to infected blood or blood products and vertical transmission from mother to child.

1.3.1 Heterosexual transmission

Heterosexual transmission is the predominant mode of acquisition of HIV infection world-wide, accounting for nearly three quarters of all infections (Quinn, 1996). Incidence of HIV infection has been highest in developing countries where heterosexual contact is the main route of transmission. In Europe, there has been a steady increase in heterosexual acquisition of infection among women (Franceschi *et al,* 1996) and nearly half of the women with AIDS reported by the end of 1996 had been heterosexually infected (WHO-EC Collaborating Centre on AIDS, 1997). Heterosexual transmission is increasing especially among women at risk of acquiring other sexually transmitted diseases and those with IDU sexual partners (WHO-EC Collaborating Centre on AIDS, 1996).

Women are biologically more vulnerable to heterosexual acquisition of HIV infection than men, with the rate of male-to-female transmission of HIV nearly double that of female-to-male transmission of HIV (O'Brien *et al,* 1994; De Vincenzi, 1994). Furthermore, some women at risk of acquisition of infection are unable to negotiate consistent male condom use, which provides effective protection against sexually transmitted diseases, including HIV (Anonymous, 1997; Plummer *et al,* 1991; De Vincenzi, 1994) and there is a lack of widely available female-controlled methods of HIV prevention which are safe, acceptable and affordable (Masters *et al,* 1996; Carlin and Boag, 1995).

1.3.2 Parenteral transmission

This transmission group includes IDUs exposed to infected blood, recipients of contaminated blood transfusions or other blood products, such as factor VIII used by haemophiliacs (Donegan *et al,* 1990) and patients infected in health care settings where there is inadequate sterilization of injecting equipment. By December 1996, 51% of women with AIDS reported to the WHO-EC Collaborating Centre had acquired their infection through IDU (compared to 37% of men with AIDS), with less than 6% having acquired HIV nosocomially or through contaminated blood/blood products (WHO-EC Collaborating Centre on AIDS, 1997).

HIV can spread very rapidly through IDU, reflecting the efficiency of parenteral transmission (i.e. sharing injecting equipment) (Richardson *et al,* 1993; Muga *et al,* 1990). Behavioural changes required to decrease risk of parenteral transmission among IDUs include not sharing injecting equipment, not backloading (which introduces blood into the syringe), reducing number of sharing partners and frequency of sharing occasions and obtaining sterile injecting equipment from needle exchanges or pharmacies. Information

campaigns and needle exchanges have been relatively successful in Western Europe, as evidenced by reports of stabilisation or even declines in incidence of infection among IDUs (Peters *et al,* 1994; WHO-EC Collaborating Centre on AIDS, 1996; Stimson, 1995; Frischer *et al,* 1996), although continued effort will be needed to maintain low-risk behaviours (Hunter *et al,* 1995). However, the increasing incidence of HIV infection among IDUs in Eastern Europe, especially Poland and the Ukraine, is of concern (WHO-EC Collaborating Centre on AIDS, 1997; Mertens *et al,* 1995). Many HIV-infected female IDUs also have sexual risk factors for HIV acquisition, including IDU sexual partners and the exchange of sex for drugs or money (Muga *et al,* 1997; Carr *et al,* 1996; Van Ameijden *et al,* 1994; Klee *et al,* 1990; Rezza *et al,* 1994). It is therefore difficult to determine by which route women with high risk injecting and sexual behaviours acquired their HIV infection.

Three-quarters of all AIDS cases due to contaminated blood or blood products in Europe have been in men (WHO-EC Collaborating Centre on AIDS, 1997), reflecting the association between AIDS and haemophilia (Centers for Disease Control, 1982a). Preventive policies including blood donor screening and heat treatment of blood initiated in most European countries in the mid to late 1980s has meant that there should be no new infections due to this route of transmission. Occupational transmission of HIV is rare, with only 63 confirmed cases of HIV seroconversion following accidental exposure of health care workers world-wide, the vast majority of which were the result of percutaneous injuries (mostly hollow bore needlesticks) (Najera Morrondo, 1995).

1.3.3 Other routes of transmission

Other routes of transmission are of theoretical concern in the household setting, where close contact may occur between parent and child, or siblings, although epidemiological evidence for horizontal transmission within families is lacking (Newell and Dunn, 1994). There have been a total of 16 reports of individuals who had been bitten by HIV-infected people (Vidmar *et al,* 1996; Richman and Rickman, 1993), of which only one offers persuasive evidence of HIV transmission through a human bite (Vidmar *et al,* 1996). In a further two cases where the bitten individual was retrospectively found to be infected this could not be definitely linked to the biting incident (Anonymous, 1987; Wahn *et al,* 1986). Two incidents of HIV transmission from health care professionals to their patients have been reported from the USA (a dentist) and France (a surgeon); in both cases the lack of major risk factors in the infected patients suggested that the health care professional was the source of infection and genotyping of the viral strain provided further evidence (Communicable Disease Report, 1997; Ciesielski *et al,* 1992).

1.4 Characteristics of HIV-infected women in Europe

Women at risk of HIV infection in Europe are likely to have pre-existing social and economic problems, including drug use, single parenthood, unemployment, unstable housing or homelessness, imprisonment and immigration problems (Imrie and Coombes, 1995; Melvin and Sherr, 1995; Mok *et al,* 1996; Kunzel and Kind, 1992; Giaquinto *et al,* 1991; Honigsbaum, 1995; Mayaux *et al,* 1995). The social environment of HIV-infected women is therefore a crucial factor in determining what services they and their families require, many of which are not directly related to the HIV infection itself. In developed countries, established HIV services tend to be male-dominated and not designed to meet women's needs (Hankins, 1995) and in response to this, a number of non-governmental

organisations (NGOs) have been developed specifically for women, such as Positively Women in the UK.

Drug use is a major issue for many HIV-infected women in Europe, whether this is their own or their partners' IDU. Active IDUs are often socially marginalized and those with HIV infection may be doubly stigmatized, which is likely to affect their access to health and welfare services. Drug-users are recognised to have poor access to health services generally (Morrison and Ruben, 1995) and women, in particular those with children, may have problems in gaining access to drug rehabilitation programmes (Black *et al,* 1994) and services specifically aimed at reducing risk of HIV acquisition, such as needle-exchanges (Weissman *et al,* 1995; Hart *et al,* 1989). Drug-using mothers may be a particularly difficult group for the health and welfare service-providers to target, since they may actively avoid existing provisions for fear that their children may be taken away (Baller, 1994). Other drug-related issues facing HIV-infected women include imprisonment, domestic violence and exchange of sex for drugs or money.

In Europe, a substantial number of HIV-infected women are those originating from a country where heterosexual transmission is frequent (mainly from sub-Saharan Africa) (WHO-EC Collaborating Centre on AIDS, 1997). The issues facing these women include residency problems, language and cultural difficulties and inexperience with the welfare or health care infrastructure, in addition to possible social discrimination. Many of these women, particularly refugees from countries affected by war, are isolated from their extended family, which is traditionally an important source of support, particularly with child care.

Although HIV-infected women have additional medical needs compared to their male counterparts, such as those relating to family planning and obstetric and gynaecological services, many have limited access to optimal health care. This is shown by lower rates of antiretroviral use, fewer enrollments in clinical trials and more admissions to hospitals with less experience of HIV/AIDS (Cotton *et al,* 1993; Hankins and Handley, 1992; Stein *et al,* 1991), which are all predictors of survival (Bennett *et al,* 1995; Stone *et al,* 1992). Shorter survival in women with AIDS compared to men is not therefore an indication that gender is an independent risk factor for progression of disease, but rather a reflection of women's poor access to medical care (Mocroft *et al,* 1997; Morlat *et al,* 1992; Cozzi Lepri *et al,* 1994; Ellerbrock *et al,* 1991; Lemp *et al,* 1992; Selwyn *et al,* 1992; Phillips *et al,* 1994).

Gender differences in the incidence of opportunistic infections and other manifestations of HIV diseases (excluding female-specific conditions) include a lower incidence of Kaposi's sarcoma and higher incidence of toxoplasmosis, candidiasis and herpes simplex virus among women (Fleming *et al,* 1993; Sha *et al,* 1995; Phillips *et al,* 1994). Some of this gender variation can be explained by differential exposure rates to infectious agents (Sha *et al,* 1995). With regard to female-specific conditions, HIV infection is associated with an increased risk of cervical dysplasia and invasive cervical carcinoma was added to the Centers for Disease Control (CDC) AIDS surveillance case definition in 1993, with moderate to severe cervical dysplasia added to the list of HIV-related symptoms (Centers for Disease Control, 1993). Little data are available on the presenting characteristics of women with HIV infection compared to men, allowing for route of acquisition (i.e. IDU or heterosexual transmission) and it is difficult to disentangle the effect of mode of transmission on clinical manifestations from gender per se.

1.5 HIV and Pregnancy

During pregnancy, cell-mediated immunity is reduced, with an accompanying decline in the T-cell helper-suppresser ratio (Weinberg, 1984; Sridama *et al,* 1982). On the basis of case reports of women dying of AIDS in pregnancy or shortly after delivery and of the immunosuppressive effect of HIV, it was hypothesised that pregnancy in HIV-infected women could lead to an accelerated decline in CD4 cell count and to progression of disease (Koonin *et al,* 1989; Minkoff *et al,* 1987; Scott *et al,* 1985). However, prospective studies have found no convincing evidence that pregnancy accelerates the progression of HIV disease (Alger *et al,* 1993; Berrebi *et al,* 1990; Selwyn *et al,* 1989a; Minkoff *et al,* 1987), while natural history studies have found no gender effect for progression or overall survival, providing indirect evidence against the existence of a pregnancy effect on disease progression (Brettle *et al,* 1996; Cozzi Lepri *et al,* 1994; Blaxhult *et al,* 1990). Other studies have reported stable levels of HIV activity during pregnancy, in terms of viral load and CD4 cell percentage (European Collaborative Study and Swiss HIV Pregnancy Cohort, 1997; O'Shea *et al,* 1997; Lindgren *et al,* 1996; Weiser *et al,* 1994).

However, it may be advisable that women with advanced HIV disease avoid pregnancy, since little is known about the pregnancy-associated risk of deterioration for such women and because treatment of HIV-related infections may be more complicated in pregnant women (Johnstone, 1995). Furthermore, the risk of vertical transmission of infection is greater in women at advanced stages of immunosuppression (European Collaborative Study, 1996; Mayaux *et al,* 1995). Potential adverse effects of maternal HIV infection on pregnancy outcome in developed countries seem limited to a possible increased rate of spontaneous abortion (Langston *et al,* 1995) and early delivery among

immunosuppressed women (with CD4 counts of less than 200 cells/mm^3) (European Collaborative Study, 1996). However, studies in developed countries have been limited by their lack of uninfected controls.

1.6 Prevalence of HIV infection in pregnant women in Europe

The HIV epidemic among children is closely linked to that among women, since the vast majority of paediatric infections are the result of vertical transmission from mother to infant. In order to estimate the number of children at risk of perinatally acquired infection, knowledge of both the prevalence of infection among women of childbearing age and the rate of vertical transmission is required. AIDS case surveillance provides some information on the prevalence of HIV among women but owing to the long latency period between infection and developing AIDS, this relates to the prevalence a decade or more ago. In addition, reporting delays and under-recognition/reporting may introduce bias. As expected of a primarily sexually transmitted disease and given the association with IDU in young women, female AIDS cases are concentrated among women of childbearing age, with approximately 60% of women with AIDS in Europe aged between 25 and 34 years at the time of diagnosis (WHO-EC Collaborating Centre on AIDS, 1997).

Monitoring HIV seroprevalence is a more accurate way of assessing the extent of the epidemic. Arguably the best method for such monitoring is unlinked anonymous testing of residues of blood (or saliva) samples taken for other tests, since in theory this should remove both participation and selection bias. Although most monitoring of HIV prevalence is aimed at those at higher risk of infection, such as genito-urinary medicine clinic attenders or IDUs, pregnant women have also been screened in a number of countries, as a proxy for those sexually active population groups at lower risk of infection. This has occurred partly

because pregnant women represent a particularly accessible group, with blood samples taken for a number of antenatal screening tests, but also because of the valuable information provided regarding number of HIV-exposed infants and trends over time.

Another method of monitoring HIV seroprevalence among pregnant women is to test residual neonatal blood spots used for metabolic screening, since maternal immunoglobulin G is passively acquired by the infant in utero (Unlinked Anonymous Surveys Steering Group, 1996; Peckham *et al,* 1990). Although anonymous antenatal and neonatal serosurveys provide very useful information, caution is needed in using the results to estimate the prevalence in the general female population, since HIV-infected and uninfected women may have differential fertility, while pregnant and non-pregnant women may have different HIV risk behaviours (Boisson *et al,* 1996). Tables 1.1a and b show the results of unlinked anonymous HIV testing of pregnant women and neonates in Europe. The data from France illustrate that HIV-infected pregnant women are more likely to terminate their pregnancies than uninfected women, as the prevalence among pregnancies is very much higher than that among deliveries.

Voluntary named antenatal HIV testing can also be used to provide prevalence data on HIV infection in pregnant women (Table 1.2), but estimates from such surveys are likely to suffer from considerable participation and selection bias (i.e. either with women at highest risk of infection refusing testing, or with health professionals more likely to offer testing to those women whom they consider to be at high risk). However, since anonymous unlinked prevalence monitoring requires considerable funding and administration, few European countries have such programmes in place and thus results from voluntary named testing are the next best source of information available.

Tables 1.1a and 1.1b

HIV prevalence among pregnant women: unlinked anonymous testing

Table 1.1a Antenatal testing

Setting	Year	Number tested	Prevalence / 1000	Ref*
England and Wales				
London (15 hospitals)	1995	49 063	3.24	see a)
Ireland	1992-95	160 679	0.16	see b)
Eastern Health Board			0.37	
Rest of Ireland			0.05	
France				see c)
South East France	1992	7 512 deliveries	2.13	
		11 351 total	4.23	
	1994	7 277 deliveries	2.47	
		10 232 total	3.42	
Paris	1990	7 261 deliveries	2.75	
		11 593 total	4.14	
	1992	6 836 deliveries	2.49	see c)
		10 617 total	5.56	
	1994-5	10 806 total	4.62	see d)
Finland	1993	64 195	0.08	see c)

* References

a) Unlinked Anonymous Surveys Steering Group, 1996

b) National AIDS Strategy Committee, 1996

c) WHO-EC Collaborating Centre on AIDS, 1994

d) Goubar and Costagliola, 1997

Table 1.1b Neonatal testing

Setting	Year	Number tested	Prevalence / 1000	Ref*
Italy	1990	97 658	1.24	see a)
	1993	161 812	0.96	
Lazio (includes Rome)	1990	20 944	2.82	
	1992	14 513	1.52	
Lombardy	1990	14 771	2.17	
	1992	20 370	1.47	
Germany				
Lower Saxony	1993	67 524	0.16	see a)
	1994	58 591	0.24	
Berlin	1993	27 483	0.58	
	1994	20 377	0.74	
Scotland	1990	65 773	0.29	see a)
	1993	63 629	0.28	
Edinburgh	1990	5 276	2.46	
	1993	5 093	1.57	
Glasgow	1990	16 308	0.00	
	1993	15 887	0.13	
England and Wales				
London	1990	67 153	0.82	see b)
	1992	106 946	1.50	
	1995	104 501	1.80	
Thames Region	1990	43 374	0.07	
outside London	1992	81 600	0.09	
	1995	79 447	0.16	
England and Wales	1990	11 242	0.09	
outside the South East	1992	124 411	0.10	
	1995	259 769	0.10	

* References

a) WHO-EC Collaborating Centre on AIDS, 1994

b) Unlinked Anonymous Surveys Steering Group, 1996

Table 1.2 HIV prevalence among pregnant women: voluntary testing

Setting	Year(s)	% tested	Number tested	Prevalence / 1000	Ref*
United Kingdom					
Central London	1993-1994	41%	1 340	3.6	see a)
The Netherlands					
Amsterdam region	1988-1991	93%	23 827	1.2	see b)
Switzerland	1986-1989	-	-	1.0	see c)
France					
Limoges	1985-1992	-	14 642	1.6 overall **	see d)
Italy					
Rome	1992	-	1 142	10.0	see e)
Norway	1988	98%	86 620	0.07	
	1990		87 435	0.06	see f)
	1993		70 821	0.00	
Sweden	1987	97%	33 224	0.03	
	1991		110 394	0.19	see f)
	1993		113 370	0.09	
Finland					
Helsinki	1990		6 710	0.15	
	1993		7 300	0.41	see f)
Bulgaria	1992		45 320	0.07	
	1993		39 797	0.00	see f)

* References

a) Mercey *et al,* 1996 b) Bindels *et al,* 1994 c) Kind *et al,* 1992 d) Denis *et al,* 1994

e) Puro *et al,* 1992 f) WHO-EC Collaborating Centre on AIDS, 1994

** 3.4/ 1000 immigrant women, 31.0 / 1000 sub-Saharan Africans

Seroprevalence among pregnant women varies within countries, with higher prevalences in urban and metropolitan areas (Tables 1.1 and 1.2). For example, if there were 100,000 births in London in 1995, there would have been approximately 180 HIV-infected mothers delivering and between 30 and 36 HIV-infected infants born, whereas in England and Wales outside the South East, if there had been 500,000 births, 50 women would have been HIV-infected and approximately eight of their infants would have vertically acquired HIV infection.

1.7 Antenatal HIV screening

As more information has become available concerning interventions to reduce mother-to-child transmission, the effect of pregnancy on progression of maternal disease and the changing patterns of the spread of HIV, there has been a reassessment of antenatal HIV screening policies. The advantages for a woman in knowing her HIV infection status in pregnancy apply to both the woman and her infant. Antenatal diagnosis of infection provides the opportunity to offer antiretroviral therapy to reduce vertical transmission, to recommend the avoidance of breastfeeding, to diagnose the infant promptly and initiate prophylaxis and therapy if the infant is infected. With regard to the mother, identification in pregnancy allows for early management of her own infection, while a diagnosis sufficiently early in pregnancy may allow her to make an informed choice regarding the continuation of the pregnancy. It may also enable the woman to reduce the risk of transmitting HIV to her sexual partner. However, the adverse consequences of antenatal HIV screening include anxiety and the psychological stress of a positive result (Lester *et al,* 1995; Macquart-Moulin *et al,* 1995).

Universal testing involves offering the HIV test to all pregnant women, while under a selective testing policy, only women perceived to be at high risk of HIV infection are offered the test. It is generally accepted that informed consent should be obtained before carrying out a named HIV test (Sherr, 1991; Beevor and Catalan, 1993; MacDonagh *et al,* 1996a). Although consent for the test may be explicitly obtained, either verbally or written (an "opt-in" system), there may be a policy whereby women are informed that they will be tested unless they specifically request not to be (an "opt-out" system). Voluntary antenatal screening policies often reflect the estimated seroprevalence among pregnant women in the area and economic considerations.

1.8 Summary

By December 1996, nearly 30 500 women with AIDS had been reported in Europe, more than half of whom had acquired HIV infection through IDU. Women at risk of HIV infection in Europe tend to be those with pre-existing social and economic problems, including drug use, single parenthood, unemployment, unstable housing and immigration problems. Although HIV-infected women have additional medical needs compared to their male counterparts, including need for family planning and antenatal care, many have limited access to optimal health care because of their socioeconomic circumstances. Prospective studies have found no convincing evidence that pregnancy accelerates the progression of HIV disease, although an increased risk of low birthweight and of extreme prematurity among infants born to immunosuppressed women has been reported, which would have a bearing on service needs in the neonatal period. HIV seroprevalence among pregnant women varies within and between countries in Europe, with higher prevalences in urban and metropolitan areas. Antenatal diagnosis of infection provides the opportunity

to offer antiretroviral therapy and advice to avoid breastfeeding and also facilitates optimal clinical management of both the mother and the infant.

Chapter 2 Children and HIV infection: background

2.1 Introduction

The first cases of AIDS in children were reported in 1982 (Centers for Disease Control, 1982b) and by the end of 1995, there were more than 1.5 million children with AIDS worldwide (Mertens *et al,* 1995). The WHO defines a "child" as being less than 13 years of age and this will be the definition used here, unless otherwise stated. More than 90% of all HIV infections in children are vertically transmitted from mother to infant and as prevalence of HIV infection in women of childbearing age increases, more children will be at risk of vertically acquired HIV infection. Other modes of acquisition of infection in children include parenteral transmission (which has been predominantly nosocomial) and sexual transmission as a result of sexual abuse and exploitation.

It is estimated that by the year 2000, five million children will have acquired HIV infection through mother-to-child transmission (Mertens and Low Beer, 1996). In Europe, a total of 6 969 children with AIDS had been reported to the WHO-EC Collaborating Centre by December 1996. Of these, 4 005 were from Romania, where only 6% of children being vertically infected and the majority infected nosocomially or via contaminated blood / blood products (see section 2.3). If Romania is excluded from the calculation, 2 463 (83%) of the 2 964 children with AIDS in Europe by the end of 1996 had acquired infection from their mothers (WHO-EC Collaborating Centre on AIDS, 1997).

2.2. Vertical transmission

2.2.1 Vertical transmission rates

Mother-to-child transmission of infection may occur during pregnancy and delivery and through breastfeeding. Vertical transmission rates vary considerably and are estimated to be between 25-40% in Africa, 16-30% in the USA and 15-20% in Europe, before the introduction of prophylactic antiretroviral therapy (Working Group on Mother-To-Child Transmission of HIV, 1995) (Table 2.1). Reasons behind variation between populations include different prevalences of breastfeeding, risk factors and interventions to reduce vertical transmission between countries as well as methodological differences between studies (Ryder and Behets, 1994). In 1994 the results of a French-American clinical trial were published, which indicated that administration of antenatal, intrapartum and neonatal zidovudine therapy reduced vertical transmission from 25% to 8%; subsequent results from observational studies have shown that vertical transmission has declined to levels of less than 8% following increased use of antiretroviral therapy (Mayaux *et al,* 1997; Simpson *et al,* 1997; Matheson *et al,* 1995).

2.2.2 Diagnosis of infection

Early diagnosis of infection in children born to HIV infected mothers using antibody testing is not possible owing to passive acquisition of maternal immunoglobulin G (IgG) antibodies in utero. As maternal antibody loss does not usually occur until about 10 to 15 months of age (European Collaborative Study, 1988), alternative diagnostic methods which detect the virus itself, or viral markers, have been developed including viral culture, HIV DNA and RNA polymerase chain reaction (PCR) and p24-antigen enzyme immunoassay (Report of Consensus Workshop, Italy, 1992; Newell *et al,* 1995).

Table 2.1 Estimates of vertical transmission rates

Setting	Year*	n	VT rate (95% CI)	Ref.
Europe				
Switzerland	1992	201	14% (9 -19%)	(Kind *et al*, 1992)
Italy	1996	1033	18% n.a.	(Tovo *et al*, 1996)
France	1996	1033	20% (17.5 - 22.5%)	(Mandelbrot *et al*,1996)
W.Europe (ECS)	1996	1945	16% (14.5 - 18.3%)	(European Collaborative Study, 1996)
The Americas				
New York	1989	55	29% n.a.	(Goedert *et al*, 1989)
Miami	1991	82	30% n.a.	(Hutto *et al*, 1991)
Haiti	1990	230	25% n.a.	(Halsey *et al*, 1990)
Atlanta	1994	165	17% (11 - 24%)	(Nesheim *et al*, 1994)
United States	1996	190	12% (8.3 - 18.2%)	(Melvin *et al*, 1996)
	1996	952	22% (19.4 - 24.7%)	(Matheson *et al*, 1996a)
New York	1997	201	24% (18.7 - 31.0%)	(Bulterys *et al*, 1997)
Montreal	1996	109	26% (17.8 - 34.9%)	(Lapointe *et al*, 1996)
Rio de Janeiro	1996	103	40% (30.3 - 49.9%)	(Rubini *et al*, 1996)
Africa				
Zambia	1989	109	39% n.a.	(Hira *et al*, 1989)
Zaire	1989	475	39% n.a.	(St Louis *et al*, 1993)
Butare, Rwanda	1993	184	29% (22 - 36%)	(Bulterys *et al*, 1994)
Kigali, Rwanda	1994	218	25% (19 - 32%)	(Simonon *et al*, 1994)
Ivory Coast	1994	138	25% (15.8 - 33.7%)	(Adjorlolo Johnson *et al*, 1994)
Kenya	1994	220	43% (36.7 - 48.9%)	(Datta *et al*, 1994)
South Africa	1994	111	27% n.a.	(Moodley *et al*, 1994)
Congo	1994	118	40% (30.7 - 50.1%)	(Lallemant *et al*, 1994b)
Kampala, Uganda	1996	387	25% (20.3 - 29.2%)	(Marum *et al*, 1996)
Soweto, S.Africa	1996	163	38% (30.6 - 46.0%)	(McIntyre *et al*, 1996)
Asia				
India	1995	143	48% n.a.	(Kumar *et al*, 1995)
Bangkok, Thailand	1996	281	24% (19.3 - 24.7%)	(Shaffer *et al*, 1996)
Philippines	1996	11	18% (2.3 - 51.8%)	(Manaloto *et al*, 1996)

* of publication

The estimated median period between birth and emergence of viral markers is 10 days (Rouzioux *et al,* 1995) and a review of 12 studies of early diagnosis of HIV infection using DNA PCR found that test sensitivity reached 93% (90% CI, 76-97) by 14 days post-partum in non-breastfed infants (Dunn *et al,* 1995). Infection in the child is defined by persistence of antibodies beyond 18 months of age, detection of virus or antigen in two blood samples taken on separate occasions or the diagnosis of AIDS. A child is considered uninfected when he or she has lost maternal antibodies and has no virological or clinical signs of infection (Centers for Disease Control, 1994a).

2.2.3 Transmission: timing and risk factors

The relative contributions of the three routes of vertical transmission of HIV are difficult to quantify, mainly because of diagnostic problems. For example, it is difficult to distinguish between in utero transmission late in pregnancy and intrapartum transmission (De Rossi, 1995; Rouzioux *et al,* 1995; Dunn *et al,* 1995), or between intrapartum and early postnatal transmission in breastfeeding populations (Bertolli *et al,* 1996). Detection of HIV in fetal and placental tissue following termination of pregnancy (Sprecher *et al,* 1986; Lyman *et al,* 1990; Maury *et al,* 1989) first suggested that transmission of HIV could occur in utero, but the mechanisms of intra-uterine transmission remain poorly understood (Anderson and Johnson, 1994). It is estimated that between a fifth and a third of infected children acquire their infection in utero (Chouquet *et al,* 1997; Kuhn *et al,* 1997; Kalish *et al,* 1997; Dunn *et al,* 1995; Bertolli *et al,* 1996).

Various pieces of indirect evidence led to the suggestion that about two-thirds of vertical transmission occurs around the time of delivery in non-breastfeeding populations (Bertolli *et al,* 1996; Rouzioux *et al,* 1995): virological studies have shown that most (50-70%) non-

breastfed infected children have no detectable viral markers at birth (Bryson, 1996), HIV infection is not associated with an increased prevalence of congenital abnormalities or low birthweight (European Collaborative Study, 1994c) and first-born twins are more likely to be infected than those born second (Duliege *et al,* 1995). Furthermore, a large number of delivery-related risk factors have been identified (Table 2.2). The above estimate has recently been raised to between 73 and 80% following the results of studies which used early PCR tests and virus cultures (Chouquet *et al,* 1997; Kuhn *et al,* 1997; Kalish *et al,* 1997).

Postnatal transmission, via breastmilk, has been documented where the mother was infected before or during pregnancy, or shortly after delivery (Rubini and Passman, 1992; Van de Perre *et al,* 1992; Ziegler *et al,* 1985; Van de Perre *et al,* 1991; Dunn *et al,* 1992). The additional risk of transmission through breastfeeding over and above that of intra-uterine or intra-partum transmission is estimated to be between 7 and 22% (Bertolli *et al,* 1996; Dunn *et al,* 1992; Simonon *et al,* 1994). The relationship between the intensity and duration of breastfeeding and risk of transmission is unclear (Datta *et al,* 1994), but the trial ongoing in Nairobi will hopefully provide additional information (Nduati *et al,* 1995). The estimated additional risk of late postnatal transmission in African cohorts after three to six months of age contributes 4-6% of the overall risk associated with breastfeeding, although this may be an underestimate (Simonon *et al,* 1994; Bertolli *et al,* 1996; Ekpini *et al,* 1997).

Table 2.2 lists potential risk factors for vertical transmission, although it is important to note that there have been inconsistent findings between studies, probably reflecting differences in both methodologies and populations. Risk factors for vertical transmission may have different or stronger effects depending on the route and timing of transmission,

but these have yet to be fully elucidated. For example, some sexually transmitted diseases may increase risk of transmission by disrupting placental membranes (thus increasing the risk of intrauterine transmission) or through increasing viral load in the vagina and cervix (affecting both intrauterine and intrapartum transmission), while maternal viral load may exert an influence at all times.

Table 2.2 Potential risk factors for vertical transmission of HIV infection

Risk factor	References for a positive finding
Viral characteristics	(Albert *et al,* 1995; Rowland Jones *et al,* 1995; Mulder Kampinga *et al,* 1993)
Viral load	(Sperling *et al,* 1996; Dickover *et al,* 1996; Fang *et al,* 1995)
Maternal immune response	(Husson *et al,* 1995; Scarlatti *et al,* 1993; Lallemant *et al,* 1994a; Jansson *et al,* 1992; Rossi *et al,* 1989)
Maternal STD infection	(Nair *et al,* 1993)
Chorioamnionitis	(Ryder *et al,* 1989)
Mode of delivery	(Moodley *et al,* 1994; Dunn *et al,* 1994; ECS, 1994a)
Invasive obstetric procedures	(Boyer *et al,* 1994)
Time from rupture of membranes to delivery	(Lapointe *et al,* 1996; Landesman *et al,* 1996)
Infant prematurity	(Italian Register for HIV Infection in Children, 1994; Mandelbrot *et al,* 1996; ECS, 1996)
Maternal severe vitamin A deficiency	(Greenberg *et al,* 1997; Semba *et al,* 1994; Nduati *et al,* 1995)
Illicit drug use in pregnancy	(Bulterys *et al,* 1997; Rodriguez *et al,* 1996)
High frequency of unprotected sex in pregnancy	(Bulterys *et al,* 1997; Bulterys and Goedert, 1996; Lallemant *et al,* 1994a; Matheson *et al,* 1996b)

2.2.4 Interventions

Avoidance of breastfeeding is effective in reducing the risk of mother-to-child transmission and in Europe exclusive formula feeding is recommended to prevent postnatal transmission. Zidovudine therapy during pregnancy, labour and in the neonatal period is another effective intervention and can reduce vertical transmission by as much as 65% (Matheson *et al,* 1995; Simpson *et al,* 1997; Mayaux *et al,* 1997; Kind, 1996; Sperling *et al,* 1996; Connor *et al,* 1994). Zidovudine may reduce the risk of vertical transmission both by decreasing maternal viral load and as a post-exposure prophylaxis, by inhibiting viral replication in the infant (Sperling *et al,* 1996). Reductions of two- to eight-fold in plasma HIV RNA levels in zidovudine-naive pregnant women have been reported following zidovudine therapy, but little is known about within-woman fluctuations in viral load over pregnancy and this may be within the normal range (Bryson, 1996; Dickover *et al,* 1996).

The CDC currently recommend zidovudine therapy to start between 14 and 34 weeks gestation (Centers for Disease Control, 1994b), although the finding of a maximum decrease in viral load after two weeks of therapy (Loveday *et al,* 1995) suggests that starting therapy later in pregnancy could be more efficacious. Other questions include the possible long-term effects on mother and infant (Kumar *et al,* 1995; Connor *et al,* 1994; Boyer *et al,* 1994), the applicability of results to women with CD4 counts of less than 200 cells/ mm^3 or those who have already been prescribed zidovudine (Boyer *et al,* 1994), the potential for accelerating selection of zidovudine-resistant strains of HIV (Siegrist *et al,* 1994) and the implications of temporary zidovudine monotherapy for the subsequent clinical management of the mothers given the clinical superiority of combination therapy (Delta Co-ordinating Committee, 1996).

Other antiretroviral drugs including didanosine (ddI), lamivudine (3TC) and nevirapine, are currently under assessment for use in combination therapy to reduce vertical transmission (Newell and Gibb, 1995), with a WHO trial underway in South Africa evaluating the short regimen combination of zidovudine and 3TC and the French perinatal cohort study assessing the addition of 3TC to zidovudine. Full-course zidovudine programmes are inappropriate for most developing country settings and trials of short-course zidovudine programmes are currently underway in West Africa and Thailand, which should also help elucidate the relative importance of the different components of the ACTG076 regimen (Cohen, 1995). A pilot study of zidovudine therapy in late pregnancy in the Ivory Coast documented a significantly increased viral load in one woman after termination of therapy one week postpartum (Wiktor *et al,* 1996), which may have implications for transmission in breastfeeding populations.

Observational studies have produced conflicting results regarding the effect of caesarean section on vertical transmission. In the European Collaborative Study (ECS), caesarean section was found to approximately halve the risk of vertical transmission after controlling for other risk factors (European Collaborative Study, 1994a), while in the French perinatal study, which is of comparable size, no such reduction was found (Mayaux *et al,* 1995). A meta-analysis of European and US studies, involving over 3000 mother-child pairs, estimated a one-fifth reduction in risk of transmission following caesarean sections (elective and emergency) compared to vaginal delivery, but could not control for other risk factors for vertical transmission (Dunn *et al,* 1994). The lack of consensus and differences in the definition of elective caesarean section in more recent studies (Schaefer and Schwartlander, 1996; Kind, 1996; Mandelbrot *et al,* 1996; McIntyre *et al,* 1996; Bobat *et al,* 1996; Moodley *et al,* 1994) means that this issue remains unresolved and routine

caesarean section for all HIV infected women cannot currently be recommended. A randomised trial to evaluate the effectiveness of caesarean section in preventing vertical transmission is underway in Europe (Bazin *et al,* 1996). In addition, the National Institutes of Health in the USA are currently carrying out an individual patient meta-analysis, involving 15 observational studies and about 10 000 mother-child pairs, with four categories for mode of delivery.

A clinical trial in Malawi which assessed the effect of cleansing the birth canal with chlorhexidine on vertical transmission found no significant impact on transmission rates, except where the time between duration of membranes and delivery exceeded four hours (Biggar *et al,* 1996). A similar trial ongoing in Kenya (Temmerman, personal communication, 1996) may help to determine whether the limited effect of the intervention was real or due to methodological problems. Clinical trials to assess passive immunoprophylaxis and active immunisation using recombinant envelope vaccines are currently underway in Uganda and the USA (Lambert, 1995).

Given the reported associations between increased vertical transmission and unprotected sexual intercourse and illicit drug use in pregnancy (Rodriguez *et al,* 1996; Matheson *et al,* 1996b), behavioural interventions such as promoting condom use in pregnancy and drug rehabilitation programmes may have an impact on vertical transmission rates. HIV infected women have been shown to be at increased risk of acquiring genital infections in pregnancy (Leroy *et al,* 1995) and promotion of barrier methods in pregnancy may also help reduce the incidence of genital infections, which are associated with increased vertical transmission (Nair *et al,* 1993).

2.2.5 Barriers to the implementation of interventions

Low rates of identification of previously undiagnosed HIV infected women during pregnancy may prevent the optimum reduction in the rate of vertical transmission (Cadogan *et al,* 1996; Ippolito *et al,* 1996; Wiznia *et al,* 1996). For example, fewer than 10% of previously undiagnosed HIV infected women in London are identified through antenatal screening (MacDonagh *et al,* 1996b). Antenatal screening policies have therefore become a focus of attention (Touchette, 1995; Hoffman *et al,* 1995; Wilfert, 1994). Limited access of HIV infected women to antenatal care (Shakarishvili *et al,* 1996; Thomas *et al,* 1996; Turner *et al,* 1995), non-completion of the zidovudine regimen (Seals *et al,* 1996), pregnant women's non-acceptance of zidovudine therapy (Fiscus *et al,* 1996; Wiznia *et al,* 1996) and lack of education of women's health care providers regarding zidovudine prophylaxis (Parham *et al,* 1996; Burr *et al,* 1996), could all significantly modify the impact of interventions on vertical transmission rates.

In Europe, the vertical transmission rates of 15 to 20% (Table 2.1) refer to cohorts of non-breastfed infants, before widespread use of zidovudine. Experience from the USA has shown that vertical transmission rates of less than 10% can be achieved under the ACTG076 regimen (Sperling *et al,* 1996), but the extent to which this will be achievable in some parts of Europe will depend on the degree to which the barriers to implementation can be overcome. However, in France, where there is high uptake of antenatal screening and very low rates of refusal of zidovudine, routine use of antiretroviral therapy in pregnancy has already resulted in documented significant reductions in the vertical transmission rate (Mayaux *et al,* 1997).

2.3. Other routes of transmission

Other modes of acquisition of HIV infection in children include parenteral transmission and sexual abuse and exploitation, although this thesis does not focus on such children. In Europe, nearly 3000 children with AIDS who had acquired their infection parenterally had been reported by December 1996 (7% in haemophiliacs, 35% in transfusion recipients and the remaining 58% through nosocomial transmission) (WHO-EC Collaborating Centre on AIDS, 1997). The vast majority of the children infected nosocomially were Romanian, infected during the epidemic among children living in public institutions in the 1980s (Hersh *et al,* 1991), with the remainder infected in a much smaller nosocomial epidemic in Russia in the late 1980s (Pokrovski *et al,* 1990). The Romanian children had high exposures to injections (antibiotics, vaccines and vitamins) and a strong association was found between number of injections and HIV infection. Investigation of injection practices revealed multiple use of injecting equipment between sterilizations, and lack of adequate sterilization facilities (Hersh *et al,* 1991).

Sexually-abused children may be at risk for HIV infection and a small number of cases have been documented in the literature (Leiderman and Grimm, 1986; Gellert *et al,* 1993; Gutman *et al,* 1991). Children may also be exposed to HIV infection as a result of child prostitution. Transmission of HIV between children in the same household has been reported, but this has been limited to households in which opportunities for parenteral, cutaneous or mucocutaneous exposure to infected blood existed (Dunn and Newell, 1994; Fitzgibbon *et al,* 1993).

2.4. Natural history of perinatally acquired HIV infection

Perinatally infected children have a distinct natural history of HIV disease and a proportion progress to symptomatic disease differently and more rapidly than adults, probably due to their immature immune systems at the time of infection. Information on the natural history of perinatally acquired HIV disease has been provided by AIDS case registries and prospective studies of children born to HIV-infected mothers. However, current understanding is limited by the duration of prospective studies (about 10 years) and little is known regarding long term prognosis of perinatally infected children.

European prospective studies of children with perinatally acquired HIV infection show that approximately 20-25% of infected children rapidly become immunosuppressed, have early onset of signs of HIV disease and progress to AIDS in the first year of life (French Pediatric HIV Infection Study Group and European Collaborative Study, 1997; Mayaux *et al,* 1996; European Collaborative Study, 1994b; Tovo *et al,* 1992; Italian Register for HIV Infection in Children, 1994). A higher proportion of rapid progressors has been reported in the USA, with 36% of infected children in a New York cohort progressing to AIDS or death in the first year of life (Bamji *et al,* 1996). It has been hypothesised that children with early onset of AIDS acquired their infection in utero rather than around the time of delivery, since many of these children have high viral loads at birth, reflecting high maternal viral load (Blanche, 1995; Pizzo *et al,* 1995; Blanche *et al,* 1990). However, in the ECS, children developing AIDS in their first year of life had similar gestational age, birthweight and perinatal findings to infected children with slower progression of disease (European Collaborative Study, 1994c). It therefore seems likely that a combination of factors affect whether or not an infected child has early progression

to AIDS, including genetic susceptibility, viral phenotype and possibly primary immune response (Henrard *et al,* 1995).

Paediatric HIV infection involves a wide spectrum of clinical presentations ranging from mild symptoms such as lymphadenopathy to AIDS-defining opportunistic infections such as *Pneumocystis carinii* pneumonia (PCP), and cancers. The median age at onset of HIV-related symptoms is between five and 10 months (Galli *et al,* 1995; Frederick *et al,* 1994; Scott *et al,* 1989; Blanche *et al,* 1990; Tovo *et al,* 1992). Rapid progressors present with severe manifestations of HIV disease such as PCP and encephalopathy, while early clinical manifestations among the remaining 75-80% of children include lymphadenopathy, hepatomegaly and splenomegaly, although episodes are often transient (French Pediatric HIV Infection Study Group and European Collaborative Study, 1997; Bamji *et al,* 1996; European Collaborative Study, 1994b). Approximately 60-80% of perinatally infected children have developed HIV-related symptoms by 24 months of age (French Pediatric HIV Infection Study Group and European Collaborative Study, 1997; Galli *et al,* 1995; Pizzo *et al,* 1995). In a joint analysis of data from the European Collaborative and the French Prospective Studies based on 400 infected children progression to AIDS (excluding lymphoid interstitial pneumonitis) or HIV-related death was estimated to be 20% in the first 12 months of life and 36% by 6 years of age (French Pediatric HIV Infection Study Group and European Collaborative Study, 1997).

The most common AIDS-defining conditions in children in developed countries are PCP and lymphoid interstitial pneumonitis (LIP), which have different prognostic significance. PCP, usually diagnosed in the in the first six months of life, is associated with a median post-diagnosis survival time of less than six months (Pizzo *et al,* 1995;

Bamji *et al,* 1996; Morris *et al,* 1996; Scott *et al,* 1989; Simonds *et al,* 1993), while LIP is generally diagnosed later (Scott *et al,* 1989; Pratt *et al,* 1993; Blanche *et al,* 1990; Thomas *et al,* 1992; Bamji *et al,* 1996; Morris *et al,* 1996), with a median post-diagnosis survival time of between 22 and 72 months (Thomas *et al,* 1992; Morris *et al,* 1996; Scott *et al,* 1989). It has been estimated that by two years of age, approximately 70% of children with LIP as their sole AIDS-defining condition are alive compared to 15% of those with PCP (Scott *et al,* 1989); LIP has therefore been consigned to category B and not C of the updated CDC classification of paediatric infection (Centers for Disease Control, 1994a).

Age-specific mortality of HIV-infected children in Africa is higher than in Europe and North America, which may reflect an increased exposure to pathogens, such as tuberculosis (TB), poor access to both general and HIV-specific therapy and malnutrition (Lallemant *et al,* 1994b; Lepage and Hitimana, 1991). For example, in Rwanda a 19% mortality rate in the first two years of life has been reported, approximately two to three times higher than that in European children (Blanche *et al,* 1989; European Collaborative Study, 1994b; Lepage *et al,* 1993). The natural history of HIV disease in African children differs from that in children from developed countries, with less PCP, but more *Cryptosporidium* diarrhoea, TB and measles (Lepage and Hitimana, 1991), although there are relatively few natural history studies of children in Africa.

European prospective studies of children born to HIV infected mothers have shown that approximately 70-75% of infected children are still alive at five to six years of age (Italian Register for HIV Infection in Children, 1994; European Collaborative Study, 1994b; Mayaux *et al,* 1995). Median survival after diagnosis of AIDS in developed

countries is estimated to be in the range of 19 to 26 months (French Pediatric HIV Infection Study Group and European Collaborative Study, 1997; Morris *et al,* 1996; Krasinski *et al,* 1989; European Collaborative Study, 1994b; Frederick *et al,* 1994; Bamji *et al,* 1996), with no significant differences according to gender or race/ethnicity (Thomas *et al,* 1992; Tovo *et al,* 1992; Blanche *et al,* 1990). Early age at onset of symptoms and at AIDS diagnosis have been identified as independent markers for shortened survival (Turner *et al,* 1993; Tovo *et al,* 1992; Galli *et al,* 1995). Poor prognosis is also associated with low age-specific CD4 counts (Duliege *et al,* 1992; Bamji *et al,* 1996; Galli *et al,* 1995; Butler *et al,* 1992), PCP or progressive encephalopathy (Turner *et al,* 1993; Thea *et al,* 1996; Tovo *et al,* 1992; Scott *et al,* 1989; Blanche *et al,* 1990) and low birthweight (Galli *et al,* 1995). Two European studies reported that the rate of disease progression in the infant is associated with that in the mother (Blanche *et al,* 1994; Tovo *et al,* 1994), which may be related to viral phenotype and/or genetic factors. However, not all studies have shown the above factors to be significant predictors of poor clinical outcome. Quantitative RNA PCR measurement techniques have been shown to be useful prognostic tools (Munoz-Fernandez *et al,* 1996; Mofenson *et al,* 1996; Abrams *et al,* 1996) and are likely to surpass other prognostic indicators in the near future in developed country settings.

Zidovudine has been the predominant antiretroviral drug used in the treatment of symptomatic children in Europe and the USA and is associated with improvements in immunological markers and clinical status (McSherry and Connor, 1995). Monotherapy with other antiretroviral drugs such as ddI and ddC is uncommon in children, being limited to the few who are intolerant to zidovudine or those in whom HIV disease is progressing despite zidovudine therapy (Gibb, 1995). However, given the clinical

superiority of combination therapies over zidovudine monotherapy in adults (Delta Co-ordinating Committee, 1996), trials of combination therapy in children are now underway in the United States and Europe (Gibb, 1995; McSherry and Connor, 1995). The best time to start antiretroviral therapy in children is unclear, but new techniques of monitoring viral load will hopefully make this more apparent. With regard to preventing opportunistic bacterial infections, intravenous immunoglobulin has been shown to prolong the time to serious bacterial infections in children with relatively intact immune systems and trimethoprim-sulphamethoxazole may have a similar effect (French Pediatric HIV Infection Study Group and European Collaborative Study, 1997; NICHD IVIG Study Group, 1994).

In developed country settings, with improvements in therapy and in survival, paediatric HIV infection has therefore come to be seen as a chronic disease of childhood, characterised by relatively long stable periods without symptoms or with mild symptoms such as lymphadenopathy, interspersed with acute episodes which may require hospitalisation (Duggan and Mitchell, 1995; Meyers and Weitzman, 1991).

2.5. Living in a family affected by HIV / AIDS

Perinatally-acquired paediatric HIV disease is unique in terms of the coinfection and concurrent illness of at least one other family member and the stigma, discrimination and social ostracism relating to HIV. The social context of HIV/AIDS is important in understanding the needs of affected families: HIV disproportionately affects families from socially and materially disadvantaged backgrounds and is often just one of the many social, economic and psychological problems that affected families must face, including parental drug abuse, immigration problems, single parent families, poor housing and

imprisonment (Imrie and Coombes, 1995; Melvin and Sherr, 1995; Mok *et al,* 1996; Caldwell *et al,* 1992; Kunzel and Kind, 1992; Giaquinto *et al,* 1991; Honigsbaum, 1995; Mayaux *et al,* 1995). HIV disease therefore frequently occurs in those families who may be least able to cope with the stresses associated with chronic disease.

Most children born to HIV-infected mothers will not be infected themselves, but will be profoundly affected by the HIV infection in their family and are likely to have complex medical and social needs. As the median time to AIDS in adults is approximately 10 to 15 years (Rothenberg *et al,* 1987; Cozzi Lepri *et al,* 1994; Brettle *et al,* 1996; Lemp *et al,* 1992; Mocroft *et al,* 1997), many affected children will lose one or both of their parents, while some will require social care regardless of parental health, as a result of their families' social problems. Table 2.3 outlines some of the factors affecting children living in families affected by HIV (Imrie and Coombes, 1995; Honigsbaum, 1995; Abrams, 1993; Hindmarch, 1995; Forsyth *et al,* 1996).

Table 2.3 The impact of HIV/AIDS on perinatally-exposed but uninfected children

- adverse social circumstances (e.g. parental drug use, housing problems)
- (multiple) alternative caregivers
- acting as carer for sick parents, younger siblings etc.
- taking on domestic responsibilities
- (multiple) bereavement
- psychological impact - depression, anxiety, attention problems
- stigma and discrimination
- secrecy

HIV-infected children have to contend with many of the same problems as children with other chronic and/or terminal diseases, such as cystic fibrosis, leukaemia and diabetes and there is an extensive literature on the effect of such diseases on the lives of children and their families (Garralda, 1994; Gortmaker *et al,* 1990; Westbom, 1992; Committee on Children with Disabilities and Committee on Psychosocial Aspects of Child and Family Health, 1993). Chronic disease can impact upon a child's physical, psychological and social functioning not only as a result of the disease itself, but also because of repeated hospitalisations, side effects of therapy and frequent school absences. Some of the features of living with chronic paediatric HIV disease are listed in Table 2.4.

Table 2.4 The impact of HIV/AIDS on the lives of HIV-infected children

- frequent outpatient visits to clinics / hospitals for monitoring and therapy
- repeated hospital admissions
- side effects of therapy
- repeated absence from school
- (multiple) alternative care-givers
- stigma and discrimination
- (multiple) bereavement
- adverse social circumstances (e.g. parental drug use, housing problems)
- living with a terminal disease
- secrecy
- impaired neuropsychological functioning - including language and mobility
- looking different to other children

To conclude, relatively little is known about the specific needs of HIV-affected children and their families in terms of medical services and psycho-social support, especially regarding their long-term requirements. The lack of research into the needs of the uninfected children in particular is of concern, since, with the increasing use of antiretroviral therapy, risk of infection is likely to decline from about one in six to one in 16 and a growing number of children born to HIV-infected mothers will be uninfected.

Chapter 3 Methods

3.1 Aims and objectives

The aim of this thesis is to describe HIV-infected pregnant women in Europe, with regard to their mode of acquisition of HIV infection, timing of diagnosis, clinical and immunological characteristics and obstetric management and to describe their children in terms of their clinical and psycho-social care. The objectives are as follows:

1. To document policies relating to antenatal HIV testing and management of pregnancy and delivery in HIV-infected women and to describe clinical and immunological characteristics of HIV-infected mothers in Europe.

2. To describe the social circumstances, social care and hospital in-patient service use of children born to HIV-infected women and followed prospectively from birth, mainly focusing on the first five years of life.

3. To document the organisation of clinical and psycho-social services for families with children affected by HIV, to obtain information on the characteristics of the families using these services and to obtain feedback from parents and carers of children affected by HIV regarding their needs for and satisfaction with current service provision.

3.2 The European Collaborative Study

The European Collaborative Study (ECS) is an on-going multi-centre prospective study, set up in 1986 to determine the rate of mother-to-child transmission of HIV, to identify risk factors associated with mother-to-child transmission and to investigate the natural history of paediatric HIV disease. The ECS involves 21 centres from seven European countries (Appendix 3.1). Pregnant HIV-infected women are enrolled in the study and their children followed from birth according to one of three standard clinical and laboratory protocols (ECS1, ECS2 and ECS3), which are described in more detail below. Women having spontaneous abortions, terminations of pregnancy or stillbirths are not included in the study. Informed parental consent is obtained before enrollment and local ethics approval has been obtained in all centres.

ECS1 is the original paediatric arm of the study, started in 1986, with more intensive follow-up of the infant in the first six months of life established as ECS3 from 1992 (Table 3.1). A total of 10 centres are participating in the paediatric arm. ECS2, the obstetric arm of the study which collects more detailed information on pregnancy-related risk factors for vertical transmission of HIV, was started in 1992. A further 11 centres joined the study at this time (obstetric centres). Thus, whether or not a child is enrolled into the paediatric or the obstetric arm of the study depends on their centre (and not on the decision of the mother). ECS2 involves clinical and immunological evaluations of the mother during pregnancy, at approximately 16-24 weeks and 28-32 weeks, and at delivery; paediatric follow-up is less detailed and generally shorter than in the paediatric arms of the study. Children enrolled in ECS2 can switch protocols in the neonatal period, to be followed up under ECS1 and children in ECS3 transfer to ECS1 after the intensive first six months of follow-up is completed (Table 3.1).

Table 3.1 Schedule of paediatric follow-up visits in the ECS

ECS 1	ECS 2	ECS 3
Paediatric follow-up	**Maternal and obstetric risk factors for vertical transmission of HIV**	**Intensive paediatric follow-up**
Examinations:		
Shortly after birth, then at 3-monthly intervals until 24 months. Infected children then seen at least once every 6 months and uninfected children every year.	Shortly after birth, then at 3, 6, 12, 18 and 24 months. Some children switch to ESC1.	Shortly after birth, then at 3 weeks, 6 weeks, 3 months, 4.5 months, 6 months. Children switch to ECS1 after six months.
Earliest stage at which termination of follow-up can occur:		
Uninfected: 60 months. Infected: follow-up continues.	Children remaining in ECS2: 24 months, or until infection status is known.	As in ECS1

At enrollment, information is collected on maternal socio-demographic characteristics, HIV risk factors, clinical and immunological characteristics, obstetric history and drug use, on the basis of maternal self-report and clinical examination. At each examination of the child, a detailed medical history is recorded and immunological/virological testing carried out. Lymphocyte phenotyping, other immunology and virology, including HIV DNA PCR, virus culture, p24 antigen enzyme immunoassay, are carried out locally. Certain

variables used in the following analyses are not collected in all three arms of the study: the range of information collected in the different protocols at enrollment and during follow-up are shown in Tables 3.2 and 3.3 respectively.

Table 3.2 Data on maternal characteristics at enrollment, by ECS protocol

Maternal characteristics	ECS 1	ECS 2	ECS 3
mode of acquisition of HIV	√	√	√
clinical status (CDC staging)	√	√	√
age at delivery	√	√	√
marital status	√	x	√
ethnic group	√	√	√
country of birth	√	√	√
age at completion of full-time education	√	x	√
injecting drug use history	√	√	√
details of injecting drug use in pregnancy	x	√	x
obstetric history (delivery details vary)	√	√	√
HIV infection status of previous children	x	√	x
details of antiretroviral therapy in pregnancy	√	√	√

Table 3.3 Type of data collected at paediatric follow-up visits, by ECS protocol

Information collected	ECS 1	ECS 2	ECS 3
clinical and immunological assessment of child	√	√	√
therapy	√	√	√
child's social care setting	√	√	√
hospital admissions of child	√	x	√
maternal vital status	√	√	x
maternal clinical status (CDC staging)	x	√	√

Definitions

Infection status

Children are classified as infected after any of the following events: the onset of AIDS, detection of virus or antigen in at least two blood samples (taken on different occasions) or persistence of antibody beyond the age of 18 months. A child is presumed to be uninfected if at least two blood samples (again, taken on different occasions) are antibody-negative and if no virus or antigen has ever been identified. Children who do not meet the above criteria are classified as having indeterminate infection status; this is usually because they have only been recently enrolled in the study, but also includes children who have died or been lost to follow-up while aged less than 18 months and still antibody-positive.

Other definitions

The paediatric AIDS definition used reflects the CDC classification in use at the time of diagnosis (Centers for Disease Control, 1987a; Centers for Disease Control, 1994a), but with LIP only accepted as an AIDS indicator disease where clinical symptoms accompanied radiological findings. Maternal clinical status has been recorded according to either the 1987 or the 1993 CDC classification of HIV staging, depending on the time at which the diagnosis was made (Centers for Disease Control, 1993; Centers for Disease Control, 1987b). "Parent" refers to the birth parent of a child and "adopted parent" will always be used in the context of adoption. With regard to social care data, the exact date of a child's move between care settings (e.g. leaving parental care for an alternative care setting) is not collected and therefore temporary absences may not be recorded if the episode falls between two follow-up visits. A hospital admission is defined as a stay in hospital overnight and thus day admissions are excluded. Hospital admissions for medical reasons were excluded from the analyses of social care setting. Data on injecting drug use are collected at enrollment and during pregnancy, but there is no additional information collected during follow-up of the child; therefore, "active/current" or "former" IDU is used to describe women with a history of IDU in terms of their drug use during pregnancy.

Data management

A range of data collection forms are completed by obstetricians and/or paediatricians at enrollment and at each subsequent follow-up visit. These forms are then returned to the co-ordinating centre in London, where the data is coded and entered into a database using SAS statistical software (SAS Institute, Cary, North Carolina, USA). Data checking programmes are used, with the data also checked manually during the processes of coding and entry. There is constant liaison with the key physicians in each centre to address any

data queries and to maintain enrollment. In addition to the routine data quality control, specific checking of the relevant data was carried out prior to the analyses presented here.

The analyses

Four separate analyses of ECS data were all carried out by the researcher, with limited advice from the ECS statistician (Table 3.4) (for statistical methods see section 3.6.1).

Table 3.4 ECS analyses

Analysis	Subjects	Date	Type of data / issue addressed
1	1 123 children (10 paediatric centres)	September 1996	Social care (Chapter 5)
2	1 189 children (10 paediatric centres)	January 1997	Hospitalisation (Chapter 5)
3	2 131 mothers (all 21 centres)	July 1997	Mode of acquisition and timing of diagnosis, clinical and immunological status (Chapter 4)
4	2 262 children (all 21 centres)	July 1997	Social circumstances (Chapter 5)

3.3. Survey of the management of pregnancy and delivery in HIV infected women in Europe

This survey was carried out to obtain information on the policies and practices relating to the identification and obstetric management of HIV-infected pregnant women in Europe. The subjects were obstetricians from a sample of hospitals in each of the 21 countries affiliated to the European College of Obstetrics and Gynaecology (ECOG) and the survey was carried out with an Italian obstetrician visiting fellow. The chosen method was a self-completed questionnaire postal survey. To identify subjects for the survey, the national administrators of the 21 countries affiliated to the ECOG were contacted by letter in February 1994. The aims of the survey were described in the letter and it was explained that the survey was being carried out under the auspices of the ECOG.

The national administrators were asked to identify a specified number of major obstetric centres with experience of HIV infection in their country, and to provide the name of the key obstetrician in each centre, to whom the questionnaire could be sent. The number specified depended on the size of the country and the extent of the problem of vertically-acquired HIV infection. A draft version of the questionnaire was included with the letter to the national administrators, who were asked if the subjects they had identified would require it to be translated.

The final version of the questionnaire consisted of 33 multiple choice and semi-structured questions. The form included questions on the organisation and content of antenatal care (with particular emphasis on antenatal screening policies for HIV and other infections), the management of labour and delivery and postnatal care (Appendix 3.2). To avoid confusion

relating to changes in practice that might have taken place over time, all questions related to 1992, with the exception of one question relating to current practices regarding interventions to reduce vertical transmission of HIV (Appendix 3.2, question 27).

By May 1994, responses had been received from all the national administrators, none of whom suggested that translation of the questionnaire was necessary. A total of 56 obstetricians were named by the national administrators (Appendix 3.3). Each was sent a postal questionnaire, together with a covering letter, explaining the aims of the study and asking for their participation in the survey. Obstetricians who had not responded by the middle of July were sent reminders by fax and/or contacted by phone. Data collection ceased at the end of August 1994.

3.4. Survey to assess the use of therapeutic and other interventions to reduce the risk of vertical transmission of HIV in Europe

This survey was carried out to update the 1994 obstetric survey with regard to antenatal HIV testing policies and interventions to reduce the risk of vertical transmission. This was in recognition of the fact that policies and practices may have changed since the publication of the results of the ACTG076 trial in 1994, which showed the effectiveness of zidovudine therapy during pregnancy, labour and in the neonatal period in reducing the risk of vertical transmission (Connor *et al,* 1994). As in the 1994 study, a postal self-completed questionnaire method was chosen. The questionnaire was designed to obtain descriptive quantitative and qualitative information on the centre's policies and practices with regard to interventions to reduce the risk of vertical transmission of HIV and consisted of eight semi-structured or multiple-choice questions (Appendix 3.4). A questionnaire was sent in December 1996 to 54 obstetricians who had taken part in the 1994 survey. Fourteen of

these obstetricians were also participating in the ECS. First and second reminder letters were sent out after nine and 13 weeks respectively, the second with a copy of the questionnaire. The analysis is based on replies received by May 1997. Data were entered onto a database using an epidemiological software package, Epi-Info, (version 6.02, CDC/WHO 1994).

3.5 Children and Families Affected by HIV: A European Perspective

The final part of the thesis presents the results of two related surveys carried out in 1996/7, which were designed to provide a background for the ECS. These surveys were carried out as a separate project, funded by the European Union's Public Health Directorate. The first, a service-provider survey, aimed to obtain information on the provision and organisation of clinical and psycho-social services for families with children affected by HIV in a sample of 15 paediatric HIV centres in Europe. The aims of the second, a parent and carer survey, were to obtain information on the characteristics of families cared for in each centre and to obtain feedback from parents and carers of HIV-affected children on their needs for medical and psycho-social services, service utilisation and satisfaction with current service provision. The 15 centres (Appendix 3.5) were selected since they were known to care for relatively large numbers of children perinatally exposed to HIV. Most (80%) were collaborating centres in the European Collaborative Study on children born to HIV infected mothers, while the remaining three centres had close links with the ECS.

3.5.1 Service-Provider Survey

The subjects for this survey were the key paediatrician and psycho-social professionals working in the paediatric HIV service in the 15 centres. The survey consisted of two detailed questionnaires, a medical services questionnaire (for the paediatricians) and a psycho-social questionnaire (for the psycho-social professionals), which were administered by the researcher during interviews in all but one centre (Madrid). There was no psycho-social professional working at the paediatric HIV clinic at Madrid, so the medical services questionnaire and a modified psycho-social services questionnaire were sent by post and completed by the paediatricians themselves. Since the researcher was the sole interviewer, the potential for interviewer bias was reduced. Data collection took place between December 1995 and June 1996.

The questionnaires were designed with input from an HIV-infected parent representative. Although not formally piloted, feedback on draft questionnaires was obtained from paediatricians and psycho-social professionals from two centres. The final versions of the Medical and Psycho-Social Services Questionnaires consisted of 47 and 38 multiple-choice and semi-structured questions respectively (Appendix 3.6). The Psycho-Social Services Questionnaire contained questions on both psychological and social services and if there was more than one professional at the clinic working in these areas (e.g. a social worker and a psychologist), each could take part in the interview, answering the questions in the section most relevant to them.

3.5.2 Parent and Carer Survey

The subjects of this survey were the parents or other carers (other relatives, foster parents, adoptive parents) of children affected by HIV using the paediatric HIV services

at the participating centres (see Appendix 3.5). The chosen method was an anonymous self-completed questionnaire survey. In order to maximise the response rate, the questionnaire was kept as short and straightforward as possible, with most questions having multiple-choice answers. The key paediatrician, a health visitor and a social worker from one of the centres were asked to comment on the content and wording of the final draft of the questionnaire, to assess its content validity. The questionnaire was modified accordingly and then translated into French, Italian, Spanish, Portuguese and German. The final version had a total of 30 multiple-choice and semi-structured questions (Appendix 3.7). Space was provided at the end of the questionnaire for additional comments.

With regard to the survey protocol, in each participating centre the questionnaires were distributed to parents and carers by clinic staff, coordinated by the centre coordinator (usually the social worker or psychologist). When designing the survey protocol, initially an eight-week data collection period was planned, with the parent or carer of any child affected by HIV attending the centre during that period being invited to complete a questionnaire. However, as the frequency of paediatric HIV clinic-sessions and the size of the population cared for varied considerably by centre, this would have resulted in bias, with more subjects from the larger centres than the smaller ones. As the aim of the survey was to study a representative sample of parents of HIV-affected children in Europe, it was decided that centre coordinators be asked to try to distribute between 15 and 20 questionnaires in total to parents of consecutive HIV-affected children attending the clinic.

If more than one parent or carer per child attended the clinic with a child, the one who most frequently accompanied the child was asked to complete the questionnaire. Every parent or carer was informed that participation was optional and that the questionnaire was anonymous. The centre coordinators collected the completed questionnaires and returned them to the co-ordinating centre in London in all but two of the participating centres (London and Edinburgh), where a stamped addressed envelope was provided with each questionnaire for the respondents to return the completed questionnaires directly to the co-ordinating centre.

To investigate whether the use of the centre coordinators to collect and return the questionnaires to London resulted in bias with regard to the questions relating to satisfaction with services, the level of satisfaction of respondents from the centres who replied by post was compared to that among the other respondents, and no significant difference was found. After the analyses were completed (see next section), service-providers and parent representatives were invited to a workshop in London at which the results were presented and additional comments invited.

3.6 Statistical analysis

3.6.1 European Collaborative Study data

Univariate comparisons for categorized variables were tested with χ^2 test and in testing for trends, the Mantel-Haenszel χ^2 test was used. Life-table analyses were carried out by the researcher using Kaplan-Meier survival analysis techniques (Kaplan and Meier, 1958) and Cox proportional hazards models were used in multivariate analyses of hospitalisation and social care setting to calculate adjusted odds ratios and 95% confidence intervals (Cox and Oakes, 1984). No extrapolation beyond the data was

carried out. In the analysis of the maternal immunological status, a log transformation was applied to CD4 cell count before multivariate analysis. Unless otherwise stated, the adjusted odds ratios and 95% confidence intervals are presented in multivariate analyses. All probability values were two-tailed and the threshold of significance was set at 0.05. Analyses were performed using SAS statistical software.

3.6.2 Obstetric, service-provider and service-user surveys

The mix of closed- and open-ended questions resulted in both quantitative and qualitative data. Epi-Info was used for data entry, to summarise the data and for statistical analysis. Univariate comparisons for categorized variables were tested with χ^2 test and in testing for trends, the Mantel-Haenszel χ^2 test was used.

3.7 The researcher's role within the collaborative studies

As this work was carried out within the framework of a large and on-going prospective study, it is appropriate to clarify my role in the research. With regard to the ECS data, I had limited involvement in coding questionnaires and data entry, but was responsible for data checking and correspondence with collaborators regarding data queries. I performed all analyses mentioned in Table 3.4 and presented in this thesis and prepared various manuscripts for publication (Appendix 3.8).

The lead researcher in the 1994 survey of the management of pregnancy and delivery in HIV-infected women was a visiting obstetrician from Italy. I was involved in the design of the questionnaire and was responsible for the survey administration (correspondence, distribution of questionnaires and reminders etc.). I set up the database, analysed results and helped to prepare manuscript for publication (Appendix 3.8). The visiting fellow

spent only limited periods of time in London and I was responsible for maintaining the research. With regard to the 1997 obstetric survey, I was involved in questionnaire design and was solely responsible for survey administration (distribution of questionnaires and reminders), setting up the database and analysing results. I also prepared the manuscript submitted for publication (Appendix 3.8).

I was closely involved in the European Union grant application for the project, "Children and families affected by HIV: a European perspective" and was the designated researcher. I took a lead in designing questionnaires for service-provider and service-user surveys, was responsible for survey administration (correspondence, ethics approval, travel to centres, survey expenses) and data collection, which involved travelling to 14 centres to interview the service-providers (I was the sole interviewer) and to co-ordinate the service-user survey. I set up the database and analysed the survey results, and presented the findings at the workshop.

Chapter 4 Results: HIV- Infected Pregnant Women in Europe

"Find a cure. I want to see my kids grow up" ***(HIV-infected mother)***

4.1. Introduction

This chapter describes HIV-infected pregnant women with live births in Europe, with regard to their mode of acquisition of HIV infection, timing of diagnosis, clinical and immunological characteristics and obstetric management. As presented in more detail in the methods section, the data sources for this chapter are the ECS and the 1994 and 1997 obstetric surveys.

4.2. Antenatal screening policies

In 1994 and again in 1997, obstetricians in Europe were sent a questionnaire relating to antenatal HIV screening policies in their unit. Fifty-five (98%) of the 56 obstetricians contacted in the 1994 survey returned their questionnaire. Of the 54 obstetricians contacted in 1997, 44 (81%) responded; four of the ten centres from which no response was received were from countries with a low prevalence of HIV among women of childbearing age (Greece, Israel, Austria and Iceland) and were known to have limited experience of HIV-infection from the previous survey. The remaining six centres were in Germany, Norway, Belgium, Switzerland and Italy, and at least one other centre from these countries responded. In addition, in one centre no HIV-infected women had been cared for in the obstetric unit in the years 1994 to 1996 and this centre was excluded from analysis. Analyses comparing trends over time are limited to the 43 centres which participated in both surveys.

Testing policies and trends over time

Table 4.1 shows the prevalence of different antenatal HIV testing policies in 1994 and 1997. Six (35%) of the 17 respondents from centres with selective testing policies in 1994 and two of the six in 1997 listed the groups to whom selective testing was directed (IDUs, blood/blood product recipients, women with HIV-infected partners, those reporting high numbers of sexual partners or prostitution, women reporting sexual contact in sub-Saharan Africa or the Far East, partners of bisexuals and hospital workers). The six centres with selective policies in 1997 had fewer than 1.5 births to HIV-infected women per 1000 births, compared to a mean of 4.8 per 1000 in centres with universal testing. By 1997, all centres had adopted either a policy of selective or universal HIV testing. However, although the prevalence of universal testing increased between 1994 and 1997 among those centres participating in both surveys, this was not statistically significant (p=0.11). The 14 ECS centres all either had universal testing policies or were referral centres for women at high risk of acquisition of HIV infection (e.g. active drug users).

Consent and pre-test counselling

Data on how consent for HIV testing was obtained and on the provision of pre-test counselling were collected in the 1994 survey only, in 48 (89%) of the 52 centres with selective or universal testing policies. In 32 (67%) centres, pre-test counselling was routinely provided and this was usually carried out by obstetricians and/or midwives, although eight centres had specially trained counsellors and one centre HIV-specialist midwives. No pre-test counselling was available in the remaining 16 centres. There was a trend towards a higher likelihood of provision of pre-test counselling in centres with universal screening policies (23/32, 72% v. 9/16, 56%), but this did not reach significance

(p=0.28). There was no trend in provision by country and no significant difference according to the number of HIV-infected pregnant women cared for.

Table 4.1 Antenatal HIV testing policies, by year of survey

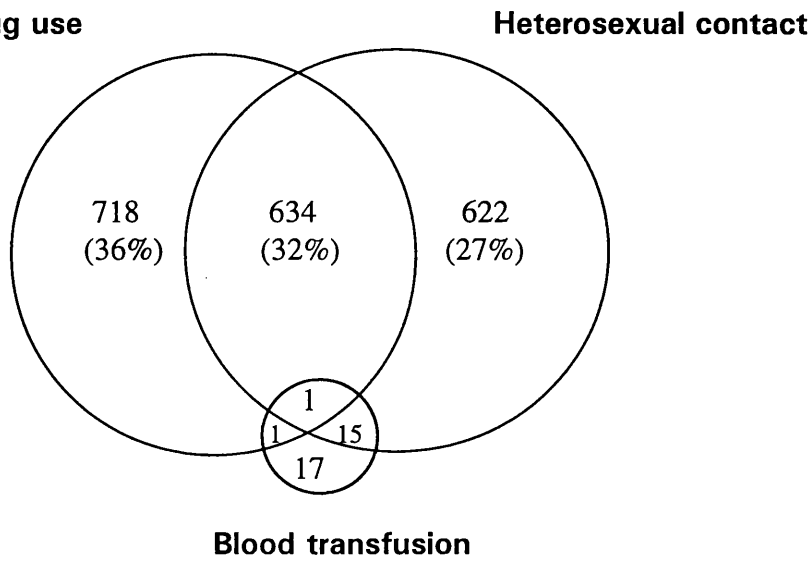
Year	Universal testing	Selective testing	No testing or on request only
1994			
Total (n=55)	35 (64%)	17 (31%)	3 (5%)
Respondents in 1997 (n=43)	31 (72%)	11 (26%)	1 (2%)
1997			
Total (n=43)	37 (86%)	6 (14%)	0

In more than three-quarters (41, 77%) of the 53 centres which provided HIV testing, there was a policy of verbally obtaining pregnant women's consent to testing, although there was no information available about whether this policy was upheld in all cases; fewer than a quarter (12, 23%) of centres had a policy of obtaining written consent. Obstetricians were usually (in 41 (77%) centres) responsible for obtaining consent (whether verbal or written), although trained counsellors and midwives undertook this task in five (9%) and seven (13%) centres respectively.

4.3. Mode of acquisition of HIV infection

By July 1997, 2 131 mothers were enrolled in the ECS. Nearly all (2008, 94%) women specified their most likely mode of acquisition of HIV and in most (1352, 68%) cases this was associated with maternal injecting drug use (IDU) (Figure 4.1).

Figure 4.1 Mode of acquisition of HIV infection (n=2008)



A total of 413 (30%) women with a history of IDU provided information about their needle-sharing practices. Of the 365 (88%) who reported needle-sharing, this was usually (291, 80%) in the past, although 74 (20%) still shared needles during the index pregnancy. The proportion of IDUs who reported at enrollment that it was still their practice to share injection equipment declined from a high of 57% in 1987-88 to 3% in 1991-92 and 0% thereafter (χ^2=16.0, p<0.02). Needle-sharing practices also varied geographically: although Edinburgh had the highest prevalence overall (32/35, 91%), this all related to past habits and no women reported that they were still sharing injection

equipment at the time of enrollment. The centre with the highest proportion of IDUs reporting current needle-sharing (32%) was Madrid (31/98 IDUs).

Of the 634 women with a history of IDU as well as heterosexual risk factors, 571 (90%) reported sexual contact with IDUs, 15 (2%) reported multiple sexual partners or prostitution, three had bisexual partners, two had haemophiliac partners and 43 (7%) reported heterosexual risk factors, but did not give specific details. It was impossible to determine whether these 634 women had acquired their infection parenterally, through heterosexual transmission or by both routes.

Of the 622 women with no history of IDU or of blood transfusion who acquired their infection through heterosexual contact, 291 (47%) were sexual partners of IDUs, 210 (34%) were from areas of high HIV prevalence (mainly sub-Saharan Africa) or had sexual partners from such areas, 13 reported multiple sexual partners, nine had bisexual partners and six were partners of haemophiliacs; specific risk factors were not available for the remaining 93 (15%) women, who had indicated that they had probably acquired infection heterosexually. Women who had acquired their infection heterosexually were more likely to be married or cohabiting than women with a history of IDU (76% vs. 64%, $\chi^2=11.2$, $p<0.02$), which supports the reliability of the data.

Patterns of transmission varied by country, with IDU-related modes of acquisition most common in the centres in Spain, Italy, the UK and Berlin (Figure 4.2). The proportion of heterosexually acquired infection in the absence of maternal IDU increased significantly over time from 13% in 1984-86, to 41% in 1991-92 and 55% in 1995-97 ($\chi^2=55.8$, $p<0.02$), a trend which persisted after controlling for centre (Figure 4.3).

Figure 4.2 Mode of acquisition of HIV infection, by centre

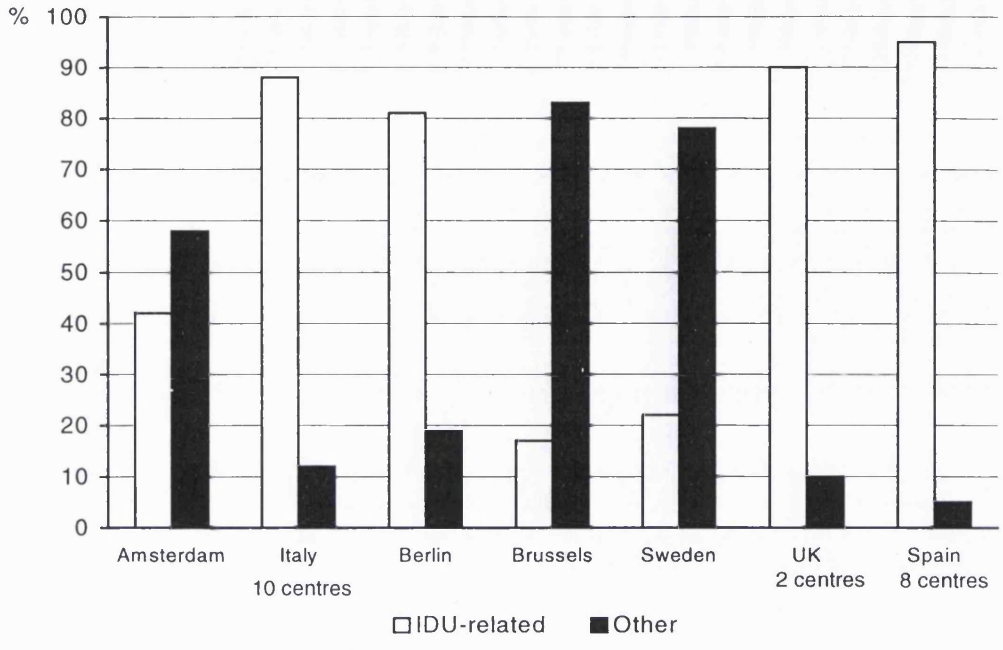
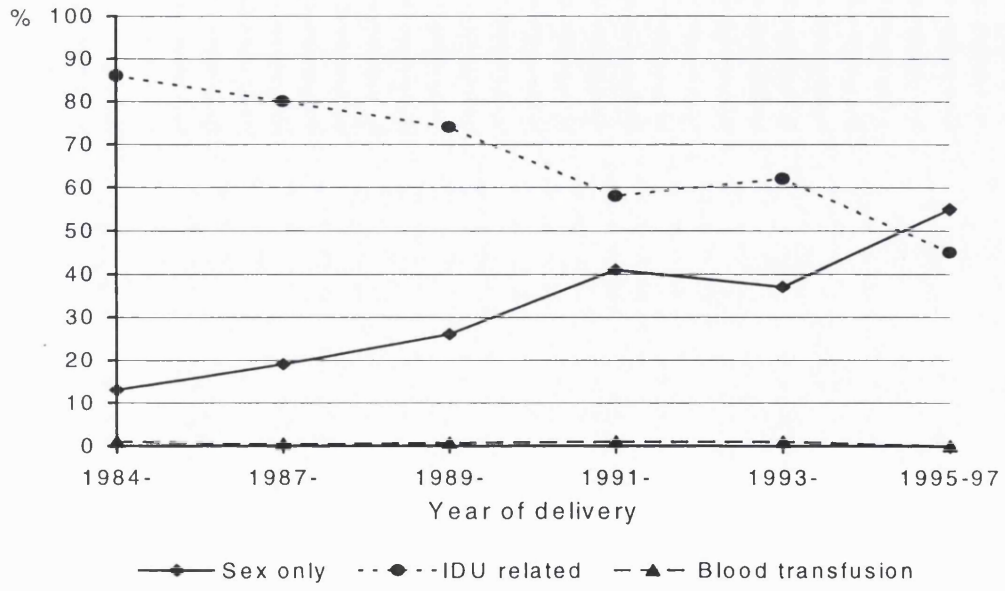


Figure 4.3 Trends in mode of acquisition of HIV infection over time



4.4. Timing of diagnosis of HIV infection

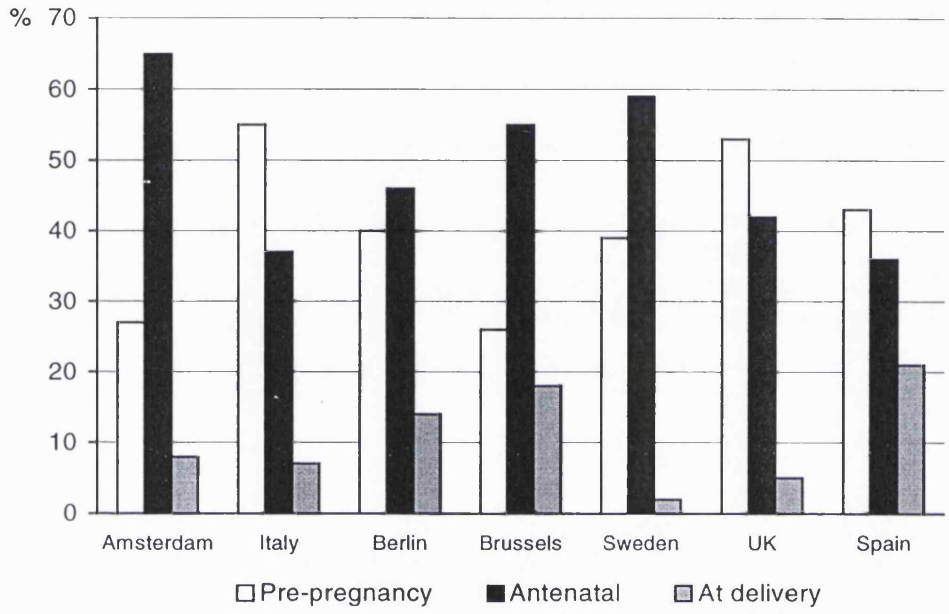
Nearly half (1013, 48%) of the 2 131 women in the ECS who delivered by July 1997 had been diagnosed as HIV infected before their current pregnancy, with a further 869 (41%) women diagnosed during pregnancy as the result of antenatal screening and 249 (12%) on the basis of a blood sample taken at delivery. Data on gestational age were available for 839 (97%) women first diagnosed in pregnancy and in 258 (31%) cases, the diagnosis of HIV infection had been made before 24 weeks of pregnancy; termination of the pregnancy could therefore have been an option in some of these cases.

One of the most important factors determining whether or not the mother had previously been tested for HIV was mode of acquisition of infection. The most likely mode of acquisition was available for 2016 (95%) mothers; in those where there was a history of maternal IDU, diagnosis had been confirmed before pregnancy in more than half (753/1352; 56%), compared to 29% (5/17) of deliveries where infection was probably acquired through blood transfusion and 36% (235/647) with heterosexual acquisition. The country of birth was known for 2083 (98%) mothers and maternal origin in sub-Saharan Africa was found to be associated with a later diagnosis of maternal infection: diagnosis occurred before pregnancy in 60 (30%) of the 199 women from sub-Saharan Africa compared to 946 (50%) of the 1884 other women, of whom 98% were from Europe (χ^2=27.5, p<0.02); however, this association disappeared when controlling for IDU.

There were also national variations in the timing of diagnosis of HIV infection (Figure 4.4): for example, over half of the women from the Italian centres had already been tested for HIV before their pregnancy, while only about a quarter of women from Brussels and Amsterdam knew of their HIV infection before becoming pregnant. These centre

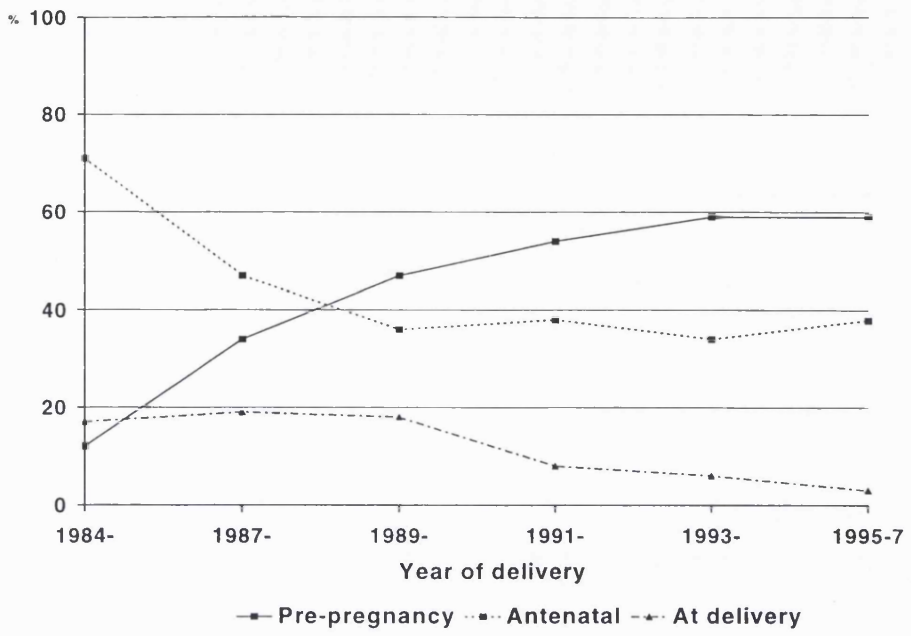
differences largely reflect the variation in the locally predominant mode of acquisition and the proportion of women from sub-Saharan Africa.

Figure 4.4 Timing of diagnosis of HIV infection, by centre



Over the study period there was a trend towards earlier diagnosis of HIV infection, with the proportion of deliveries to women known to be infected before pregnancy increasing from 12% in 1984-86, to 47% in 1989-90 and 59% in 1995-7 (χ^2_{trend}=150.0, p<0.02) (Figure 4.5). This trend applied to women with both IDU and heterosexual modes of acquisition and was particularly noticeable in the Italian and Spanish centres, which had low pre-pregnancy detection rates in the early years of the study.

Figure 4.5 Trends in timing of diagnosis of HIV infection over time



4.5. Clinical and immunological status of HIV-infected pregnant women

This section uses data from the ECS on the 2 230 deliveries taking place to the 2 131 women enrolled by July 1997. Information on maternal CD4 cell count was available for half (1 157, 52%) these pregnancies and the count taken closest to delivery was used in the analyses. The mean maternal CD4 count was 490 cells/mm^3 (range = 1 to 2350 cells/mm^3) and in 86% of deliveries the CD4 count was more than 200 cells/mm^3 (Table 4.2).

A multivariate analysis of CD4 count, controlling for centre and including injecting drug use, ethnic group and year of delivery was carried out in a subgroup of 1134 women with information on all the variables available (Table 4.3). To illustrate, the geometric mean CD4 count for black women was 311 cells/mm^3, i.e. 24% lower than that of white women.

After adjustment for centre, year of delivery and IDU, this difference increased to 41% ($p<0.02$). The lower CD4 count in black women, who were predominantly from East and Central Africa, is likely to be due to a longer duration of infection or possibly to lower initial levels of CD4 cells in these women due to exposure to other infections. There was a significant decline in adjusted average CD4 count over the course of the study, from 531 cells/mm^3 in 1985-8 to 353 cells/mm^3 in 1995-7, which reflects the increased number of women enrolling in the study who have been infected for longer before becoming pregnant.

Table 4.2 Distribution of CD4 counts for 1157 women in the ECS

CD4 count	n	(%)
< 200 cells/mm^3	157	(14)
200 - 499 cells/mm^3	521	(45)
≥ 500 cells/mm^3	479	(41)

A total of 105 (5%) mothers progressed to AIDS during the follow-up period and 118 (6%) died. From survival analysis it is estimated that two years after delivery 3% of mothers will have died and 7% will have developed AIDS, rising to 14% and 18% respectively at five years post-partum. The majority of women will therefore remain free of serious HIV-related manifestations of disease for at least the first five years of their child's life. An estimated 21% of women with CD4 counts of less than 200 cells/mm^3, 3% with CD4 counts of 200 to 499 cells/mm^3 and 0.5% with CD4 counts over 500 cells/mm^3 will have

progressed to AIDS by 12 months post-partum; rising to 27%, 11% and 4% respectively by three years after delivery, a significant difference, (χ^2=78.4, p<0.02). A history of IDU was not found to be associated with the rate of progression of HIV disease.

Table 4.3 Multivariate analysis of CD4 count (n=1134)

Variables	n	Average CD4 count* (cells/mm^3)	CD4 count relative to baseline category	
			crude	adjusted**
Injecting drug use				
Ever	663	401	1.00	1.00
Never	471	389	0.97	0.95
				p=0.5#
Race				
White	965	411	1.00	1.00
Black	141	311	0.76	0.59
Other	28	368	0.90	0.85
				p<0.02#
Year				
1985-1988	154	531	1.00	1.00
1989-1990	172	464	0.87	0.86
1991-1992	272	376	0.71	0.74
1993-1994	360	356	0.67	0.70
1995-1997	176	353	0.66	0.70
				p<0.02$^\Psi$

* geometric mean
** adjusted for the other variables in the analysis and centre
\# test for heterogeneity
$^\Psi$ test for trend

4.6. Management of pregnancy and delivery

Information on policies for the management of pregnancy and delivery in HIV-infected women in Europe was obtained in the 1994 and 1997 obstetric surveys. A 98% (55/56) response rate was achieved in the first survey and 43 of the 55 (78%) centres in the first survey participated in the follow-up survey, although one had no experience of HIV infection in the years 1994-6 and was excluded from analysis (Appendix 3.3).

Interventions to reduce the risk of vertical transmission of HIV

Policies in 1994

Of the 55 centres in the 1994 survey, four had no experience of caring for HIV-infected pregnant women and thus the following data on interventions relate to 51 centres. All centres routinely advised HIV-infected women not to breastfeed and in over a third (19, 37%), no other intervention to reduce the risk of mother-to-child transmission was available. Although results of the ACTG 076 trial were released in early 1994 (Connor *et al,* 1994), before the survey started, in 30 (59%) centres zidovudine was not prescribed at all, or only for clinical indications, i.e. for immunosuppressed (CD4 count less than 200 cells/mm^3) and/or symptomatic women. A total of nine (16%) centres had a policy of performing elective caesarean sections on HIV-infected women and in 12 (24%) centres, disinfection of the birth canal (with either chlorhexidine or benzalkonium chloride) was a routine procedure (Table 4.4).

Policies in 1997

By the time of the second survey, prevalence of routine zidovudine use had increased significantly from 41% to 98% (χ^2=27.9, p<0.02), with only one centre (Sofia) not providing antiretroviral therapy to reduce vertical transmission (Table 4.4). Unlike the

initial survey, information was collected on the precise antiretroviral therapy regimen adopted: in 38 (90%) centres all three components of the ACTG076 protocol (i.e. pregnancy, intrapartum and neonate therapy) were routinely provided, with two centres only administering the pregnancy component and two prescribing zidovudine in pregnancy and to the infant, without intrapartum therapy.

Zidovudine therapy in pregnancy was reported to start at a median of 14 weeks (range, 12 to 34 weeks), with 10 centres not starting therapy until the third trimester. In the 39 centres where intrapartum use of zidovudine was part of the usual regimen, this was given intravenously in 35 centres (including one with a policy of universal elective caesarean section with zidovudine given intravenously during the procedure), orally in two and by either route of administration in the remaining two. The duration of prophylactic treatment of the infant was six weeks in 36 (90%) of the 40 centres providing this part of the regimen, 10 days in two centres, 28 days in one and one month to six weeks in another.

An important change seen in the follow-up survey was the introduction of combination antiretroviral therapy to reduce the risk of mother-to-child transmission: other antiretroviral drugs with zidovudine were routinely used in nine centres, including three where combination therapy (zidovudine and 3TC or ddI) was routinely prescribed to all infected women and in one case, to the neonates for six weeks. In the remaining six centres (from Sweden, the UK, Germany, France and Austria), one or more subgroups of women were routinely offered zidovudine and 3TC (and rarely zidovudine and ddI or ddC): those previously treated with zidovudine (2 centres), women with symptomatic disease, severe immunosuppression or a high viral load (3 centres) and cases where seroconversion took

place in pregnancy (1 centre). In one centre offering 3TC and zidovudine, if zidovudine intolerance developed, zidovudine was substituted with d4T (stavudine).

To estimate the extent of zidovudine uptake among pregnant women, respondents were asked to indicate the approximate proportion of women currently receiving zidovudine to reduce vertical transmission. In 32 of the 33 centres which cared for HIV-infected pregnant women in 1996, it was estimated that three-quarters or more of the women identified to be HIV-infected received zidovudine, and in the remaining centre half were estimated to have received zidovudine. Of the 18 centres, where a quarter to a half of women identified as HIV-infected did not receive zidovudine therapy, one or more reasons for this were specified: refusal of therapy was the most common reason given (15 cases), in addition to late obstetric booking/lack of antenatal care (8), non-compliance (1) and contra-indication or discontinuation of therapy because of side effects (1).

Although the effectiveness of caesarean section remains unproven, the percentage of centres offering routine elective caesarean section for all HIV-infected women increased from 19% (8 centres) in 1994 to 26% (11 centres). There was an even greater change at the centre level whereby over a quarter (11) of centres changed their caesarean section policies: four of the eight centres routinely offering this procedure in 1994 no longer did so by 1997, while an additional seven centres had adopted a policy of offering elective caesarean sections to all HIV-infected women. In an additional 18 (42%) centres, a subgroup of women were offered this intervention: 10 centres were participating in the Mode of Delivery Trial (Newell *et al,* 1997b), with consenting women allocated to vaginal or caesarean section delivery randomly, seven centres had a policy of offering caesarean sections to women who had potential risk factors for intrapartum transmission of infection

(e.g. history of long labour and early rupture of membranes, cervico-vaginal infection) and in the remaining centre the policy was to offer the procedure to women who refuse antiretroviral therapy.

Cleansing of the vagina and cervix of HIV-infected women in labour was routine in nine (21%) centres. The agents most commonly reported were benzalkonium chloride and chlorhexidine. Although the number of centres with a policy of routine disinfection of the birth canal was the same in 1997 as in 1994, three of the nine centres with this policy in 1994 stopped providing this intervention by the second survey, with an additional three initiating a new policy of vaginal lavage. All centres had a policy of advising HIV-infected women not to breastfeed.

These policies have been confirmed by results from the ECS, which have shown a gradual but significant increase in zidovudine use to reduce vertical transmission from 24% (59/248 deliveries) in 1994 to 62% (103/211) in 1995 and 76% (69/91) in 1996 (χ^2=95.3,p<0.02). This has been associated with a significant temporal decline in the vertical transmission rate from an estimated 19% in 1993 to 6% in 1996 (p<0.02); however, the confidence intervals around these estimates are wide in 1995 and 1996 due to small numbers and this trend needs further confirmation. Over the same period of time, the elective caesarean rate has stayed stable at approximately 31%.

Organisation of obstetric care: policies and practice in 1994

Multi-disciplinary specialist HIV teams, including obstetricians, infectious diseases specialists, paediatricians, midwives, psychologists, counsellors and social workers, had been set up in 10 (20%) of the 51 centres with obstetric experience of HIV infection

(Goteborg, Huddinge, Brussels (2), Warsaw, Copenhagen, Paris, Munich, Amsterdam and London), five of which had a specialist HIV outpatients unit. Specially trained social workers, counsellors or midwives were provided in a further six centres. The provision of these special services and facilities was not related to the number of HIV-infected women seen.

Most obstetricians reported close collaboration with internal medicine or infectious diseases specialists in the management of pregnancies of HIV-infected women, especially in cases of women with advanced disease. Infected women were seen more frequently during pregnancy than uninfected women in 18 (35%) centres and the shortest interval between antenatal visits was two to three weeks. HIV infected women routinely underwent more antenatal investigations than uninfected women, including screening for infections (including hepatitis C, CMV, toxoplasmosis, chlamydia and gonorrhoea) and cervical neoplasms, plus more frequent ultrasound scans in 15 (29%) centres. Immunological tests such as CD4 and CD8 measurement and viral detection were part of routine care for HIV infected women. With regard to invasive obstetric procedures, most centres had a policy of avoiding the use of scalp electrodes for HIV infected women: of the 27 centres routinely using scalp electrodes in uninfected women, 93% (25) avoided them in infected women. In the post-natal period, care of the HIV-infected mother was usually transferred to internal medicine or infectious diseases departments.

Table 4.4 Use of interventions to reduce vertical transmission, by year of survey[#]

Year	Zidovudine therapy only	Zidovudine therapy & elective caesarean section	Zidovudine therapy & birth canal washing	Elective caesarean section only	Birth canal washing only
1994					
Total (n=51)	11 (22%)	5 (10%)	7 (14%)	4 (12%)	5 (10%)
Participants in 1997 survey (n=42*)	10 (24%)	4 (10%)	6 (14%)	4 (10%)	4 (10%)
1997	22 (52%)	10 (24%)	8 (19%)	1** (2%)	0
Total (n=42*)					

[#] all centres recommended the avoidance of breastfeeding

* total = 42 because one centre had no experience of HIV infection in 1994-6 and was excluded from analysis

** birth canal washing provided for women not having an elective caesarean section delivery

4.7. Key points

- prevalence of universal voluntary antenatal testing in Europe increased between 1994 and 1997

- two-thirds of mothers in the ECS had a history of IDU
- the proportion of women with heterosexually acquired infection increased significantly from 13% in 1984-6 to more than 50% by 1995-7
- patterns of mode of acquisition varied geographically

- nearly half the mothers in the ECS had been diagnosed as HIV-infected prior to pregnancy and there was a trend towards earlier diagnosis of infection over time
- women with a history of IDU were identified as HIV-infected earlier than those with other modes of acquisition
- women originating from sub-Saharan Africa were diagnosed later than other women

- most women in the ECS were only moderately immunosuppressed in pregnancy, but average CD4 count in pregnancy declined over time
- black women had significantly lower CD4 counts than white women
- five years after delivery, 14% of mothers will have died and 18% progressed to AIDS

- zidovudine use to reduce vertical transmission has increased significantly in Europe since 1994
- a quarter of centres surveyed routinely offered elective caesarean sections and a fifth washed the birth canal of HIV-infected women as an intervention to reduce vertical transmission
- avoidance of invasive obstetric procedures was a common policy
- in the ECS there has been an increase in antiretroviral therapy and a decrease in the vertical transmission rate

Chapter 5 Results: Children born to HIV-infected mothers - family circumstances, social care and hospitalisation

"I can only give praise for the treatment given to myself and grandchildren by the doctors and health visitors from the [hospital name] over the past 7½ years. It gives me peace of mind knowing the kids are in very good hands. God bless them all." ***(grandmother of two perinatally-exposed children)***

"I feel priviledge that I have this child in my care, officially as a foster parent, whilst her mother is mostly unable to care" ***(foster mother of an infected child)***

5.1. Introduction

The social circumstances of a large group of children born to HIV-infected mothers and enrolled in the ECS are described in this chapter, including social care setting and medical and non-medical hospital admissions. The prospective nature of the ECS provides the opportunity to study the needs for social and medical care not only of perinatally HIV-infected children, but also of the 80 to 85% of children born to HIV-infected mothers who are not themselves infected. As all children in families affected by HIV may be at increased risk of social deprivation and poor health as a result of family circumstances, rather than HIV infection, comparisons between HIV-infected and uninfected children clarify the relative contribution of HIV infection and maternal social characteristics.

5.2. Social circumstances

Between 1986 and 30 June 1997, 2262 children born to 2131 mothers were enrolled in the obstetric and paediatric arms of the ECS (Table 5.1). Most mothers were relatively young and primiparous. The mean age at delivery was 26 years (range= 10 to 44 years),

with a slight increase from 24 to 28 years over the study period. There were small variations in maternal age between countries, with the youngest mothers coming from the UK (mean = 24.8 years) and the oldest from Amsterdam (28.3 years).

Table 5.1 Numbers of mothers and children in the ECS, by centre

	Mothers n (%)	**Children** n
Brussels	152 (7)	171
Berlin	110 (5)	113
Italy (10 centres)	1042 (49)	1096
Amsterdam	62 (3)	63
UK (2 centres)	83 (4)	106
Spain (6 centres)	578 (27)	599
Stockholm	104 (5)	114
Total	2131 (100)	2262

Information on parity at the time of enrollment was available for 2010 (94%) women, of whom 1272 (63%) had no previous children, 476 (24%) had one child, 159 (8%) had two and 103 (5%) had three or more children. A history of termination of pregnancy was reported by over a third of women (714/1947, 37%), of whom 456 (64%) reported a single termination, 188 (26%) two and 70 (10%) three or more. Women with a history of IDU were more likely to have had a previous pregnancy termination than other women (42% vs. 26%, χ^2=47.5, p<0.02). Marital status was known for 909 (43%) women, since

this information was only collected in the paediatric arm of the study. As would be expected for a group of pregnant women, most (68%) were either married (n=380) or cohabiting (n=235) at the time of enrollment, with a further 246 (27%) single and 48 (5%) separated, divorced or widowed. Current IDUs were significantly less likely to be married or cohabiting (58%) than women with no history of IDU (78%) (χ^2=28.0,p<0.02) and former IDUs (76%) (χ^2=17.4, p<0.02).

Nearly two-thirds of all mothers (1 356/2 086, 65%) had a history of IDU; information on current usage (i.e. at the time of enrollment) was available for 1136 (84%) of these women, of whom 473 (42%) were former and 663 (58%) current IDUs. The type of drug taken in pregnancy is important with regard to the effect of exposure of the fetus, especially on neuro-development and the prevalence of drug withdrawal symptoms in the neonate. Information on the type of drug(s) used in pregnancy was only collected in ECS2 and was available for 198 women, most (169, 85%) of whom took heroin. Most heroin-users also reported use of other drugs during pregnancy, with 98 (58%) reporting methadone, seven (4%) cocaine and 22 (13%) both methadone and cocaine. Of the remaining 29 women, 26 took methadone alone and three only cocaine. There were no reports of crack cocaine use. This pattern of drug use confirms previous reports regarding IDU in Europe (De la Fuente *et al,* 1994; Nicolosi *et al,* 1992; Hartgers *et al,* 1991).

Educational attainment was rather minimal, with 309 (57%) of 546 mothers leaving school before the age of 15 years, 192 (35%) between 15 and 18 years and only 45 (8%) at or after 19 years. Age of cessation of full-time education varied geographically, with an average school-leaving age of 16 years (range = 13 to 24 years) in the northern

European centres and 14 years (range = 8 to 27 years) in Italy and Spain, which correspond to the legal requirements in these countries.

The majority of women (1811/2096, 86%) enrolled in the ECS were white, 220 (11%) were black, 33 (2%) were Asian and the remaining 32 were of other ethnic groups, mainly Arab, Hispanic and "gypsy". Information on country of birth was available for 2083 (98%) women, of whom 299 (14%) were not living in their country of birth at the time of delivery: two-thirds (199, 67%) were born in sub-Saharan Africa, 51 (17%) were born elsewhere in Europe, 32 (11%) in the Americas and the remainder (17) in Asia, the Middle East or North Africa. Of the 199 women from sub-Saharan Africa, over half were from two countries, Zaire (77, 39%) and Uganda (34, 17%). Three-quarters of the mothers not currently living in their country of birth were enrolled in Brussels, Stockholm and Amsterdam and accounted for over two-thirds of all mothers from each of these centres; the majority of these women (91%, 66% and 78% respectively) were from sub-Saharan Africa, reflecting prior colonial links and/or liberal immigration policies. A quarter (11/41) of all women in Amsterdam were from other European countries, most (90%) of whom had a history of IDU, which suggests that the tolerant drug laws and drug-related services provided in the Netherlands may have prompted their move (Hartgers, 1992).

5.3. Social care

The following description of the social care of children born to HIV-infected mothers uses data on 1123 mother-child pairs enrolled in the 10 paediatric centres of the ECS by the end of September 1996 (see Chapter 3). The infection status of 935 (83%) children had been determined by the time of their most recent follow-up visit; 150 (13%) were

infected and 785 (70%) uninfected. Mean length of follow-up was 47 months for infected children, 45 months for uninfected children and 8 months for the 188 children with indeterminate infection status (range = 0 to 129 months).

Care setting

At the time of their last follow-up visit (average age, four years), nearly three-quarters (785, 70%) of the children had always been cared for by one or both of their parents and 338 (30%) had spent some time in alternative care (i.e. with foster parents, adoptive parents, other relatives, or in an institution). The 338 children with a history of alternative care could be classified into three main groups: those who had never lived with their parents, having been placed in alternative care immediately after birth (n=74, 22%), those who were primarily cared for by their parents but had been in short-term alternative care at least once (n=125, 37%), and the 139 (41%) children who were in long-term alternative care, that is had lived in alternative care continuously for 12 months or longer. The initial move to alternative care was permanent for just over half (192, 57%) of the 338 children, i.e. they never returned to the social care of their parents, while the remaining 146 children returned to parental care at least once.

Determinants of alternative care placement

Older children were more likely to be in alternative care, which probably reflects progression of disease in their parents. Life table analysis suggests that an estimated 19% of children will have been in alternative care by age 12 months, rising to 41% and 60% by 60 and 96 months respectively, with no significant differences regarding infection or clinical status of the child (p=0.8). Alternative care placement was significantly associated with ethnic group, maternal injecting drug use and marital status in univariate

analysis (Table 5.2). Children with lone mothers (i.e. those single, divorced or widowed) or with mothers who were using injecting drugs at the time of enrollment were significantly more likely to have lived in alternative care, while black children (whose mothers were predominantly from sub-Saharan Africa) were less likely to have lived apart from their mother and/or father.

The proportion of children in alternative care also varied by centre (χ^2 =88.6, p<0.02) and maternal age, with mothers of children who received alternative care significantly younger than other mothers (25 years v. 27 years, p<0.02). Year of birth (controlling for age) was significantly associated with alternative care placement, with a reduced likelihood of alternative care in the later years of the study (χ^2=7.6, p<0.02); for example, at age one year, 22% of children born in 1988-9 had been in alternative care compared to 9% of those born in 1994-5. Infection status (among the 935 children with known infection status) (χ^2=0.16, p=0.7), gender (χ^2=2.31, p=0.3) and maternal clinical status at delivery (χ^2= 1.85, p=0.2) were not found to be associated with alternative care.

From a life-table analysis to investigate the association between maternal drug use and alternative care placement, it was estimated that by 6 months of age, only 75% of children whose mothers are current IDUs will still be living with their parents, compared to 95% of those whose mothers are former IDUs or have no history of IDU (p=0.07); furthermore, a consistently higher proportion (approximately double) of children whose mothers never used injecting drugs or were ex-users will still be in parental care up to five years of age compared to children of current IDUs.

Table 5.2 **Child and maternal characteristics associated with alternative care placement (univariate analysis)**

	Total	History of alternative care n (%)
Child characteristics		
Ethnic group (n=1094)		
black*	161	17 (10.6)
other	47	13 (27.7)
white	886	307 (34.7)
		χ^2=37.3, p<0.02
Age (n=1123)		
<12 months	231	30 (13.0)
12-23 months	197	24 (12.2)
24-35 months	135	31 (23.0)
36-47 months	129	40 (31.0)
48-59 months	150	56 (37.3)
≥60 months	281	160 (56.9)
		χ^2_{trend}=153.0, p<0.02
Maternal characteristics		
Injecting drug use (n=1099)		
never	384	42 (10.9)
ex-user	221	48 (21.7)
current user	494	249 (50.4)
		χ^2=161.8, p<0.02
Marital status (n=941)		
single/divorced/widowed	302	144 (47.6)
cohabiting/married	639	170 (26.6)
		χ^2=40.9, p<0.02

* 142 mothers born in sub-Saharan Africa

A multivariate analysis which controlled for age, centre and year of birth showed that maternal characteristics had more impact on a child's care setting than the child's

infection status (Table 5.3). Infected children were slightly more likely to have been in alternative care than uninfected children at the same ages, but this did not reach statistical significance. Both maternal IDU status and whether or not the mother was living with a partner at the time of enrollment were independently associated with child's care setting: the former had the stronger influence, although the effects of both characteristics were independent and additive. Poor maternal health was also significantly associated with an increased risk of alternative care.

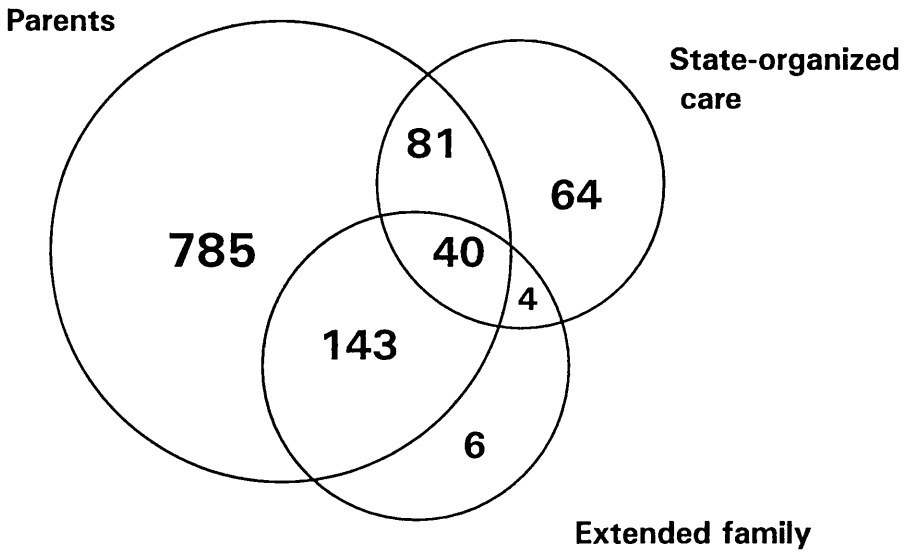
Table 5.3 Probability of alternative care placement, controlling for age, centre and year of birth (n=366)

	n	adjusted OR	95% C.I.	*p*
Child characteristics				
uninfected	307	1.00		
infected	59	1.44	0.85 - 2.43	0.17
female	170	1.00		
male	196	0.79	0.52 - 1.21	0.28
Maternal characteristics				
married/cohabiting & not a current IDU	171	1.00		
single parent & not a current IDU	46	2.30	1.06 - 5.01	0.04
married/cohabiting & current IDU	81	2.72	1.49 - 4.95	<0.02
single parent & current IDU	68	6.85	3.68 - 12.7	<0.02
clinical status				
asymptomatic	346	1.00		
symptomatic (CDC stage IV)	20	2.67	1.11 - 6.42	0.03

Patterns of care

Of the 1123 children, 1049 (93%) had lived with their parents, 193 (17%) with their extended family and 189 (17%) in state-organized care (Figure 5.1); "state-organized care" refers to alternative care organised by the child welfare services, and includes institutional and foster care and adoption. The predominant single source of alternative care for the 338 children who had lived away from their parents was the extended family. Family members (usually grandparents) often initially cared for the children on a temporary basis, but subsequently took on the responsibility of full-time care of the child (for example, when parents became too ill or died). The schedule of follow-up visits may have resulted in an underestimate of the actual prevalence of temporary stays with extended family and shorter, more informal stays, such as weekend visits will have been underestimated.

Figure 5.1 Patterns of care (n=1123)



Of the 193 children who had lived with their extended family, 44 (23%) had also been in state-organised care: 29 (66%) had been fostered, 13 (30%) had lived in an institution and 4 (9%) had been adopted, with some children having lived in two or more settings. Fostering and institutional care usually preceded the child's move to extended family care and may have been in order to locate the extended family members and/or to allow them to prepare for having the child; however, six children had been temporarily fostered after their relative had become their primary carer, which was presumably to give the grandparents or other family members a break from full-time care.

The remaining 145 children had been placed in state-organized care, with most having lived in more than one alternative care setting; overall, 90 (62%) had lived in institutional care, 85 (59%) had been fostered and 58 (40%) adopted. There was a pattern to the sequence of state-organized alternative care for many of these children, with institutional care usually preceding foster care and/or adoption. Overall, there had been a total of 112 placements in institutions, of which 96 (86%) took place in the first year of life. Periods in institutional care tended to be short-term, usually prior to transfer to a more permanent alternative care setting, such as foster care or adoption, although in 23 cases the child subsequently returned home to his or her parent(s). Of the 133 foster care episodes, three-quarters were temporary arrangements, with the child subsequently either returning to his or her parents or extended family (93 cases), or being adopted (40 cases); of the remaining 32 episodes, the child was in foster care at his or her last follow-up visit and had been in the placement for more than a year.

A total of 62 children had been adopted, 18% of those who had been in alternative care and 5% of the whole cohort. The actual dates of adoption were not available, but the

median age at which adoption was first recorded was 19 months (range, birth to 8.5 years). Two-thirds (42) of the adopted children had never lived with their parents and thus adoption was the most common care setting for the 74 children in the cohort who had been in alternative care since birth, with more than half (42/74, 57%) ultimately being adopted. Five children had been adopted at birth, and the remaining 57 (92%) had been in at least one alternative care setting, usually institutional and/or foster care prior to adoption. With regard to the infection status of the adopted children, eight (13%) were infected, 51 (82%) uninfected and three (5%) had indeterminate infection status at the time of adoption, which is a similar pattern to that of the total cohort. The infection status of all eight infected children had been confirmed before adoption.

As expected, given the significant differences across Europe in welfare and social care infrastructure, legal and administrative frameworks and funding (Bradshaw *et al,* 1993), patterns of child care varied across centres (Table 5.4). The proportion of children ever in alternative care varied significantly between centres (χ^2=83.6, p<0.02), which probably reflects the different prevalence of factors predictive of alternative care between centres. With regard to centre differences in alternative care setting, the predominant provider of alternative care in the Italian and Spanish centres was the extended family, with over half the children ever in alternative care having lived with other family members. State-organised alternative care, especially foster care was more important in the northern European centres. Adoption was the least common care setting in all centres, with the exception of Edinburgh, where a third of children in alternative care and more than 10% of all children were adopted.

Table 5.4 **Centre differences in alternative care setting**

Centre	Total	Ever in alternative care	Number ever in care setting (% of children with history of alternative care)			
		n (%)	other relatives	adopted	fostered	institutional care
Italian (2)	312	85 (27)	44 (52)	20 (24)	30 (35)	38 (45)
Berlin	100	32 (32)	8 (25)	5 (16)	22 (69)	14 (44)
Edinburgh	95	30 (32)	12 (40)	10 (33)	20 (67)	2 (7)
Spanish (3)	352	160 (45)	119 (74)	24 (15)	27 (17)	32 (20)
Amsterdam	47	7 (15)	2 (29)	2 (29)	6 (86)	4 (57)
Stockholm	100	12 (12)	3 (25)	0	6 (50)	5 (42)
Brussels	117	12 (10)	5 (42)	1 (8)	3 (25)	6 (50)
Total	1123	338 (30)	193 (57)	62 (18)	114 (34)	103 (30)

To investigate whether alternative care setting varied with the age of the child, cross-sectional analyses of social care setting at the follow-up visits taking place at three months, two years and five years were carried out (Table 5.5). The importance of institutional and foster care was greatest at age three months, accounting for more than three-quarters of alternative care placements, compared to less than a fifth in the oldest age-group. With increasing age, a growing proportion of children were adopted or lived with their extended

family, reflecting the fact that these are generally permanent alternative care settings. The relative importance of all the alternative care settings, with the exception of foster care, changed significantly with increasing age.

Certain maternal characteristics had an impact on the type of alternative care that children received (Table 5.6). Children whose mothers were active IDUs were more likely to require institutional care, which may reflect social isolation from their families and possibly the legal actions of the child welfare services (Baller, 1994; Campion, 1995). The finding that children of mothers born outside Europe were significantly less likely to be in extended family care, despite the fact that these women had more advanced HIV disease (see Chapter 4), probably reflects geographic isolation from their wider family.

Maternal death

The mothers of 98 (9%) children were known to have died during follow-up and average child age at maternal death was 49 months (range = 1 week to nine years). Nearly a third (29, 30%) of these children were already in a long-term alternative care setting by the time their mothers died. Of the remaining 69 children, 27 (39%) were subsequently cared for by their father, 37 (54%) by their extended family and 5 (7%) by foster carers. The number of children whose mothers have died reported here may be an underestimate, especially with regard to children in state-organized alternative care and adopted children, since information on the mother would not have been available.

Table 5.5 Cross-sectional analysis of alternative care settings

Age		Number (%) in alternative care	Institutional care n (%)	Fostered n (%)	Other relative n (%)	Adopted n (%)
3 months	(n=1001)	101 (10)	52 (51)	25 (25)	18 (18)	6 (6)
2 years*	(n=539)	127 (24)	11 (9)	22 (17)	60 (47)	34 (27)
5 years*	(n=231)	88 (38)	2 (2)	15 (17)	46 (53)	25 (28)
			$\chi^2_{trend}=72.5$ $p<0.02$	$\chi^2_{trend}=1.86$ $p=0.17$	$\chi^2_{trend}=24.3$ $p<0.02$	$\chi^2_{trend}=15.2$ $p<0.02$

* ± 2 months

Table 5.6 **Pattern of alternative care by maternal characteristics**

	Total	History of alternative care	Ever with other relatives	Adopted	Ever fostered	Ever in institutional care
Continent of origin (n=1088)						
Europe	903	315 (35)	185 (59)	57 (18)	103 (33)	92 (29)
Outside Europe*	185*	20 (11)	6 (30)	5 (25)	9 (45)	10 (50)
			p<0.02	*ns*	*ns*	*ns*
Injecting drug use (n=1099)						
Never IDU	384	42 (11)	20 (48)	6 (14)	14 (33)	14 (33)
Ex IDU	221	48 (22)	31 (65)	5 (10)	14 (29)	7 (15)
Current IDU	494	249 (50)	142 (57)	53 (21)	86 (35)	82 (33)
			ns	*ns*	*ns*	*p=0.04*
Marital status (n=941)						
Single/divorced/widowed	342	144 (42)	76 (53)	34 (24)	44 (31)	56 (39)
Married / cohabiting	639	170 (27)	109 (64)	26 (15)	56 (33)	33 (19)
			p=0.04	*ns*	*ns*	*p<0.02*

N.B. A child may appear in more than one care setting
* 142 from sub-Saharan Africa

5.4. Hospital in-patient service use

This section uses data on 1 189 children enrolled in the 10 paediatric centres of the ECS by January 1997 (Table 5.7).

Postnatal period

Children born to HIV-infected women might be expected to have a higher in-patient service use in the immediate postnatal period than the general child population, partly because of the high prevalence of drug use by HIV-infected pregnant women, which could be associated with adverse effects on the fetus and newborn, including prematurity and drug withdrawal symptoms (Maas *et al,* 1990; Nair *et al,* 1994; Boer *et al,* 1994). Furthermore, the social, economic and psychological pressures facing HIV-infected pregnant women may result in delayed discharge for psycho-social reasons and may also sometimes lead to infant abandonment, as in the cases of "boarder babies" in New York (Hegarty *et al,* 1988).

Table 5.7 Infection status and average length of follow-up of children (n=1189)

Infection status	n	mean length of follow-up
Infected	151	50 months
Uninfected	811	45 months
Indeterminate infection status	227	7 months

Seven newborns aged between one and 20 days died during their postnatal hospital stay, at a rate of six per 1000 livebirths, which is a slightly higher than the neonatal death rate in the UK, at four to five per 1000 (Woodroffe *et al,* 1993). The deaths were associated with severe prematurity and unlikely to be related to HIV infection in the infant. A further 133 children remained as in-patients after delivery beyond the routine post-partum stay, of whom 23 (17%) were later identified as HIV-infected and 85 (64%) as uninfected, with the remaining 25 having indeterminate infection status at their most recent follow-up visit. Thus more than one in ten children in the study remained in hospital postnatally beyond the normal period of discharge.

Table 5.8 shows the reasons for these postnatal stays. Overall, drug withdrawal was cited as the single or a contributing reason for the postnatal stay in 64 cases, that is in nearly half. There was a social reason behind the delayed discharge in 41 (31%) cases, although in nearly half of these there was the additional problem of prematurity and/or drug withdrawal. A total of 35 (85%) of these children did not go home to live with their mother or father at all, and their discharge had been delayed while an alternative care placement (e.g. foster care, care by another relative and adoption) was arranged. Of the six children who eventually went home to live with their parent(s), two had stayed in hospital because maternal illness prevented an earlier discharge and the remainder because of a combination of medical and social reasons.

Information on the duration of the post-partum stay was available for 93 (70%) of the 133 children. The median was 23 days and length of stay varied according to the reason for delayed discharge, with stays for infections or conditions including jaundice or hernia surgery lasting only a half to a third as long as those for prematurity and/or drug

withdrawal. The proportion of children with delayed postnatal discharge declined over time, from 18% in 1988-9 to 12% in 1994-5 (χ^2_{trend}, p=0.02), although only amongst uninfected children. Mean length of stay also significantly declined, from 67 days (± 63) in 1986-7 to 39 days (±34) in 1992-3 and 22 days (± 12) in 1994-5 (p<0.02).

Table 5.8 Postnatal hospital stays: diagnoses and lengths of stay

Reason for stay	Children n (%)	Length of stay* (range)	Length of stay* (mean)
prematurity**	26 (20)	2-87 days	23 days
prematurity and drug withdrawal	11 (8)	16-66 days	29 days
drug withdrawal#	39 (29)	6-55 days	28 days
infections	9 (7)	3-23 days	10 days
social and prematurity and/or drug withdrawal	20 (15)	14-370 days	99 days
social	21 (16)	5-250 days	55 days
miscellaneous$^{\Psi}$	7 (5)	1-12 days	7 days
	133 (100)	1-370 days	41 days

* available for 93 (70%) children
** 4 with infections, 1 with congenital dislocation of the hip
# 8 with infections, 2 with infection and hernia
$^{\Psi}$ congenital dislocation of the hip, blood transfusion, jaundice (2), zidovudine therapy, neonatal haemolytic syndrome, thrombocytopenia.

Uninfected children

Nearly a quarter (198, 24%) of the 811 uninfected children (with an average age of four years) had been admitted to hospital, on a total of 292 occasions (Table 5.9). From life table analysis, an estimated 17% of uninfected children will have been admitted to hospital by age 12 months, increasing to 22% and 30% by 24 and 60 months respectively. Each uninfected child with a history of hospital admission had been admitted on average 1.47 times, with a maximum of 10 admissions (of a child with cystic fibrosis). Most (179/292, 61%) admissions were for infections and the most frequent primary discharge diagnoses in the first 18 months of life (n=136) were bronchiolitis (29 admissions), gastroenteritis (22 admissions) and pneumonia (15 admissions). Thirty-seven (13%) admissions were for social reasons, 31 (84%) of which took place in the first year of life: parental drug use and illness of the mother were the most common specific reasons given for these stays, although frequently only a general reason was specified for the discharge diagnosis (e.g. "family problems" or "social indication").

Table 5.9 Hospital admissions, excluding post-partum stays

Current status	Children n	History of hospitalisation n (%)	Admissions n	Admissions per child	Admission rate (per child-year)
Uninfected	811	198 (24)	292	0.36	0.10
Infected	151	100 (61)	302	2.0	0.48

Mean length of stay declined from 26 days in 1988 to 2.5 days in 1995 ($p<0.02$). One child remained in hospital for 129 days in 1993, after a road accident. Although less than a fifth of admissions were for social reasons, these tended to last longer than other admissions (average lengths of stay of 32 and 10 days respectively), and accounted for nearly a third of all inpatient days beyond the postnatal period (1 193 / 3 792; 31%). The percentage of days spent as in-patients by uninfected children was highest in the first year of life at 1.0% and declined to extremely low levels in children aged two years or more (approximately 0.1%).

Infected children

Of the 151 infected children, 100 (66%) had been hospitalised on a total of 302 occasions (excluding the postnatal period) (Table 5.9). The maximum number of admissions per child was 14. It is estimated from life table analysis that 48% of infected children will have been admitted to hospital by 12 months of age, rising to 58% and 73% by 24 and 60 months of age respectively, that is, between two and three times the rate for uninfected children. Table 5.10 shows the number of admissions by primary discharge diagnosis and timing of diagnosis of HIV infection and AIDS. Overall, 70% (210/302) admissions were for infections, most commonly, pneumonia (67 (22%) admissions) and gastroenteritis (36 (12%) admissions).

Using life table analysis and the age-specific hospitalisation rates in the ECS, it is estimated that 100 infected children would have spent just over 4 000 days in hospital by their fifth birthday (Table 5.11). The percentage time spent in hospital by infected children was highest in the first year of life and children with AIDS contributed the highest proportion of hospital-days, at all ages (Figure 5.2).

Table 5.10 Admissions of infected children by primary discharge diagnosis and timing of admission (excluding post-partum stays)

Discharge diagnosis	Before diagnosis of HIV infection	After diagnosis of HIV infection	
		Pre-AIDS diagnosis	At/post-AIDS diagnosis
	n (%)	n (%)	n (%)
Fever, failure to thrive	5 (18)	17 (12)	18 (14)
Infections:			
pneumonia	2 (7)	27 (19)	38 (29)
diarrhoea/gastroenteritis	8 (29)	17 (12)	11 (8)
URTI	6 (21)	1 (0.01)	3 (2)
bronchiolitis	1 (4)	6 (4)	0
CMV	0	0	6 (5)
other	2 (7)	48 (34)	33 (25)
Total infections	[19] (68)	[99] (69)	[92] (70)
Social reasons	2 (7)	10 (7)	4 (3)
Assessments*	0	4 (3)	12 (9)
Miscellaneous	2 (7)	13 (9)	6 (5)
TOTAL	28 (100)	143 (100)	131 (100)

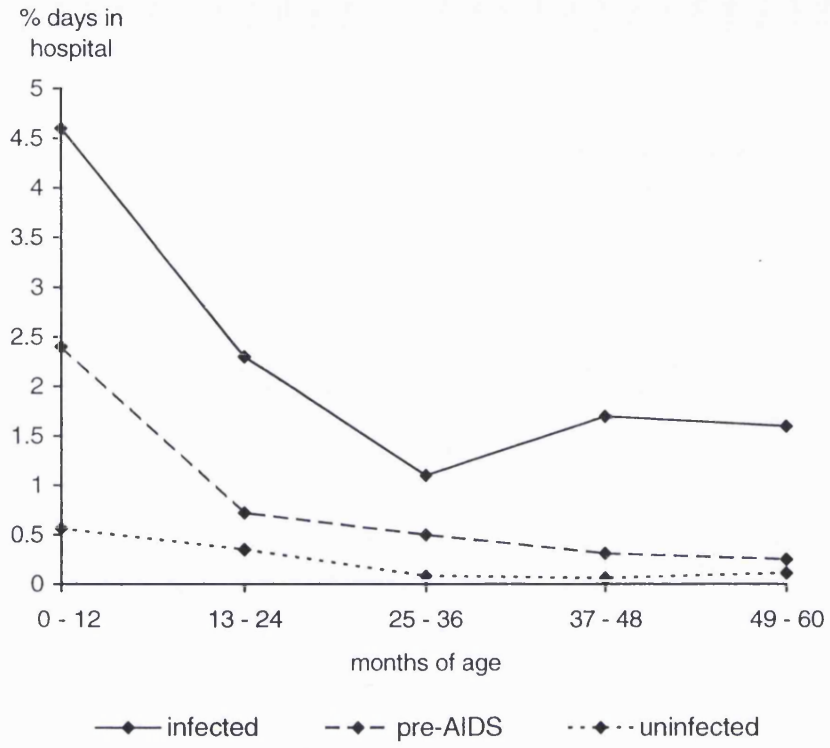
* neurological and haematological

Table 5.11 Estimated burden on inpatient hospital services in the first five years of life per 100 infected children

Age	% time in hospital	Child-years lived	Total days in hospital*	Cumulative total days in hospital
0 - 6 months	7.8	49.3	1 404	1 404
6 - 12 months	4.1	45.8	685	2 089
13 - 24 months	2.5	88.7	809	2 898
25 - 36 months	1.3	84.8	402	3 300
37 - 48 months	1.7	77.3	480	3 780
49 - 60 months	1.6	71.1	415	4 195

* % time in hospital x child-years x 365

Figure 5.2 Percentage days spent in hospital by age (medical admissions)



Despite there being only 54 children with AIDS (36% of infected children) and a median survival following an AIDS diagnosis of approximately 2 years (French Pediatric HIV Infection Study Group and European Collaborative Study, 1997; European Collaborative Study, 1994b), 59% (3,304) of the 5,604 days spent in hospital were by children with AIDS. PCP was the most important AIDS indicator disease in this cohort (Table 5.12) and a third of children with AIDS had never been admitted to hospital prior to their AIDS diagnosis, or were diagnosed with AIDS during their first hospitalisation.

Table 5.12 AIDS indicator diseases and prior hospitalisation (excluding postnatal stays)

AIDS indicator disease	Children n (%)	Number (%) hospitalised prior to AIDS diagnosis
PCP*	17 (32)	10 (59)
Encephalopathy#	10 (18)	7 (70)
LIP	4 (7)	3 (75)
Recurrent bacterial infections	9 (17)	8 (89)
Wasting syndrome	2 (4)	1 (50)
Other opportunistic infections	12 (22)	8 (67)
TOTAL	54 (100)	37 (69)

* 3 also with CMV; 1 with encephalopathy

1 also with cerebral toxoplasmosis; 1 also with recurrent bacterial infections

Hospital admissions ranged from one to 307 days in length, and average length of stay declined from a high of 30 days in 1988 to 8.5 days in 1995 ($p<0.02$). Mean length of stay for admissions taking place prior to AIDS was 18 (±38) days compared to 25 (±40) days for those at or after AIDS diagnosis, ($p=0.06$). Although there were only 16 social admissions, these accounted for 15% (841/5604) of the total number of days in hospital

(excluding the post-partum period). Day admissions for intravenous immunoglobulin (IVIG) therapy were not classified as hospital admissions in the above analyses. Seventy children received IVIG therapy, starting therapy on average at 15 months of age (range = 1 to 61 months). However, 77% started therapy before 1992 and only four children have started IVIG therapy since 1993 (Mofenson *et al,* 1994; Mofenson *et al,* 1993).

Children with indeterminate infection status

Of the 227 children with indeterminate infection status at their last follow-up visit, 18 (8%) had been admitted to hospital on a total of 22 occasions, excluding post-partum stays. Most (12, 55%) admissions were for infections and the overall mean length of stay was 11.5 days (range, 1 to 59 days).

Determinants of hospital admission

Risk of hospital admission varied by year, centre and child's age. Two multivariate analyses were carried out to determine the independent effects of child and maternal characteristics on the likelihood of a child being admitted to hospital for medical and for non-medical reasons (Table 5.13). As expected, the most important influence on hospitalisation both for medical and for non-medical reasons was infection status of the child. Maternal clinical status was significantly associated with non-medical but not with medical admissions. No association was found between child's race, maternal IDU and marital status and hospitalisation, although children whose mothers were using injecting drugs at the time of enrollment were slightly more likely to be admitted to hospital for non-medical reasons.

Table 5.13 Multivariate analysis of hospital admission*, controlling for age, centre and year of birth (n=775)

	n (%)	**medical admissions** adjusted OR (95% CI)	**non-medical admissions** adjusted OR (95% CI)
Infection status of child			
uninfected	655 (84)	1.00	1.00
infected	120 (16)	4.73 (3.36-6.66) $p<0.02$	4.29 (1.72-10.7) $p<0.02$
Race			
white	682 (88)	1.00	1.00
black	62 (8)	1.09 (0.55-2.15) $p=0.8$	1.41 (0.41-4.91) $p=0.6$
other	31 (4)	1.02 (0.48-2.18) $p=0.9$	0.18 (0.01-2.17) $p=0.2$
Maternal IDU#			
never	215 (28)	1.00	1.00
ex-user	174 (23)	0.74 (0.45-1.20) $p=0.2$	0.32 (0.06-1.84) $p=0.2$
current user	386 (50)	1.20 (0.81-1.78) $p=0.4$	2.79 (0.83-9.43) $p=0.1$
Maternal marital status#			
single/divorced/widowed	233 (30)	1.00	1.00
married/cohabiting	542 (70)	1.25 (0.90-1.75) $p=0.2$	0.62 (0.26-1.47) $p=0.3$
Maternal clinical status#			
asymptomatic	755 (97)	1.00	1.00
symptomatic**	20 (3)	1.23 (0.81-1.78) $p=0.6$	12.9 (2.50-67.1) $p<0.02$

* Hospital admissions exclude immediate postpartum stays.

at the time of enrollment

** CDC Stage IV

5.5 Key points

- in the ECS, most mothers were white, married or cohabiting and primiparous
- two-thirds of mothers had a history of injecting drug use
- 16% were not living in their country of birth, of whom 67% were born in sub-Saharan Africa (mainly Zaire and Uganda)

- 70% of children had always been cared for by their parents in their first four years of life, but by age eight, an estimated 60% will have lived in alternative care
- nearly a quarter of children in alternative care had never lived with a parent
- a child's infection status did not influence the likelihood of living in alternative care
- maternal IDU, single parenthood and maternal clinical status were the main reasons necessitating alternative care
- the extended family was the predominant source of alternative care, especially in Southern Europe

- one in ten infants had delayed postnatal discharge from hospital, often associated with social issues
- an estimated 48% of infected children will have been admitted to hospital by 12 months of age, compared to 17% of uninfected children
- infected children were four times more likely to be admitted to hospital than uninfected children of the same age
- children with symptomatic mothers were 13 times more likely to have a non-medical admission than other children
- nearly 60% of the total in-patient days of infected children occurred after AIDS diagnosis

Chapter 6 Results: Services for families with children affected by HIV

"I am satisfied up to now with the service at the children's hospital"
(infected mother of an infected child)

"Ten years ago when I first had contact with the centre I now use, the services locally were very poor, which is why I chose to go further to find specialist services. My confidence in the centre means I am reluctant to consider nearer facilities even if they exist and will carry the additional costs / time / effort for as long as I can to ensure my daughter has the best care by staff she (and I) know and trust"
(adoptive mother of an infected child)

6.1. Introduction

Families affected by HIV often present with complex health, social, psychological and practical needs, which change over time with the progression of disease in the child and/or the parent. This chapter describes the provision of medical and psycho-social services for families affected by HIV in Europe and the characteristics of the service-users themselves, particularly in terms of their uptake of and satisfaction with current service provision. Data were collected in two complementary cross-sectional surveys, one among service-providers and another among service-users (see Chapter 3).

6.2. Medical and psycho-social service provision for children and their carers: results from the service-provider survey

Centre background

All 15 centres surveyed were based in public hospitals, including two children's hospitals (Zurich and London) and most (93%) were also university hospitals. All had extensive experience of caring for families affected by HIV, although the number of HIV-infected and affected children seen as out-patients per week varied, with centres in the Southern

European countries tending to see more children (Table 6.1). HIV-infected children and those perinatally exposed to HIV most commonly received their out-patient care in the general paediatrics out-patient clinics/policlinic or day hospital (8/15, 53%). However, four (27%) centres had specialist paediatric HIV clinics (in one case, a family clinic) and in the remaining three centres, HIV-infected and exposed children were seen in paediatric infectious diseases clinics.

Table 6.1 Approximate number of HIV-infected and affected children seen per week, by centre

Number of children	n (%)	Centres
≤ 10	6 (40)	Bologna, Stockholm (2), Zurich, Edinburgh, Amsterdam
11 - 20	6 (40)	Barcelona, Lisbon, Padua, London, Berlin, Brussels
21 - 35	3 (20)	Milan, Madrid, Brescia

Out-patient care

Referrals

Most children attending the paediatric HIV service had been referred from the hospital's obstetric unit (excepting the two children's hospitals, which received referrals from obstetric units of neighbouring hospitals), with some also referred from other paediatric

units and the adult HIV service. Although other hospitals were the next most important source of referrals, community physicians, non-governmental organisations (NGOs), refugee camps and private nursing homes also occasionally made referrals. In most (14, 93%) centres, parents and other primary carers could also bring children to the clinic without referral from a health or social care professional.

Access to care

Although only two of the 15 out-patient paediatric HIV clinics were routinely open outside working hours (Brussels and Lisbon), 24 hour emergency care was available in all centres, including eight (53%) where a clinical member of the paediatric HIV team was always on call for emergencies. Some families travelled long distances in order to attend the clinic, mainly because of a lack of appropriate local services or a preference for the study centre over local centres, because of its status as a referral centre and expertise. Other reasons included avoidance of local services because of concerns regarding confidentiality and a desire for continuity of care among families who had moved away from the vicinity of the study centre. A contribution towards travel costs was provided in 12 centres; in addition, in one centre a voluntary organisation provided families with transport to hospital.

Clinic staff

The paediatric HIV out-patient service was run by a general paediatrician in seven (47%) centres, by a paediatric infectious diseases specialist in five (33%) and by paediatricians with a specialisation in nephrology, oncology or neonatology in the remaining centres. The median number of full-time equivalent paediatricians working at the out-patient

clinic was two (range, one to four) and this was not associated with the size of the centre (in terms of the number of children seen per week).

Thirteen (87%) centres had at least one psycho-social professional routinely available to see HIV-affected families attending the clinic (including nine where staff worked exclusively in HIV); in one of the remaining centres, social workers only saw families of admitted children. Most centres had a social worker routinely available at the clinic and about half (8) had both a social worker and a psychologist (Table 6.2). There was a trend towards the largest centres having the fewest psycho-social staff, although this did not reach statistical significance. In addition, three centres (all in Italy) routinely had at least one volunteer (usually from a NGO specialising in children and HIV) at the clinic, to provide support and information to parents and carers and in one centre, to help co-ordinate appointments.

Organisation of clinical and psycho-social follow-up

Children could be seen by the same doctor at each appointment if requested in all centres where there was more than one paediatrician on the paediatric HIV team. A regular medical appointment schedule for children perinatally exposed to HIV and other infected children in follow-up was a universal finding. Nine (60%) centres actively reminded parents and carers of forthcoming appointments and 11 (73%) centres contacted parents and carers if appointments were missed (in both cases, by telephone or letter). Other ways of maintaining contact with children in follow-up were liaison with community-based medical and /or psycho-social staff working with the family outside the hospital (5 centres), home visits (3 centres), running a local family HIV clinic outside the main

centre (1 centre) and as a last resort in cases of consistent non-attendance, contact with legal authorities (1 centre).

Table 6.2 Psycho-social professionals routinely available at the paediatric HIV out-patient clinics

Psycho-social professional	Centres n (%)
social worker	13 (87)
child psychologist	8 (53)
neuropsychiatrist	5 (33)
play therapist	3 (20)
child neurologist	1 (7)
social nurse	1 (7)
health visitor	1 (7)
pedagogist	1 (7)
clinical nurse specialist	1 (7)

Two centres had no clinic-based psycho-social professionals and families therefore had to be referred by the paediatrician if psychological or social services were required; there was no routine psycho-social assessment of families in these centres. Most of the remaining centres had a policy of encouraging families to see a psycho-social staff member at least once. The organisation of initial contact between families and clinic-based psycho-social staff varied by centre and according to the characteristics of the family, especially with regard to the timing of HIV diagnosis in the family. For example,

with some families, first contact with a psycho-social professional would occur in pregnancy or in the immediate postnatal period, while with others this would not take place until after the first appointment with the paediatrician.

Similarly, organisation and frequency of subsequent contact with psycho-social professionals varied: in three (20%) centres, the policy was for regular contact to continue only with certain families, for example, those with particular needs, or with infected children. Organisation of follow-up included a regular appointment system (usually in tandem with the clinical appointment), routine availability of a psycho-social professional at clinic times and home visits. In Edinburgh, the psycho-social team (consisting of a specialist social worker and specialist health visitor) was entirely community-based, with all contact taking place in families' homes.

Problems maintaining psycho-social follow-up of families were reported from 13 (87%) centres and the responding psycho-social professionals were asked to suggest reasons for this. In some cases parents and carers did not want psycho-social follow-up because they felt no need for the available services and support at that particular time. However, a variety of other reasons for families' lack of contact or resistance to follow-up were suggested, including parents' avoidant coping styles, previous negative experiences with psycho-social staff (especially true for drug-users), distrust and/or fear that their children will be "taken away" and logistical problems of access to the clinic.

Centres had different strategies regarding follow-up of perinatally-exposed children after they were diagnosed as uninfected: 10 (67%) centres, which were all participating in cohort studies of children born to HIV-infected mothers, continued to invite uninfected

children for follow-up appointments on an annual basis; in four of these centres, there was a limited duration of follow-up of uninfected children, lasting for one to six years after seroreversion. However, it was reported that in some cases it was the parents' choice to transfer their child's care to community paediatricians or general practitioners. In a further centre, although the clinical care of uninfected children was transferred to the community, the clinic social worker continued to maintain contact with as many families as possible. In the remaining four centres, seroreverters were referred to community-based care as soon as they were identified as uninfected; in one of these centres, it was reported that follow-up had to be terminated earlier than they would like, because of the pressure on the clinic by the increasing number of children being referred.

Information provision

Paediatricians tended to provide parents and carers with general clinic information (e.g. the follow-up schedule and who to contact in an emergency) and HIV-specific information (e.g. routes of and prevention of transmission), since they usually had first (and most frequent) contact with families. Psycho-social staff (mainly social workers) were the predominant source of information on community health and social services, including support groups, although this information was sometimes provided by other team members. In all centres, parents and carers were encouraged to telephone the clinic with questions or problems.

HIV-infected women were routinely seen antenatally by a member of the paediatric HIV team in 11 (73%) centres, primarily to provide information on paediatric HIV infection and the services available after delivery; this included the two children's hospitals, whereby visits were made to the obstetric units of neighbouring hospitals. In more than

half (six) of these centres, both a paediatrician and a psycho-social professional made these visits, usually at the same time.

Written information on HIV/AIDS for parents and carers was provided in nine (60%) centres, with four translating the information into alternative languages. Information content was variable, ranging from clinical trial information sheets to a comprehensive pack covering clinic services, voluntary organisations and HIV-specific literature. In four (27%) centres, books or leaflets specifically written for children were available at the clinic. Paediatricians were asked how often parents and carers request written information: eight (53%) reported never, five (33%) occasional, with only two (13%) reporting frequent requests.

Psycho-social services and activities

Information on social circumstances of families attending the clinic, including employment, housing and financial status, was collected in all centres, mainly by social workers or other psycho-social professionals, but sometimes by paediatricians, depending on the relative timing of clinical and psycho-social appointments and whether or not families were routinely seen by psycho-social staff. Social workers (and sometimes other clinic staff) were usually available to provide help regarding housing and eligibility for welfare benefits or other financial support.

Developmental assessments of HIV-infected children were routinely carried out in 13 (87%) centres, including eight where uninfected children were also routinely assessed; the team members primarily responsible for this were child psychologists, neurologists

and neuropsychiatrists. It was reported from 14 (93%) centres that support and advice for parents and carers was available if their children had behavioural or psychological problems; ten of these centres also provided interventions such as counselling or therapy for children with such problems. In 14 centres, support was provided to parents and carers regarding disclosure of their or their child's infection status (although in one this was only on request) and in the remaining centre such support was likely to be available in the future. Bereavement counselling for children and parents or carers was provided in 11 (73%) centres; one clinic was planning to provide such counselling in the future, as this was currently provided by the internal medicine department. In one of the remaining three centres, no bereavement counselling was provided because this was being carried out in the community by a HIV/AIDS NGO.

Support regarding **planning and organisation of current and future social care** of HIV-infected and affected children was provided in 14 (93%) centres (mainly by psycho-social staff); in the one centre (Madrid) where no such support was provided, there was no psycho-social professional routinely available at the clinic. Helping to arrange children's social care involved talking with parents about future options for the social care of their children (13 centres), talking with children about their preferences and experiences, depending on the age of the child and parental consent (12), helping parents to contact appropriate services (e.g. lawyers, voluntary organisations, government agencies etc.) (12) and advising child welfare agencies (7). Other aspects of social care in which clinic staff were involved included providing information on family background to child welfare services, writing up parental requests for the future care of their children and helping parents to understand the legal situation.

In 11 (73%) centres, participation in the organisation of social care of HIV-affected children also involved occasional contact with the legal authorities. This included informing the authorities of cases of neglect, helping to arrange guardianships within the extended family, providing information for custody or divorce cases and liaising with the courts in immigration cases. In one of the four centres reporting no contact with the legal authorities, the clinic staff liaised with solicitors and legal advisors rather than directly with the courts.

Dental service

In 10 (67%) centres, a dental service was provided for HIV-infected children either in the clinic itself or elsewhere in the hospital; in an additional centre, children were referred to another hospital or provided with a list of recommended dentists in the local area. No information about where to obtain dental care was provided to parents or carers in the remaining four (27%) centres.

Support groups

Two clinics organised regular support groups for parents and carers of HIV-affected children: in Berlin, there was a monthly breakfast group meeting, organised jointly with a foster care organisation with a special interest in HIV/AIDS, and a regular baby group; in Zurich, the support group involved a psychologist from a voluntary organisation, AIDShelf, and extended to HIV-affected children themselves, with older children encouraged to contact and support their peers where appropriate. Attempts to organise a regular support group were reported by four centres (Edinburgh, Huddinge, Danderyd and London) and in one case, multiple attempts had been made over the years. Lack of attendance was the main reason for failure of support groups in these centres, with

responders reporting that a regular support group was too structured to suit most parents and carers, who preferred more informal support. Other barriers to the success of support groups reported included problems with the venue (parents and carers wanted to meet in a neutral setting, rather than at the hospital) and lack of staff and time to organise the group, which needed to be held outside normal working hours.

Adult HIV services

One children's hospital (London) had a family out-patient clinic one morning per week, where HIV-infected parents could obtain care at the same time as their children, with an adult physician, adult HIV nurse and health advisor available. Regarding services for HIV-infected parents in the remaining centres, there were adult HIV clinics at the same hospital (not necessarily on the same site) in 11 centres and the paediatric and adult teams tried to co-ordinate clinic appointments for families. Of the three hospitals lacking adult HIV services, one was a children's hospital and had close contact with the adult HIV clinic in a neighbouring hospital.

Facilities

All 15 centres had private consultation rooms, with 14 (93%) also providing a waiting room. With regard to play facilities, all centres provided toys and games, 13 (87%) had an indoor play area, one an outdoor play area only and eight (53%) had play assistants. Other facilities provided by some centres included free food, free nappies, videos and television and child-friendly consultation rooms.

In-patient care

The out-patient team always participated in the in-patient care of children in follow-up. HIV-infected children were usually (in 11 centres) admitted to general paediatric wards, with one centre having dedicated HIV beds on a general paediatric ward. In three centres, HIV-infected children were cared for in paediatric infectious diseases wards and in the remaining centre, there was a special paediatric HIV ward with six beds, also used for day hospital cases. Two centres had family units where sick parents and sick children could be admitted as in-patients together and a further two centres had in the past admitted ill children with their parents to an adult ward; one paediatrician reported that this could happen in theory, but there had been no experience of this as yet.

Support for hospital-based staff

In 11 (73%) centres, a member of the psycho-social team provided psychological support for medical and nursing staff working with families affected by HIV. Support was largely provided on an informal, ad hoc basis, especially with regard to medical staff, although formal support (seminars for nursing staff, regular staff support groups, bereavement counselling) was reported from three centres. Two centres reported attempts at regular staff support groups, which had failed because support was generally only needed at certain times (e.g. when a child dies) and because it was difficult to get staff to attend.

Community-based services

Medical care

Three paediatricians reported that all their out-patients also received medical care from community-based physicians (e.g. general practitioners, community paediatricians); another, who was uncertain what happened in practice, reported that this should be so in

theory. A variable proportion of clinic attenders were reported to receive medical care in the community in the remaining 11 centres. The policy for continuity of care between hospital and community varied between centres, with a letter sent to the child's community physician after every follow-up clinic visit in some, while contact was only be made in the event of a problem in others. A number of respondents emphasised the need to gain parental consent before contacting the community doctor.

Some form of home-based paramedical care such as home nursing, parenteral nutrition and physical therapy was available for infected children in 11 (73%) centres. Such services were most frequently provided by the government or health insurance, but NGOs also provided some services in five centres. In no centre did all infected children receive home-based paramedical care and respondents were asked to suggest reasons why this was: apart from the fact that some infected children do not need such care, the most common reason was a lack of services (6 responses), although parental preference for hospital-based care and/or concern regarding the experience of home care paramedics (4 responses), non-conducive home environments (2 responses) and parental concerns regarding confidentiality (2 responses) were also suggested. Home-based terminal care was available for infected children from 10 (67%) centres, although in one of these, this was an adult service which children could use. With regard to hospice terminal care for infected children, there was a children's hospice in the local area of only two centres, although plans for a children's hospice near a further centre were reported.

Psycho-social care

In three (20%) centres, families were able to routinely obtain support at home from hospital-based psycho-social staff, with psycho-social staff making only occasional home

visits in 10 centres. Community-based psychologists and social workers specialising in HIV were available in the local area of six (40%) centres, with specialist social workers more common than psychologists (four versus two centres).

Other services

Child care services

In most centres, clinic staff provided support and information to parents and carers regarding both the current and future social care of their children, if required [see earlier section]. Responding psycho-social professionals in 14 centres were also asked about the provision of respite child care services for families attending the clinic and the existence of any additional financial support for parents and carers of HIV-infected. In cases where alternative care of HIV-affected children was urgently and unexpectedly required, for example, as a result of parents having an unplanned hospital admission, the response was usually to try to place the child with family, friends or neighbours in the first instance. However, if care was not available from the informal support network, alternatives included respite foster care (10 centres), temporary admission of the child to a residential children's home (9 centres) or to hospital (12 centres), although the residential home and hospital options tended to be used rarely. In one centre, although in principle foster care was available for HIV-affected children, the respondent commented that it took too long to organise in emergencies.

Respite services available to give parents and carers a break from full-time care of HIV-affected children were provided by the clinic, as well as NGOs and the state. Information on the type of respite services provided was available from 14 centres (no data from Madrid); this included free holidays (paid for by voluntary donations) (9 centres),

subsidized holidays (1 centre), subsidized creche or day nursery (1 centre), supported accommodation (1 centre), kindergarten for HIV-infected children (1 centre), home visits by volunteers (1 centre) and respite fostering (1 centre).

Welfare provisions

In four countries represented in the survey (Belgium, Spain, Italy and the UK), it was reported that parents and carers of HIV-infected children (usually only those with symptomatic disease) can claim for additional welfare benefits from the government because of the HIV-infection, although this is often only available to families with low income. In all nine countries surveyed, foster carers of HIV-infected children receive payment or an allowance, although in seven of these, all foster carers receive financial remuneration, regardless of any special needs that the child in care might have (such as HIV-infection). However, with regard to family foster-carers, in three countries a relative (e.g. a grandmother) acting as the primary carer of a child could not claim the same benefits as a non-family foster carer, with family foster carers' eligibility for financial support dependent on formal registration in a further three.

School

In eight of the nine countries represented in the survey, parents or carers of HIV-infected children attending school have no legal obligation to inform the school authorities of the HIV infection, while in the remaining country (Spain), this is a recommendation rather than law. National guidelines on HIV infection and schools have been developed in five countries (UK, Italy, Germany, Switzerland, Belgium) and in three of the four countries with no national guidelines there is local education authority guidance (Sweden, Spain, The Netherlands). These guidelines address training for teaching staff and HIV education

programmes for pupils. Legislation declaring that HIV-infected children should not be excluded from access to school nor participation in any normal school activities exist in seven countries, with guidelines rather than legislation existing in the remaining countries (Belgium and Spain).

With regard to individual centres, although in 14 centres a member of the clinic team was available to advise and support schools in the area with regard to their HIV education programmes if requested, only two (13%) clinics were routinely involved in such programmes. In four centres (Milan, Padua, Berlin and Edinburgh), clinic staff (usually the paediatricians) often provided information to teachers and/or trained teachers to talk to children about HIV/AIDS. Clinic staff were reported to have occasionally visited schools to talk to children about HIV/AIDS in four centres, although in one, this was only in cases where there was an HIV-infected child in the class. With regard to the schooling of infected children in follow-up at the clinic, 11 (73%) centres were able to offer support and advice to teachers who had been informed of the situation by the parents.

6.3. Service-user survey: family characteristics

There were a total of 182 respondents, from 10 centres in seven countries (Table 6.3). With regard to the five centres which were not able to participate in the service-user survey for practical reasons (Stockholm (2), Madrid, Brussels, Brescia), some information on the type of families cared for in these centres was available because of their participation in the ECS. It was therefore possible to investigate possible biases arising from their non-inclusion. In these five centres a cross-section of the types of families affected by HIV in Europe are seen: in the three northern European centres,

children with one or both parents from sub-Saharan Africa (between 75 and 90%) predominate, while in Madrid and Brescia, most (between 64 and 100%) children have IDU parents (mostly former IDUs). As the service-user survey encompassed centres with both types of caseload, it is therefore likely that many of the findings and conclusions will also be applicable to the non-responding centres. However, the hospital in Madrid is very large, with a heavy case-load; there is no clinic-based psycho-social worker and clinical services for HIV-infected women are somewhat marginalised.

Table 6.3 Number (%) of respondents, by geographic location (n=182)

Country	City / cities	N (%)
Germany	Berlin	18 (10)
Italy	Bologna, Padua, Milan	69 (38)
The Netherlands	Amsterdam	12 (7)
Portugal	Lisbon	13 (7)
Spain	Barcelona	19 (10)
Switzerland	Zurich	22 (12)
United Kingdom	London, Edinburgh	29 (16)

Nearly three-quarters (132) were the birth parents of the HIV-affected child in their care (henceforth to be referred to simply as parents) and most were female (Table 6.4). Most (150, 82%) respondents were looking after one HIV-affected child, but 23 (13%) were caring for two, 8 (4%) for three and one for six, giving a total of 226 children. A quarter

of the children were aged two years or less (range, 2 days to 19 years) (Figure 6.1). Forty-nine of the 50 alternative carers were caring for one child and one was looking after twins; these children had been living with their alternative carers for a median of four years (range, 2 months to 11 years) (data not available for six children).

Table 6.4 Carer type

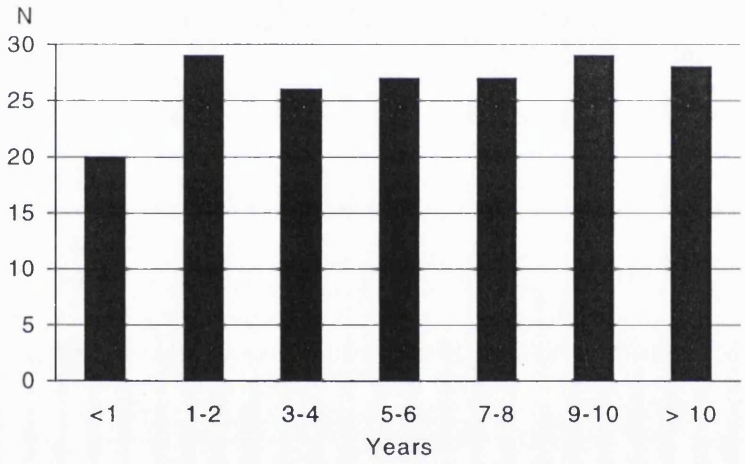
Carer type	N	(%)	% female
Parent	132	(73)	85*
Grandparent	21	(12)	86
Foster carer	14	(8)	64
Adoptive parent	12	(7)	75
Other**	3	(2)	67
Total	182	(100)	83

* gender not known for two parents
** step-father, carer from an institution and aunt

Socio-demographic background Most respondents were aged over 30 years, had been born in Europe and were married or cohabiting (Table 6.5). There were many similarities between the parents in the survey and the women in the ECS, bearing in mind the different timings of the data-collection in relation to the child's birth. A total of 170 (93%) respondents specified their country of birth; three of the remaining 12 respondents reported their continent of origin (Africa) and it was known that a further five were not living in their country of birth. Twenty-one of the 24 respondents from Africa specified their country of birth: Angola (5), Guinea (4), Ghana (3), Uganda (3), Zaire (2), Liberia

(1), Rwanda (1), Guinea Bissau (1) and Sudan (1). The four respondents from the Americas were from Argentina, Venezuela, Brazil and the USA. Overall, a total of 41 (23%) respondents were not living in their country of birth, including eight who were born in Europe. Of the 33 non-Europeans, 22 (67%) had permanent residency status in their current country of residence. The median time lived in the current country of residence was six years (range, 1 to 22 years).

Figure 6.1 Ages of the children in the care of the respondents in the service-user survey



HIV infection in the family

Information on infection status was available for all 132 parents, of whom 121 (92%) were infected. Of the 43 alternative carers with known infection status, one (2%) was infected (a step-father). Overall, two-thirds (122/182) of respondents were known to be HIV-infected, of whom 23 (19%) reported that they were "ill". The median length of time since diagnosis was 5½ years (range, 6 months to 15 years). Infection status was significantly associated with gender, with 76% of females infected compared to 44% of males (χ^2=10.51, p<0.02).

Table 6.5 **Socio-demographic characteristics of the respondents, compared with mothers in the ECS**

	Parents		Alternative carers		Women in the ECS	
	n	(%)	n	(%)	n	(%)
Age						
<25 years	5	(4)	3	(6)	737	(36)
25-29	35	(27)	3	(6)	837	(41)
30-34	61	(47)	3	(6)	379	(19)
35-39	28	(21)	7	(15)	68	(3)
>39	2	(2)	32	(65)	7	(0.3)
		n=131		n=48		n=2028
Marital status						
single	17	(13)	3	(6)	246	(27)
married	48	(37)	29	(62)	380	(42)
cohabiting	39	(30)	4	(9)	235	(26)
divorced/separated	11	(8)	6	(13)	}	
widowed	15	(12)	5	(11)	} 48	(5)
		n=130		n=47		n=909
Continent of origin						
Europe	97	(78)	48	(98)	1835	(88)
Africa	24	(19)	0		204	(10)
The Americas	3	(2)	1	(2)	32	(2)
Asia & the Middle East					12	(0.6)
		n=124		n=49		n=2083
Employment						
Full-time	25	(19)	13	(27)	information	
Part-time	11	(8)	4	(8)	not	
Not employed	94	(72)	31	(65)	available	
		n=130		n=48		

Mode of acquisition of infection was known for 103 (84%) infected respondents: 55 (53%) had acquired HIV through heterosexual contact (in 60% of cases with an injecting drug using sexual partner), 41 (40%) were injecting drug users (IDUs) and seven (7%) had received contaminated blood or blood products (in four cases in Africa). Of the 19 infected respondents with no information on mode of acquisition, eight had lived in an endemic area (sub-Saharan Africa), although one had first gone to live in Europe in childhood. Infected respondents were significantly more likely to have an infected current partner than non-infected respondents: among those married or cohabiting respondents, 51% had an infected partner compared to 6% of uninfected respondents (χ^2=26.5, p<0.02). Male respondents were slightly more likely to have an infected partner than women, but this did not reach statistical significance.

This survey was biased towards parents and carers of infected children, which was presumably associated with their more frequent contact with the clinics. Of the 226 children, 140 (62%) were HIV-infected, 56 (25%) were uninfected and 30 (13%) had indeterminate or unknown infection status. Most (87, 62%) infected children were reported to be "currently well". There was at least one infected child in 138 (76%) of the 182 families in the survey, with 124 (68%) families having at least one infected parent (Table 6.6). In 80 of the 88 families with both an infected adult and child, information regarding the relative timing of the diagnoses was available: in 12 (15%), the diagnosis of HIV infection in the child had been the first indication of HIV in the family.

Table 6.6 HIV co-infection in the family (n=182)

PARENT OR CARER INFECTION STATUS	INFECTION STATUS OF CHILD / CHILDREN: At least one infected	Indeterminate or unknown	Uninfected
at least 1 infected	88 (48%)	18 (10%)	18 (10%)
(both) uninfected	42 (23%)	2 (1%)	4 (2%)
unknown	8 (4%)	1 (0.5%)	1 (0.5%)

6.4. Service-user survey: service use and satisfaction

Information provision

Service users' views on the importance of information provision

The relative degree to which respondents valued various types of information is shown in Table 6.7, with their additional comments regarding information provision included in Appendix 6.1. Certain aspects of information provision were valued more highly by some groups of respondents than others. The importance of written information significantly varied according to both carer type and immigrant status: significantly more alternative carers than parents considered written information to be very important (61% v. 46%, χ^2=7.64, p=0.05), whereas respondents not living in their country of birth valued written information significantly less than other respondents, with 29% considering it unimportant versus 7% of the other respondents (χ^2=14.8, p=0.02). Alternative carers and lone parents/carers tended to value information on support groups and voluntary organisations more than parents and married/cohabiting respondents respectively, but this

did not reach statistical significance in either case. There were significant differences by centre regarding the importance of both written information ($\chi^2 = 66.7$, $p<0.02$) and information on social services and payments ($\chi^2=43.5$, $p<0.02$), which remained after controlling for centre variation in prevalence of immigrants, single parents and alternative carers.

Table 6.7 Respondents' ratings of the importance of various aspects of information provision

	n	not important	quite important	important	very important
To be kept up to date with my child's health	173	1%	0%	5%	94%
To be provided with information on treatments and clinical trials	173	1%	5%	15%	79%
To receive written information on HIV/AIDS	169	12%	6%	32%	50%
To be provided with information on support groups, voluntary organisations etc.	165	13%	21%	33%	32%
To be helped with obtaining social welfare services and payments	169	12%	7%	23%	59%

Whether or not their clinic currently provided written information significantly influenced respondents' views regarding the importance of written information. Nearly a fifth (14/73) of the respondents from the five centres not providing written information considered it to be unimportant compared to only 6% of those from the five centres where information sheets and leaflets etc. were available (χ^2=12.7, p<0.02).

Telephoning the clinic

A total of 174 (96%) respondents provided information on their level of telephone contact with the clinic, of whom 149 (86%) reported phoning the clinic with questions or problems, including 46 (25%) who telephoned frequently. The 25 (14%) respondents who never telephoned the clinic provided one or more reasons for this: in most (18, 72%) cases there was no perceived need to telephone, although no phone at home and a belief that telephoning the clinic was discouraged were also reported (three responses each). There was no gender difference in the level of telephone contact with the clinic, although infected parents and carers were less likely to phone the clinic than those uninfected (χ^2_{trend}=7.7, p=0.01). Slightly more respondents in frequent telephone contact with the clinic had an infected child (37/46, 80%) than those who phoned less often (76/103, 74%) or not at all (16/25, 64%), but this was not statistically significant.

Service-users' satisfaction with information provision

A third (52/158) of respondents agreed or strongly agreed with the statement "I sometimes feel that I have not been given sufficient information" (Figure 6.2). Satisfaction with the level of information provision was not associated with gender, infection status, caring for a sick child, marital status, immigrant status or carer type, although there was a trend toward parents being less satisfied than alternative carers. The

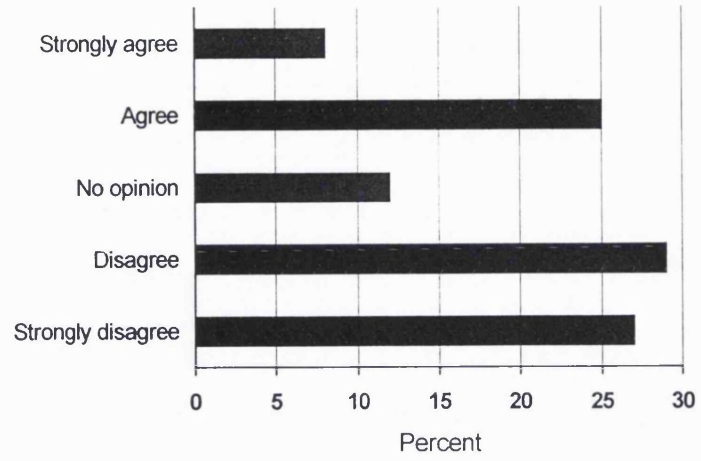
same proportion of respondents were dissatisfied with the level of information provision regarding other services for families affected by HIV, with 48/145 disagreeing or strongly disagreeing with the statement "I am well enough informed about the availability of other services for families affected by HIV (e.g. support groups, voluntary organisations)" (Figure 6.2). Male respondents were more satisfied with this aspect of information provision than women (72% satisfied v. 46% of women; χ^2=8.8, p=0.01). Fifty percent (19/38) of immigrants and refugees were dissatisfied with the provision of information on other services, compared to 27% (29/107) of other respondent (χ^2=7.3, p=0.03). Lone parents were slightly more likely to be dissatisfied, but this did not reach statistical significance.

Disclosure of infection status

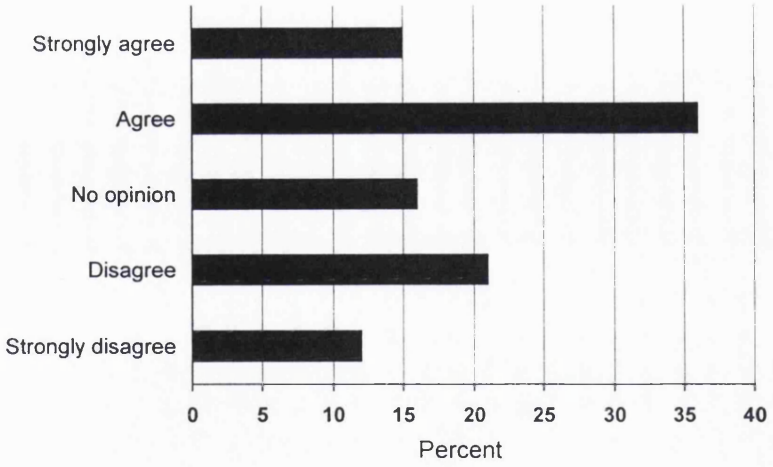
A total of 109 (89%) of infected adults answered the questions relating to disclosure of their own diagnosis to their children. The 12 (11%) adults who had told their children (n=14) that they were HIV-infected had been diagnosed for slightly longer than the 97 who had not disclosed (n=126) (7.0 years versus 6.1 years). The median age of children who had been told of their parents' diagnoses was 10 years (range, 5 to 12 years), compared to two years (range <1 month to 13 years) for children of non-disclosing parents. There was a significant increase in the proportion of children who had been told about their parent's diagnosis with increasing age, with only 9% of children aged between five and nine years having been told, rising to 37% of children aged 10 years or more (χ^2=22.5, p<0.02).

Figure 6.2 Parents' and carers' satisfaction with information provision

"I sometimes feel that I have not been given sufficient information" (n = 158)



"I am well enough informed about the availability of other services for families affected by HIV" (eg support groups, voluntary organisations) (n = 145)



In 122 (88%) of the 138 families with at least one HIV-infected child, information on whether or not the child knew about his or her diagnosis was available. In 22 (18%) families, the child had been told of their diagnosis (of the four families with two infected children, none knew their diagnosis). The median age of the 22 children who had been

told was 10 years (range, 5 to 16 years), while that of the 103 infected children from the remaining 100 families was six years (range, <1 month to 12 years). Child's age was also a predictor of disclosure among infected children, with 10% of children aged less than 10 years old having been told their diagnosis, compared to 45% of those aged 10 years or more (χ^2=18.1, p<0.02).

Some people may find it helpful to be supported in the process of disclosure and respondents provided information on whether or not they would like support from a professional in talking to their children about their own and/or their children's HIV infection (Table 6.8). The same proportion of infected parents and carers reported that they would like professional support, regardless of the infection status of their children. However, significantly more uninfected than infected respondents wanted professional help in telling their infected child about his or her infection status.

In all 10 centres participating in the service-user survey, some degree of assistance with the process of disclosure was available, although this was only on request in one and just being introduced in another. In the eight centres where support with disclosure was more established, most (48/89, 54%) infected parents and carers knew that this was available with regard to disclosure of their own infection status and/or that of their child; however, 16 (18%) thought that there was no such support available and the remaining 25 did not know. In the same eight centres, two-thirds (26/38) of the uninfected parents and carers of infected children knew that clinic staff could help them in talking to their child about the HIV infection, one reported that this was not provided and the remainder were not certain. Overall, there was no association between knowledge of availability of support from the clinic and perceived need for professional support.

Table 6.8 Parents' and carers' perceived need for professional support in disclosing to their children about their own and/or their child's infection status

	Would you like support from a professional regarding disclosure?		
	Yes	Don't know	No
Disclosure of their own infection status			
to infected child (n=68)	18 (27%)	15 (22%)	35 (52%)
to uninfected child (n=33)	9 (27%)	5 (15%)	19 (58%) χ^2=0.7, p=0.7
all infected parents/carers (n=101)	27 (27%)	20 (20%)	54 (53%)
Disclosure of child's infection status			
by infected parent/carer (n=64)	17 (27%)	14 (22%)	33 (52%)
by uninfected parent/carer (n=36)	18 (50%)	10 (28%)	8 (22%) χ^2=8.8, p<0.02
all parents/carers of infected children (n=100)	35 (35%)	24 (24%)	41 (41%)

With regard to actual service use, fewer than half (21/57, 37%) of the infected respondents who knew that support with disclosure was available at the clinic had talked to clinic staff about disclosing to their children, although slightly more (14/27, 52%) uninfected parents and carers of infected children reported that they had obtained support from the clinic.

Planning for the future

Infected respondents were asked whether they had made any short-term child care arrangements (e.g. if they become unwell or need a rest) and/or long-term arrangements for the future social care of their children. Of the 119 (98%) infected parents who provided information, 82 (69%) had made short-term and 65 (55%) long-term plans. Those with short-term plans were also more likely to have made plans for the future, while those without had rarely made long-term plans (χ^2=41.2, p<0.02): 61 (51%) respondents had made arrangements for both types of care, 21 (18%) for the short-term only, 4 (3%) for the long-term only and 33 (28%) reported to have made no care arrangements. Those who had organised child care had known about their HIV infection status for significantly longer than those who had not (p=0.05), but had similar clinical status (Table 6.9). There were no significant differences by gender, centre or by the infection status of their children.

Most (94/114, 83%) respondents reported that they had not received help from clinic staff in planning for the long-term care of their children. Although 51 (54%) had already made plans for their children's future social care, this did not necessarily mean that they did not want support from the clinic and 15/51 (29%) reported that they would like to have the opportunity to talk to clinic staff about this. Of the 43 respondents without plans for the future social care of their children, 15 (35%) said that they would like the chance to discuss the issue with clinic staff and a further 15 were uncertain as to whether or not they would like this kind of support. An unmet need for help and support in planning for the long-term social care of children attending the clinics was therefore identified, despite the fact that service-providers in all 10 centres participating in the survey reported that such support was available in their clinics. However, over a third (33) of the 94

respondents had no perceived need for help from the clinic with regard to planning for the future of their families.

Table 6.9 Factors associated with existence of short- and long-term plans for social care of children

	Short-term plans		Long-term plans	
	Yes	No	Yes	No
Years since diagnosis of HIV mean (±sd.)	6.5 (±3.8)	5.1 (±3.6)	7.1 (±3.9)	4.8 (±3.1)
		p<0.05		p<0.05
Clinical status				
"Well"	64 (78%)	32 (86%)	51 (78%)	44 (83%)
"Ill"	18 (22%)	5 (14%)	14 (22%)	9 (17%)
		χ^2 = 1.15, p=0.3		p=0.5
Age of child*				
< 4 years	33 (43%)	16 (46%)	28 (45%)	21 (44%)
5 - 9 years	26 (34%)	17 (49%)	21 (34%)	21 (44%)
≥ 10 years	17 (22%)	2 (6%)	13 (21%)	6 (13%)
		χ^2=5.19, p=0.07		χ^2=1.83, p=0.4

* if >1 child then older / oldest child's age has been used

Service use

Help with financial problems was the service that respondents reported to use most often, while respite child care was used the least (Table 6.10). Ill HIV-infected parents and unemployed respondents had the highest reported level of service use. Ill parents were significantly more likely than other respondents to have practical help around the home

(25% v. 15%, χ^2=10.4, p<0.02), to use day child care services (26% v. 16%, χ^2=6.01, p=0.05) and to obtain frequent assistance with legal matters (11% v. 2%, χ^2=7.2, p=0.03). Furthermore, sick parents also had slightly higher use of respite child care services (25% v. 9%) and home medical care (30% v. 12%) than other respondents, although this was statistically insignificant in both cases. Respondents who were not employed had significantly more help with financial problems than employed respondents (48% v. 23%, χ^2=8.4, p<0.02) and were also slightly more likely to use legal help (28% v. 11%, p=0.07). Parents and carers of sick children used support groups and single parents or carers (including those divorced, separated and widowed) used services providing practical help in the home slightly more often than other respondents (32% v. 19% and 25% v. 11% respectively).

Table 6.10 Parents' and carers' service use

Type of service	Often use n (%)	Sometimes use n (%)	Never use / not available n (%)
Self-help / support groups (n=157)	10 (6)	26 (17)	121 (77)
Help with financial problems (n=158)	17 (11)	47 (30)	94 (59)
Day child care services (n=151)	14 (9)	11 (7)	126 (83)
Practical help around the home (n=156)	12 (8)	12 (8)	132 (85)
Home medical care (n=155)	7 (5)	16 (10)	132 (85)
Respite child care (n=151)	9 (6)	11 (7)	131 (87)
Help with legal matters (n=155)	7 (5)	28 (18)	120 (77)

The only two areas of service use which varied significantly by centre were legal assistance and help with financial problems; the latter association disappeared when controlling for employment status, although centre variation with regard to obtaining help with legal matters remained despite controlling for whether or not the respondent was a sick parent or not ($p<0.02$). The lowest level of service use regarding legal assistance was reported from the Italian centres (4%) and the highest from Amsterdam (55%).

A respondent was determined to have an unmet need for a particular service if he or she was not already using the service and reported that they would like to have the service provided in their local area (Table 6.11). Overall, 143 (79%) respondents were included in the estimation of the prevalence of unmet needs: 107 (75%) had at least one unmet need for the services listed and a quarter (36) reported no unmet needs. Parents and infected respondents were significantly more likely to have an unmet need than other respondents (80% v. 64%, $\chi^2=4.0$, $p=0.05$; 81% v. 62%, $\chi^2=4.91$, $p=0.03$ respectively). Parents and carers of infected and of uninfected children did not differ with regard to prevalence of unmet needs ($\chi^2=0.09$, $p=0.76$).

Satisfaction with services and views on current service provision

Overall there was a high degree of satisfaction with the organisation of appointments, facilities for waiting children and the level of privacy available at the clinic (Figure 6.3), although some infected parents were concerned about confidentiality at the clinic (Appendix 6.1). The level of satisfaction with two of these aspects of service provision varied significantly by centre: satisfaction with the degree of privacy varied from less than half (47%) to complete satisfaction ($\chi^2=19.3$, $p<0.02$), while there was even more

variation by centre with regard to satisfaction with facilities for waiting children, with a range from zero to complete satisfaction (χ^2=76.5, p<0.02). There was no significant difference according to gender or carer type.

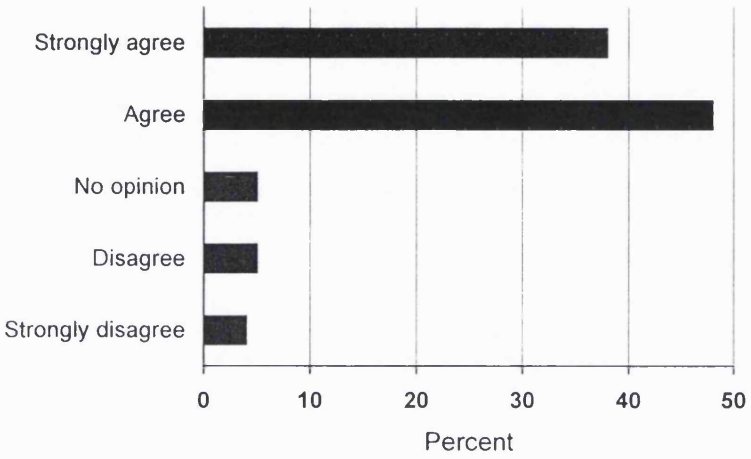
Table 6.11 Unmet need for services

Type of service	N	Number (%) with unmet need
Self-help / support groups	101	52 (52%)
Help with financial problems	77	51 (66%)
Day child care services	98	50 (51%)
Practical help around the home	102	49 (48%)
Home medical care	106	57 (54%)
Respite child care	108	55 (51%)
Help with legal matters	92	52 (57%)

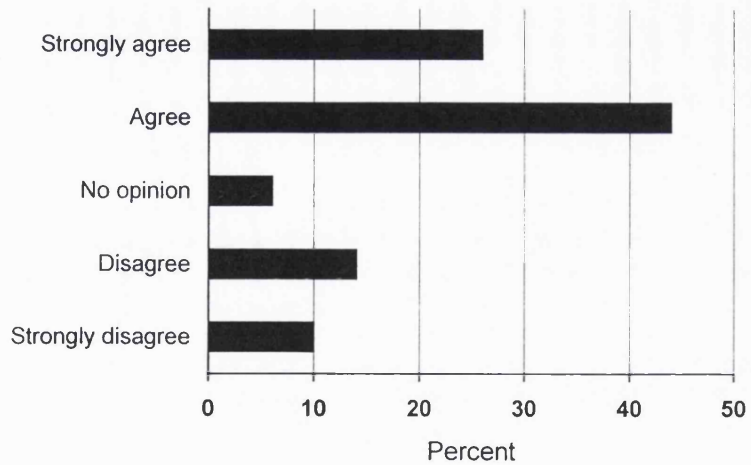
The large majority of respondents reported a preference for seeing the same doctor at every visit (Figure 6.4), which indicates that the current policy (whereby children can be seen by the same doctor at each appointment on request in all centres with more than one paediatrician on the paediatric HIV team) should be maintained. This preference was consistent across all centres.

Figure 6.3 Parents' and carers' satisfaction with organisation of clinic services

"It is easy to get an appointment at a convenient time" (n = 163)



"There are suitable facilities for waiting children" (n = 164)



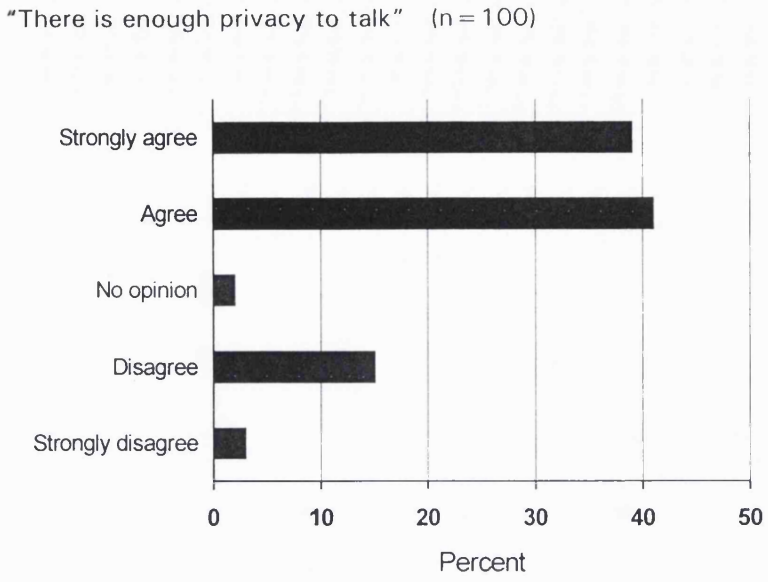
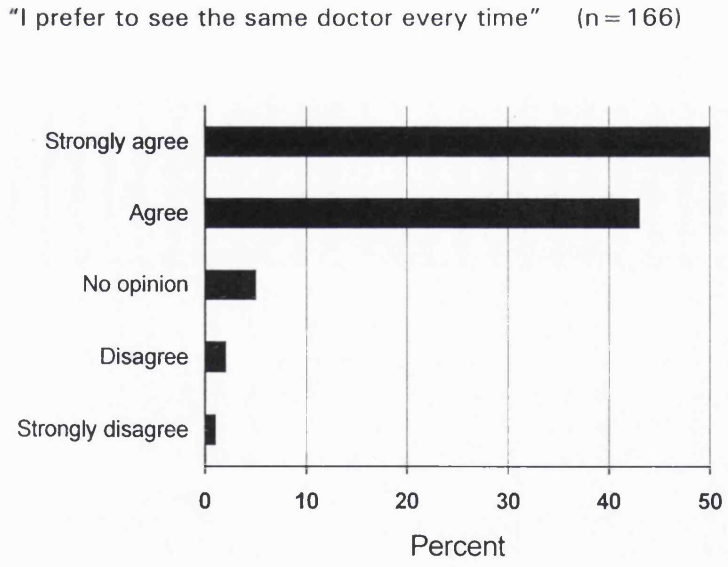


Figure 6.4 Parents' and carers' preferences regarding continuity of care



6.5. Key points

- most centres saw more than 10 HIV-infected and affected children per week
- most responding service-users were European, married or cohabiting, female and HIV-infected
- nearly a quarter of service-users were not living in their country of birth
- alternative carers of HIV-affected children (mostly grandparents) accounted for just over a quarter of service-users
- in nearly all centres some families travelled long distances in order to attend the clinic
- problems maintaining psycho-social follow-up of families were frequent
- a quarter of centres did not continue to follow up uninfected children once they seroreverted
- most service-users were satisfied with the organisation of and facilities at the clinic, but this varied by centre
- although help with planning and organisation of the social care of the children was available in nearly all centres, infected parents reported an unmet need for professional support regarding long-term plans for the future social care of their children
- options for emergency respite care included care with neighbours, friends or family, respite foster care and temporary admission to a children's home or to hospital
- two-thirds of infected parents had made arrangements for short-term, temporary child care
- the provision of welfare benefits to HIV-affected families and to alternative carers varied by country
- help with financial problems was the service respondents reported to use the most, but was also the service with the most reported unmet need

- most respondents were satisfied with the level of information provided at the clinic, although parents tended to be less satisfied than alternative carers
- sick parents and unemployed respondents had the highest reported level of service use
- disclosure to children regarding their own and their parents' HIV status was rare, with older children significantly more likely to have been told
- there was a remarkable similarity in the type of services provided by centres although they were from countries with different medical and social infrastructures

Chapter 7 Discussion

"My child ... is not infected so she does not need any special care and she is also not in need of any other "specials" like care for abuse or neglect. Most places for children are organised around topics to which my child does not relate. Nobody is really organising much for the affected children"

(infected mother of an uninfected child)

7.1 HIV infected pregnant women in Europe

The increase in heterosexual transmission seen in the ECS over the last ten years reflects trends seen in AIDS case reporting in Europe (WHO-EC Collaborating Centre on AIDS, 1997) and those reported by other epidemiological studies (Franceschi *et al,* 1996). This not only has ramifications for the dynamics of the epidemic in Europe, including the potential for increasing infections in children, but also for the development of public health strategies, including health promotion for the general population, since HIV has spread beyond specific and easily recognisable risk groups. Increasing heterosexual acquisition among women and the finding that zidovudine therapy is effective in reducing vertical transmission have been driving forces behind the increasing prevalence of universal antenatal HIV screening policies in Europe, as evidenced by the 1994 and 1997 obstetric surveys. Until recently IDU was the main mode of acquisition among women in Europe (WHO-EC Collaborating Centre on AIDS, 1997) and two-thirds of women in the ECS had a history of IDU, although only about a third were active drug users at the time of enrollment. This has important implications for the medical and social care of their children, which will be discussed later, while the shift towards heterosexual transmission may necessitate adaptation of existing service provision, particularly with regard to health promotion.

Although safer drug-using practices have been adopted among IDUs, as illustrated here by the significant decline in needle-sharing, their sexual behaviour seems to be more resistant to change (Helal *et al,* 1995; Klee *et al,* 1990; Nicolosi *et al,* 1992; Kall and Olin, 1990; Robert *et al,* 1990; Van Ameijden *et al,* 1996). Condom use in IDUs remains low (Delgado-Rodriguez *et al,* 1994; Helal *et al,* 1995; Robert *et al,* 1990; Van Den Hoek *et al,* 1990; Klee *et al,* 1990) and even relatively high percentages (up to half) of HIV-infected IDU have been reported to rarely or never use condoms (Van Den Hoek *et al,* 1990; Robert *et al,* 1990). This lack of behaviour change is of concern since IDUs represent a major reservoir for heterosexual transmission of HIV in Europe, as illustrated by the finding that nearly half the women in the ECS with heterosexual acquisition of HIV were the sexual partners of current or former IDUs; this is consistent with the increasing incidence in Europe of heterosexually-infected AIDS cases whose sex partners were IDUs (WHO-EC Collaborating Centre on AIDS, 1996). More information on sexual mixing patterns between IDU and non-IDU populations would help in targeting future health education messages and testing programmes (Arca *et al,* 1992).

The overall impact of interventions to reduce vertical transmission rates will depend on the proportion of infected women who are identified before or during pregnancy and who accept the interventions offered. Early diagnosis of HIV-infected women (i.e. before or during pregnancy) allows the woman to make an informed decision about continuation of the pregnancy, ensures optimum obstetric management, facilitates early diagnosis of the infant and allows timely initiation of prophylaxis and therapy if the infant is infected. Furthermore, prompt diagnosis of the mother also enables her own medical care to be planned, including monitoring her immune functioning and viral load, and the initiation of combination antiretroviral therapy if appropriate (Hammer *et al,* 1996; Delta Co-

ordinating Committee, 1996). Although the increase in universal antenatal HIV testing policies found in the obstetric surveys is encouraging, whether or not this policy change will result in a significant decline in paediatric HIV infections will depend on the uptake of testing by pregnant women and the access of infected women to antenatal care.

Uptake of antenatal testing varies across Europe, with high uptake rates in France (Mayaux *et al,* 1997) and Sweden (Lindgren *et al,* 1993); however, in the UK and Italy, few HIV-infected women are identified in pregnancy (MacDonagh *et al,* 1996a; MacDonagh *et al,* 1996b; Ippolito *et al,* 1996b), for example, 80% of pregnant HIV-infected women in London are unaware of their infection status at the time of delivery (Unlinked Anonymous Surveys Steering Group, 1996). In the ECS, women with a history of IDU were more likely to be identified as HIV infected before pregnancy than other women; these women were probably more likely to have been offered an HIV test outside pregnancy, through contact with drug rehabilitation programmes, needle-exchanges and other drug services or possibly as part of research projects or seroprevalence surveys (Stark *et al,* 1995; Rhodes *et al,* 1994; Hartgers, 1992). Furthermore, former and current IDUs may be more likely to seek testing themselves than other women (Shuter *et al,* 1997; Johnson *et al,* 1996). Lack of recognition by some health care professionals and the general public that heterosexual women who are not IDU can become HIV-infected, in addition to women being unaware of their sex partners' risk factors may be major reasons why non-IDU women do not seek HIV testing, refuse testing if it is offered or are not offered testing (Rezza *et al,* 1994; Siegel *et al,* 1997).

Data from the ECS add to the growing literature on HIV-infected women's fertility and reproductive decisions following diagnosis, but are limited in that, by study definition, all women completed their pregnancies. Nearly half the deliveries in the ECS were to women who already knew that they were HIV-infected, although no information was available regarding whether or not the pregnancy had been planned. Furthermore, some women antenatally identified as HIV-infected were diagnosed early enough to have a termination of pregnancy, but instead continued with the pregnancy. These findings are consistent with a large European study of natural history of HIV in women in which two-thirds of infected women initiated pregnancy after HIV status was known (De Vincenzi, 1996). Studies comparing HIV-infected women and uninfected controls have suggested that HIV-infected women may not consider their infection or risk of vertical transmission to be sufficient reasons for avoidance or termination of pregnancy. Instead, psycho-social factors, cultural/religious beliefs, previous obstetric history, partner's wishes and age have been suggested as having more impact on decisions to become pregnant or continue with a pregnancy (Lester *et al,* 1995; Selwyn *et al,* 1989b; Kline *et al,* 1995; Johnstone *et al,* 1990; Sunderland *et al,* 1992) and the finding here that women with a history of IDU were more likely to have had a previous pregnancy termination supports this. However, studies looking at fertility before and after HIV diagnosis in cohorts of infected women have reported significant declines in pregnancy incidence and/or live birth rates following a diagnosis of HIV infection (Stephenson *et al,* 1996; De Vincenzi *et al,* 1997). It remains to be seen whether the finding that zidovudine therapy is effective in reducing vertical transmission (Connor *et al,* 1994) will influence HIV-infected women's reproductive decisions.

7.2 Obstetric management and interventions to reduce vertical transmission

The obstetric surveys documented the changing use of interventions to reduce vertical transmission of HIV over a three year period, in particular, a significant increase in zidovudine therapy throughout Europe. In the ECS, increasing zidovudine use has been accompanied by a significant temporal decline in vertical transmission, despite the 30% decline in mean CD4 cell count in enrolling pregnant women over the study period. In addition to the need for effective identification of HIV-infected pregnant women, acceptance of and compliance with zidovudine therapy are important in determining the impact of antiretroviral therapy on incidence of paediatric HIV infections. Most infected women in the centres participating in the 1997 obstetric survey received antiretroviral therapy, with refusal of therapy and late booking the main reasons for non-receipt of therapy. Studies in the USA have reported that between 6% and 25% of HIV-infected pregnant women refuse all components of the 076 regimen (Orloff *et al,* 1996; Landsberger *et al,* 1996; Wiznia *et al,* 1996), while the reported refusal rate in France is only 1% (Mayaux *et al,* 1997). In the UK, the proportion of HIV-infected pregnant women not receiving zidovudine declined from 45% in mid 1994-5 to 29% in 1996 (Gibb *et al,* 1997a) and in Switzerland, 75% of infected pregnant women have received zidovudine since mid-1994 (Kind, 1996). Uptake of therapy varies according to transmission group, prior experience of zidovudine, clinical stage, access to antenatal care and cultural factors (European Collaborative Study, 1997; Orloff *et al,* 1996; Seals *et al,* 1996; Thomas *et al,* 1996; Mayaux *et al,* 1997).

Over a quarter of centres in the 1997 obstetric survey had a zidovudine policy which deviated from the 076 regimen, particularly regarding the intrapartum and neonatal

components; this may actually have little impact on vertical transmission rates since antenatal zidovudine therapy alone has already been shown to be associated with significant reductions in transmission (Frenkel *et al,* 1997; Simpson *et al,* 1997). The finding that 10% of centres prescribed shorter duration of therapy to newborns probably reflects concerns regarding the possible long-term consequences of zidovudine exposure. Questions remain regarding the applicability of the 076 regimen to women outside the eligibility criteria in the trial, for example, those previously prescribed zidovudine (Connor *et al,* 1994; Mayaux *et al,* 1997), which is indicated by the survey results, with some centres prescribing zidovudine monotherapy to these groups of women and others prescribing combination therapy.

The clinical superiority of combination/triple antiretroviral therapy over zidovudine monotherapy in the treatment of HIV-infected adults (Delta Co-ordinating Committee, 1996; Hammer *et al,* 1996) and the survey finding that some centres are routinely prescribing combination therapy to pregnant women highlight the need for guidelines regarding treatment protocols in pregnancy and after delivery. Clinicians face complex therapeutic decisions, since both the needs of the woman and the need to reduce vertical transmission should be considered (Minkoff and Augenbraun, 1997). Didanosine (ddI), lamivudine (3TC) and nevirapine are currently under assessment for use in combination therapy, and a WHO trial is currently underway in South Africa, Uganda and Tanzania evaluating the combination of a short regimen of zidovudine and 3TC (Newell *et al,* 1997a; Newell and Gibb, 1995a). Diffusion of up-to-date and relevant information to health care professionals working with pregnant HIV-infected women, especially those working in centres with little experience of HIV, should therefore be a priority.

Given the uncertainty regarding the effectiveness of caesarean section (Newell *et al,* 1997b), an unexpectedly large proportion (a quarter) of centres in the 1997 obstetric survey routinely offer this intervention to all HIV-infected women. Although an unbiased estimate of the effect of caesarean section on vertical transmission rates can only be achieved through a randomised trial, low participation rates in the European mode of delivery trial and the declining rate of vertical transmission due to zidovudine use may result in recommendations for clinical practice being based on results from meta-analyses instead (Newell *et al,* 1997b). A one-fifth reduction in risk of transmission associated with caesarean section (elective and emergency) was found in a meta-analysis carried out in 1994 (Dunn *et al,* 1994) and the forthcoming meta-analysis from the National Institutes of Health in the USA, using observational data from Europe and North America, should update this. Washing the birth canal was the least-used intervention, which probably reflects the finding that it has only been shown to be effective where the time between rupture of membranes and delivery exceeds four hours (Biggar *et al,* 1996) and may be more applicable to the developing country setting, where it is associated with additional benefits in terms of a marked reduction in maternal and neonatal morbidity from septic causes and a significantly reduced infant mortality rate (Taha *et al,* 1997).

The obstetric surveys documented significant changes in policies for obstetric care of HIV-infected pregnant women in Europe in the three years since zidovudine was shown to significantly reduce the risk of vertical transmission. However, many questions remain regarding both the identification of HIV-infected pregnant women and the optimal care of these women and their infants, particularly with regard to the role of combination antiretroviral therapy and management after delivery.

7.3 HIV-exposed children's needs for medical care

The finding that infected children in the ECS were four times more likely to be admitted to hospital than uninfected children and that children with AIDS had more frequent and longer hospital admissions were not surprising but, with supplementary information on costs, may help to plan for services. The hospital rates for infected children are in the range reported by studies in the United States (Turner *et al,* 1996; Hsia *et al,* 1995; Hegarty *et al,* 1988; Kemper and Forsyth, 1988), but there is no available data from other European studies for comparison. The declining length of hospital stay for infected children is consistent with other studies of children with HIV/AIDS (Hsia *et al,* 1995) and is probably the result of earlier diagnosis of infection, PCP prophylaxis, increased experience of medical care of children with HIV/AIDS and improved outpatient and community health services. The surveys showed that, despite national differences in health care infrastructure across Europe (McCarthy and Rees, 1992), clinic provisions for medical care for children born to HIV-infected mothers are very similar and there is general satisfaction among the service-users.

Intensive monitoring of perinatally-exposed infants is needed in the first few months of life to allow for early diagnosis of infection and may also help to promote avoidance of breastfeeding and compliance with neonatal zidovudine therapy to reduce vertical transmission. With regard to infected children, frequent follow-up appointments facilitate detection of indicators of early onset disease and prompt initiation of prophylaxis against PCP and antiretroviral therapy, in addition to allowing for monitoring of viral load, growth and development. All centres had regular medical appointment schedules for perinatally-exposed children and there were various mechanisms in place to ensure that contact with children in follow-up was maintained, although many service-providers

reported that parents and carers were usually very conscientious regarding keeping appointments (data not shown). The organisation of follow-up in these centres probably reflects their extensive experience with and interest in paediatric HIV disease, in particular, the fact that most were participating in prospective cohort studies. The clinical management of perinatally-exposed and infected children in centres with less interest in or experience of this area may be very different, and future research could address this issue (see section 7.5).

With regard to perinatally-exposed children diagnosed as uninfected, it has been recommended that follow-up is continued on an annual basis, partly to continue to monitor the health and development of the child, but also to provide psycho-social support (Mok, 1995); policies in most centres in the service-provider survey reflect this recommendation and the fact that many are participating in prospective studies. The increasing use of zidovudine therapy to reduce vertical transmission may also influence policies for follow-up of zidovudine-exposed uninfected children, since little is known about the long-term effects of intra-uterine and neonatal zidovudine exposure (Wilfert, 1996).

The observation that many HIV-infected women experienced problems in accessing medical care for themselves, including family planning services, and the finding that presenting sick infected children were often the first members of their family to be diagnosed were driving forces behind the development of family HIV clinics, including the family out-patient clinic which participated in the service-provider and -user surveys (Brady *et al,* 1996b; Melvin and Sherr, 1995; Gibb *et al,* 1997b). The finding that the paediatric and adult HIV teams tried to co-ordinate appointments for family members in

most centres may help to explain the high levels of satisfaction among parents regarding the appointment system, since this avoids the inconvenience and expense of different appointments.

Continuity of both in- and out-patient medical care, in terms of children being consistently seen by the same clinicians, was a universal finding and an aspect of service provision with which there was a high level of satisfaction among service-users. Most parents and carers were also satisfied with child facilities and the level of privacy at the clinic, although some infected parents provided additional comments about their concerns regarding confidentiality (Appendix 6.1). HIV-infected adults and parents of children with HIV and other chronic illnesses frequently cite the importance of effective communication with medical professionals in needs assessments reported in the literature (Reidy *et al,* 1991; Bain *et al,* 1995). As expected given that most parents and carers cared for infected children, health-related information was reported as the most important aspect of information provision. Although it was encouraging to find that two-thirds of parents and carers were satisfied with the level of information they had received at the clinic, it could be argued that it is unacceptable that a third were dissatisfied. Some of the parents' and carers' additional comments (Appendix 6.1) highlight the short-comings of current information provision, including lack of information on side effects of therapy and how to prevent transmission within the family.

7.4 HIV-affected families' needs for social services

7.4.1 Alternative care

Children born to HIV-infected mothers are predominantly cared for by their mother and/or their father in the first five years of life as found here and elsewhere (Kunzel and Kind,

1992; Blanche *et al,* 1996). However, some infants with HIV-infected mothers require alternative care from birth, as was the case for 7% of children in the ECS. This, in addition to the finding that a small number of newborns in the ECS remained in hospital for an average of two to three months while alternative care was arranged, highlights the need for better social care provisions and support for HIV-infected mothers during pregnancy and after delivery. However, these data reflect experience over the past 10 years and the proportion of infants with delayed postnatal discharge has declined over time. This may be partly explained by increased experience of the problems and issues around HIV infection and better service provision, for example, the existence of foster carers who can be called upon at short notice. The practice of psycho-social staff and/or paediatricians establishing contact with HIV-infected women during pregnancy, as reported in the service-provider survey, may facilitate identification of women at risk of abandoning their child or of having their child taken into care (for example, active drug users) and may allow appropriate steps to be taken, such as providing intensive psycho-social support.

These findings suggest that some children with HIV-infected mothers would require alternative care regardless of HIV because of their family circumstances; for example, children of active IDU mothers, because of the actions of child welfare authorities or due to separation because of maternal enrollment in residential drug rehabilitation programmes or imprisonment (Kunzel and Kind, 1992; Mok *et al,* 1996; Baller, 1994; Black *et al,* 1994). The finding that children of former IDUs in the ECS have similar characteristics to those whose mothers have no history of IDU, provides a strong argument for drug rehabilitation services and support to be provided to mothers identified as active drug users. However, access to drug rehabilitation programmes may be difficult for many women, particularly

mothers, some of whom may be reluctant to use existing statutory provisions because of fears that their children may be taken away (Finnegan *et al,* 1993; Baller, 1994).

Maternal ill-health is an important factor affecting the social care of children with HIV-infected mothers, reflected by the finding that children in the ECS with symptomatic mothers (CDC Stage IV) were three times more likely to be in alternative care than children of the same age and 13 times more likely to have been admitted to hospital for a social reason. Although very few mothers were symptomatic at the time of their child's delivery, by the time their children are aged five, nearly a fifth are likely to have developed AIDS, which corresponds to the approximate fifth of ill infected parents in the service-user survey. Ill mothers with no partner to share child-care and those caring for sick children and/or a sick partner are likely to be in particular need of support and services, such as respite care and domestic help (see section 7.4.3).

As mothers progress to symptomatic disease, their children are likely to need more frequent temporary alternative care stays, for example, when their mothers are admitted to hospital. It is not known from ECS data the extent to which the high risk of non-medical hospital admission found for children with symptomatic mothers is the result of well children being admitted at the same time as their ill mothers. However, the service-provider survey documented that temporary admission of well children to hospital in such cases does occasionally occur, where there is no family member, friend or respite foster carer available to look after the child. Although ECS findings suggest that the availability of temporary alternative care for children with ill mothers has been limited over the past 10 years, the service-provider survey shows that provision has now

improved (for example, with respite foster care now available in two-thirds of centres for families without an informal support network).

The importance of the extended family (largely grandparents) in the alternative care of children with HIV-infected mothers has been highlighted by both the ECS social care data and the service-user survey; however, this partly reflects the predominance of centres from Southern Europe, where the traditional importance of the extended family has been preserved. The extended family may actually be more involved in the care of children affected by HIV than reported here for children in the ECS, since the schedule of follow-up visits may have led to under-reporting of shorter, more informal stays, such as weekend visits, while no data on aspects of care such as baby-sitting are available. The importance of the extended family in caring for HIV-affected children may have implications for service delivery, which are discussed in section 7.4.3.

The findings of the French Prospective Study with regard to social care (Blanche *et al,* 1996) are very similar to those presented here; for example, in the former a 37% cumulative risk of long-term or permanent separation of a child from his or her mother was reported, compared to 41% in the ECS. The impact of maternal IDU on children's social care was also similar, approximately doubling or tripling the likelihood of a child living in alternative care. However, the French study could not investigate the interaction between maternal drug use and single parenthood. Fewer of the French children in alternative care were living with their extended family than in the ECS, reflecting the impact of Southern European traditions within the latter study (see paragraph above). The finding in the ECS of a reduced likelihood of alternative care in the first years of life for children born in the later years of the study is encouraging and suggests that psycho-

social and practical support for HIV-infected parents may have improved, allowing them to continue caring for their children for longer.

7.4.2 Planning for the future and disclosure of infection status

There is now relatively widespread acceptance that HIV-infected parents should be provided with sufficient support and services in order to continue caring for their children for as long as possible (Imrie and Coombes, 1995; National Forum on AIDS and Children, 1995). However, as seen in the ECS, most children with HIV-infected mothers will require temporary or permanent alternative care by the time they reach school age and it has been suggested that planning for the future social care of children with HIV-infected mothers should be an integral component of the medico-social care of affected families (Blanche *et al,* 1996). Just over half of the infected parents in the survey had made long-term care arrangements for their children, but an unmet need for professional help in planning for the future was identified, despite the fact that this was reported by service-providers to be available in all centres. This unmet need may be partly due to a lack of communication between service-providers and users, whereby the fact that help and support are available at the clinic is not actively promoted by clinic staff. Alternatively, the tendency for families to have irregular (or no) contact with psycho-social professionals, in whose realm the organisation of children's social care tends to fall, may have resulted in unmet need. This situation requires attention, particularly since the service-provider survey suggests that uninfected children's follow-up at the clinic may cease before parents perceive a need for help in planning for the future, for example, because they themselves are currently well.

Closely linked to planning for the future care of children affected by HIV is disclosure of the HIV infection in the family to the child. The timing and impact of disclosure is likely to depend on whether the child or the parent is infected (or both). In practice, disclosure can take place at different levels, ranging from partial disclosure, whereby the illness but not the cause is acknowledged, to complete disclosure of the HIV infection. The service-user survey did not capture such subtleties, since respondents were asked whether their children knew about their parents' or their own infection status and thus lack of disclosure here does not necessarily imply a total lack of acknowledgment of the illness. For example, one infected mother wrote "I also had a tumour in my cervix which my child thinks has made me terminally ill".

Disclosure was rare in the study sample, which may be partly explained by the relative youth of the children, since child's age is an important predictor of disclosure (Wiener *et al,* 1996; Brady *et al,* 1996a; Rotheram-Boras *et al,* 1997). However, the level of disclosure was not particularly high even among the oldest children (e.g. with 40% of infected children aged 11 years or more not officially informed of their diagnosis), and similar to that found for HIV-infected children and children of HIV-infected parents in the US (Niebuhr *et al,* 1994; Brady *et al,* 1996a). Disclosure of a parent's or child's HIV infection status is an emotionally distressing experience (Wiener *et al,* 1996; Rotheram-Boras *et al,* 1997), but proponents of age-appropriate disclosure to children argue that this is preferable to the impact of disclosure when the parent or child is terminally ill (or after the parent's death) and recognise that it is important for infected children to be able to talk about their illness (Rotheram-Boras *et al,* 1997; Siporen, 1996; Bor, 1997). Parents' desire to keep the diagnosis from their children (particularly teenagers) can therefore lead to complex ethical dilemmas for clinic staff (Gibb *et al,* 1997b). To

encourage disclosure about HIV infection in either parents or children, a supportive environment should be created in the clinic in which parents feel free to discuss their views and anxieties at any stage (i.e. even if their children are deemed too young for disclosure to take place at that time). Clinic staff should be available to provide both practical and emotional support when parents reach the stage at which they feel able to disclose to their children.

7.4.3 Service use

Given that most children with HIV-infected parents in Europe are cared for by their parents in the first five years of life and that HIV disproportionately affects families with pre-existing socio-economic disadvantages, it was not surprising that the parents in the service-user survey identified practical services including financial support, domestic help and respite care as important aspects of service provision. Research into the needs of families with terminally ill children has shown that parents often need to be demanding and articulate to obtain the welfare benefits, practical assistance and respite services appropriate to their family's needs (Simons, 1994). HIV-infected parents may have particular problems in accessing services, since, as illustrated by the ECS and survey findings, many are from socially disenfranchised groups, such as active drug users and also tend to have minimal educational attainment. This is supported by the finding in the service-user survey that infected parents were significantly less likely to telephone the clinic with questions or problems than uninfected parents and carers.

Nearly half of the mothers in the ECS were either active drug users or not living in their country of birth. Although no information was available on immigration status of women in the ECS, a third of immigrants/refugees in the service-user survey did not have

permanent residency status. Parents with uncertain immigration status and active drug users often have poor access to health and welfare services, with the former reluctant to identify themselves to service-providers because of fear of discrimination and concerns that they will not be granted political asylum if their HIV status is known (Lindsay Smith, 1993; Honigsbaum, 1995), while the latter group may avoid existing provisions because they fear that their children may be taken away (Baller, 1994).. The chaotic lifestyles of active drug users have been reported to be another factor contributing to their irregular service contact (Mok *et al,* 1996), which is supported by the finding in the service-provider survey that psycho-social contact with active drug users was difficult to establish and maintain. Not only are these groups likely to have limited contact with formal (i.e. statutory) services, but as the ECS social care data indicates, they are also least likely to have the support of their family because of social or geographic isolation. Innovative methods of service delivery, including outreach, out-patient clinics with open access, close collaboration between generic and specialist psycho-social professionals, may therefore be necessary to reach these families.

The service needs of alternative carers of HIV-affected children also need to be addressed. It has been suggested that extended family carers have poor knowledge of and reduced access to services compared with state-registered foster carers, who are more likely to be "invested in" with regard to provision of special education and resources (Moore and Heyman, 1994). Grandparents may be in particular need of support, both because of their own health status (Hilton *et al,* 1996) and because they may be at risk of financial hardship, since most will have a limited income (e.g. from a pension) and may not necessarily receive a foster care allowance, as demonstrated by the service-provider survey.

Information provision is an important aspect of service provision, because it can affect access to and uptake of other services (Petrou *et al,* 1996). A third of parents and carers were dissatisfied with the amount of information they had received on other services for families with HIV, such as voluntary organisations and support groups. Social workers were the predominant source of information on community-based social services; however, nearly 90% of psycho-social workers in the service-provider survey reported that they had experienced problems in establishing and maintaining contact with families, which may help to explain the unmet need for information on other services. Given this situation, it is difficult to suggest ways in which the provision of such information could be improved. However, the regular contact between families and the paediatrician could be utilised to facilitate better information provision, for example, with literature or posters in the waiting area, or more directly, with the paediatrician providing families with information on other services or reminding them that they can talk to the social worker about accessing such services. The higher levels of dissatisfaction found among migrants and refugees suggests that language problems may be a contributing factor and thus the provision of written information in appropriate languages may help to alleviate the problem. In centres where a large proportion of families are migrants and refugees, provision of occasional translator support (possibly using peer group translators) could be investigated.

Although a considerable degree of unmet need with regard to practical services was identified, individuals with the greatest need for a service were more likely to receive help: for example, those with no income from employment were more likely to receive financial support and ill parents to have domestic help. Given the limited resources for service provision, it is important that existing service provision is equitable, with those

most in need receiving the available services. The survey findings therefore indicate that current service provision is going some way to meeting the needs of families affected by HIV, although the challenge of meeting the outstanding needs of certain families remains.

Although the ECS and survey findings showed that certain types of family are more at risk of HIV infection than others, every family unit has its own distinct characteristics and thus different service needs. For example, an infected mother and her children (whether infected or not) or a grandparent caring for an infected child will have different needs for medical and social services compared with adoptive parents of a perinatally-exposed but uninfected child. Furthermore, families' needs for services change over time, for example, as the infection status of a child is determined, as an infected child or parent progresses to symptomatic disease and as a child grows older. There is therefore no "ideal" model of care for HIV-affected families, although this research has highlighted what services parents consider to be important and where improvement in provision could be made. The service-user survey showed that low use of services did not necessarily represent unmet need, since some parents and carers did not want to use a particular service, such as a support group. This reflects the aim of many parents in achieving as normal a life as possible for their children (A parent, 1995; Barrett and Victor, 1994) and is highlighted by the comment of an adoptive father of an infected child in the service-user survey, "So far we have managed without special help and we hope to maintain that in the future".

7.5 Suggestions for further research

A limitation of the service-user survey was its bias towards parents and carers of infected children, because of their more frequent contact with the clinic. With the increasing use of antiretroviral therapy to reduce vertical transmission, risk of infection is likely to decline from about one in six (16%) to one in 16 (6%) and there will therefore be an increasing number of uninfected but affected children. The emphasis of service provision may have to shift from medical to psycho-social services and support, to meet the needs of all affected children and not just those infected.

One of the key arguments for research into the needs of affected children is also a major barrier to carrying out such research, namely, the fact that many of these children are not known to or in contact with the medical or social service-providers. As the service-provider survey showed, some centres terminate follow-up of seroreverters as soon as they are diagnosed as uninfected, while others only have limited follow-up, due to lack of logistic support and resources. Contact with the paediatric HIV service therefore ceases while these children are still young and before a need for help with planning for the future and disclosure (including the issue of disclosure at school) or bereavement counselling are realised. Further research is needed into the degree to which affected children's needs are currently being met, although this will require innovative methods to reach the study population.

Since many uninfected children with HIV-infected mothers are likely to be of school age when their mothers become ill and die, future research could focus on the future role that schools could play in supporting HIV-affected children, who may be identified as the result of behavioural or other problems and who may otherwise not be in contact with

supportive services. With regard to HIV-infected children, there is an increasing number of school-age children with HIV (Grubman *et al,* 1995), some of whom will have special educational needs as a result of impaired neuro-psychological functioning (Trad *et al,* 1994; Hanna and Mintz, 1995; European Collaborative Study, 1990; Papola *et al,* 1994). Future research could include an investigation of factors associated with disclosure to schools, of communication between health care providers and the educational services (including school medical services) and of ways in which support can be directed to children, families and teachers (Clement *et al,* 1996; Adams, 1996; A primary school teacher, 1995).

With regard to infected children, the increasing use of zidovudine and of combination antiretroviral therapy to reduce vertical transmission could potentially alter the natural history of paediatric HIV infection, which in turn might influence the needs of infected children for particular types of clinical services, for example, hospitalisation or out-patient services. It is therefore important that on-going prospective studies such as the ECS should continue in order to monitor the presentation and progression of HIV disease in infected children exposed to antiretroviral therapy. Furthermore, follow-up of uninfected children exposed to zidovudine in such cohorts would provide further information on the long-term effects of this exposure.

As the findings here have shown, the social needs of children born to HIV-infected mothers are strongly influenced by their family environment, including the health status of their mother and socio-demographic characteristics. In the ECS, data on maternal clinical status are collected at enrollment and during paediatric follow-up, but socio-demographic information is only collected at enrollment; furthermore, maternal

information was not always available to paediatricians involved in the child's follow-up, for example in cases where the child is no longer living with the mother. Since maternal clinical status will change over time and important determinants of the needs of HIV-affected children for social care, such as maternal drug use and marital status may also change, it would be interesting to incorporate a more detailed follow-up of mothers in the ECS in tandem with the paediatric follow-up in order to describe the associated changing needs of the children.

This research concentrated on hospital-based services for women with HIV and their children and although community-based provision has been described, a more comprehensive assessment was beyond the scope of the thesis. Furthermore, all hospitals in the ECS and the service-provider and -user surveys were tertiary referral centres with a high level of experience of HIV infection, which has been shown to be a significant predictor of outcomes of care with adults (Bennett *et al,* 1992; Stone *et al,* 1992). As more children are born to HIV-infected women, the scale of need for services will increase and it is likely that medical and social service provision will need to be shared between tertiary centres and other hospitals and community-based services. Future research could address this issue, for example, looking at how shared care can be achieved, whether HIV-infected children could share services provided for children with other chronic diseases, the effect of shared care on service-user satisfaction and the needs of future service-providers.

7.6 Recommendations

In summary, proposed ideal components of a service for families affected by HIV would include the following:

Support during pregnancy

- information (translated where appropriate)
    - interventions to reduce vertical transmission
    - diagnosis and follow-up of the child
    - clinical management of the mother
    - services available for the woman, her child and other family members
- psycho-social support
    - post-test counselling of women identified through antenatal HIV testing
    - planning for the delivery and decisions around breastfeeding

Close collaboration between specialists working with the family

- in pregnancy
    - a multidisciplinary team appropriate to the setting. This could include the obstetrician, midwife, infectious diseases specialist, psycho-social worker, primary care physician and the paediatrician.
- paediatric HIV team to consist of clinical and psycho-social providers

Co-ordination of services for infected children and parents

- liaison between the child's providers and those of his/her parents
- consideration could be given to a family clinic model, although this would not necessarily suit all settings

Emphasis on information provision

- promotion of the range of services available at the clinic itself
- provision of information on services in the community (including NGOs)
- provision of written information, in alternative languages where appropriate

Practical support

- provide families with help in accessing services (state- or NGO-provided)
    - eligibility for welfare benefits, domestic help etc
    - liaising with child welfare authorities, lawyers etc in organising social care

Psycho-social support for affected children and their families

- maintain follow-up at the clinic of perinatally-exposed children found to be uninfected

  OR
- encourage families with uninfected children to contact the clinic if they have any problems or need help once follow-up has been terminated **OR**
- utilise / promote links with adult HIV services to direct support to affected children in need of services **OR**
- promote the services available at the clinic (e.g. relating to disclosure and planning for the future) to generic psycho-social professionals working in the community who may be able to refer families if a need is identified

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Appendix 3.1 Collaborators in the European Collaborative Study

Paediatric Centres

Universita degli Studi di Padova, Italy: **Dr C Giaquinto, Dr E Ruga, Dr O Rampon, Dr R D'Elia, Dr S Cozzani, Dr A De Rossi**, Dr V Giacomet, Prof F Zacchello, Prof L Chieco-Bianchi, Dr AM Laverda, Dr A Mazza, Ms S Oletto, M Vigolo, C Novello, Dr S Girotto, S Casella.

Universitätsklinikum Rudolf Virchow, Berlin, Germany: **Dr I Grosch-Wörner**, Dr M Langhof, Dr Schulz, Dr Steinmüller, Ms Agnes Runde.

City Hospital, Edinburgh, UK: **Dr J Mok,** Dr F Johnstone, Dr S Burns, Dr PL Yap, Dr J Peutherer, Dr G Bird, Mrs F Mitchell, Ms C Smith.

Hospital Infantil La Paz, Madrid, Spain: **Dr MC Garcia-Rodriguez, Dr I Bates, Dr I de José, Dr F Hawkins, Dr R Martinez Zapico,** Dra B Sancho, Dr G Fontan-Casanego, Srta ML Gonzalez, Srta ML Prieto.

Hospital 12 De Octubre, Madrid, Spain: **Dr F Omeñaca**, Dr J Jiminez, Dra C de Alba.

Hospital La Fe, Valencia, Spain: **Prof F Asensi-Botet, Dr MC Otero, Dr D Pérez-Tamarit, Dr A Gonzalez Molina, Dr C Canosa**, Dr A Gobernado, Dr M Sanchez, Dr A Moya, Dr MJ Galbis, Dr JL Lopez.

Academisch Medisch Centrum, Amsterdam, The Netherlands: **Dr H Scherpbier,** Dr K Boer, Dr G Mulder, Mevr. M Kreyenbroek, Mevr. T Kosten, Mevr. M.C.A. van Leeuwen.

Huddinge and Danderyd Hospitals, Stockholm, Sweden: **Dr AB Bohlin, Dr E Belfrage,** Dr C Ottenblad, Dr K Elfgren, Dr B Christensson, Dr G Lidin-Jansson, Dr R Ljung, Dr A Ehrnst, Dr B Anzén, Ms AB Bengtsson, Ms AS Åsander.

Hospital St Pierre, Brussels, Belgium: **Dr J Levy, Dr A Alimenti,** Dr A Hottard, Dr M Poncin, Dr S Sprecher, Dr B Lejeune, Dr G Zississ, Prof N Clumeck, Ms M-C Lecroart, Ms M-N Vanderhofstadt.

Hospital San Martino, Genova, Italy: **Dr A Ferrazin, Dr A De Maria, Dr C Gotta,** Dr G Di Siena, Prof F Melica, Dr C Cirillo, Dr C Lorusso.

Hospital del Mar, Laboratorio Referencia de Cataluña, Barcelona, Spain: **Dr A Mur, Dra MT Rovira Puges**, Dr J Llorens, Dr M Vinolas, Dr M A López-Vílchez.

Obstetric centres

Hospital Clinic, Barcelona, Spain: **Dr O Coll, Dr C Fortuny**

Hospital Sant Joan de Deu, Barcelona, Spain : **Dr J. Boguña**

Hospital Vall D'Hebron, Barcelona, Spain: **Dr M, Casellas Caro**

Hospital Parc Tauli de Sabadell, Barcelona, Spain: **Dr Y Canet**

Ospedale San Paolo, Milan, Italy: **Prof G Pardi, Dr AE Semprini, Dr M Ravizza, Dr C Castagna, Dr S Fiore**

Policlinico S.Orsolo, Bologna, Italy: **Dr B Guerra, Prof P Dallacasa, Dr S Bianchi, Dr L Bovicelli**

Universita di Brescia, Brescia, Italy: **Dr E Prati, Dr S Zanelli, Prof M Duse, Dr A Soresina**

Universita La Sapienza, Rome, Italy: **Dr G Scaravelli, Dr M Stegagno**

Universita Cattolica, Rome, Italy: **Dr M De Santis**

Ospedale L.Sacco, Milan, Italy: **Dr M-L Muggiasca, Dr P.Marchisio**

Policlinico S.Matteo, Pavia, Italy: **Dr A Iasci, Dr A Spinillo**

Clinica Mangiagalli/Clinica De Marchi, Milan, Italy: **Dr A Bucceri, Dr A Bucceri, Dr E Grossi, Dr L Rancilio**

Chelsea and Westminster Hospital, London, UK: **Mr R Smith, Ms A-M Lewis**

Appendix 3.2 1994 Obstetric Survey Questionnaire

Management of pregnancy and delivery in HIV-infected women in Europe

Please tick the appropriate box(es) and/or write your response in the space provided. We welcome any additional comments you may have.

1. What is the **main** setting of antenatal care in your country?

   a) public hospital-based ☐
   b) private hospital-based ☐
   c) non-hospital-based ☐

   In what type of centre are you based? (ie private hospital, public hospital etc)

   .....

   Who is the **main** provider of antenatal care:

	in your country	at your centre
a) obstetrician	☐	☐
b) midwife	☐	☐
c) general practitioner	☐	☐

2. Where do most deliveries in your country occur?

   a) public hospital ☐
   b) private clinic ☐
   c) home ☐
   d) other (please specify) ☐

   .....

   Who is usually responsible?

   a) obstetrician ☐
   b) midwife ☐
   c) general practitioner ☐
   d) other (please specify) ☐

   .....

3. Does your hospital act as a referral centre? YES ☐ NO ☐

If yes, please specify for which conditions:

.....

.....

4. How many births were there at your centre in 1992?

a) < 2,000 ☐
b) 2,000 - 3,000 ☐
c) >3,000 ☐

5. What percentage of births in 1992 were delivered by Caesarean section? _____%

The following questions concern antenatal care:

6. For which infectious diseases do you screen in the antenatal period?

	all women	on request	selected groups (please specify)
a) rubella	☐	☐	☐ .....
b) syphilis	☐	☐	☐ .....
c) hepatitis B	☐	☐	☐ .....
d) cytomegalovirus	☐	☐	☐ .....
e) toxoplasmosis	☐	☐	☐ .....
f) other(s) (please specify)			
.....	☐	☐	☐ .....
.....	☐	☐	☐ .....
.....	☐	☐	☐ .....

7. Do you offer antenatal testing for HIV infection? NO ☐ YES ☐

If yes, is it offered to:

a) all women ☐
b) on request only ☐
c) to selected groups (please specify): ☐

.....

8. How is consent for HIV testing obtained?

a) written consent ☐
b) verbal consent ☐

Who obtains consent? (eg trained counsellor, obstetrician)

.....

9. Is pre-HIV test counselling offered at your centre? NO ☐ YES ☐

If yes, please specify who does it (eg a trained counsellor):

.....

10. How many HIV infected pregnant women were seen in your centre in 1992? _____

11. Please specify the **main** mode of transmission in this HIV infected population:

a) intravenous drug use ☐
b) heterosexual contact in a country with high HIV prevalence ☐
c) heterosexual contact in a country with low HIV prevalence ☐
d) transfusion recipient ☐
e) other (please specify ☐

.....

12. Do you have local guidelines for the care and management of HIV infected women? NO ☐ YES ☐

If yes, please could you enclose a copy.

13. Is there formal training for hospital staff in the management of HIV infected women? NO ☐ YES ☐

If yes, please specify: .....

.....

14. From which centres have your HIV infected pregnant women been referred? **(please tick all that apply)**

a) infectious diseases clinic ☐
b) drug users' clinic ☐
c) genito-urinary medicine clinic ☐
d) general practitioner unit ☐
e) community health centre ☐
f) first identified in this centre ☐

15. Who provides information and counselling about HIV infection in pregnancy and vertical transmission for those identified as HIV infected? **(please tick all that apply)**

a) obstetrician ☐
b) midwife ☐
c) general practitioner ☐
d) infectious disease specialist ☐
e) trained counsellor ☐
f) other(s) (please specify) ☐

.....

.....

16. Please describe the routine follow-up schedule for HIV infected pregnant women (for instance, intervals between visits):

.....

.....

17. Is this routine schedule different for uninfected women? NO ☐ YES ☐

If yes, please specify: .....

.....

18. Do you have special antenatal facilities for HIV infected pregnant women? NO ☐ YES ☐

If yes, please specify: .....

.....

19. Do you perform prenatal diagnostic procecdures such as chorionic villous sampling, amniocentesis or cordocentesis on HIV infected pregnant women?

Never ☐ Rarely ☐ Always ☐

20. If HIV status is unknown, do you perform an HIV test prior to invasive prenatal diagnostic procedures, such as chorionic villous sampling, amniocentesis or cord blood sampling?

always	never	for selected groups (please specify)
☐	☐	.....
☐	☐	.....
☐	☐	.....
☐	☐	.....
☐	☐	.....

21. Which of the following procedures do you **routinely** perform on HIV infected pregnant women?

	YES	NO
a) ultrasound examination (if yes, please specify how many) _____	☐	☐
b) echocardiography	☐	☐
c) Doppler ultrasound scan	☐	☐
d) colposcopy	☐	☐
e) antenatal cardiotocography	☐	☐

f) other(s) (please specify): .....

The following questions concern labour:

22. Does your centre have a separate labour room for HIV infected pregnant women? YES ☐ NO ☐

23. Which of the following methods of induction of labour do you use for HIV infected women at your centre?

a) extra-amniotic prostaglandin ☐
b) oxytocin ☐
c) cervical ripening ☐
d) none of the above ☐
e) other ☐

(please specify) .....

24. Is this similar for non-infected women? YES ☐ NO ☐

If no, please specify: .....

.....

25. Do you routinely perform the following procedures?

	HIV infected women YES	HIV infected women NO	uninfected women YES	uninfected women NO
a) amniorexis	☐	☐	☐	☐
b) scalp electrodes	☐	☐	☐	☐
c) episiotomy	☐	☐	☐	☐

26. Do you ever use the following for HIV infected women?

	frequently	occasionally	never
a) forceps	☐	☐	☐
b) vacuum extractor	☐	☐	☐

27. Do you perform any of the following procedures specifically to try to reduce vertical transmission?

	YES	NO
a) Treatment with antiviral drugs during pregnancy?	☐	☐
If yes, please specify:		
.....		
Has your policy changed recently?	☐	☐
If yes, please give details:		
.....		
b) Cleansing of the birth canal	☐	☐
If yes, please specify:		
.....		
c) Elective Caesarean section	☐	☐
If yes, please specify:		
.....		
d) Do you advise women to avoid breastfeeding?	☐	☐

28. Is there a policy regarding deliveries for women who are current intravenous drug users?

a) avoid C-section ☐
b) recommend C-section ☐
c) no different policy ☐
d) other procedures ☐

(please specify) .....

.....

The following questions concern the postnatal period:

29. Do you routinely wash the neonates born to:

	YES	NO
a) HIV infected women	☐	☐
b) uninfected women	☐	☐

If yes, when? .....

30. How many days does a woman usually remain in hospital after:

	HIV infected women	uninfected women
a) vaginal delivery	_____ days	_____ days
b) C-section delivery	_____ days	_____ days

31. Are there extra consultations with the obstetrician planned after delivery for HIV infected women? YES ☐ NO ☐

32. To which clinical specialist do you refer HIV infected women for follow-up?

.....

33. Would you consider being part of a future European trial evaluating methods aiming to reduce vertical transmission?

YES ☐ NO ☐ MAYBE ☐

Please feel free to write any additional comments here:

Name and address of respondent

Name: .....

Position: .....

Address: .....

.....

.....

.....Post code: .....

Telephone number: .....

Fax number: .....

Thank you for your cooperation in completing this questionnaire.

Please return to:

Dr M-L Newell & Dr G Scaravelli
Dept of Epidemiology
Institute of Child Health
30 Guilford Street
London WC1N 1EH

Tel: +44 71 242 9789/829 8699

Fax: +44 71 831 0488
813 8233

Appendix 3.3 Participants in the 1994 and 1997 obstetric surveys

The Management of Pregnancy and Delivery in HIV-infected Women in Europe (1994)

Univ. Prof. Dr. Otto Dapunt, Universitatsfrauenklinik Innsbruck, Austria

Univ. Prof. Dr. A. Staudach, Frauenklinik Salzburg, Austria.

Univ. Prof. Dr. Peter Husslein, Frauenklinik fur Geburtshilfe und Gynakologie, Vienna, Austria.

Dr Marleen Temmerman, Universitair Ziekenhuis R.U.G., Ghent, Belgium.

Dr H. Thoumsin, Universite de Liege, Liege, Belgium.

Dr G Donders, University Hospital, Leuven, Belgium.

Dr. W. Foulon, A.Z.V.U.B., Brussels, Belgium.

Dr P. Barlow, Hospital St Pierre, Brussels, Belgium.

Prof P. Buytaert, University Hospital Antwerp, Edegem, Belgium.

Prof Todor Chernev, University Ob/Gyn Hospital "Maichin dom", Sofia, Bulgaria.

Dr M Olofsson, Hvidovre Hospital, University of Copenhagen, Denmark.

Dr Jorma Paavonen,University of Helsinki, Finland.

Dr L Mandelbrot, Hôpital Port-Royal, Paris, France.

Dr M. Leclaire, Hôpital de la Conception, Marseille, France.

Prof. A. Berrebi, Hôpital de la Grave, Toulouse, France.

Prof. Jean-Yves Gillet, Hôpital Saint-Roch, Nice, France.

Dr A. Schäfer, Frauenklinik der Freien Universitat Berlin, Germany.

Prof. Dr. Dr. E.R. Weissenbacher, Ludwig-Maximillians-Universitat Munchen, Germany.

Prof. Dr. M. Stauber, I. Frauenklinik der Universitat Munchen, Germany.

Dr S von Eckardstein, University Hospital of Dusseldorf, Germany.

Prof. Dr. E.-J. Hickl, Frauenklinik Finkenau, Hamburg, Germany.

Prof. S.P. Michalas, Hellenic Obstetrical and Gynecological Society, Athens, Greece.

Dr Ferenc Hamvas, Szuleszeti-Nogyogyaszati Osztaly, Budapest, Hungary

Dr Thora Fischer, Landspitalinn, National University Hospital, Reykjavik, Iceland.

Dr Michael Darling FRCOG, Master, Rotunda Hospital, Dublin, Ireland.

Professor Jenkins, Erinville Hospital, Cork, Ireland.

Prof J Schenker, Hadassa University Hospital, Jerusalem.

Prof. A Pachí, Policlinico Umberto I, Rome, Italy.

Dr. B. Guerra, Policlinico S. Orsola, Via Massarenti 13, Bologna, Italy.

Professor G. Pardi, Ospedale S. Paolo, Milan, Italy.

Dr M. Muggiasca, Ospedale L. Sacco, Milan, Italy.

Prof. L. Selvaggi, Clinica Ostetrica e Ginecologica, Universita', Bari, Italy.

Dr M De Santis, Universita Cattolica Del Sacro Cuore, Rome, Italy.

Prof M. Brincat, University of Malta, Malta.

Dr K. Boer, Academisch Medisch Centrum, Amsterdam, The Netherlands.

Prof.dr. H.P. van Geijn, Academisch Ziekenhuis Vrije Universiteit, Amsterdam, The Netherlands.

Prof.dr. H.C.S. Wallenburg, Academisch Ziekenhuis Rotterdam/ Dijkzigt, Rotterdam, The Netherlands.

Prof. Babill Stray-Pedersen, Aker University Hospital, Oslo, Norway.

Dr U. Kirst, Ulleval University Hospital, Oslo, Norway.

Prof.B.Chazan and Dr. Tomasz Niemiec, National Research Institute of Mother and Child, Warsaw, Poland.

Dr Oriol Coll, Hospital Clinic, University of Barcelona, Barcelona, Spain.

Prof L Cabero-Roura, Hospital Vall d'Hebon, Barcelona, Spain.

Dr V. Maiques-Montesinos, Hospital La Fe, Valencia, Spain.

Dr A Herruzo, Hospital Virgen de las Nieves, Granada, Spain.

Dr I. Bates, Hospital La Paz, Madrid, Spain.

Dr Klas-Henry Hökegård, Ostra Sjukhuset, Göteborg, Sweden.

Dr. S. Lindgren, Huddinge Hospital, Huddinge, Sweden.

Prof. Dr. Albert Huch, Universitatsspital, Zurich, Switzerland.

Prof. H. Schneider, Universitäts-Frauenklinik, Bern, Switzerland.

Prof. Dr. F. Béguin, Hopital Univ. Maternite, Geneva, Switzerland.

Ms Sandra Dick, St Mary's Hospital, London, UK.

Mr Richard Smith, Chelsea and Westminster Hospital, London, UK.

Mr P. Vinall, Leeds General Infirmary, Leeds, UK.

Dr. Rob Smith, Ninewells Hospital, Dundee, UK.

Dr Frank Johnstone, Royal Infirmary of Edinburgh, UK.

The use of therapeutic and other interventions to reduce the risk of mother-to-child transmission of HIV-1 in Europe (1997)

Univ. Prof. P. Husslein, University Hospital of Vienna, Austria.

Dr R. Klieber, University of Innsbruck Hospital, Austria.

Dr P. Barlow, Hospital St Pierre, Brussels, Belgium.

Dr M.Temmerman, University Hospital, Ghent, Belgium.

Dr G. Donders, University Hospital Gasthuisberg, Leuven, Belgium.

Dr W.Foulon, Akademisch Ziekenhuis V.U.B., Brussels, Belgium.

Prof. H.Thoumsin, Université de Liège, Hôpital de la Citadelle, Liege, Belgium.

Prof. T.Chernev, University Ob/Gyn Hospital "Maichin Dom", Sofia, Bulgaria.

Dr N.Valerius, Hvidovre Hospital, University of Copenhagen, Denmark.

Dr J.Paavonen, University Hospital of Helsinki, Finland.

Dr A.Berrebi, Hôpital la Grave, Toulouse, France.

Prof J.Y. Gillet and Dr A.Bongain, Centre "Femme-Mère Enfant", Nice, France.

Dr L.Mandelbrot, Hôpital Port Royal, Paris, France.

Dr M.Leclaire, Maternite Hôpital Conception, Marseille, France.

Dr A.Schaefer, Humboldt-University of Berlin, Germany.

Dr R. Lutz-Friedrich, Frauenklinik, University of Munich, Germany.

Dr E-M.Baumgartner, Frauenklinik Finkenau, Hamburg, Germany.

Dr D.Bánhegyi, Saint Lasló Hospital, Budapest, Germany.

Prof. D.Jenkins, Erinville Hospital, Cork, Ireland.

Dr M.Darling, Rotunda Hospital, Dublin, Ireland.

Prof. G.Pardi and Dr A.E.Semprini, San Paolo Biomedical Institute, Milan, Italy.

Dr G.Scaravelli, University Hospital "La Sapienza", Rome, Italy.

Dr B.Guerra, Hospital S.Orsola, Bologna, Italy.

Prof. L. Selvaggi, Clinica Ostetrica e Ginecologica, Universita', Bari, Italy.

Dr M.L.Muggiasca, Hospital L.Sacco, Milan, Italy.

Dr K.Boer, Academic Medical Centre, Amsterdam, The Netherlands.

Dr H.Wallenburg, Erasmus University, Rotterdam, The Netherlands.

Prof.Dr H. van Geijn, Academic Hospital, Vrije Universiteit, Amsterdam, The Netherlands.

Dr B.Stray-Pedersen, National Hospital, Oslo University, Norway.

Dr T.Niemiec, National Research Institute of Mother and Child, Warsaw, Poland.

Dr R. de la Torre and Dr V.Maiques Montesinos, University Hospital "La Fe", Valencia, Spain.

Dr A.Hurruzo, University Hospital "Virgen del las Nieves", Granada, Spain.

Dr I. Bates, Hospital "La Paz", Madrid, Spain.

Dr O.Coll, Hospital Clinic, Barcelona, Spain.

Dr A. Paya, Hospital del Mar, Barcelona, Spain.

Dr S. Lindgren ,Huddinge Hospital, Huddinge, Sweden.

Dr G.Lidin-Janson and Dr R-M.Holst, Östra Hospital, Göteborg, Sweden.

Dr R.Smith, Ninewells Hospital, Dundee, UK.

Dr F.Johnstone, Simpson Memorial Maternity Pavilion, Edinburgh, UK.

Mr R.Smith, Chelsea & Westminster Hospital, London, UK.

Ms S.Dick, St Mary's Hospital, London, UK.

Mr P.Vinall, Dr J.Wilson and Dr M.Reynolds, The General Infirmary at Leeds, UK.

Appendix 3.4 1997 Obstetric Survey Questionnaire

A SURVEY TO ASSESS POLICY AND PRACTICE OF THERAPEUTIC AND SURGICAL INTERVENTIONS TO REDUCE THE RISK OF VERTICAL TRANSMISSION OF HIV-1 IN EUROPE

Please answer as many of the following questions as possible, by ticking the appropriate box and/or writing your response in the space provided.

1. What is the **antenatal screening policy** for HIV-1 in your centre?

   a) No policy ☐

   b) Universal (test offered to all women) ☐

   c) Test offered to women perceived to be at increased risk eg. injecting drug users. **Please specify:** ☐

   .....

   .....

2. How many **births** took place at your centre in:

   1994? .....

   1995? .....

   1996? .....

3. **How many** HIV infected women whose pregnancy went to term were identified in your centre in 1994, 1995, 1996?

   1994? .....

   1995? .....

   1996? .....

THE MANAGEMENT OF PREGNANCY IN HIV-1 INFECTED WOMEN

Therapeutic Interventions

4a. When was zidovudine to reduce the risk of vertical transmission **licensed** for use in your country? *(eg. November 1994)*

.....

4b. Are HIV infected women in your unit offered **zidovudine** to reduce the risk of vertical transmission?

No ☐

Yes ☐ **If yes**, please provide details of **usual** regimen:

Pregnancy from ..... weeks

Labour oral ☐ intravenous ☐

Neonate for how long? .....

4c. Are **other anti-retroviral drugs** prescribed in addition to zidovudine?

No ☐

Yes ☐ **If yes**, please specify **which** *(eg 3TC, ddC, Protease inhibitor, ddI)*, **when** it is given and **how** it is administered?

.....

.....

4d. Do **most** women receive:

a) the full regimen ☐

b) part of the regimen ☐ **Please specify which part:**

.....

.....

.....

4e. What proportion of women currently receive zidovudine to reduce vertical transmission?

a) all ☐

b) approximately 3/4 ☐

c) approximately 1/2 ☐

d) approximately 1/4 ☐

e) none ☐

4f. Please could you specify why some women do not receive zidovudine (eg. refusal of therapy, booked too late etc).

.....

.....

5. **After the delivery**, what is the drug-treatment policy for the women?

a) zidovudine therapy discontinued ☐

b) zidovudine therapy continued ☐

c) combination therapy started ☐ **Please specify:**

.....

.....

Other Interventions

6.a Are **all** HIV infected women **routinely** offered an **elective caesarean section** (CS) delivery?

Yes ☐ No ☐

If yes, when was this policy introduced and **why**?

.....

.....

If no, is an elective CS offered to a **subset** of HIV infected women?

No ☐

Yes ☐ **please specify:** .....

6b. What percentage of total births in your centre are currently delivered by elective caesarean section delivery?

..... %

7. Is there a policy of **routinely** cleansing the vagina and cervix specifically for HIV infected women?

No ☐

Yes ☐ **If yes**, please specify **what agent** you use and **when** you carry out the cleansing:

.....

.....

8. Does your centre collaborate in a **trial** investigating interventions to reduce vertical transmission?

No ☐

Yes ☐ **please specify:** .....

Name and address of respondent

Name: .....

Address: .....

.....

.....

.....

Tel: ..... Fax: .....

Thank you for your co-operation in completing this questionnaire. If you have any additional comments, please feel free to include them.

Please return to:
Dr Marie-Louise Newell,
Department of Epidemiology, Institute of Child Health,
30 Guilford Street, London WC1N 1EH. United Kingdom.
Tel: +44 171 829 8699 Fax: +44 171 831 0488

Appendix 3.5 Participating centres in the "Children and Families Affected by HIV: A European Perspective" service-provider and service-user surveys

Academisch Ziekenhuis by de Universiteit van Amsterdam, Academisch Medisch Centrum, Amsterdam, The Netherlands **Dr H Scherpbier, M Kreyenbroek, T Kosters.**

Great Ormond Street Hospital for Children, London, UK **Dr D Gibb, S Trickett, M Clapson.**

City Hospital, Edinburgh, UK **Dr J Mok, F Mitchell, J Morkis, C Smith.**

Huddinge Hospital, Huddinge, Sweden **Dr AB Bohlin, J Crafoord, A-B Bengtsson**

Danderyd Hospital, Danderyd, Sweden **Dr E Belfrage, A-S Asander**

University Children's Hospital of Zurich, Zurich, Switzerland **Dr D Nadal, Dr T Stricker, R Baumann**

Hospital St. Pierre, Brussels, Belgium **Dr J Levy, Dr A Alimenti, M-C Lecroart, M-N Vanderhofstadt**

Universita Degli Studi di Padova, Instituto di Clinica Pediatrica, Padova, Italy. **Dr C Giaquinto, Dr S Girotto, S Oletto, S Casella, L Zerbinati**

Clinica Pediatrica, Cattedra di Pediatria, Universita delgi Studi di Brescia, Italy. **Dr M Duse, Dr A Soresina, D Aimo.**

Ospedale L. Sacco, Milan, Italy. **Dr P Marchisio, E Preatoni**

Ospedale Policlinico S.Orsola, Bologna, Italy **Dr P Dallacasa, Dr G. Missiroli, Dr D Cavallo, C Bulgarelli**

Hospital de D. Estefânia, L222isbon, Portugal. **Dr L Rosado, Dr ML Rolo Duarte**

Hospital del Mar, Barcelona, Spain. **Dr A Mur, Dr O Valle**

Hospital Materno Infantil 'La Paz', Madrid, Spain. **Dr MC Garcia Rodriguez, Dr I de Jose, Dr F Hawkins**

Medizinische Fakultät der Humbolt-Universität zu Berlin, Germany. **Dr I Grosch-Wörner, A Runde**

Parent representatives attending the workshop in April 1997:

P Garriga, ACTUA, Barcelona, Spain; **C Rakas,** c/o European Forum on HIV/AIDS, Children and Families, London

Appendix 3.6 "Children and Families Affected by HIV" service-provider questionnaires

Medical Services Questionnaire

Respondent information

Name of respondent: .....

Position held: .....

Centre: .....

Clinic Information

1. In what type of hospital is your centre? *(please tick all that apply)*

   a) public hospital ☐
   b) university hospital ☐
   c) private ☐
   d) general hospital ☐
   e) children's hospital ☐

2. Approximately what proportion of your time is spent in:

   a) research-associated work? .....

   b) routine clinical service? .....

3.a How is your work funded? (eg. government, private organisation, EU etc)

   a) clinical work

.....

.....

.....

   b) research work

.....

.....

3.b Does your clincal contract cover a specified period?

a) No - I am in a permanent position ☐

b) Yes ☐ *Please specify how long:* .....

3.c Which of the following does your research funding cover? *(please tick all that apply)*

a) specific projects with limited duration ☐

b) general longer-term research ☐

c) no research funding available ☐

d) other *(please specify)*

.....

4.a How often do you use funding for routine clinical work to pay for research work?

Never	Sometimes	Often
☐	☐	☐

4.b How often do you use funding for research work to pay for routine clinical work?

Never	Sometimes	Often
☐	☐	☐

5. Where are HIV infected children (and children born to HIV infected women with indeterminate HIV status) seen for their medical care in your hospital? (eg paediatric HIV outpatient unit, general paediatrics department, paediatric infectious diseases unit)

.....

6. Is there an adult HIV clinic in the hospital?

a) Yes ☐ *(please go to next question)*

b) No ☐ *(please go to question 9)*

7. Do you try to co-ordinate clinic appointments for children and HIV-infected parents so that they take place at the same time, if required?

Yes ☐ No ☐

8. Are the adult HIV clinic and the paediatric HIV clinic (or wherever HIV affected children are seen) in close physical proximity to each other (eg same building within the hospital)?

Yes ☐ No ☐

Referrals and Access to Clinic

9. Are HIV infected pregnant women attending the hospital for antenatal care **routinely** seen by any members of the paediatric clinic team during their pregnancy (eg. to provide information on paediatric HIV infection and the clinic facilities available)?

Yes ☐ No ☐ Not applicable ☐

If yes, which of the following members of the team participate. *(Please tick all that apply)*

a) paediatrician ☐
b) HIV counsellor ☐
c) psychologist ☐
d) health educator ☐
e) social worker or equivalent ☐
e) other *(please specify)*.....

.....

10. How frequently are referrals of children to the paediatric HIV clinic made from or by the following:

	Never	Sometimes	Frequently
a) obstetrics department within the hospital	☐	☐	☐
b) adult HIV unit within the hospital	☐	☐	☐
b) other hospitals	☐	☐	☐
c) the community (eg by community physicians)	☐	☐	☐
d) other *(please specify)*			
.....	☐	☐	☐
.....	☐	☐	☐

11. Can parents and other carers bring their child to the clinic for the first time without being referred by a health or social care professional?

Yes ☐ No ☐ Don't know ☐

12. Are parents and carers encouraged to phone the clinic if they have any questions or problems?

Yes ☐ No ☐ Don't know ☐

13. How frequently is the paediatric HIV outpatient clinic open outside normal working hours, for example, in the evening or at the weekend?

a) never ☐
b) at least once per week ☐
c) at least once per month ☐
d) other *(please specify)* ☐

.....

14. Is there access to emergency medical care for infected children at all times (24 hours/day)?

a) No ☐
b) Yes - general emergency medical care only ☐
c) Yes - general paediatric emergency medical care ☐
d) Yes - there is always a member of the clinic team on call for emergencies involving HIV infected children ☐
e) Yes - other *(please specify)* ☐

.....

.....

15. Do some parents/carers travel long distances in order to bring their children to the clinic?

Yes ☐ No ☐ Don't know ☐

If yes, please could you indicate the reasons for this. *(tick all that apply)*

a) not known ☐
b) they have no appropriate local services ☐
c) they believe that confidentiality may be under threat if they use local medical services ☐
d) they consider your centre to be the best ☐
e) other *(please specify)* ☐

.....

.....

16. Do parents have any help in paying for their travel costs?

Yes ☐ No ☐

Clinic Staff and Facilities

17. Approximately how many children per week are seen on average in the outpatient paediatric HIV clinic? *(a range may be given, eg. 5-10)*

.....

18. Which medical specialist has the main responsibility for running the paediatric HIV day hospital / outpatient clinic?

a) paediatric infectious diseases specialist ☐
b) general paediatrician ☐
c) neonatologist ☐
d) other *(please specify)*

.....

19. For the next question I would like to know who works in the paediatric HIV clinic (ie. how many paediatricians, psychologists etc). Please could you write down whether they only work with children and families affected by HIV or not, and whether they work full-time or part-time.

Staff member	**Exclusively in HIV?**	**Full-time/part-time?**
eg. 3 paediatricians	*2:work exclusively in HIV* *1:works in other areas too*	*3: full-time workers*
.....		
.....		
.....		
.....		
.....		
.....		
.....		
.....		
.....		
.....		

20. Can children be seen by the same doctor every time they have an appointment, if they or their parents/carers wish?

Yes ☐ No ☐

21. How is continued contact with families maintained? *(please specify all that apply)*

a) regular appointment schedule ☐
b) appointment reminders ☐
c) through liaison with community medical staff ☐
d) reminders if appointments are missed ☐
e) other *(please specify)*

.....

.....

.....

22. Is there a dental service provided for children:

a) at the paediatric HIV clinic Yes ☐ No ☐

b) elsewhere in the hospital Yes ☐ No ☐

If there is no dental service at the hospital, do you provide parents/carers with the names and addresses of recommended dentists in the local area?

Yes ☐ No ☐

23. Which of the following facilities are provided at the clinic?

a) play area ☐
b) play assistant ☐
c) toys and games ☐
d) waiting room ☐
e) private consultation rooms ☐
f) free food ☐
g) others *(please specify)* ☐

.....

.....

Information Provision

24. Please could you specify which staff (eg paediatrician, social worker) provide information to parents/carers on the following:

a) general information on clinic facilities and services (eg. follow-up schedule, who to contact in an emergency)

.....

.....

b) HIV-specific information (eg. how HIV is transmitted, how to prevent transmission, diet and hygiene)

.....

.....

c) community health and social services (eg. support groups, helplines etc.)

.....

.....

25. Is written information (eg leaflets) available for parents/carers to take home?

a) Yes ☐
b) No ☐

If yes, is this information available in other languages? Yes ☐ No ☐

26. In your experience, how frequently do parents/carers ask for leaflets and other written information to take home?

Never	Sometimes	Often
☐	☐	☐

27. Do you have available at the clinic any books or leaflets on HIV infection, which have been written specifically for children?

Yes ☐ No ☐

In-Patient Care

28. Does the outpatient clinic team play a part in the inpatient care of children who have been attending the paediatric HIV clinic (for example, in making decisions about their treatment)?

Yes ☐ No ☐

If No, how is continuity of care maintained for children who have been attending the outpatient clinic when they are admitted as inpatients?

.....

.....

.....

29. In which of the following wards may HIV infected children be cared for when they are admitted to hospital? *(please specify all that apply)*

a) general paediatric ward ☐
b) paediatric infectious diseases ward ☐
c) paediatric HIV ward ☐
d) infectious diseases ward ☐
e) HIV ward ☐
f) other *(please specify)* ☐

.....

.....

30. If both a parent and their child are admitted to hospital at the same time, can they be cared for in the same ward? (eg family unit)

Yes ☐ No ☐

Community Medical Services

31. What proportion of the children attending the clinic also receive community-based physician care (eg. community paediatrician, general practitioner)?

All ☐ Some ☐ None ☐

32. Is there a **formal** system in place for the continuity of care for children whose care is shared between the paediatric HIV clinic and community health services (eg. case management or community liaison nurses)?

a) No ☐
b) Yes ☐ *(pleasespecify)*.....

.....

.....

33.a Does the clinic have a policy regarding referring uninfected children born to HIV infected mothers to community-based physician care?

Yes ☐ No ☐

33.b When is it policy/practice to refer uninfected children born to HIV infected mothers to community-based physician care?

a) as soon as they are identified as uninfected ☐
b) once they reach a certain age ☐ ..... years
c) only in the absence of medical or psychosocial problems ☐
d) parental request ☐
e) there is no specific policy ☐

f) other *(please specify)* .....

34. Is home-based paramedical care available in your local area?

a) No ☐ *(please go to question 35)*
b) Yes ☐ *(please go to next question)*

35. Is home-based paramedical care only provided for infected children? Yes ☐ No ☐

36. Which of the following types of home-based paramedical care are available? *(please specify whether the service is provided by governmental, non-governmental or voluntary organisations)*

	None	Governmental	Non-governmental	Voluntary
a) community nursing	☐	☐	☐	☐
b) parenteral nutrition	☐	☐	☐	☐
c) physical therapy	☐	☐	☐	☐
d) other *(please specify)*				
.....	☐	☐	☐	☐
.....	☐	☐	☐	☐

37. What proportion of the children attending the clinic receive home-based paramedical care?

All ☐ Some ☐ None ☐

If you answered "Some" or "None", why don't more children receive home-based paramedical care, in your opinion?

.....

.....

38.a Is home terminal care for children available in your local area?

Yes ☐ No ☐

If yes: who is this provided by? *(please tick all that apply)*

a) governmental organisations ☐
b) non-governmental organisations ☐
c) voluntary organisations ☐

38.b Is hospice terminal care for children available in your local area?

Yes ☐ No ☐

If yes: who is this provided by? *(please tick all that apply)*

a) governmental organisations ☐
b) non-governmental organisations ☐
c) voluntary organisations ☐

Legal issues, consent and confidentiality

39. Who advises the clinic team on the ethical and legal problems relating to the care and testing of HIV infected children and their families?

a) no-one ☐
b) hospital ethics committee ☐
c) national AIDS ethics committee ☐
d) a medical lawyer ☐
e) a judge ☐
f) other *(please specify)*

.....

40. Who in the hospital is aware of child care laws and legislation?

.....

.....

41. Before giving a child a test or medical treatment, who are you obliged **always** to ask for consent from? *(please specify what should happen in principle and what you do in practice)*

	In principle	In practice
a) one parent	☐	☐
b) both parents	☐	☐
c) the child (depending on age)	☐	☐
d) the parents and the child	☐	☐

42. Before giving a child a test or medical treatment, which of the following are you obliged to **always** inform? *(please specify what should happen in principle and what you do in practice)*

	In principle	In practice
a) one parent or carer	☐	☐
b) both parents	☐	☐
c) the child (depending on age)	☐	☐
d) the parents and the child	☐	☐

43. Does your centre have a protocol or guidelines, specifying situations and cases where consent need not be obtained prior to testing and interventions?

a) No ☐

b) Yes ☐ *(please specify)* .....

.....

If no, is it accepted practice that such situations/cases exist? Yes ☐ No ☐

44. In your country, at what age is an adolescent legally entitled to request an HIV test, without the consent or knowledge of his or her parents:

a) in practice ..... years

b) in law ..... years

45.a If a sick child, identified as HIV infected, is the first indication of HIV infection in the family, are there set policy guidelines concerning the counselling and testing of the parents and other children?

a) No ☐

b) Yes ☐ *please specify:* .....

.....

45.b What do you do in practice?

.....

.....

46. Does the clinic follow a **written** policy on confidentiality?

Yes ☐ No ☐

If no, is this considered unnecessary, since staff are bound by professional rules of conduct, including confidentiality?

Yes ☐ No ☐

47. Is the confidentiality policy explained to **all** parents/carers?

Yes ☐ No ☐

Thank you very much for your co-operation in answering these questions

Psycho-social Services Questionnaire

Name of respondent: .....

Position:.....

Centre:.....

CLINIC-BASED PSYCHO-SOCIAL SERVICES AND ACTIVITIES

1. Are you:

   a) a social worker ☐
   b) a social nurse ☐
   c) a psychologist ☐
   d) an HIV counsellor ☐
   e) other *(please specify)* .....

2. Where do you work? *(please tick all that apply)*

   a) centre for paediatric infectious diseases in a paediatric clinic ☐
   b) paediatric HIV clinic ☐
   c) adult HIV clinic ☐
   d) in the community ☐
   e) other *(please specify)*

   .....

   .....

3. Which of the following staff members are involved in psycho-social support activities for HIV affected families at the clinic?

   a) social worker/assistant ☐
   b) social nurse ☐
   c) psychologist ☐
   d) HIV counsellor ☐
   e) paediatrician ☐

   f) other *(please specify)*.....

   .....

4. Are there regular meetings attended by the psycho-social and medical staff of the paediatric HIV clinic to discuss particular cases and other clinic matters?

a) No ☐

b) Yes ☐ *Please specify how often these meetings are held* .....

.....

5. Which of the following staff members attend these regular meetings?

a) social worker/assistant ☐

b) social nurse ☐

c) psychologist ☐

d) paediatrician ☐

e) other *(please specify)* .....

.....

6.a Which of the following people affected by HIV do you care for? *(please tick all that apply)*

a) perinatally exposed children

infected ☐

uninfected ☐

b) other infected children ☐

c) uninfected children with infected siblings and/or parents ☐

d) parents/carers

infected ☐

uninfected ☐

e) infected adults with no children ☐

6.b With which of the above groups do you work with primarily?

.....

.....

7. Which of the following policies for psycho-social assessment and support of families is followed at the clinic?

a) all families should be seen by a psycho-social worker at least once ☐

- *social worker/nurse/assistant* ☐
- *psychologist* ☐
- *both* ☐

b) assessment is only required if requested by the family ☐

c) there is no routine psycho-social assessment of families ☐

d) other .....

8. For each family attending the clinic, do you try to see:

a) parents/carers and children both separately and together ☐

b) parents/carers and children separately ☐

c) parents/carers and children together ☐

d) people from the family's support network ☐
(eg extended family, friends, neighbours)

e) other .....

9. How is the initial psycho-social session organised?

.....

.....

.....

.....

10. How is psycho-social follow-up organised?

a) follow-up schedule with appointment system ☐

b) reminders if appointments are missed ☐

c) arrange for follow-up session to immediately follow next appointment with paediatrician ☐

d) no appointment system, but a psychosocial worker is always available at the clinic if required ☐

e) other *(please specify)*

.....

.....

11. Have you experienced problems in maintaining psycho-social follow-up of families?

Yes ☐ *(please go to question 11.a)* No ☐ *(please go to question 12)*

11.a Can you suggest why maintaining psycho-social follow-up is difficult?

.....

.....

.....

.....

12. How frequently do you visit HIV affected families at their homes?

Never	Sometimes	Often
☐	☐	☐

12.a Do any other psycho-social clinic staff visit families at their homes?

Yes ☐ No ☐

If yes, who?

.....

.....

<u>Psychological services and activities</u>

13. Are you involved in the psychological care of clinic attenders? Yes ☐ No ☐

If yes: Do you consider your expertise to be in the psychological care of:

a) children ☐
b) adults ☐
c) both children and adults ☐

14. Please could you specify the approximate proportion of families attending the paediatric HIV clinic who attend:

a) no psychological sessions .....

b) only one psychological session .....

c) more than one psychological session .....

15. Is there a regular support (self help) group for parents/carers at the clinic or organised by the clinic psycho-social staff?

Yes ☐ *(please go to question 16)* No ☐ *(please go to question 15.a)*

15.a Has there ever been an attempt to run a support group at the hospital?

No ☐ *(please go to question 16)*

Yes ☐ Why do you think the attempt was unsuccessful?

.....

.....

.....

16. Are there support/self help groups in the community which parents/carers can be referred to?

a) Yes - in most areas ☐
b) Yes - but only in some areas ☐
c) No ☐
d) Don't know ☐

17. Do you provide psychological support for medical and nursing staff working with families affected by HIV at the hospital?

Yes ☐ What kind of support do you provide? (informal/formal, regular or only on demand?)

.....

.....

No ☐ Is this sort of psychological support provided by anyone else?

No ☐

Yes ☐ Who? .....

18. For each of the following activities, please could you say whether they are part of the clinic's work with HIV affected families, whether you are involved in these activities and which other staff are involved:

	Clinic work	Respondent's work	Who else?
a) child development assessment - *for infected children*	☐	☐	.....
- *for uninfected children*	☐	☐	.....
b) helping and advising parents/carers regarding children's behavioural, psychological and relationship problems	☐	☐	.....
c) providing interventions (therapy, counselling etc) for children with behavioural, psychological and relationship problems	☐	☐	.....
d) helping and advising parents/carers regarding disclosure of their positive serostatus and/or that of their child	☐	☐	.....
e) helping children come to terms with their own infection status and/or that of their parents	☐	☐	.....
f) counselling in preparation for and following death in the family			
- *for parents/carers*	☐	☐	.....
- *for children*	☐	☐	.....
g) general counselling (guilt, isolation, relationship problems etc)			
- *for parents/carers*	☐	☐	.....
- *for children*	☐	☐	.....

h) other *(please specify)*

.....

.....

Social support services and activities

19. What proportion of families attending the clinic are seen **regularly** by the social worker/nurse/assistant?

All ☐ Some ☐ None ☐

20. For each of the following areas, could you specify whether you and/or other clinic members discuss them with families?

	Respondent	Other staff members:
a) family structure	☐	.....
b) social problems		
-employment	☐	.....
-housing conditions	☐	.....
-financial situation	☐	.....
-immigration	☐	.....
-legal problems (prison etc)	☐	.....
c) health problems		
-number of family members infected with HIV and problems relating to their seropositive condition	☐	.....
-parental drug use	☐	.....
-parental alcohol abuse	☐	.....
d) support network structure:		
- *extended family*	☐	.....
- *informal support network (friends, neighbours etc)*	☐	.....
e) the other services/organisations already used by the family	☐	.....
f) other *(please specify)*		

.....

.....

OTHER PSYCHO-SOCIAL SERVICES
Community psycho-social services

21. In your local area, which of the following community-based psycho-social professionals may take care of HIV affected families?

a) community psychologists specialising in HIV ☐
b) community social workers specialising in HIV ☐
c) general community psychologists ☐
d) general community social workers ☐
e) none *(if none go to question 21.a)* ☐
f) don't know ☐
g) other *(please specify)*

.....

21.a *If none,* why is this?

a) all the needs of HIV affected families are satisfied in our centre
b) there are no community services able to offer adequate support
c) families don't ask for support in the community
d) other *(please specify)*

.....

22. Do voluntary associations for the help and support of HIV affected families with children exist in your country?

No ☐
Yes ☐ HIV-specific ☐ Not HIV-specific ☐

23. Is your clinic involved in any joint ventures with local non-governmental organisations, for example, information campaigns, fundraising, developing collaborative activities?

Yes ☐ *(please go to question 23.a)* No ☐ *(please go to question 24)*

23.a Please specify:

.....

.....

.....

Financial support

24. Are the following carers of children affected by HIV are entitled to extra financial support (ie. because of the HIV infection)?

	Yes	No
a) birth parent - HIV-infected	☐	☐
b) birth parent - uninfected	☐	☐
c) foster carer (family)	☐	☐
d) foster carer (non-family)	☐	☐
e) adoptive parent	☐	☐
f) none of the above *(please go to question 24)*	☐	☐

24.a Who provides financial support to these families? *(please tick all that apply)*

a) government ☐
b) non-governmental organisation ☐
c) voluntary organisation ☐
d) other *(please specify)*

.....

.....

24.b Which of the following factors are considered in assessing how much financial support to provide to a family:

a) the infection status of the child ☐
b) the progression of disease in the child/parent ☐
c) care expenses ☐
d) parental/carer income ☐
e) the immigration status of the parent ☐
f) the length of time the child has been cared for (ie. for substitute carers) ☐
g) other *(please specify)*

.....

.....

.....

Housing support

25. What type of housing support is available for families affected by HIV?

a) rent subsidies (grant/allowance) ☐
b) supported accomodation, with medical/child care support ☐
c) state-provided housing ☐
d) NGO-provided housing ☐
e) help in finding accommodation ☐

f) other *(please specify)* .....

.....

.....

Child care

26. When parents/carers are unable to look after their children in acute circumstances, such as hospitalisation, imprisonment, what services exist for the temporary care of their children?

	HIV infected parents with infected child	HIV infected parents with uninfected child	Uninfected parents/ carers with infected child
a) respite foster care	☐	☐	☐
b) temporary admission of child to a residential children's home	☐	☐	☐
c) temporary admission of child to hospital	☐	☐	☐

d) other *(please specify)* .....

.....

.....

27. What respite care services are available to give parents/carers a break from full-time care of their children?

(please specify whether they are provided by governmental, non- governmental or voluntary organisations)

	Not available	Governmental	Non-governmental	Voluntary
a) creche / day nursery	☐	☐	☐	☐
b) day centres for after-school care	☐	☐	☐	☐
c) day centres for child care in school holidays	☐	☐	☐	☐
d) supervised holidays for children	☐	☐	☐	☐
e) boarding school	☐	☐	☐	☐
f) other *(please specify)*				
.....	☐	☐	☐	☐
.....	☐	☐	☐	☐
.....	☐	☐	☐	☐

(If none of the above services are available, please go to question 28)

27.a Are the following services ever provided free of charge to families affected by HIV, and if so, who is eligible for the free services (eg infected parents only, those on welfare only)?

	Free? Yes	Free? No	Who qualifies for free services?
a) creche / day nursery	☐	☐	.....
b) day care after school	☐	☐	.....
c) day care during school holidays	☐	☐	.....
d) supervised holidays	☐	☐	.....
e) boarding school	☐	☐	.....

28. How frequently are you or other clinic staff involved in the planning and/or organisation of social care of HIV infected and affected children attending the clinic?

Never ☐ Sometimes ☐ Often ☐

28.a *If sometimes or often,* what does this involve?

a) talking with parents about options for the social care of their children ☐
b) talking with children about their preferences and experiences ☐
c) helping parents to contact appropriate services (eg lawyers, support organisations) ☐
d) advising child welfare agencies (eg fostering and adoption agencies) ☐
e) reporting to legal authorities (eg juvenile court) ☐ *(go to question 27.b)*
f) other *(please specify)*

.....

.....

.....

28.b What does reporting to the legal authorities involve? *(please tick all that apply)*

a) informing the legal authorities if a child is not being adequately cared for by his parents ☐
b) informing the legal authorities if a child has been abandoned by his parents ☐
c) informing the legal authorities of the death of parents ☐
d) other *(please specify)*

.....

.....

29. In principle, can birth parents specify certain characteristics of their child's prospective adoptive parents, such as religion, cultural background and number of other children?

Yes ☐ *(please go to question 29.a)* No ☐ *(please go to question 30)*

29.a Does this actually happen in practice?

Yes ☐ No ☐

30. Do national and local child care legislation include specific guidelines concerning social aspects of HIV, for example, on HIV testing before placement in foster care or adoption?

	Yes	No	Don't know
a) national	☐	☐	☐
b) local	☐	☐	☐

31. Which of the following people would be informed if a child in their care is HIV infected or has indeterminate HIV status?

(please could you specify what is established in principle and what actually happens in practice)

	In principle	In practice
a) adoptive parent	☐	☐
b) long-term or repeated short-term foster carer	☐	☐
c) short-term foster carer/respite carer	☐	☐
d) day carer (eg childminder)	☐	☐
e) carer in residential children's homes	☐	☐
f) teacher	☐	☐
g) others	☐	☐

32. Which of the following carers would receive general information on hygiene and universal precautions regarding children with HIV?

	In policy	In practice	On demand
a) day carers (eg childminder, nursery assistant)	☐	☐	☐
b) teachers	☐	☐	☐
c) carers in residential children's homes	☐	☐	☐
d) none of the above			

32.a Who is responsible for this information provision and training?

.....

.....

.....

SCHOOL

33. Is the parent / carer of an HIV infected child legally obliged to inform the child's school of the HIV infection?

Yes ☐ No ☐ Don't know ☐

34. Have guidelines on HIV infection and schools been developed by the:

a) Ministry of education

Yes ☐ *(please go to question 34.a)* No ☐ Don't know ☐

b) local education authorities

Yes ☐ *(please go to question 34.a)* No ☐ Don't know ☐

34.a Please specify whether guidelines on the following issues exist for primary and secondary schools.

	Primary schools	Secondary schools
a) specific HIV education programmes for pupils	☐	☐
b) in-service training for all staff members	☐	☐
c) control of confidential information	☐	☐

35. Does legislation exist declaring that HIV infected children should not be excluded from:

a) access to school	Yes ☐	No ☐
b) participation in any school activities	Yes ☐	No ☐

36. Prior to informing a teacher about the infection status of a child, are you obliged to ask for authorization from:

	In principle	In practice
a) one parent (birth or adoptive)	☐	☐
b) both parents (birth or adoptive)	☐	☐
c) neither parent	☐	☐

(please could you specify what is established in principle and what actually happens in practice.)

37. Are you and/or other members of the clinic team involved in school HIV education programmes?

a) Yes - routine involvement ☐ *(please go to question 37.a)*

b) Yes - only if requested ☐ *(please go to question 37.a)*

c) No ☐ *(please go to question 38)*

37.a How frequently do you:

	Never	Occasionally	Often
a) provide information on HIV and AIDS for teachers	☐	☐	☐
b) train teachers to talk to children about HIV and AIDS	☐	☐	☐
c) talk directly to children about HIV and AIDS	☐	☐	☐

38. If a child is showing behavioural, relationship and/or developmental problems at school, to whom can his teacher contact for help, support and advice?

a) your clinic/centre ☐

b) community children's services ☐

c) other *(please specify)* .....

.....

Thank you very much for your help in answering these questions

Children and Families Affected By HIV: A European Perspective

Parent and Carer Questionnaire

We are researchers from the Institute of Child Health in London, UK and we are co-ordinating this survey which is funded by the European Union. We aim to describe the needs of families with children affected by HIV for medical and psycho-social services and to see how far these needs are being met.

This clinic is one of 14 paediatric HIV centres in Europe which has been chosen to take part in our project. We would be grateful if you could complete this form, which should only take about 15 minutes of your time. By answering these few questions you will help us to understand the needs of families affected by HIV for services. This is an anonymous survey so we do not need to know your name, and the information given will only be reported in summary form.

Please tick the appropriate box(es) and/or write your answer in the space provided.

Background information

1. Are you: female ☐ male ☐

2. How old are you?
   - a) under 24 years ☐
   - b) 25-29 years ☐
   - c) 30-34 years ☐
   - d) 35-39 years ☐
   - e) over 40 years ☐

3. In what country were you born?
   .....

4. How long have you lived in the country you are living in now?
   .....

5. If you were born outside the European Union, what is your residency status in this country?
   - a) not applicable ☐
   - b) asylum-seeker ☐
   - c) refugee status ☐
   - d) permanent residence status ☐
   - e) illegal immigrant ☐
   - f) other *(please specify)* .....

6. Are you:

- a) married ☐
- b) cohabiting ☐
- c) single ☐
- d) divorced or separated ☐
- e) widowed ☐

7. What is your main source of financial support?

- a) full-time employment ☐
- b) part-time employment ☐
- c) financially supported by partner ☐
- d) financially supported by other family member ☐
- e) welfare ☐
- f) other *(please specify)* .....

.....

HIV infection in the family

8. What is your relationship with the HIV affected child/children in your care?

- a) natural parent ☐
- b) adoptive parent ☐
- c) grandparent ☐
- d) aunt or uncle ☐
- e) other relative ☐
- f) foster carer ☐
- g) other *(please specify)* .....

9. Please could you specify the ages and the HIV infection status of the child / children in your care. For infected children, please indicate whether they are **currently** well or unwell.

Age(s)	infected: well	infected: unwell	not infected	unknown
.....	☐	☐	☐	☐
.....	☐	☐	☐	☐
.....	☐	☐	☐	☐
.....	☐	☐	☐	☐

If you are the natural parent, please go to question 11. Otherwise, please answer question 10.

10. How long have you looked after this child/children?

Age(s)	Length of time in your care
.....	.....
.....	.....
.....	.....

11. Are you HIV infected yourself?

- a) yes - well ☐
- b) yes - unwell ☐
- c) no ☐
- d) don't know ☐

12.a Is your current partner HIV infected?

- a) yes ☐
- b) no ☐
- c) don't know ☐
- d) not applicable ☐

12.b How long have you been with this partner? .....

If you are HIV infected, please answer the following section. Otherwise, please go to question 19.

13. For approximately how long have you known that you are HIV infected?

.....

14. How do you think you acquired HIV?

- a) injecting drug use ☐
- b) sex with an injecting drug using (IDU) man ☐
- c) sex with an IDU woman ☐
- d) sex with a non-IDU man ☐
- e) sex with a non-IDU woman ☐
- f) blood transfusion ☐
- g) do not know ☐

h) other *(please specify)* .....

15. Who was the first person to be identified as HIV infected in your family?

- a) you ☐
- b) your partner ☐
- c) your child ☐

16. Have you told the child/children that you are infected?

If you have one child: Yes ☐ No ☐ Not applicable ☐

If you have two or more children: All ☐ Some ☐ None ☐

If you have told your child/children about your infection, please go to question 18. Otherwise, please answer the following question.

17. Would you like support from a professional to talk with your child or children about your infection?

Yes ☐ No ☐ Don't know ☐

Do you know what kind of support you would like? *If yes,* please give details.

.....

.....

.....

18. Does the clinic you attend provide support to infected parents/carers in talking to their children about HIV?

Yes ☐ No ☐ Don't know ☐

If yes, have you used this service? Yes ☐ No ☐

19. If your child is HIV infected, does he or she know?

If you have one infected child: Yes ☐ No ☐

If you have two or more infected children: All ☐ Some ☐ None ☐

If your child knows that (s)he is infected, please go to question 21. Otherwise, please answer the following question.

20. Would you like support from a professional to talk with your child or children about their HIV infection?

Yes ☐ No ☐ Don't know ☐

Do you know what kind of support you would like? *If yes,* please give details.

.....

.....

.....

21. Does the clinic you attend provide support to parents/carers in talking to their infected children about HIV?

Yes ☐ No ☐ Don't know ☐

If yes, have you used this service? Yes ☐ No ☐

Information provision

22. How important do you think the following aspects of information provision are?

	not important	quite important	important	very important
To be kept up to date with my child's health	☐	☐	☐	☐
To be provided with information on treatments & clinical trials	☐	☐	☐	☐
To receive written information on HIV/AIDS	☐	☐	☐	☐
To be provided with information on support groups, voluntary organisations etc	☐	☐	☐	☐
To be helped with obtaining social welfare services and payments	☐	☐	☐	☐

23. If you have any questions or problems, do you telephone the clinic?

Often ☐ Sometimes ☐ Never ☐

If you telephone the clinic sometimes or often, please answer question 24.a. If you have never telephoned the clinic, please answer question 24.b.

24.a Which of the following clinic staff do you speak to regarding medical and other problems or questions? *(please tick all that apply)*

	Medical	Other
a) paediatrician/doctor	☐	☐
b) social worker	☐	☐
c) psychologist	☐	☐
d) counsellor	☐	☐
e) health visitor	☐	☐
f) other *(please specify)*		
.....	☐	☐

24.b Why don't you telephone the clinic with queries or problems? *(please tick all that apply)*

a) I have had no need to telephone the clinic ☐
b) I have no telephone at home ☐
c) It is not encouraged ☐
d) I have other support I prefer ☐

e) other *(please specify)* .....

.....

Planning for the future

If you are HIV infected yourself, please answer the following section. If you are not infected, please go to question 28.

25. Have you made any short-term arrangements for your children to be looked after if you become unwell or need a rest?

Yes ☐ No ☐

26. Have you made any long-term arrangements for your children to be looked after in the future?

Yes ☐ No ☐

27. Have you had help from the staff at the clinic in planning for the long-term care of your children?

Yes ☐ No ☐

If no, would you like to have the opportunity to talk to clinic staff about the future care of your children?

Yes ☐ No ☐ Don't know ☐

Services

28. How frequently do you use the following services? *(Please specify if they are not available in your local area)*

	Not available	Often use	Sometimes use	Never use
Self-help / support groups	☐	☐	☐	☐
Help with financial problems	☐	☐	☐	☐
Day child care services	☐	☐	☐	☐
Practical help around the home	☐	☐	☐	☐
Home medical care	☐	☐	☐	☐
Respite child care (eg. if you need a rest)	☐	☐	☐	☐
Help with legal matters	☐	☐	☐	☐

29. If any of the following services are not currently available in your local area, would you like them to be provided in the future?

	Yes	No	Already available
Self-help / support groups	☐	☐	☐
Help with financial problems	☐	☐	☐
Day child care services	☐	☐	☐
Practical help around the home	☐	☐	☐
Home medical care	☐	☐	☐
Respite child care (eg if you need a rest)	☐	☐	☐
Help with legal matters	☐	☐	☐

30. To what extent do you agree with the following statements concerning the paediatric HIV services:

	strongly disagree	disagree	no opinion	agree	strongly agree
I sometimes feel that I have not been given enough information	☐	☐	☐	☐	☐
It is easy to get an appointment at a convenient time	☐	☐	☐	☐	☐
There is enough privacy to talk	☐	☐	☐	☐	☐
There are suitable facilities for waiting children	☐	☐	☐	☐	☐
I prefer to see the same doctor every time	☐	☐	☐	☐	☐
I am well enough informed about the availability of other services for families affected by HIV (eg support groups, voluntary organisations)	☐	☐	☐	☐	☐

If you have any additional comments, please feel free to write them here.

Thank you very much for your time and help in answering these questions.

Appendix 3.8 List of publications arising from the research

Scaravelli, G., Thorne, C., Newell, M-L (1995) The management of pregnancy and delivery in HIV infected pregnant women in Europe. *European Journal of Obstetrics and Gynaecology and Reproductive Biology*, **62**, 7-13.

Thorne, C. for the European Collaborative Study (1996) Hospitalisation of children born to HIV infected mothers. *XI International Conference on AIDS, Vancouver, Canada, July 1996*; Tu.C.2585.

Thorne, C. for the European Collaborative Study (1996) Children born to HIV-1 infected mothers in Europe. *Society for Social Medicine, Annual Scientific Meeting, Dundee, 1996.* Oral presentation.

European Collaborative Study (prepared by Thorne, C., Newell, M-L, Dunn, D., Peckham, C.) (1997) Hospitalization of children born to human immunodeficiency virus infected women in Europe. *Pediatric Infectious Disease Journal*, **16**, 1151-6.

European Collaborative Study (prepared by Thorne, C., Newell, M-L, Peckham, C.). The social care of children born to HIV-infected women in Europe. *AIDS Care*, **10** [in press].

European Collaborative Study (prepared by Thorne, C., Newell, M-L, Bailey, A., Peckham, C.) The use of therapeutic and other interventions to reduce the risk of mother-to-child transmission of HIV in Europe. [submitted].

Thorne, C., Newell, M-L., Peckham, C.S. Clinical and psycho-social service needs of children and families affected by human immunodeficiency virus in Europe. [submitted].

Appendix 6.1 Parent and Carer Questionnaires: additional comments from respondents

"Please note, to obtain the very high quality service I receive from my centre, I travel approximately 120 miles on a round trip. I have answered the questions according to my experiences of that centre. I do not know what is available locally, nor do I make use of support services near the centre, because of the distance.

Ten years ago when I first had contact with the centre I now use, the services locally were very poor which is why I chose to go further to find specialist services. My confidence in the centre means I am reluctant to consider nearer facilities even if they exist and will carry the additional costs/time/effort for as long as I can to ensure my daughter has the best care by staff she (and I) know and trust"

[adoptive mother of infected child]

"Find a cure. I want to see my kids grow up"

[infected mother of one infected and five uninfected children]

"I think when distributing pills to patients, a letter or note saying what they are, what they do and what side effects occur. It's all well being told what they do etc. but what about the people with say short term memories - they could be experiencing a side effect, forgetting its a side effect and start to panic"

[infected mother of a child with indeterminate infection status]

"My granddaughter has a yearly check on her general health, she has been negative now for 10 years"

[grandmother of uninfected child]

"As I am the foster carer, some of the questions seem irrelevant in my case"

[foster carer (of 9 weeks only) of an infected child]

"I can only give praise for the treatment given to myself and grandchildren by the doctors and health visitors from the [hospital name] over the past 7½ years. It gives me peace of mind knowing the kids are in very good hands. (God bless them all)."

[grandmother of two children with indeterminate HIV status]

"It is difficult to contact a doctor familiar with my son's health problem, outside clinic hours (in case of emergency or advice) in the hospital"

[uninfected mother of an infected child]

"I have not much to say except that we are living in anxiety and we feel that death is near. I would like that researchers do at least something because a whole generation is going to disappear. My only hope is God."

[infected mother of two children: one infected and one uninfected]

"The media portray AIDS/HIV as contagious. Perhaps more information on TV and newspapers to suggest otherwise. Majority of people are frightened to mix with infected people, especially teachers with HIV children. That is certainly my experience! Ostracism is not too strong a word."

[adoptive parent of infected child]

"It's sometimes embarrassing finding other members [of staff] in the doctors room and making no introductions. I don't feel comfortable sometimes sharing my information and about my child with strangers. So please look into that. Seeing a different doctor every visit puts me off coz different medical professionals have different opinions about treatment so it leaves me confused. Being asked my country of origin also puts me off, when I got infected etc x 100. I realise it's for statistics, but how many times do I have to specify my country of origin. I wonder what it has to do with HIV and AIDS."

[infected mother of infected child]

"I live on my own with three kids but I've always wanted to get one of my relatives to stay with me and there's no help at all. I think social services should look into such matters for people like us because it is a worry for many of us"

[infected mother of an infected child]

"Status like these should be kept private and notes should be read through by doctors so that confidential matters are not passed to other parties what-so-ever. Because errors/mistakes are hard to rectify and sometimes when the party involved in HIV may be discriminated which is not very nice. I think patients should have a right in say who the info have been provided to. What happens if the info has been sent, when "consented" by the patient? What rights does the patient have? How do you rectify this problem? How do you make sure this does not happen again? How safe are patient files? How safe is patient data confidentiality?"

[infected mother of an infected child]

"I think HIV does not matter which country you come from and how long you've lived in Great Britain. I think we should all work hand in hand to stop the spread of the virus globally other than asking where people come from."

[infected mother with two children: one infected, one uninfected]

"I have a child of 11 years (a daughter) who is not infected, I would like to know how and what I need to do to protect her."

[father of two children: one infected, one uninfected]

"I have no comment. My wish is to find rapidly treatment against this virus to save millions of human beings who are condemned to die."

[father of a child with indeterminate infection status]

"In the six years the child's with us now, we had no major problems. Only once we received financial aid for going on holiday. Up til now the child is quite alright given the circumstances. So far we can manage without special help and we hope to maintain that situation in the future"

[adoptive father of infected child]

"It is difficult to telephone at the hospital. It takes ages before they switch you to the right person. Waiting time also when you need to make appointments at the desk. In the outpatient clinic staff / personnel is alright. However, in the clinic some nurses discriminate you, make you feel ashamed that you are HIV-positive. Privacy on the diagnosis is not 100% at the clinic"

[infected mother of two children, one infected]

"I would like to have more money / income to pay for food to keep up good health for my daughter and myself. Life at the moment is too expensive for our means."

[infected mother of an infected child]

"I am a parent trying to cope with everything that's happening (despite the HIV)"

[infected mother of an infected child]

"I feel priviledge that I have this child in my care, officially as a foster parent, whilst her mother is mostly unable to care"

[foster mother of an infected child]

"I feel that my needs in gathering information and support is hardly ever met at great conferences on HIV/AIDS. Almost always they only discuss the situation of adults."

[grandparent of an infected child]

"I changed the hospital after knowing my child was not infected. We moved over to the hospital of my husband because it was nearer to our home. I miss facilities in which I can bring my child when I am too ill or tired to take care of her. She is not infected so she does not need any special care and she is also not in need of other "specials" like care for abuse or neglect. Most places for children are organised around topics to which my child does not relate. Nobody is really organising much for the affected children"

[infected mother of an uninfected child]

"AIDS counsellors tend to know far more on adults than on children"

[grandparent of an infected child]

"The toys are not clean enough. You can see the dust everywhere.

The paediatrician is too busy. I like her very much, however she has no spare time for me to talk about myself"

[grandmother of an infected child]

"I am satisfied up to now with the service at the children's hospital"

[infected mother of an infected child]

"The [hospital name] is too old. There is no WC on the parents' floor; the room is far too small; in parts, very out of date rooms; not enough parking spaces; lack of staff -ward change/shifts"

[infected mother of two infected children]

"I would like more general media coverage and noise about this in the general population"

[foster mother of an infected child]

"Don't know who to go to [for help with legal matters].

Home help was taken off me when I went into hospital for hysterectomy.

Since [name of support group] closed down I don't go to any support groups."

[infected mother of infected child]