

# **Client Needs and Satisfaction in an HIV Facility**

by

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**THESIS**

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## **Abstract**

Health care evaluation serves the purpose of monitoring the quality of health care provided by Health Care Providers (HCP), so that health care services can be provided most effectively and efficiently. Patient satisfaction studies are widely used to assess the quality of outpatient care. A client satisfaction study was conducted at an HIV health care facility in Sydney, Australia during 2007-2008. There were three objectives: 1.) To validate a questionnaire for future determination of client satisfaction in HIV health care facilities. 2.) To identify the levels of satisfaction of clients, and investigate any dissatisfaction and unmet needs towards HIV health care. 3.) To provide recommendations for improving client satisfaction levels in HIV health care.

This research used a mixed method approach and consisted of two phases. The first phase was a quantitative survey conducted with 166 clients (both HIV positive and negative) at Albion Street Centre (ASC) using a newly-devised questionnaire. Clients were asked to answer demographic questions, rate their levels of satisfaction with each aspect and each HCP category, and provide suggestions for improvement. Quantitative statistical analysis was conducted to obtain a general view of client satisfaction levels.

Dissatisfaction and unmet needs of clients were then investigated in-depth in the second phase of the research through qualitative face-to-face semi-structured interviews. Twenty-two clients (both HIV positive and negative) at ASC were interviewed individually and asked about their attitudes, perceptions, and experiences towards their HCP and the HIV health care services received. Thematic analysis was used to categorise and interpret the qualitative data.

More than 90% of the clients were satisfied with most of the aspects covered in the survey, with a mean overall satisfaction score of 84 out of 100. Clients were most

satisfied with the “technical quality” and “interpersonal manner” of the HCP, and were least satisfied with “waiting time” and “availability of HCP”. The HCP category with which the clients has the highest level of satisfaction was “nurses” (86%), followed by “psychologists” (84%), then “doctors” (83%). Clients who were HIV negative, had a full time job, visited ASC less frequently, or did not possess any type of Health Care Card were more satisfied with the services overall. No common dissatisfaction or unmet needs towards HIV health care service were identified.

“Technical quality of HCP” and “the relationship with HCP” were the two most important determinants of client satisfaction, which outweighed the inconvenience contributed by the poor availability of HCP and the location of ASC. The maintenance of “confidentiality/privacy” was shown to be fundamental in HIV health care facilities. The multi-disciplinary nature of ASC increased the degree of convenience and satisfaction level among clients.

Suggestions for improvement in client satisfaction levels include increasing the attractiveness of the physical environment and the variety of educational reading materials in the waiting area; introducing beverages, and encouraging clients to be involved in their treatment decisions. Health care administrative staff in particular are reminded not to neglect the importance of the availability of HCP, accessibility, and physical environment when establishing a new HIV health care facility.

The mixed method approach (quantitative survey and qualitative interviews) proved beneficial. It increased the validity of the findings by assessing client satisfaction levels using more than one method. This enabled clarification of ambiguities noted in the initial survey through probes used in the interviews, and also allowed investigation of the determinants of client satisfaction through understanding their experiences in HIV health care. Future client satisfaction studies would benefit from using this approach.

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# Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ANOVA	Analysis Of Variance
ASC	Albion Street Centre
ASC-CSQ	Albion Street Centre-Client Satisfaction Questionnaire
HCP	Health Care Provider
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug User
PLWHA	People Living With HIV/AIDS
SPSS	Statistical Package for the Social Sciences

## Definition of terms

The following terms were utilised for the purpose of this research:

Ambulatory care                      Medical care provided to persons who are not confined to a hospital on an outpatient basis.

Health care provider (HCP)                      A medical or paramedical staff member at a health care facility who provides health care services.

People living with HIV/AIDS (PLWHA)                      People who are diagnosed as having HIV or those who are living with AIDS.

Patient satisfaction                      A measure of health care quality, and as a means of including patient perspectives in the evaluation of services.

Unmet need                      A need in health care service by patient(s) which is not fulfilled.

Terms regarding the methodologies of this research (Minichiello 1990):

Closed-ended questions                      Questions in which the respondent is asked to respond by choosing between several predetermined answers.

Open-ended questions                      Questions in which there are no sets of predetermined answers for the respondent to choose from. Respondents can choose to give any answer they wish to.

In-depth interviews	Repeated face-to-face encounters between the interviewer and the participant that are directed toward understanding the participant's perspectives on his/her own experiences as expressed in his/her own words.
Semi-structured interviews	Interviews in which the interviewer uses an interview guide (also called aide memoire), which is a list of topics to be discussed with no fixed wording or ordering of questions.
Qualitative research	It allows the researcher to observe, discover, and describe the themes and underlying dimensions of social life using non-numerical data.
Quantitative research	It allows the researcher to measure the magnitude, size or extent of a phenomenon using numerical data.
Reliability	A measure or a study is reliable if it consistently gives the same result.
Validity	A measure, a judgment or a piece of research is valid if it really shows what it is supposed to show.
Mixed method (or Triangulation)	The combination of different techniques for collecting data in a study of the same phenomenon. For example, a combination of quantitative and qualitative methods for studying the same research question.

## **Chapter 1—Background and Overview**

In the 21<sup>st</sup> century, five out of the ten leading causes of death worldwide are infectious diseases (Lopez et al. 2006). Every year, infectious diseases kill 14 million people (Heymann 2002). Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) is one of the ten leading global disease burdens in low and middle income countries (Lopez et al. 2006). Although HIV/AIDS does not pose a serious threat in high income countries, it is still a fatal disease and not only affects the quality of lives and lifespan of people, but also affects the economy, security, social stability and politics (Gellman 2000; Dodge 2002).

## **1.1 Definition of HIV/AIDS and its epidemic**

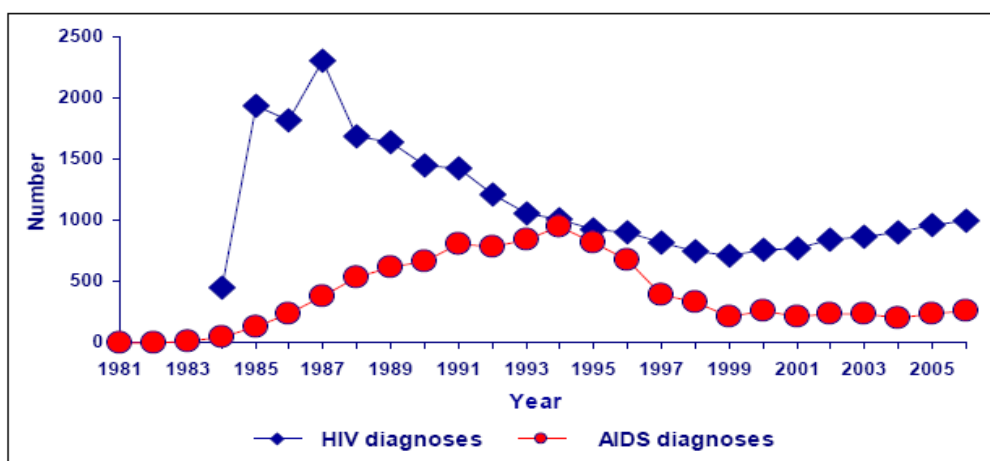
HIV is a retrovirus that infects the T cells (or CD4 cells) of the human immune system, and destroys and impairs their function. An individual with HIV will have a detectable presence of HIV anti-bodies, but may not have opportunistic infections or clinical symptoms of AIDS. However as infection progresses, the immune system becomes weaker and the individual becomes more susceptible to opportunistic infections (WHO 2008a). AIDS is the most advanced stage of HIV infection and it can take 10 to 15 years to develop in an HIV-infected individual (CDC 2007). HIV is transmitted through unprotected sexual intercourse (anal or vaginal), transfusion of contaminated blood, sharing of contaminated needles, and from a mother to her infant during pregnancy (vertical transmission), birth or through breastfeeding (WHO 2008a).

The World Health Organisation (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) recorded that there were approximately 33.2 million People Living With HIV/AIDS (PLWHA), and there were 2.1 million AIDS deaths worldwide in 2007 (UNAIDS and WHO 2008a). Although the number of HIV diagnoses per year decreased from 4.1 million in 2005 to 2.5 million in 2007, the HIV prevalence rate continues rising due to population growth and the life-prolonging effects of the Highly Active Anti-Retroviral Therapy (HAART) (UNAIDS 2006).

## 1.2 HIV/AIDS in Australia

Australia has a relatively low HIV/AIDS prevalence when compared with other developed countries. AIDS was first diagnosed in November 1982 in Australia and the first AIDS death was in July 1984 (Bowtell 2005). Since then the number of HIV notifications increased rapidly and peaked in 1987 (Hardwick and Cotton 2005). There were a total of about 26,000 diagnoses of HIV infection, 10,000 diagnoses of AIDS, and 6,700 AIDS deaths in Australia from 1982 to the end of 2006 (UNAIDS 2008). The majority of the HIV cases were caused by male homosexual contact (85%), and the rest were due to heterosexual contact (8%) and injecting drug use (5%) (UNAIDS 2008).

Although there was a stable long-term decline in the number of HIV diagnoses from 1995 to 2000, the number gradually increased from 763 in 2000 to 998 in 2006 (UNAIDS 2008). The number of PLWHA also increased in the past decade due to the effectiveness of the combination antiretroviral treatment in improving the chance of survival (UNAIDS 2008). Fig. 1 shows the number of HIV and AIDS diagnoses in Australia from 1981 to 2006.



**Fig. 1** Number of HIV and AIDS diagnoses in Australia from 1981 to 2006.

Adopted from UNGASS Country Progress Report Australia. (UNAIDS 2008)



### **1.3 HIV/AIDS in New South Wales**

In 2007, NSW is the home of 62% (9,933) of 16,000 PLWHA in Australia (WHO 2008b). It has the highest rate of HIV infection among all the states in Australia, with 5.8 diagnoses per 100,000 people from year 2000 to 2005 (Hardwick and Cotton 2005). The largest city in NSW, Sydney, was the home to 80% PLWHA in NSW in 2006 (NSW Department of Health 2006a). Till 2007, AIDS has caused over 3,600 deaths in NSW and there were 404 cases of HIV diagnoses in 2007 alone (NSW Department of Health 2008). PLWHA were predominantly males (87% in 2007) and men aged 30-34 were the largest group of people with HIV (NSW Department of Health 2008).

It was observed that the number of HIV diagnoses in NSW has been increasing each year since 2001. In 2003 it was predicted that if the number of HIV diagnoses continues to increase slightly over the next five years, and the number of deaths remains constant at about 35 annually, there would be an additional 2,000 PLWHA in NSW in 2008 (Hardwick and Cotton 2005).

HIV/AIDS has led to a significant economic impact in NSW. It was reported that the monetary value of the morbidity and premature mortality avoided by preventing one HIV infection was \$2.64 million in 2006 (NSW Department of Health 2006b). The costs to individuals and the health system could be most effectively minimised through a strong focus on disease prevention and early intervention (NSW Department of Health 2006b).

## **1.4 The role of health care evaluation**

In view of the threat posed by HIV, HIV health care clinical facilities are key to the treatments of PLWHA and for controlling the spread of HIV. Services from these facilities directly reach a large cohort of those who are infected and at risk of being infected, in helping them to achieve a better quality life, and in educating them about the risks of transmission (Palen et al. 2004).

In public health, one of the major concerns is “whether quality health care is provided to patients in need”. However, quality health care is not clearly defined, and its definition varies with place, provider, participant, time, and available budget. Donabedian, a renowned researcher spending years investigating the quality of medical care, stated the significance of assessing the quality of health care service as early as in the 1970s (Donabedian 1978). He pointed out that assessment of quality health care is to determine how successful health care providers (HCP) have been in providing care, and to monitor them so that departure from standards can be detected and corrected as early as possible (Donabedian 1978). Apart from surveillance, health care evaluation also involves defining the objectives of care, measuring the extent of the outcomes achieved, and assessing any unintended or harmful consequences of the intervention (Sitzia and Wood 1997).

Numerous studies have been conducted in the past decades searching for the most appropriate method of health care service evaluation, and this search continues. Hospitals and ambulatory health care facilities now incorporate “evaluation” as one of their strategies of managing the quality of health care services. Information obtained from evaluation can be viewed as a guide for HCP and policy makers in delivering

effective and efficient health care services to patients.

## 1.5 Methods of health care evaluation

The success of health care service evaluation depends very much on the types and varieties of aspects to be evaluated. Sitzia and Wood conducted a comprehensive and in-depth meta-analysis on one of the evaluation methods—patient satisfaction. They discussed two health care evaluation models which can be used as guidelines for consideration in the health care context: Cochrane’s model and Donabedian’s model (Sitzia and Wood 1997).

*Cochrane’s model* uses three criteria to assess medical therapies: (Sitzia and Wood 1997)

- **Effectiveness** — does the treatment alter the natural history of the disease for the better?
- **Efficiency** — does the input justify the output?
- **Equality** — is there equal access to the treatment or service on the part of the population being served?

*Donabedian’s model* looks at three basic areas to evaluate the quality of care:

(Donabedian 1978; Donabedian 1988; Sitzia and Wood 1997; Donabedian 2005)

- **Structure** — organisation and conditions of the facilities delivering care. It includes:
  - material resources (facilities, equipment and money)
  - human resources (number and qualifications of personnel), and
  - organisational structure (medical staff organisation, methods of peer review, and methods of reimbursement)

- **Process** — professional activities related to providing care (practitioners' activities in making a diagnosis and recommending or implementing treatment)
- **Outcome** — a change in a patient's current and future health status that can be confidently attributed to care. It includes improvements of patients' knowledge and salutary changes in patients' behaviour

Cochrane's model has a narrower focus and stresses treatment only, in which the two aspects "efficiency" and "equality" are comparable to the "process" of Donabedian's model, while "effectiveness" is equivalent to "outcome", which is the ultimate goal that patients come to seek health care services.

According to Donabedian, assessing the quality of health care with respect to the above models can be conducted mainly through three methods: *clinical records*, *direct observation*, and *study of behaviours and opinions*. Donabedian compared these three methods in detail (Donabedian 2005). Although clinical records are of primary source documents, they are highly confidential and have been restricted to the assessment of care in hospitals and outpatient departments, and therefore are not readily accessible to other researchers. Also there have been concerns about the veracity and the completeness of the clinical records, because sometimes summaries and abstracts are prepared by less skilled persons, and records are written not for the sake of evaluation. Even if the records are reliable, it is difficult to generalise from the findings (Donabedian 2005).

Direct observation, on the other hand, enables researchers to evaluate the quality of health care directly from first hand information. However, neither overt nor covert observations are appropriate. Because HCP and patients tend to change their habits if

they know they are being observed which can result in an overestimation of quality (in overt observations). Also it is time-consuming and depends greatly on the skill of the researcher. Whereas observing secretly using surveillance cameras without the consent of HCP and/or patients (in covert observations) is not possible due to ethical issues (Donabedian 1978; Mays and Pope 1999).

Study of behaviours and opinions is an indirect way of obtaining information. It can be done through “health care quality evaluation reports” through peer judgements by HCP within a health care facility, or conducted through “patient satisfaction surveys” with patients rating the quality of health care services. Donabedian regarded patient satisfaction surveys as “the ultimate validation of quality care”, and the information obtained should be indispensable to the design and management of health care systems (Donabedian 1988; Nelson and Niederberger 1990).

Referring to Cochrane’s and Donabedian’s models and considering the advantages and disadvantages of each method (clinical records, direct observation, and study of behaviours and opinions), studying of behaviours and opinions through patient satisfaction surveys are regarded as a very appropriate method for conducting health care evaluation. As ultimate receivers of health care, patients are the best group of people to evaluate services. Asking patients’ perceptions on quality care enables HCP to understand patients’ needs, and then HCP are able to provide quality care by matching patients’ needs.

## **1.6 The role of patient satisfaction in health care**

The effects of patient satisfaction can be important. Previous studies showed that patients who are more satisfied are more likely to adhere to treatment regimens, cooperate with treatment and HCP by disclosing important medical information, continue receiving care and return to follow-up sessions more easily, which more often lead to improved clinical outcomes (Stein et al. 1993; Eriksen 1995; AIDS Weekly 2000; Hudak and Wright 2000; Sullivan et al. 2000; Bova et al. 2006).

In contrast, less satisfied patients have been found to be less adherent to their doctors' recommendations, associated with poor physical health, lack of access to care, and more likely to receive inadequate knowledge about disease processes from HCP (Dodge 2002; Beach et al. 2005), which not only delay the recovery of the patients, but also waste the financial and human resources that would be better spent on those in real need. However, past researchers commented that there is a lack of consensus within the medical profession on what role patient satisfaction should play, therefore, results drawn from patient satisfaction studies are often not accorded much weight (Aharony and Strasser 1993; Yellen et al. 2002).

## **1.7 The role of patient satisfaction in HIV health care**

Although numerous patient satisfaction studies have been conducted in general health care facilities, few have been conducted among PLWHA. It is more difficult to recruit HIV positive patients due to confidentiality reasons, and therefore researchers cannot approach a potential sample group of PLWHA as easily as in other general patients (Fowler et al. 1992). Although PLWHA have been increasingly accepted by the general public, many are still living under stigma and being discriminated against. Therefore, PLWHA are a special group of people whose satisfaction towards health care services has received little attention.

In addition, PLWHA have a complex, multi-system illness that commonly requires the frequent use of health services, and clinical care remains an important part of maintaining their wellness through medications and monitoring. Also, due to the efficacy of Highly Active Anti-Retroviral Therapy (HAART) and the increasing use of prophylactic drugs to prevent secondary AIDS opportunistic infections, PLWHA are living longer (Carr 2001; Hardwick and Cotton 2005). As a result, HIV has become an even more chronic disease than previously, which also indicates that more and more people are living with HIV at a time. Therefore it was suspected that PLWHA may manifest higher levels of dissatisfaction in health care than those with general illness (Stein et al. 1993).

Since patient satisfaction has proven to be associated with patients' knowledge of their diseases, the control of HIV infection can be better with higher levels of patient satisfaction (Beach et al. 2005). Previous studies also indicated that much more research is needed in this area with community-based AIDS service organisations (Canales 1998; Dykeman 1998; Dodge 2002; Raya-Fernandez 2004).

## **1.8 The need to conduct patient satisfaction research in Australia**

In Australia, health promotion, treatment, care, support, and research for HIV/AIDS are shared by the Government Area Health Services, community-based organisations, non-government organisations and state-wide agencies (NSW Department of Health 2006b). The NSW Department of Health has developed a NSW HIV/AIDS Strategy: 2006-2009 to address the rising number of HIV diagnoses in recent years. There are three goals (NSW Department of Health 2006a):

1. To reduce new HIV infections in NSW.
2. To improve the health of People Living With HIV/AIDS (PLWHA).
3. To reduce HIV-related discrimination and address systematic barriers to HIV health promotion.

The Lowy Institute of International Policy, which provides policy options for Australia, stated that social and behavioural research is of particular relevance to HIV prevention (Bowtell 2005). Goal 1 can be achieved by studying patient satisfaction among PLWHA, because high levels of satisfaction are the outcome of a good patient-provider relationship and trust, in which a good relationship and trust help facilitating education to prevent HIV infection (Wilson and Kaplan 2000; Keating et al. 2002; Miles et al. 2003).

As mentioned previously that satisfaction has a role to play in influencing patients' adherence to treatment plans, utilisation of health services, continuity of care, and health status (Stein et al. 1993; Eriksen 1995; Hudak and Wright 2000; Sullivan et al. 2000; Roberts 2002; Ingersoll and Heckman 2005; Bova et al. 2006; Bodenlos et al. 2007; Thiedke 2007). As a result, a higher level of satisfaction indicates that HIV patients are



more willing to cooperate with HCP, which makes Goal 2—“to improve the health of PLWHA” possible to accomplish.

Furthermore, by investigating the characteristics of HIV patients who are less satisfied and by exploring their unmet needs, it is possible to address the health care barriers patients encounter, and ensure that their expectations are met. So Goal 3—“to reduce HIV-related discrimination and address systematic barriers” can be fulfilled.

The background illustrated above concluded that health care evaluation is widely acknowledged as a means of assessing health care quality. Not only can it help determine how successful HCP are in delivering health care services, it also keeps the whole health system within optimal standards. Patient satisfaction studies are considered one of the most effective strategies in evaluating health care services because patients are the ultimate beneficiaries. Furthermore, PLWHA often utilise HIV/AIDS health care services for a considerable length of time, and due to their vulnerable characters, assessing their satisfaction with such services is worthwhile.

## **1.9 Study setting**

This research project reported in this thesis focussed on studying the levels of satisfaction of clients in an HIV health care facility in Sydney, NSW, Australia. The following describes the system of HIV health care services in NSW and the HIV health care facility where this research took place.

### **HIV/AIDS health care services in NSW**

HIV health care services are categorised into six levels in NSW. Areas providing levels 5/6 HIV/AIDS services are those with highest prevalence of PLWHA (Hardwick and Cotton 2005). They provide the most comprehensive and specialised services comparing with lower levels of services. Apart from providing basic clinical services for PLWHA, levels 5/6 services also provide on-site specialist services such as oncology, psychiatry, respiratory, dermatology, ophthalmology, rheumatology and gastroenterology. They are also responsible for conducting research, community education, and professional development (Hardwick and Cotton 2005). Levels 1 to 4 HIV/AIDS services are offered in all areas other than those covered by levels 5/6 and they are in more rural regions in NSW. Only levels 5/6 HIV/AIDS services are considered in this thesis because the study setting in this research is under levels 5/6, and levels 5/6 provide services to more than 80% of PLWHA in NSW (Hardwick and Cotton 2005).

There are two types of levels 5/6 HIV/AIDS health care facilities: ambulatory care centres and inpatient hospitals. Inpatient services provide beds and have wards for hospitalisation, whereas ambulatory care centres run day-care sessions for PLWHA on an out-patient basis. These ambulatory care facilities provide clinical checkups, blood-

testing, and pharmacy; some even provide auxiliary services such as counselling, dental hygiene, nutrition, and others (Linder-Pelz and New South Wales. AIDS Bureau. 1990; Burcham et al. 1993). There are 11 ambulatory care centres and 7 inpatient hospitals of levels 5/6 in NSW in 2005, where the majority are located in Sydney (Hardwick and Cotton 2005).

More and more PLWHA are becoming long-term survivors who often have co-morbidities associated with their treatment. From the perspective of human and material resources, ambulatory care facilities provide more efficient services to these people than inpatient hospitals which are most useful when admitting terminal AIDS patients. Over the years of 1998 to 2005, the NSW Department of Health noted a dramatic decline of an average of 35% in the utilisation of inpatient services and an increase in the utilisation of ambulatory care services, but there has not been a similar shift in HIV/AIDS resources from inpatient to ambulatory facilities (Hardwick and Cotton 2005). It is foreseen that HIV ambulatory care will continue to play an essential role in treating HIV patients and will be in much greater demand than inpatient hospitals.

### **The Albion Street Centre (ASC)**

Located at South Eastern Sydney, ASC was chosen as the setting for this research. Attached to the Prince of Wales Hospital, it is the largest public community-based ambulatory day care facility for people with HIV/AIDS and Hepatitis in Australia (ASC 2008a). Between 1998 and 2002, 42% of NSW's new HIV infection was diagnosed at ASC (Hardwick and Cotton 2005).

Established in 1985, ASC provides medical, nursing, counselling, nutrition, pharmacy and other specialist services. It aims to promote the well being of people with HIV/AIDS, hepatitis and other emerging infectious diseases, to maximise the quality of life and to minimise hospitalisation of patients with HIV and Hepatitis. It is also the World Health Organisation Collaborating Centre for Capacity Building and Health Care Worker Training in HIV Care, Treatment and Support since 2006 (ASC 2008a).

## **1.10 Objectives of the research**

There are three main objectives in this research:

1. To validate a questionnaire for future determination of client satisfaction in HIV health care facilities.
2. To identify the level of satisfaction, and investigate any dissatisfaction and unmet needs towards HIV health care of clients attending an HIV health care facility in Sydney (ASC).
3. To suggest recommendations for improving client satisfaction levels in HIV health care, specific to ASC and for HIV health care facilities in general.

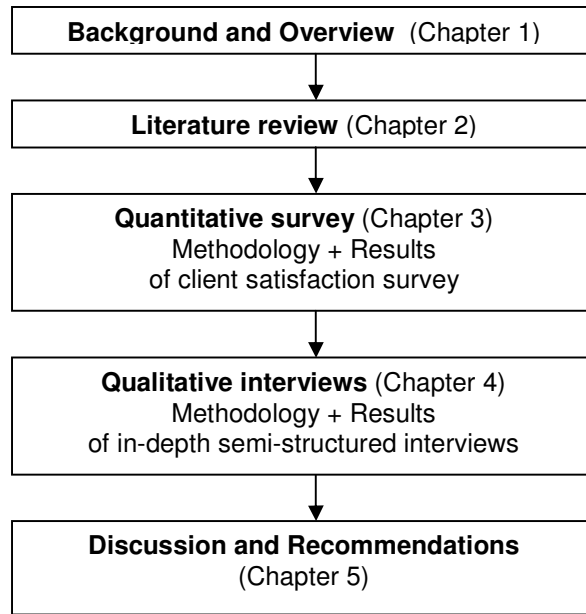
## **1.11 Research questions**

Six research questions are addressed in this thesis:

1. How satisfied with care and the HCP are clients attending an HIV/AIDS health care facility?
2. What aspects of HIV health care are perceived as important among clients?
3. Are there any significant differences in satisfaction among clients with different characteristics?
4. Is there any dissatisfaction among clients with HIV care provided?
5. Are there any unmet needs among clients about HIV care?
6. What, if anything, has to be done to address the dissatisfaction and unmet needs?

## 1.12 Structure of the thesis

This thesis is presented according to the schematic diagram shown in Fig. 2:



**Fig. 2** Structure of the thesis

This research investigated client satisfaction through two phases chronologically: Chapter 3 presents the first phase, in which a quantitative survey was conducted using a newly-devised questionnaire to give a general view about client satisfaction and its determinants. These findings provided a basis for the qualitative semi-structured interviews conducted in the second phase of the research presented in Chapter 4, in which in-depth and quality data about reasons for dissatisfaction (or satisfaction) and unmet needs from clients was obtained. The discussions of both phases and recommendations are then presented in Chapter 5.

The following shows the summaries for the remaining chapters of this thesis:

Chapter 2: It first presents the similarities and contrasts between health care evaluation by conducting “health care quality evaluation reports” and by “patient satisfaction studies”, and then discusses the definitions, importance, and determinants of patient satisfaction suggested in the literature. Factors affecting patient satisfaction levels and the difficulties of conducting patient satisfaction research are also illustrated, followed by a summary of previous research on patient satisfaction and their limitations.

Chapter 3: It delineates the HIV health care facility where the quantitative survey was conducted. The methodology of developing a questionnaire for measuring patient satisfaction is described in detail, with its strengths and limitations discussed. Next, results are analysed quantitatively and findings are presented, which include the satisfaction levels for overall and individual aspects of the services, the important levels of the aspects from the patients’ perspectives, differences in satisfaction levels of patients’ of various characteristics, and the demonstration of validity and reliability of the questionnaire used.

Chapter 4: Client satisfaction is investigated qualitatively by semi-structured interviews with questions based on the findings from the quantitative survey reported in Chapter 3. A combination of the qualitative interviews and the quantitative survey comprise a mixed method approach for increasing the validity of the findings. This chapter focuses on clients’ dissatisfaction and their unmet needs towards health care services. Results are analysed qualitatively and findings are presented, which can provide valuable information on an understudied population and suggestions for improving the quality of health care services.

Chapter 5: It discusses the findings of both the quantitative survey (Chapter 3) and qualitative interviews (Chapter 4), and integrates them for meaningful interpretations. Based on the findings and information from existing literature, recommendations are suggested for improving client satisfaction. This chapter also highlights the strengths of using the mixed method approach and implications for future research.



## **1.13 The significance of this thesis to HIV patient satisfaction research**

This thesis will contribute to the field of HIV patient satisfaction research in the following areas.

1. Both the quantitative survey and qualitative interviews will contribute significantly to the limited HIV patient satisfaction research in Australia by enabling a better understanding of clients' satisfaction/dissatisfaction levels and their unmet needs at a public HIV ambulatory care facility. Comparison of the findings of this research with those from previous patient satisfaction studies will allow identification of the quality of HIV health care in Sydney with respect to those in other parts of Australia and in foreign countries.
2. This research will enable a better understanding of the determinants of patient satisfaction and their levels of importance. This is achieved by using both in the quantitative survey, where respondents are requested to rate the importance of each aspect to them, and in the qualitative interviews, where participants are asked to share their personal experiences in receiving health care at ASC. Health care administrators can then improve or modify policies by referring both on satisfaction levels and on importance levels. Also, when future researchers devise new questionnaires for measuring patient satisfaction, they can include those aspects that are important determinants of satisfaction, because they are not decided by researchers who devise the instruments, but by the clients themselves.

3. Satisfaction levels of clients with different demographic characteristics are examined in detail for the first time in the Australian context to determine if clients' demographic characteristics have any significant effect on their satisfaction levels. The results can reflect if health care was delivered equitably to clients with different demographics, and if they have different expectations of health care. Although such analyses have been conducted before in other countries, no general consensus is reached about types of demographic factors affecting satisfaction levels. Instead, the findings in this study will offer a basis for future researchers to investigate this issue further in Australian HIV health care, as well as for HIV health administrators to evaluate health care policies according to the demographic trend.
4. This research highlights the importance of evaluating all HCP and paramedical workers involved in health care, because not just doctors and nurses, all staff members contribute to client satisfaction at different points. In chronic care, such as HIV treatment, clients usually utilise a wider range of services as compared with other diseases, which signifies the need to have a comprehensive health care evaluation for a broader range of HCP.
5. The instrument ASC-CSQ devised with rigorous validity and reliability measures can foster easy HIV client satisfaction evaluation in Australia and in other countries. Other HIV health care facilities can amend the list of HCP categories and demographic questions to suit their settings. The same questionnaire can be used in longitudinal studies, and the quality of health care can be monitored over a long period of time. Also, it can also be used for assessing the success of a policy or administrative change with time, as causality is able to be established in longitudinal studies.

6. Unlike most previous HIV patient satisfaction studies in which only HIV positive clients were involved, this research points the necessity to include HIV negative clients (who are at risk of infection) for a more comprehensive HIV health care evaluation. This group of clients is usually neglected in the process of evaluation because they are not considered to be “patients”. However, many of them utilise HIV services regularly and should be considered as “clients”, whose perceptions of health care are as valuable as those from HIV positive clients.
  
7. In addition to assessing client satisfaction, recommendations for improving the quality of HIV health care are suggested based on the findings and by balancing the urgency, feasibility, and effects on satisfaction. These recommendations not only provide practical solutions for ASC to increase client satisfaction, but also act as guidelines for HCP and health care administrators of already established HIV health care facilities, or those who are preparing to establish a new HIV health care facility.
  
8. This study itself will be a good opportunity to increase client satisfaction. This is because inviting clients to participate in the quantitative survey and qualitative interviews provides a channel for them to raise their dissatisfaction and needs. This also conveys a message to them that their beliefs, attitudes and perceptions towards HIV health care are not neglected, and researchers and health care administrators are willing to improve health care quality.

## **Chapter 2—Literature Review**

As discussed in section 1.5 on page 8, studying the behaviour and opinions of patients is regarded as one way of exploring the quality of health care, and it can be achieved using any one of the two methods: “health care quality evaluation reports” and “patient satisfaction studies”. It is necessary to understand the nature of these two methods thoroughly in order to choose the most appropriate one for health care evaluation in different circumstances, taking into account the availability of resources and the focus of implementation.

## **2.1 “Health care quality evaluation reports” versus “patient satisfaction studies”**

“Health care quality evaluation reports” and “patient satisfaction studies” are two distinct methods for evaluating health care services (Ware et al. 1983). Ware, an authority of behavioural sciences in the field of medical care, stated that “health care quality evaluation reports” are evaluations of health care facilities, HCP and health care administrators conducted by themselves through referring to clinical records, patients’ appeals, their professional experiences, and meetings of administrators and policy makers (Ware et al. 1983). For “patient satisfaction studies”, health care services are evaluated individually by the destined recipients—patients themselves. Since the two evaluation methods are conducted by different parties, the standpoint of each finding is biased differently for each method according to the benefits gained by the conducting party (Hekkink et al. 2003).

The conducting parties of “health care quality evaluation reports” are medical professionals who tend to be more influential than the general public and the physically weak. Although Ware commented that “health care quality evaluation reports” are intentionally more factual and objective (Ware et al. 1983), Donabedian pointed out that evaluation conducted by medical professionals tends to over-estimate the quality of care provided and lack true external validity (Donabedian 2005). In addition, it was reminded that HCP or administrative staff tend to conduct their evaluations based on financial considerations, clinical interests, and commitments to current projects, as opposed to clients’ real needs (Ryan 1993). Therefore, their reports will be easily biased toward their own interests and not reflect the true experiences of patients.

Despite the possibility of potential bias, Ware commented that “patient satisfaction surveys” have the unique strength of reflecting different perceptions in satisfaction, like personal preferences and opinions of patients, as compared with “health care quality evaluation reports”. This is important because service recipients are considered to be a more vulnerable and passive group. (Ware et al. 1983). Ware and Hays highlighted that patient satisfaction is a determinant of the choice of a HCP or system, the use of services, complaints and malpractice suits (Ware and Hays 1988). These issues can only be evaluated objectively by a group of people NOT part of the service provider, who are the service recipients—the patients.

However, It should be noticed that “patient satisfaction surveys” were not popular in Western cultures before 1980 and have not been brought to full potential (Nelson and Niederberger 1990). The benefits of conducting “patient satisfaction surveys” were only gradually known in and around the 1980s, where there was a surprising five-fold increase in the number of articles devoted to “patient satisfaction” between 1980 and 1996 (Thiedke 2007).

With the discussion above, it is evident that both methods can be used to evaluate the health care services and institutions for patients. Comprehensive consideration of the results obtained from both methods is imperative in order to strike a balance, and not be biased toward either the HCP or the patient. In addition, due to different standpoints, a gap in perception of satisfaction is inevitable between the two methods. Analysis of this gap helps to identify the inconsistencies between the perceptions of services of HCP and patients, so as to ensure consistent expectations and experiences, which are needed in quality health care (Aharony and Strasser 1993). An ideal quality health care should yield similar findings from “health care quality evaluation reports” and “patient satisfaction

studies”, as a compassionate HCP should understand the needs of its patients, and a considerate patient should realise limitations and inadequacies that exist in the current health care system.

## **2.2 Evolution of the term “Patient satisfaction”**

The term “patient satisfaction” evolved chronologically, which reflected the role it played in the field of health care and its impact on patients and HCP. It is significant to understand the impacts brought by “patient satisfaction”, as they can assist patients, researchers, HCP and health care administrators to examine their roles, responsibilities and expectations in providing or receiving health care, and understanding all these will be a milestone in approaching the ultimate goal of health care—to provide services efficiently and effectively while balancing the interests of service providers and recipients.

The term “patient satisfaction” was not commonly used in the field of health care until the 1960s. Investigators started measuring patient satisfaction and correlated it with patients’ demographic variables from the 1960s onwards (Hall and Dornan 1988). During this time, budgets for health care services in the West shrank, which led to criticisms and active claims of rights from service users in the planning of health care services (Sitzia and Wood 1997). From 1980s, HCP began to incorporate opinions of patients into their strategies for improving health care services, which reflected that patients became the central focus of health care delivery and quality assurance efforts (Aharony and Strasser 1993).

Throughout this time, using the term “patient” to describe a service recipient was generally and traditionally accepted. However, it was criticised for giving a feeling of powerlessness to the medical establishment (Sitzia and Wood 1997). McIver from UK also argued that a general shift towards consumerism was evident in public services (Abramowitz et al. 1987). Therefore, the term “consumer” was used to enable more equality in the patient-provider relationship (Sitzia and Wood 1997). Later, some replaced “consumer” by “customer”, and it was said “the customer comes first” (Carr-Hill 1992).

Yet, some researchers challenged this consumerist concept, believing it was wrong to adopt a commercial attitude to health care, as it was not easy to make a proper comparison of medical skills and abilities (Sitzia and Wood 1997). This issue remained contentious, but now social and community health care services commonly refer this group of people more neutrally as “clients” or “service users”. Therefore, “patient satisfaction” and “client satisfaction” both refer to the same target group in this thesis.

Unlike other medical research, little breakthrough has taken place in patient satisfaction research although numerous studies have been conducted in the past few decades. It was thought to be due to the ambiguous concept of patient satisfaction (Dykeman 1998), as it was commented that “the lack of attention to the meaning of patient satisfaction has been seen as the greatest single flaw in patient satisfaction research ” (Sitzia and Wood 1997 (p.1832)). Without an agreed definition, it will be impossible for researchers to make full use of this method to evaluate health care services.



## 2.3 Definition of patient satisfaction

In the existing literature, four definitions of patient satisfaction are worthy of attention.

1. **“Individual’s positive evaluations of distinct dimensions of the health care.”**

(Linder-Pelz 1982)

Linder-Pelz observed that even in studies that do not explicitly study satisfaction, the attitudes and perceptions of patients on care can be used for seeking evaluations and responses to care (Linder-Pelz 1982). Interestingly, she asserted patient satisfaction as “positive evaluations” after citing a positive example of job satisfaction. However, according to her philosophy, health care evaluation will not be exhaustive if “dissatisfaction” aspects are not covered. If “dissatisfaction” is not considered, improvements would not be possible.

2. **“A cognitive evaluation of an emotional reaction to health care.”**

(Fitzpatrick 1993)

Fitzpatrick provided a more incisive explanation than the above, as he described the subjective nature of patient satisfaction, with emphasis more on feelings than tangible dimensions. Evaluating the emotional reactions of patients is an obvious way of ascertaining their satisfaction, as their emotional reactions reflect their attitudes towards the health care services. Yet, this definition emphasises the psychological aspects of a patient, which can fluctuate a lot as it relies much on the mind and mentality of the patient at the time when the patient satisfaction study is conducted.

3. **“The extent to which services gratify the client’s wants, wishes, or desires for treatment.”** (McMurtry and Hudson 2000)

A similar, but more specific definition than Fitzpatrick’s was proposed by McMurtry and Hudson. In their definition, the words “gratify” and “client” mean that patients have expectations and are able to actively judge the services they receive. However, health care services are broad in nature and clients should be given chances to evaluate components other than “treatment”.

4. **“Patient satisfaction is commonly used as a measure of health care quality, and as a means of including patient perspectives in the evaluation of services.”** (Burke et al. 2003)

The definition of patient satisfaction from Burke is considered by the researcher to be the most appropriate, as it is not only broad and general, but also clearly states the function of patient satisfaction and its nature (based on patients’ perspectives). Furthermore, it does not contain the loopholes of the previous definitions and indicates the value of conducting patient satisfaction.

## **2.4 Importance of patient satisfaction**

The primary benefit of conducting patient satisfaction studies is that it enables patients to evaluate policies of service provision and the quality of services they received. Aharony and Strasser stated that patient satisfaction can help HCP identify potential areas for improvement, such as program planning, patient education and follow-up, specific quality of care issues, and hospital procedures (Aharony and Strasser 1993). Carr-Hill also pointed out that patient satisfaction not only works towards the good of the patients, but also serves their needs and wishes, as well as relates to their concerns and interests (Carr-Hill 1992).

Results obtained from previous patient satisfaction studies can imply behaviours of patients which have direct effect on their health status. Patients treated with dignity and those involved in making decisions are more satisfied and are more likely to follow their doctors' recommendations (Beach et al. 2005; Bodenlos et al. 2007). A couple of other studies also show that patients with higher satisfaction are more likely to adhere to treatment regimens, cooperate with treatment and the HCP by disclosing important medical information, and have a high level of continuity with their HCP, which in return result in improved clinical outcomes (Stein et al. 1993; AIDS Weekly 2000; Hudak and Wright 2000; Sullivan et al. 2000; Bova et al. 2006). Patients with lower satisfaction levels are associated with delayed care seeking, which is a significant predictor of changing one's HCP or even the health care facility (Ware and Davies 1983; Dykeman 1998)

## 2.5 Determinants of patient satisfaction

Early in 1965, Abdellah and Levine attempted to identify the key determinants of patient satisfaction, they are (Abdellak and Levine 1988):

1. adequacy of the facilities
2. effectiveness of the organisational structure
3. professional qualifications and competency of personnel
4. effect of care on consumers

Then in 1983, Ware provided eight dimensions of patient satisfaction (Ware et al. 1983). They are explicit, exhaustive and accurately present what patients are concerned about during their visits at health care facilities. The eight dimensions are (Ware et al. 1983):

- **Interpersonal manner**  
The way in which providers interact personally with patients (e.g. concern, friendliness, courtesy, disrespect, rudeness)
- **Technical quality**  
The competence of providers and their adherence to high standards of diagnosis and treatment (e.g. thoroughness, accuracy, unnecessary risks, making mistakes)
- **Accessibility/convenience**  
Time and effort required to get an appointment, waiting time at the reception, ease of reaching the health care facility
- **Finances**  
Factors involved in paying for medical services (e.g. reasonable costs, alternative payment arrangements, comprehensiveness of insurance coverage)

- **Efficacy/ outcomes**  
The results of medical care encounters (e.g. helpfulness of medical care providers in improving or maintaining health)
- **Continuity**  
Sameness of provider and/ or location of care (e.g. see the same physician)
- **Physical environment**  
Features of setting in which care is delivered (e.g. orderly facilities and equipment, pleasantness of atmosphere, clarity of signs and directions)
- **Availability**  
Presence of medical care resources (e.g. enough hospital facilities and providers in the area)

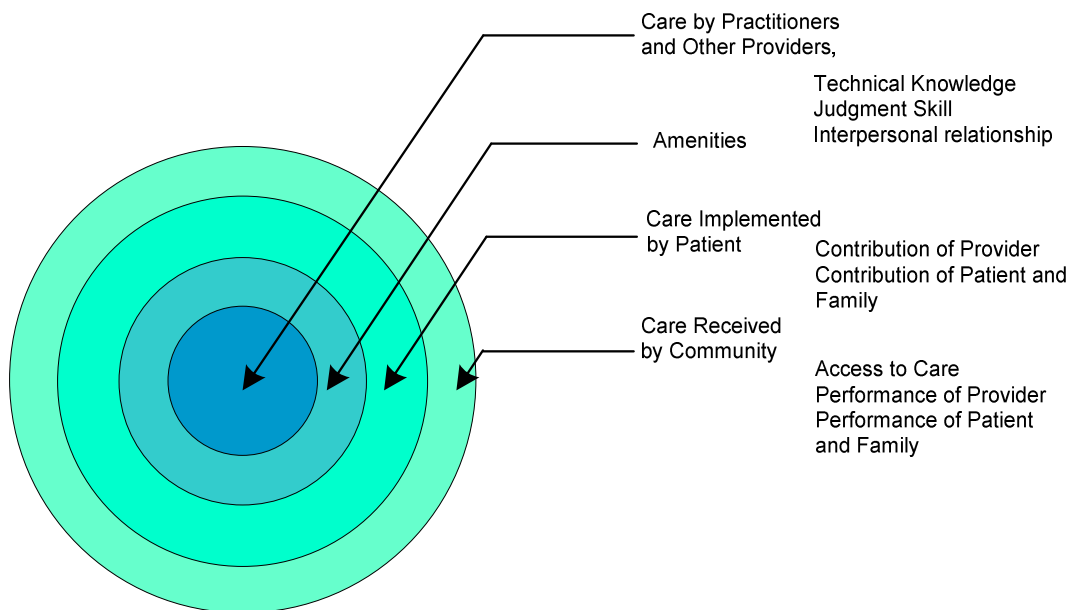
The first four dimensions (interpersonal manner, technical quality, accessibility/ convenience, finance) are by far the most commonly measured features of care. This list was used as a blueprint for designing new questionnaires in future patient satisfaction research (Stein et al. 1993; Bodenlos et al. 2004). Given the comprehensiveness of this list of dimensions, the questionnaire used in the quantitative study for this thesis (Chapter 3) was prepared based on this list.

These eight dimensions imply that patient satisfaction is a multi-dimensional construct, as presented by Donabedian, who believed that health care should not be a unitary concept (Donabedian 2005). He suggested a four-level assessment scheme as illustrated in Fig. 3 on page 34. The first level (starting from the core) is “*technical*” and “*interpersonal*” aspects of care, which are the most critical in the evaluation of health care quality (Donabedian 1988). He explained that the “*technical*” aspect is “the application of medical knowledge in a manner that maximises its benefits and minimises

its risks, taking account of the preferences of each patient” (Donabedian 1978 (p.856)). The “*interpersonal*” aspect, on the other hand, is more subjective in nature, which can be reflected by the attitudes and perceptions of health care recipients towards HCP. It covers issues such as privacy, confidentiality, informed choice, concern, empathy, honesty, tact, sensitivity and other virtues (Donabedian 1988).

The first level is then followed by “*amenities*” at the second level, which includes convenience, comfort, quiet, and privacy of the health care facility environment. Hudak and Wright agreed that “*amenities*” is a prominent issue and should be included in patient satisfaction (Acorn and Barnett 1999; Hudak and Wright 2000).

In addition to the first two core levels, the contribution to care by patients and by their family members should be assessed on the third level, because they are also involved in the success of health care. Finally, the care received by the community should also be assessed on the fourth level, as this implies the accessibility to care, and subsequently, the quality of care in the community, which in turn is linked to the performances of individual practitioners and health care facilities (Donabedian 1988). Due to the impracticability of gaining access to the families and communities of the patients, this thesis only focuses on the first two core levels.



**Fig. 3** Levels at which quality may be assessed.

Adapted from “The Quality of Care. How can it be assessed?” (Donabedian 1997)

Although the determinants of patient satisfaction were all explicitly proposed by medical researchers, it must be remembered that patients are the ultimate health care recipients. Therefore they are also qualified and able to define the quality of care (Cleary and McNeil 1988). However, it was pointed out that new patients are unlikely to have any expectations and they may not believe that they can express their own expectations under the highly technological treatments (Williams 1994). Therefore aspects and instruments used for patient satisfaction assessments are still commonly developed by researchers rather than patients, despite the fact that it is important to include patients’ views to determine what aspects of service patients are truly concerned about.

## **2.6 Factors affecting patient satisfaction levels**

There are many factors that affect the level of patient satisfaction, and their relationships to the satisfaction levels are still being investigated. The considered factors are geographic origin, sexual orientation, employment status, previous visits to clinics, educational level, gender, age, severity of symptoms, depression, involvement of Highly Active Anti-Retroviral Therapy (HAART) medication in treatment, and patient-provider communication. Among these, geographic origin, sexual orientation and employment status were found to be of little or no association. Involvement of HAART medication and better patient-provider communication can lead to higher patient satisfaction levels. However, the relationship with satisfaction level is unknown for the rest of the factors. Table 1 shows a list of all considered factors and their association with patient satisfaction levels.



**Table 1** Factors that may affect patient satisfaction levels and their observed influences

<b>Factor</b>	<b>Influence on patient satisfaction levels</b>
Geographic origin	No significant association (Beck et al. 1999; Erwin 2000; Marx et al. 2001; Miles et al. 2003)
Sexual orientation	No significant association (Beck et al. 1999; Marx et al. 2001; Miles et al. 2003)
Employment status	No significant association (Beck et al. 1999)
Previous visits to clinics	Conflicting data - patients who spent more years at the clinic were associated with higher levels of satisfaction (Dykeman 1998) - no significant association (Miles et al. 2003)
Education level	Conflicting data - less educated patients were associated with higher levels of satisfaction (Hall and Dornan 1988; Canales 1998) - less educated patients were associated with lower levels of satisfaction (Thiedke 2007) - no significant association (Katz et al. 1997; Erwin 2000; Miles et al. 2003)
Gender	Conflicting data - women were associated with higher levels of satisfaction (Aharony and Strasser 1993; Burke et al. 2003) - men were associated with higher levels of satisfaction (Saila, Mattila et al. 2008) - no significant association (Stein et al. 1993; Stone et al. 1995; Dykeman 1998; Beck et al. 1999; Erwin 2000; Sullivan et al. 2000; Marx et al. 2001)
Age	Conflicting data - older patients were associated with higher levels of satisfaction (Hall and Dornan 1988; Aharony and Strasser 1993; Katz et al. 1997; Tsasis et al. 2000; Bodenlos et al. 2004) - no significant association (Dykeman 1998; Beck et al. 1999; Miles et al. 2003)
Severity of symptoms	Conflicting data - patients with more severe symptoms were associated with lower levels of satisfaction (Aharony and Strasser 1993; Stein et al. 1993; Katz et al. 1997; Burke et al. 2003) - no significant association (Beck et al. 1999)
Depression	Conflicting data - patients with depression were associated with lower levels of satisfaction (Burke et al. 2003; Frosthalm et al. 2005) - patients with depression were associated with higher levels of satisfaction (Kersnik et al. 2001)
HAART medication	Patients with HAART medication were associated with higher levels of satisfaction (Burke et al. 2003; Malcolm et al. 2003)
Patient- provider communication	Better communication was associated with higher levels of satisfaction (Sullivan et al. 2000; Keating et al. 2002)

## 2.7 Difficulties in conducting patient satisfaction research

As mentioned at the beginning of this chapter, a lack of an agreed definition for patient satisfaction has been considered one of the difficulties in conducting patient satisfaction studies. In addition, lack of a conceptual or theoretical model for conducting patient satisfaction research, and inconsistency in understanding the determinants of patient satisfaction were also considered as barriers to conducting good quality patient satisfaction research (Aharony and Strasser 1993; Dykeman 1998; Yellen et al. 2002). Furthermore, it was commented that most studies not only failed to clearly identify the concept and clarify the purpose and intent, but also had methodological problems (Thomas and Bond 1996).

The most frequently used instruments for collecting patient satisfaction data are self-administered questionnaires, focus groups, individual personal interviews and telephone interviews. Among them, self-administered questionnaires are the most popular, as they ensure the anonymity of respondents and save time (Acorn and Barnett 1999; Saila et al. 2008). However, it was observed that researchers often tend to construct their own questionnaires for their own studies (McMurtry and Hudson 2000). Nevertheless, a number of self-administered questionnaires were standardised and validated for future assessment of patient satisfaction levels. For example:

- Patient Satisfaction Questionnaire (PSQ)  
(Stein et al. 1993; Katz et al. 1997; Burke et al. 2003)
- Patient Satisfaction Scale PSS (Hudak and Wright 2000)
- Primary Care Assessment Survey (PCAS) (Ingersoll and Heckman 2005)
- Attitudes Toward HIV Health Care Providers (AHHCP) (Bodenlos et al. 2004)
- Health Care Relationship (HCR) Trust Scale (Bova et al. 2006)

However, because the contents of the questionnaires are not the same, it does not allow meaningful comparisons of results between those studies. Therefore, patient satisfaction studies were often conducted on a relatively small scale, at a particular health care facility in an area, but rarely conducted nationally or internationally. This phenomenon is understandable though, as it is necessary to design the most appropriate study instruments and contents with respect to different objectives of the researchers, nature of the health care facilities, and composition of the clients receiving the services.

Furthermore, although the self-administered questionnaire is the most popular instrument, its format is still challenging. Hudak and Wright pointed out that closed-ended questions help avoid under-reporting, whereas open-ended questions are useful for assessing the priorities of patients, in which a mixture of both types of questions can provide a more thorough understanding of satisfaction (Hudak and Wright 2000). But it was also found that responses to open-ended questions are more negative than responses to closed-ended questions (Strasser and Davis 1991). Studies also revealed that specific questions are associated with lower satisfaction levels when comparing with general questions (Sitzia and Wood 1997).

Response format also has an effect on the outcome of a survey. It has been pointed out that a 5-point evaluation rating scale (excellent, very good, good, fair, poor) is associated with lower satisfaction levels and greater response variability when comparing with a 6-point rating scale (extremely satisfied, very satisfied, somewhat satisfied, neither satisfied nor dissatisfied, somewhat dissatisfied, very dissatisfied) (Hudak and Wright 2000).

Apart from the barriers mentioned above, the format of the instrument and type of data collection may also affect the validity of patient satisfaction studies. There are a number of possible biases. Their effects on the accuracy of the results are now considered:

- *Non-response bias*

There are two views towards non-response bias. Some researchers suggested that non-respondents maybe less satisfied than those who respond to patient satisfaction surveys (Ley et al. 1976), while Ware found that patients who are more satisfied are less likely to return questionnaires (Ware et al. 1983; Aharony and Strasser 1993). This type of bias is difficult to avoid as it is difficult to reach the non-response population.

- *Acquiescence response bias*

It is defined as the tendency to agree on statements of opinion regardless of content, and arises from the agree-disagree response scale used in questionnaires (Ware 1978). This does not only create equivocal responses, but may also result in response sets, which means a respondent chooses the same answer to every question regardless of what the question is asking (Yellen et al. 2002). Items of the questionnaire should be worded both positively and negatively to minimise the bias.

- *Selection bias*

It was discovered that dissatisfied patients tend to withdraw from the health care facility midway before they end their treatments or before their satisfaction levels are measured (Hudak and Wright 2000). As a result, this type of patient is under-represented in the sample of respondents, leading to a higher than average satisfaction levels than in reality. For general hospitals or clinics, this type of bias can be avoided by administering patient satisfaction surveys mid-way before the patient finishes his/her treatment (Canadian

Medical Association 1992).

- *Social desirability*

Social desirability is one of the potential confounders that leads to higher levels of satisfaction than the reality (Pascoe 1983). If respondents are strongly motivated to present themselves in a way that the society regards as positive, they may tend to report greater satisfaction than they actually feel, as they believe positive comments are more acceptable to researchers (Sitzia and Wood 1997; Le May et al. 1999). This bias can be avoided by increasing the anonymity of the respondents, such as using a central deposit box for completed self-administered questionnaires (Miles et al. 2003).

- *Halo effect*

Patients' feelings towards one aspect of care can affect their judgment of another aspect (Beck et al. 1999). For example, patients who find their doctors friendly and respectful ("interpersonal" aspect) tend to judge their technical competence ("technical" aspect) favourably (Roberts 2002). This type of bias is again difficult to eliminate as it is rarely possible to estimate its effect on the true satisfaction level.

- *Other types of bias*

Social-psychosocial artefacts such as self-interest bias, gratitude effect and simple indifference can affect patient satisfaction levels. For self-interest bias, patients ingratiate themselves with the health care facility, as they believe that expressions of satisfaction will contribute to the continuation of the service, which will benefit them eventually (Sitzia and Wood 1997). For gratitude effect, Williams proposed that dissatisfaction is only expressed when an extreme negative event occurs, which is normally associated with elderly populations (Williams 1994). For simple indifference, patients may feel that

problems are too trivial and cannot be remedied, so they tend not to comment during the surveys (Sitzia and Wood 1997).

With the concerns above, Yellen et al. concluded that questionnaires must include reliable, standardised items measuring the defined concept to make patient satisfaction truly indicative. In addition, these standardised items should also be psychometrically tested. At last, comprehensive data collection approach, ability of comparing the results across different clinical facilities and agreement on the role of the results are all demanded for a successful patient satisfaction study (Yellen et al. 2002).

## **2.8 Examples of HIV patient satisfaction research**

There are numerous patient satisfaction studies which have been conducted in general hospitals, but few were conducted in HIV health care facilities, particularly in ambulatory care facilities. Most patient satisfaction studies found from existing literature have been carried out in the US, a few were from Western Europe, but extremely few were from Australia, and none were from Asia. Tables 2 (a) to (d) on pages 44 and 45 show summaries of four patient satisfaction studies from 2000 onwards conducted in ambulatory HIV health care facilities and in a sexual health clinic.

It is interesting to note that while only one study in the existing literature focussed on investigating dissatisfaction (Burke et al. 2003), all others aimed at investigating satisfaction towards HIV services and HCP only. Aspects for evaluation in those patient satisfaction studies included: confidentiality issues, clinic environment, HCP attitudes, HCP skills, information provided by HCP, communication with HCP, access to services, and financial aspects (Beck et al. 1999; Tsasis et al. 2000; Colebunders et al. 2001; Roberts 2002; Burke et al. 2003; Miles et al. 2003; Bova et al. 2006).

A very large majority of the patient satisfaction studies were conducted by self-completed questionnaires. Although interviews and focus groups were included in some studies, most of them were only used for gathering patients' views for devising the most suitable questionnaire, and not as main instruments (Begley et al. 1994; Beck et al. 1999; Miles et al. 2003; Bova et al. 2006). A number of studies developed and validated their own questionnaires based on patients' suggestions, and by incorporating other standardised questionnaires into their own as validation standards (Begley et al. 1994; Beck et al. 1999; Miles et al. 2003; Bodenlos et al. 2004; Bova et al. 2006; Bodenlos et

al. 2007). These findings support Larsen et al.'s view that investigators of client satisfaction research tend to invent their own questionnaires (Cited in McMurtry and Hudson 2000 (p.646)).

The sample sizes of the studies varied widely, from 62 to 1,303 patients for questionnaire surveys. As these questionnaire surveys are easy to administer, a large sample group can be yielded in a short period of time. Studies indicated that levels of satisfaction were generally high. Patients were usually more satisfied with interpersonal communication with their HCP and the quality of care than the physical aspects of the clinic. "Good manner", "sufficient communication", and "more opportunities to discuss health problems" were found to be associated with satisfaction directly.

The studies also inferred that "expectation" and "trust" are pivotal in influencing satisfaction. In Keating et al's study, physicians who did not always give enough time and explanation to patients were associated with lower trust, and thus, lower satisfaction levels (Keating et al. 2002). Also, dissatisfaction occurs if there is a mismatch between the expectation of the patient and the consultation style of the physician (Roberts 2002). Another study revealed that female physicians provide higher quality HIV-specific communication than male physicians, because they are better in communicating with patients about difficult topics such as sexual conduct and substance abuse (Wilson and Kaplan 2000). Therefore, trust should be developed on the basis of interpersonal connection, respectful communication, and professional partnering (Bova et al. 2006).



**Table 2 (a)** Summary of selected studies of HIV patient satisfaction

<b>(a) Comparing doctor- and nurse-led care in a sexual health clinic: patient satisfaction questionnaire (Miles et al. 2003)</b>	
<b>Setting</b>	A central London Genitourinary Medical (GUM) Clinic in 1999
<b>Aim</b>	To develop and validate a patient satisfaction questionnaire and to compare the satisfaction levels of women attending nurse-led and doctor-led clinics
<b>Design</b>	Questionnaire designed after interviewing patients, testing for face and construct validity, reliability, and test re-test
<b>Sample</b>	282 participants (77% whites; 96% heterosexuals)
<b>Results</b>	<ol style="list-style-type: none"> <li>1.) Mean score: 4.33 out of 5</li> <li>2.) Significantly different scores: 4.47 for specialist nurses and 4.30 for doctors</li> <li>3.) No significant linear correlation between overall satisfaction and the factors: age, previous visits to clinic, further education, sexual orientation, social class and ethnicity</li> </ol>

**Table 2 (b)** Summary of selected studies of HIV patient satisfaction

<b>(b) The health care relationship (HCR) trust scale: development and psychometric evaluation (Bova et al. 2006)</b>	
<b>Setting</b>	HIV primary care sites and HIV-infected individuals previously enrolled in a longitudinal study of a home-based nursing intervention to improve adherence to anti-retroviral therapy (ATHENA) in the US
<b>Aim</b>	To develop and evaluate a scale to measure patient trust in HCP
<b>Design</b>	Health Care Relationship (HCR) Trust Scale developed by semi- structured focus groups, individual interviews, and quantitative instrument.
<b>Sample</b>	<ol style="list-style-type: none"> <li>1.) 25 took part in focus groups and individual interviews</li> <li>2.) 99 took part in the instrument development sample</li> </ol>
<b>Results</b>	<ol style="list-style-type: none"> <li>1.) Three trust domains that HCP should focus on: <ul style="list-style-type: none"> <li>• Interpersonal connection</li> <li>• Respectful communication</li> <li>• Professional partnering</li> </ul> </li> <li>2.) Level of trust was high</li> <li>3.) The use of the HCR trust scale for measuring trust in various HCP by diverse patient populations is supported</li> </ol>

**Table 2 (c)** Summary of selected studies of HIV patient satisfaction

<b>(c) Dissatisfaction with medical care among women with HIV: Dimensions and associated factors (Burke et al. 2003)</b>	
<b>Setting</b>	HIV-infected women at 6 urban sites in US, from 1995-1997
<b>Aim</b>	To examine the levels of dissatisfaction across different dimensions of care, and to identify patient characteristics associated with these dimensions
<b>Design</b>	The previously validated Patient Satisfaction Questionnaire-Short Form (PSQ-SF) was given to participants, with 7 dimensions: 1.) general satisfaction                      5.) financial aspects 2.) technical quality                            6.) time spent with provider 3.) interpersonal manner                      7.) accessibility/convenience 4.) communication
<b>Sample</b>	1303 HIV-infected women who were involved in The Women's Interagency HIV study 55% were African American
<b>Results</b>	1.) "Access to care" and the "technical quality of care" were aspects most dissatisfied. "Financial aspect of care" and "providers' interpersonal manner" were the least dissatisfied. 2.) Patients who had depression, poor health, not receiving anti-retroviral therapy (ART), no consistent care providers, or were Hispanic/Latina were more likely to be dissatisfied across most dimensions of care

**Table 2 (d)** Summary of selected studies of HIV patient satisfaction

<b>(d) The doctor-patient relationship and HIV-infected patients' satisfaction with primary care physicians (Sullivan et al. 2000)</b>	
<b>Setting</b>	2 urban medical centres in the North-Eastern US from 1994-1996
<b>Aim</b>	To assess the extent to which perceptions of specific aspects of the doctor-patient relationship are related to overall satisfaction among HIV-infected patients
<b>Design</b>	1.) Longitudinal observational study, interviews done at the beginning of the study and after 6-month follow-up 2.) Questions asked include "Does your primary care physician meet your expectations?" and "How satisfied are you with your primary care physician?"
<b>Sample</b>	146 participants (75% males; 46% IDU; 19% gays/ bisexuals; 35% heterosexuals)
<b>Results</b>	1.) Patients who <ul style="list-style-type: none"> <li>• were more comfortable in discussing personal issues with physicians</li> <li>• perceived their physicians as more empathetic</li> <li>• perceived their physicians as more knowledgeable about HIV</li> </ul> were more satisfied with physicians

Apart from the evaluation of patient satisfaction, some studies were more of an exploratory nature. Based on identifying patients' unmet needs and their perspectives, researchers identified the determinants for quality HIV health care which should be included. This information provided clear directions for HCP in providing the most optimal services to patients. Tables 3 (a) to (c) on pages 47 and 48 show the summary of three selected studies conducted from 2000 onwards at day-care or ambulatory HIV health care facilities.

In those studies, personal interviews and focus groups were commonly used for collecting data. Topics such as patients' experiences in health care, definition and determinants of quality health care, perceived barriers/unmet needs, and facilitators to entering and staying in care were covered. In particular, one study used a card-sorting exercise for focus group participants to rank their indicators for health care of high quality (Davis-Michaud et al. 2004).

Since interviews and focus groups require more time and researchers' skills than questionnaire surveys, the sample sizes of these two methods were smaller, ranging from around 20 to 100 (except in one study where there were 519 participants). It was discovered that patients had relatively fewer unmet needs for medical care as opposed to social, emotional, and financial support (Erwin 2000; Marx et al. 2001; Reif et al. 2006; Tobias et al. 2007)

Patient-provider relationship and effective communication with the HCP again emerged as the two most significant determinants of patients' perceptions, as they were mentioned more frequently than any other determinants (Davis-Michaud et al. 2004; Mallinson et al. 2007). Determinants which lead to the closeness of the relationship such

as “including patients’ decisions in treatment” and “having access to anti-retroviral treatment” were therefore also perceived as important (Davis-Michaud et al. 2004). HCP who were empathetic were also found to be able to deliver care more effectively (Mallinson et al. 2007).

**Table 3 (a)** Summary of selected studies of quality health care

<b>(a) The provider role in client engagement in HIV care (Mallinson et al. 2007)</b>	
<b>Setting</b>	PLWHA at different sites across US participating in the HRSA-funded (Health Resources and Services Administration) Outreach Initiative in 2004-2005
<b>Aim</b>	To discover what specific provider behaviours influence PLWHA’s engagement in care from the perspective of the client
<b>Design</b>	1.) Qualitative analysis using in-depth semi- structured interviews 2.) Questions asked about: <ul style="list-style-type: none"> <li>● participants’ past and current experiences with HIV testing and follow-up care</li> <li>● perceived barriers and facilitators to entering and staying in care</li> <li>● reasons for periods of no HIV care</li> </ul>
<b>Sample</b>	76 participants (51% male; 51% African Americans; 58% homosexuals)
<b>Results</b>	1.) Client-provider relationship emerged as a central determinant from clients’ perceptions 2.) Respondents desired a care partnership with an empathetic HCP who has effective communication skills 3.) HCP are obliged to improve the delivery of care, to communicate effectively, and to translate caring attitudes into observable behaviours

**Table 3 (b)** Summary of selected studies of quality health care

<b>(b) Quality Care for People with HIV/AIDS: patients' perspectives (Davis-Michaud et al. 2004)</b>	
<b>Setting</b>	At 2 community-based resource organisations in US in 1998
<b>Aim</b>	To explore patient preferences to aid in the development of quality measures to assess quality of health care for PLWHA
<b>Design</b>	1.) Focus group discussions 2.) Clients were instructed to rank quality of care indicators using a card-sorting exercise, followed by discussion about their rankings
<b>Sample</b>	29 participants (20 males; 9 females)
<b>Results</b>	First 5 most important qualities of care indicators: 1.) Effective relationship with provider 2.) Prevention of opportunistic infections 3.) Involvement of care and treatment decisions 4.) Being offered anti-retroviral treatment 5.) Access to health care services

**Table 3 (c)** Summary of selected studies of quality health care

<b>(c) Barriers to getting needed services for Ryan White CARE clients (Marx et al. 2001)</b>	
<b>Setting</b>	95 sites from the Ryan White CARE-funded agencies in San Francisco, San Mateo and Marin Counties in 1996
<b>Aim</b>	To determine the reasons HIV- infected persons do not access needed services
<b>Design</b>	1.) Face-to-face interviews 2.) Information about clients' perceived need for, receipt of, and satisfaction with 21 different services 3.) Clients with at least one unmet service need were asked about their perceived barriers to care
<b>Sample</b>	519 participants (73% males; 40% homosexuals but not IDU; 25% homosexuals and IDU)
<b>Results</b>	1.) Just over half of the clients had at least one unmet service need 2.) Gender, race and risk group were not associated with specific barriers 3.) Agency barriers, emotional issues, lack of information, and financial barriers were the most common unmet needs

## 2.9 HIV patient satisfaction research in Australia

Since this thesis is about research conducted in the Australian context, it is necessary to review past patient satisfaction studies conducted in Australia. In 1990, a survey named *“Client Satisfaction with Inpatient and Outpatient HIV/AIDS services in New South Wales”* was published by the AIDS Bureau of the NSW Department of Health (Linder-Pelz and New South Wales. AIDS Bureau. 1990). The survey aimed to assess patient satisfaction levels of HIV health care facilities funded by the NSW Department of Health and to provide recommendations for management and clinical staff to improve services provided. However, the questions in the questionnaire were too brief and general, and very little demographic information of respondents was collected. Also the survey only assessed the satisfaction levels of HIV positive clients. Other clients such as those coming for HIV screening were not included, which limited the application of the findings.

In 1992, *“The National HIV/AIDS Strategy Evaluation Quality Assurance Survey of HIV/AIDS Inpatient and Ambulatory Care Services”* was conducted using the same questionnaire and with a similar aim as the 1990 survey mentioned above. The only change was that the clinics included in the study were expanded from state-wide to nation-wide (Burcham et al. 1993). This survey also assessed the satisfaction levels of renal patients as a control group. Similar to the findings of the 1990 survey, high overall satisfaction levels were observed for HIV clients, especially on the “attitude” and “accessibility” of the staff. “Waiting times” and “information” were general issues with the lowest satisfaction ratings. There was no evidence of dissatisfaction for any particular patient group.

Due to a lack of internal evaluation within an HIV health care facility, a client satisfaction survey was implemented at ASC in 1996. Apart from assessing satisfaction levels of clients, it aimed to compare the findings with those in the above two surveys. The satisfaction levels were very high, and more than 85% of respondents were satisfied for each aspect. The aspect “caring” was the most satisfactory and “waiting time” was the least.

The ASC 1996 survey also included HIV negative clients who came for blood tests to ensure a more comprehensive sample group. The questions were based on those of the 1990 and 1992 surveys mentioned above but with modifications so that they were more specific to suit the nature of the facility. However, some questions only provided two answers for respondents to select (“YES” or “NO”), which was inappropriate for assessing satisfaction because it did not allow ratings in-between the two extremes. In addition, the questionnaire content was not comprehensive enough because only a few aspects of client satisfaction were considered and they were assessed only for particular (usually for doctors and nurses only) but not all HCP categories. Furthermore, the aspects were all worded positively, which tended to introduce acquiesce bias as discussed.

## **2.10 Limitations of previous patient satisfaction research**

Firstly, very few previous patient satisfaction studies have been conducted in Australia. They have mainly been conducted in North America and Western Europe. Although the patterns of HIV infection in Australia are comparable with those in the Western countries (the majority of PLWHA were infected through male homosexual intercourse) (UNAIDS and WHO 2008b), the trends of HIV patient satisfaction may not be the same due to differences in culture, expectations of patients, medical care system, and levels of medical technology. Hence, results from these studies cannot be simply generalised and then applied to Australia. Instead, independent research must be conducted in the Australian social context.

Secondly, even if studies are conducted in similar social contexts, results of patient satisfaction studies cannot be compared easily. This is because researchers tend to devise their own instruments for measurement (e.g. questionnaires) due to different study objectives, nature of the facilities, and composition of clients. This implies that aspects for measuring satisfaction can be different, which may not yield meaningful comparisons between studies conducted within the country, not to mention those in other countries.

Thirdly, there is a lack of evaluation conducted in ambulatory multidisciplinary facilities (clinics which provide various types of health care services). Previous studies were conducted mainly at hospitals which provided HIV medical treatment only. For those conducted in ambulatory facilities, usually only overall satisfaction was measured, which does not reflect much detail on particular aspect(s) of service or what particular type(s) of patients. It should be noted that HIV health care does not only include clinical services,



but also includes nursing, pharmacy, and other auxiliary services which involve paramedical HCP. Measurement of overall satisfaction does not allow patients to express their extreme levels of satisfaction toward different groups of HCP or types of services.

## **Chapter 3—The Quantitative Survey**

Chapter 2 presented the definition, importance, determinants of patient satisfaction, factors that affect its levels, and difficulties of conducting patient satisfaction research. It was revealed that only a few studies have been conducted at HIV/AIDS health care facilities, and none were found in the Australian context in the open literature, except the government health care quality assurance reports which were conducted more than a decade ago (Linder-Pelz and New South Wales. AIDS Bureau. 1990; Burcham et al. 1993).

The quantitative client satisfaction survey for this thesis was undertaken to evaluate the level of satisfaction of clients attending an HIV health care facility in Sydney, Australia. A newly-devised questionnaire was used in this survey and it underwent rigorous measures for ensuring its levels of validation and reliability, so it could be endorsed as a suitable instrument to identify client satisfaction at Australian HIV health care facilities in the future.

## **3.1 Research questions and outline of the chapter**

Three research questions will be addressed in this chapter. They are:

1. How satisfied with care and the HCP are clients attending an HIV/AIDS health care facility?
2. What aspects of HIV health care are perceived as important among clients?
3. Are there any significant differences in satisfaction among clients with different characteristics?

This chapter first provides a detailed description of the methodology used in the quantitative client satisfaction survey, followed by the survey results and justification for investigating client dissatisfaction and unmet needs.

## **3.2 Methodology**

### **3.2.1 Study Design**

This quantitative survey used a cross-sectional, self-administered questionnaire to measure client satisfaction towards HCP and health care services in an HIV health care facility—ASC, an ambulatory care clinic affiliated to a government hospital in Sydney. A cross-sectional study design is ideal in this case because data collection is conducted once only, so it is resource-saving and easy to administer. It also allows a large amount of data to be analysed and compared. Quantitative analysis was used to describe and interpret the findings. Due to the confidentiality of sampling PLWHA and those at risk of infecting HIV, mailed questionnaires and telephone surveys were deemed inappropriate. However, self-administered questionnaires completed on site by clients, on the other hand, will not expose their personal information, and is considered to be easier, economical, direct and efficient in collecting data (Saila et al. 2008).

### **3.2.2 Setting**

ASC is the largest public community-based ambulatory day care facility for people with HIV/AIDS and Hepatitis in Australia. It provides medical, nursing, counselling, nutrition, pharmacy and other specialist services to PLWHA and those at risk of infection (ASC 2008a). From 1998 to 2002, 42% of HIV cases in NSW were diagnosed by ASC (Hardwick and Cotton 2005).

Clinical services offered by ASC include HIV antibody testing, diagnostic procedures and investigations, prescribing and dispensing combination HIV therapies, referring patients to appropriate medical specialists, inpatient and respite care, and Hepatitis A and B vaccinations. Visiting specialists to ASC provide services including dermatology, oncology, palliative care, rheumatology and ophthalmology (ASC 2008b).

ASC is a multi-disciplinary clinic, it also provides counselling, nutrition, information, and emotional support services in addition to clinical care. Counselling services include pre- and post-antibody test counselling, psychological therapies, neuropsychological assessment, welfare and referral to psychiatric services. Dieticians provide dietary advice to help clients cope with HIV medication, and also provide symptom management and metabolic assessment. ASC also provides information and answers questions related to HIV knowledge and services through a state-wide telephone information line, which receives 25,000 to 30,000 calls a year. In addition, under the “Ankali” scheme, there are around 120 volunteers trained by ASC who provide regular visits and emotional support to clients of ASC and of other HIV health care facilities on a one-to-one basis (ASC 2008a; ASC 2008b).

ASC is located at Surry Hills near the city centre. It can be reached by train (about 10 minutes walk from the train station), by bus (bus stops in the city and near ASC), and by car (parking facilities nearby). Photo (a) of Appendix 1 shows a street view of the ASC clinical building.

The clinical building has three floors. The ground floor consists mainly of the reception, a waiting area with 12 chairs, and consultation rooms for clinical consultations. Photos (b), (c), and (d) of Appendix 1 show the waiting area beside the reception on the ground floor. The second floor consists mainly of the pharmacy, the pharmacy waiting area with 6 chairs, counselling and nutrition rooms for psychological and nutritional counselling. The third floor consists of offices of the HCP and a library which houses publications related to HIV/AIDS and hepatitis C (ASC 2008b).

In 2007, 3,302 clients utilised HIV services at ASC. About 89% were males, 11% were females, and 0.3% were transgender. A total of 23,072 services were delivered. The geographic origins of clients are more diverse than in the previous decade. The vast majority (79%) were Australians in 1996 and this reduced to just over half (53%) in 2007. Clients of other geographic origins increased by more than three times between 1996 and 2007, and there was a six-fold increase in the number of Asian clients. Table 4 shows the summary of the attendance records in ASC in 1996 and 2007 (Goulder 1996a; Goulder 1996b; Goulder 2007a; Goulder 2007b).

**Table 4** Summary of attendance records at ASC in 1996 and 2007

Note: The total numbers of clients are approximate numbers

	<b>1996</b>		<b>2007</b>	
<b>Total number of clients</b>	1,971	100%	3,302	100%
<b>Gender</b>				
Male	1,790	91%	2,900	89%
Female	170	9%	370	11%
Transgender	14	0.7%	9	0.3%
<b>Geographic origin</b>				
Australia	1,560	79%	1,760	53%
Europe	180	9%	540	16%
Asia	80	4%	480	15%
North America	45	2%	160	5%
Africa	45	2%	130	4%
New Zealand	30	2%	130	4%
Central/ South America	45	2%	100	3%

Adapted from attendance records provided by ASC (Goulder 1996b; Goulder 2007b)

### **3.2.3 Respondents and sampling**

Potential respondents for this study were all ASC clients over 18 years old who could read and write English. However, those who came to collect medication only were not included in this survey, as the ASC management staff made the decision that these people could be clinically managed by other HIV health care facilities, and therefore did not represent true ASC clients.

According to the suggestion made by the AIDS Institute, New York State (NYS) Department of Health as shown in Table 5 (NYS Department of Health 2002), the minimum sample size required for patient satisfaction studies in ASC in 2007 was 125 as the caseload (3,302) was over 1,000.

**Table 5** Minimum sample size in patient satisfaction research by caseload

<b>HIV Programme caseload</b>	<b>Minimum sample size</b>
Less than 50	All patients up to 30
51-100	40
101-500	75
501-1,000	100
More than 1,000	125

Adopted from the Patient Satisfaction Survey for HIV Ambulatory Care (PSS-HIV) from the AIDS Institute, Department of Health, New York State (NYS Department of Health 2002).

### **3.2.4 Instrument—Preparation of the questionnaire (ASC-CSQ)**

As mentioned in Chapter 2, self-administered questionnaires are the most frequently used method for collecting patient satisfaction information, as questionnaires can use a larger sample size for studies than other commonly used instruments such as interviews and focus groups (Acorn and Barnett 1999), and this study was no exception.

Instead of using previously validated questionnaires, a newly devised questionnaire—**Albion Street Centre Client Satisfaction Questionnaire (ASC-CSQ)** (Appendix 2 on page 210) was used in this survey for the following three reasons. Firstly, questionnaires designed in foreign countries may not be suitable for Australia, particularly for demographic information such as “geographic origin”, “education level” and “possession of health care card”. Secondly, the types of health care services provided in each health care facility are different, which signifies that existing questionnaires may not be completely applicable for ASC. This reason is particularly important as this survey did not only assess satisfaction levels for overall services, but also for individual services and their HCP. Thirdly, although the questionnaire used for the 1996 client satisfaction survey at ASC was designed specifically for ASC, it was not used in this survey due to its weaknesses in the format and content discussed in section 2.9 on page 50.

Despite the weaknesses identified, the content of the 1996 client satisfaction survey questionnaire were still valuable as a reference for devising the ASC-CSQ. Aspects from the 1996 client satisfaction survey questionnaire were first grouped in terms of content, followed by an extensive literature review to determine those aspects to be included in the survey. The following satisfaction questionnaires were also used as references for the content, format and wordings of the ASC-CSQ.

- The Client Satisfaction Inventory (McMurtry and Hudson 2000)
- The Client Satisfaction Questionnaire (Menz 1997)
- The Client Satisfaction Questionnaire (Linder-Pelz and New South Wales. AIDS Bureau. 1990)
- The Quality Assurance Questionnaire (Burcham et al. 1993)
- Patient Satisfaction Survey for HIV Ambulatory Care (PSS-HIV) (NYS Department of Health 2002)
- The Bamras Patient Satisfaction Scale (Martin et al. 2000)

To demonstrate the validity of an instrument is to show that the researchers measure what they intend to measure. In this survey, four types of validity (content validity, criterion-related validity, face validity, construct validity) and internal reliability will be considered, in which measures to improve the validity and reliability of the ASC-CSQ will be described in chronological order. Then justifications for choosing the aspects for measuring client satisfaction are illustrated.



### **Content validity**

Content validity refers to the extent to which the items are representative samples of those which are to be measured. The content validity of ASC-CSQ was achieved in two ways:

Firstly, literature about patient satisfaction was reviewed extensively, with particular attention to those aspects that related to patients' concerns. Previously validated national and international patient satisfaction questionnaires used in HIV health care contexts were analysed, and the results were used as references for determining the most appropriate content and format for the ASC-CSQ.

Secondly, the first draft of the ASC-CSQ prepared by the researcher was further developed collaboratively by HCP and managerial staff of ASC. A meeting was held with representatives from various units of ASC to discuss and agree on the format and content of the ASC-CSQ. The second draft was then distributed to staff members in various ASC units to review and comment on. These ASC units included: clinical, nursing, psychology, pharmacy, and research units. The resulting final version of the ASC-CSQ contained 5 sections, as illustrated in Table 6.

**Table 6** Summary of the survey instrument ASC-CSQ

<b>Section</b>	<b>Content</b>	<b>Purpose</b>
1	<p>Basic information</p> <ul style="list-style-type: none"> <li>- Services received</li> <li>- HCP consulted</li> <li>- Length of time and frequency for attending services</li> <li>- HIV status and time since diagnosed</li> <li>- Other HIV health care services accessed</li> </ul>	<p>To understand the distribution of clients in terms of:</p> <ul style="list-style-type: none"> <li>- the types and number of services utilised</li> <li>- the categories of HCP consulted</li> <li>- the length of time and frequency for attending services</li> <li>- HIV status</li> <li>- accessing other HIV services</li> </ul> <p>To determine if they are associated with levels of satisfaction.</p>
2	Client Satisfaction Inventory	Previously validated questionnaire for testing criterion-related validity
3	<p>Satisfaction aspects (see Table 7)</p> <ul style="list-style-type: none"> <li>- 10 items about individual aspects of each HCP category</li> <li>- 6 items about overall aspects</li> <li>- 1 open-ended question about how the centre can improve</li> </ul>	<p>To determine the satisfaction levels of clients for each HCP category and each aspect</p> <p>Qualitative data to understand clients' expectations and issues that need improvement</p>
4	<p>Demographic information</p> <ul style="list-style-type: none"> <li>- Geographic origin</li> <li>- Gender</li> <li>- Age</li> <li>- Education level</li> <li>- Employment status</li> <li>- Possession of Health Care Card</li> <li>- Sexual orientation</li> <li>- Main risk for HIV infection</li> </ul>	<p>Personal information of clients to determine if the participants represent clients of ASC</p> <p>To determine if demographic factors are associated with levels of satisfaction</p>
5	<p>Marlowe-Crowne Social Desirability Scale</p> <p>1 open-ended question for comments about the centre, the services or the staff</p>	<p>Previously validated questionnaire for testing criterion-related validity</p> <p>Qualitative data to enable more ideas to be collected</p>

### **Criterion-related validity**

Criterion-related validity is another type of evidence to show that the instrument measures what it is intended to measure. It refers to the degree to which the instrument is related to some already known valid instrument (Acorn and Barnett 1999). As the ASC-CSQ has not been used for assessing client satisfaction before, it will be necessary to compare the results with those from a previously validated questionnaire.

The *Client Satisfaction Inventory* and the *Marlowe-Crowne Social Desirability Scale* are previously validated questionnaires that have been incorporated into Section 2 and Section 5 of the ASC-CSQ respectively. If the results from both validated questionnaires and ASC-CSQ are comparable and compatible, it indicates that the ASC-CSQ is of a certain level of criterion-related validity, and can be used as a standardised questionnaire in the future. Also, Section 2 and Section 5 can be excluded from the ASC-CSQ in future when conducting evaluations.

The Client Satisfaction Inventory has been shown to be a valid and reliable measure of satisfaction with services among clients of human service agencies and has an excellent internal consistency (McMurtry and Hudson 2000). It is a 25-item scale with statements about perceptions and attitudes toward the facilities. Respondents were required to answer each item on a 7-point scale, ranging from score 1 (*none of the time*) to 7 (*all of the time*), or put an "X" if *not applicable*. Using a formula (which will be described in section 3.3.5 on page 96), the scores from all items could then be interpreted to a Client Satisfaction Inventory score for each respondent, which could be compared with the satisfaction level measured by the ASC-CSQ.

The Marlowe-Crowne Social Desirability Scale measures the level of social desirability response bias, one of the psychosocial determinants in determining client satisfaction mentioned in section 2.7 on page 40. The 10-item validated short version of the traditional Marlowe-Crowne Social Desirability Scale was used, with statements concerning personal attitudes both positively and negatively worded (Strahan and Gerbasi 1972). A scoring algorithm was used to assign a score for each of the 10 items, either 1 or 0. Then a Marlowe-Crowne Social Desirability Scale score was calculated for each respondent by adding up the 10 scores. A higher score indicates that the respondent was more likely to give social desirable responses, i.e. rated the aspects more satisfactorily than actually felt in the ASC-CSQ.

### **Aspects measuring client satisfaction**

Section 3 of the ASC-CSQ consists of 10 sets of questions regarding individual aspects and 6 questions regarding overall aspects of client satisfaction. The aspects are based on previous patient satisfaction survey questionnaires and Ware's list of patient satisfaction determinants mentioned in section 2.5 on page 31 and in Table 7 on page 65. The eight dimensions are: "*interpersonal manner*", "*technical quality*", "*accessibility/convenience*", "*efficacy/outcomes*", "*physical environment*", "*overall availability*", "*finance*", and "*continuity*" (Ware et al. 1983). The last two dimensions, "*finance*" and "*continuity*", were not considered in this study because the consultations for ASC clients were free of charge, and all respondents were clients who visited the centre for the first time.

For the 10 sets of questions regarding individual aspects, clients were asked to consider their experiences with each HCP category within the past 6 months, namely doctors, nurses, psychologists, nutritionists, pharmacists, researchers and receptionists, and provide a rating for each of these 10 individual aspects. The ratings were on a 5-point Likert scale. For HCP the respondents had not consulted in the previous 6 months, they had the option to tick the “*Does not apply*” box. In addition, clients were asked to rate the importance of the 10 individual aspects. It is expected that researchers can assess if any relationship exists between client satisfaction and perceived level of importance. The 6 questions regarding the overall aspects are about “appointment time”, “accessibility of the centre”, “confidentiality”, “physical environment of the centre”, “management of the staff”, and “overall satisfaction”. They were also rated in 5-point Likert scale. Table 7 shows the 16 aspects in the ASC-CSQ.

Two optional open-ended questions were included for clients to provide suggestions on how to improve the current services, and to express how they felt about the services and staff at ASC. A mixture of both closed-ended and open-ended questions provides quantitative statistical data for assessing and comparing satisfaction levels, and qualitative data for understanding perceptions of clients, obtaining information about what services should be focussed on for improvements, and providing new ideas and insights for researchers to explore attributes which were not given attention to before.

**Table 7** Aspects assessing satisfaction levels in the ASC-CSQ

<i>Dimension</i>	<i>Aspect</i>	<i>Rationale</i>
Interpersonal manner	1. Attitude of HCP	Good interpersonal manner is a crucial determinant of patient satisfaction. It directly affects patient-provider relationship and increases cooperation of patients with HCP and adherence to drugs. (Roberts 2002; Miles et al. 2003)
Technical quality	2. Knowledge of HCP	Knowledge and technical skills of HCP are core determinants of assessing quality of care, as they directly influence the health status of patients. (Ware et al. 1983; Abramowitz et al. 1987; Donabedian 1988)
Accessibility/ convenience	3. Waiting time before consultation	Longer waiting times are associated with lower patient satisfaction levels. (Anderson et al. 2007; Saila et al. 2008)
	4. Length of consultation time	Satisfaction is associated with the time spent on each consultation. (Gross et al. 1998; Feddock et al. 2005; Anderson et al. 2007; Saila et al. 2008)
	5. Uninterrupted consultation	
	6. Appointment time	Accessibility and convenience are patient satisfaction determinants, particularly for employed clients and those with poor health. (Ware et al. 1983; Donabedian 1990)
	7. Accessibility of ASC	
Efficacy/ outcomes	8. Understood clients' needs	HCP with more empathy and attention to patients' medical needs increase patient satisfaction levels. Young and undereducated patients are more likely to experience unmet needs and are less satisfied. (AIDS Alert 2000; Thiedke 2007; Saila et al. 2008)
	9. Included clients' decisions in treatment	Not being able to participate in decision-making are associated with patient dissatisfaction. (Davis-Michaud et al. 2004; Saila et al. 2008)
	10. Benefited more than expected	Expectation is a patient satisfaction determinant. Satisfaction is higher when HCP recognise and address patient expectations. (Rao et al. 2000; Thiedke 2007)
Physical environment	11. Environment	Amenities include convenience, comfort, quiet, privacy. They are distinct from quality of care but important in patient satisfaction assessments. (Donabedian 1988; Acorn and Barnett 1999; Hudak and Wright 2000)
	12. Management of staff	
Overall availability	13. Availability of HCP	The presence of medical care resources is one of the patient satisfaction determinants as it affects efficiency. (Ware et al. 1983; Donabedian 1990)
	14. Information given during consultation	Information helps HIV patients improve their quality of life, and prevent infecting other people, and improves patient satisfaction. (Wilson and Kaplan 2000; Saila et al. 2008)
N/A	15. Confidentiality	Believing HCP treating their personal information confidentially is related to patients' trust towards HCP, which is also a determinant of patient satisfaction. (Keating et al. 2002)
N/A	16. Satisfaction with services overall	An overall rating by patients about satisfaction towards the services, HCP and environment is necessary in addition to ratings for individual aspects

**Face validity (Pilot study)**

A pilot study was conducted to improve the face validity of ASC-CSQ by reviewing it with 11 ASC clients of various ethnic origins and ages on 29<sup>th</sup> May and 1<sup>st</sup> June 2007 in the clinic waiting area. They were asked to complete the ASC-CSQ, followed by a feedback session where each of them was asked if they had any problems understanding or completing it. Issues such as the clarity of the instructions, wording, language used and question content were discussed. They were also asked if they hoped to include any other questions in the ASC-CSQ.

The majority of comments from the clients in the pilot were on the excessive length of the questionnaire, especially in Section 2 (the Client Satisfaction Inventory). A few clients felt that the wording of a couple of the questions was confusing or ambiguous. No clients suggested adding more questions. In response to the feedback, some questions were reworded before the ASC-CSQ was finalised. It should be noted however that the excessive length was mainly due to the inclusion of other validated inventories and scales (Client Satisfaction Inventory and Marlowe-Crowne Social Desirability Scale) which will be removed from the ASC-CSQ once the validity of the ASC-CSQ can be shown. Appendix 2 on page 210 shows the final version of the ASC-CSQ prepared after the pilot study.

### **3.2.5 Ethical considerations**

This quantitative survey was approved by the Human Research Ethics Committee (HREC) of the South Eastern Sydney & Illawara Area Health Service (SESAHS) as a quality assurance program (Appendix 3 on page 218).

**Beneficence**—This was assured by giving out a Participation Information Statement (Appendix 4 on page 219) when inviting clients to participate the survey, in which the purpose, significance, benefits and risks of the survey were explained clearly. It was stated that “participation was completely voluntary and services they received would not be affected in any way if they refused to participate or withdrew from the survey”. Only clients who were willing to complete the ASC-CSQ were regarded as participants and were considered as giving consent for participation.

**Non-maleficence**—The ASC-CSQ was designed in such a way that it was easy to administer and inconvenience to clients was minimised. Although demographic information was collected, no items were harmful, offensive, threatening or unnerving.

**Respect for persons**—Confidentiality and anonymity were stated on the Participation Information Statement on the ASC-CSQ, and were also assured verbally by the researcher. No identifiable information (name, telephone, address) was collected. Only adult clients (over 18 years old) were considered as potential participants.

**Justice**—The ultimate purpose of this survey was to improve health care services provided at ASC, of which clients are the beneficiaries. Clients were able to give comments while completing the ASC-CSQ.



### **3.2.6 Data collection**

The survey was administered by the researcher over 11 days from 2<sup>nd</sup> to 16<sup>th</sup> July 2007 during ASC opening hours. The researcher was stationed in the waiting area beside reception and invited every client to take part in the survey, regardless of the clients' HIV status (see Appendix 5 on page 220 for verbal preamble). All respondents were given a Participant Information Statement (Appendix 4) and a verbal explanation on how to complete the ASC-CSQ.

Respondents who came to ASC regularly were instructed to complete the ASC-CSQ while waiting for consultations. Those who were visiting ASC for the first time were requested to complete all of the ASC-CSQ except the Client Satisfaction Inventory (Section 2) and the ratings of satisfaction aspects (Section 3), which could only be completed after they finished the consultations. The expected time for completing ASC-CSQ was about 15 minutes. Respondents were instructed to insert the completed ASC-CSQ into a central collection box beside the reception. In this way the researcher could not connect any questionnaires with particular respondents and their information remained unidentifiable. Everyday during the data collection period, the researcher recorded the numbers of clients visiting ASC, respondents and non-respondents, and the actual number of ASC-CSQ collected.

### 3.2.7 Data analysis

The Statistical Package for Social Sciences (SPSS) for Windows 13.0. was used to describe, organise, analyse, and summarise the data obtained.

#### Analysis of demographic data

Demographic data (Section 4) and basic information about services (Section 1) were analysed and their descriptive statistics such as mean, standard deviation, range, maximum and minimum values were computed. Tables showing the number and percentage of respondents of each demographic category were produced.

#### Conversion of ratings into scores

A satisfaction score as shown in Tables 8 was first assigned for the rating for each of the 16 aspects and each of the HCP categories (Section 3). Table 8(a) was for the 10 individual aspects (Questions 34-43 of the ASC-CSQ) and Table 8(b) was for the 6 overall aspects (Questions 44-49 of the ASC-CSQ).

**Table 8(a)** Score calculation for the 10 individual aspects

Scale for the 10 individual aspects (Questions 34-43)	Satisfaction score for positively worded items (Questions 35-38, 40-42)	Satisfaction score for negatively worded items (Questions 34, 39, 43)
Never	1	5
Rarely	2	4
Sometimes	3	3
Most times	4	2
All of the time	5	1
Does not apply	0	0

**Table 8(b)** Score calculation for the 6 overall aspects and importance of 10 individual aspects

Scale for the importance of individual aspects (Questions 34-43) + the 6 overall satisfaction aspects (Questions 44-49)	Satisfaction score (Questions 34-49)
Strongly disagree	1
Disagree	2
Neither agree or disagree	3
Agree	4
Strongly agree	5
Does not apply	0

Note: Scores 1 and 2 =Dissatisfied

Score 3 =Neutral

Scores 4 and 5 =Satisfied

### **Analysis of satisfaction levels for each aspect**

The satisfaction level for each of the 6 overall aspects was assessed by the following three steps:

- 1.) Calculate the “percentage of satisfied respondents” for that aspect. i.e. those rated scores “4” or “5” divided by the total number of respondents.
- 2.) Calculate the “percentage of dissatisfied respondents” for that aspect. i.e. those rated scores “1” or “2” divided by the total number of respondents.
- 3.) Calculate the “mean satisfaction score” of all respondents for that aspect. The satisfaction score ranges from 1 to 5. i.e. addition of the satisfaction scores and divided by the total number of respondents. A higher score indicates a higher satisfaction level.

Each overall aspect has a “percentage of satisfied respondents”, a “percentage of dissatisfied respondents”, and a “mean satisfaction score”.

However, since there was a satisfaction score for each HCP category in each individual aspect, the satisfaction level for each of the 10 individual aspects was assessed by first performing the above three steps for each HCP category, and averaging the results over all HCP categories. Therefore, each individual aspect has only a “percentage of satisfied respondents”, a “percentage of dissatisfied respondents”, and a “mean satisfaction score” which are indeed the average values over all HCP categories.

### **Analysis of satisfaction levels for each HCP category**

The satisfaction level for each HCP category was assessed by averaging the “percentages of satisfied respondents”, “percentages of dissatisfied respondents”, and “mean satisfaction scores” of the 10 individual aspects for that HCP category respectively. Thus, each HCP category has a “percentage of satisfied respondents”, a “percentage of dissatisfied respondents”, and a “mean satisfaction score”, which are indeed the average values over all individual aspects. This enables comparison of satisfaction levels between HCP categories.

It should be noted that the satisfaction rankings were based on the “percentage of satisfied respondents”, which was a fairer indicator of satisfaction than the “mean satisfaction score”. This is because a high mean satisfaction score does not necessarily mean a large proportion of respondents are satisfied, but rather, it might only be due to a small group of respondents with extremely high satisfaction scores.

### **Analysis of satisfaction levels of each client**

An overall satisfaction score for each respondent called the “ASC-CSQ score” was calculated by combining each of their mean satisfaction scores based on a formula which will be discussed in section 3.3.2 on page 85. This enabled each respondent’s

satisfaction levels of all aspects to be grouped and reflected in the ASC-CSQ score which gave simpler assessment of overall satisfaction levels in clients. It was also useful in determining the general distribution of satisfaction levels of the whole sample group, and the trends in satisfaction with respect to different demographic characteristics.

### **Analysis of importance of each aspect**

An “importance score” ranging from 1 to 5 was assigned for each of the 10 individual aspects according to the ratings of the client (see Table 8(b)). A higher score indicated a higher level of importance. The importance of each individual aspect was determined by the mean importance score of all respondents.

### **Analysis of satisfaction levels for each client group**

A mean ASC-CSQ score was first calculated for each group of clients with the same demographic characteristic, and then the One-way ANalysis Of VAriance (ANOVA) function from the SPSS was used to determine whether there were any significant differences in satisfaction levels among clients of each group. Differences with probabilities (p-value) smaller than or equal to 0.05 are considered to be significantly different.

### **Analysis of qualitative data (open-ended questions)**

The answers to the open-ended questions were examined using thematic analysis. They were first grouped into “positive” and “negative” comments with respect to the content. They were further categorised according to the dimensions suggested by Ware (Ware et al. 1983). Comments which did not belong to the existing dimensions were classified into another group according to its content. Similarities and common themes discovered in the comments were particularly noted.

### **Analysis of criterion-related validity**

The level of criterion-related validity of ASC-CSQ was assessed by the correlation of the ASC-CSQ score to Client Satisfaction Inventory score (from Section 2), and the correlation of ASC-CSQ score to the Marlowe-Crowne Social Desirability Scale score (from Section 5). A higher level of correlation of ASC-CSQ score to Client Satisfaction Inventory score indicates higher level of criterion-related validity because they are congenial. Similarly, a lack of correlation of ASC-CSQ score to Marlowe-Crowne Social Desirability Scale score indicates that the ASC-CSQ is free from social desirability bias.

### **Analysis of construct validity**

Construct validity was one of the methods in proving the validity of ASC-CSQ. It was hypothesised that respondents with positive comments in the open-ended questions should be more satisfied than those with negative comments, and thus they should have higher ASC-CSQ scores. Therefore independent samples t-tests were calculated using the SPSS to find out if there were differences in ASC-CSQ scores occurring in clients with different types of comments. This ascertained whether higher ASC-CSQ scores were associated with positive comments and vice versa.

### **Analysis of internal reliability**

Internal reliability indicates how well different items measure the same issue. If an instrument is reliable, it consistently measures what it is intended to measure. Reliable measures are said to be reproducible, consistent, and stable (Erwin 2000). Cronbach's alphas were commonly used in the statistical field to demonstrate the level of internal reliability, and they were calculated for each HCP category and each Ware's dimension of satisfaction using the SPSS. The Cronbach's alpha ranges from 0 to 1.0, with a higher value representing a higher reliability.

### **3.2.8 Strengths of the methodology**

Three strengths have been identified. Firstly, this survey strikes a balance between the length of the questionnaire and the depth of the information obtained. It was shown that the most optimal moment to administer a questionnaire would be prior to consultation (Wensing et al. 1994). The ASC-CSQ was distributed to clients waiting for consultations, which could be completed in an average of 15 minutes. Although it is not lengthy, it includes important demographic information for identifying the characteristics of the client to determine whether the clients' satisfaction levels differed from others.

Secondly, the ASC-CSQ consists of both closed-ended and open-ended questions. There are four advantages for the inclusion of open-ended questions. Firstly, they can help avoid over-estimating satisfaction levels, as it was reported that respondents tend to answer closed-ended questions more positively than open-ended questions (Strasser and Davis 1991). Secondly, qualitative information generated from the questions can give clearer directions and specific suggestions to HCP and managerial staff for service improvement. Thirdly, themes identified from the qualitative information may not have been discussed in the literature before, and researchers will be able to build on these themes for future research, such as in needs assessments. Fourthly, because the ASC-CSQ has not proven to accurately measure true satisfaction levels, comments from open-ended questions can be used to show the construct validity of the ASC-CSQ.

Thirdly, a number of potential biases were avoided in this study. Acquiescence response bias was prevented by wording the questions both positively and negatively (Ware 1978; Yellen et al. 2002). The possibility of having interviewer bias was reduced because the researcher did not select which client to be invited, but instead, approached every client

at the waiting area during the collection period (Canales 1998). Non-response bias could also be minimised, especially when comparing with mailed questionnaires or structured telephone interviews, because clients were required to complete the questionnaires on the spot at the waiting area and insert them into a central collection box (Ware et al. 1983; Aharony and Strasser 1993). This collection method yielded anonymous and confidential results, so respondents did not need to answer in a way to look more acceptable to researchers, thus decreasing the level of social desirability bias (Sitzia and Wood 1997; Le May et al. 1999).

### **3.2.9 Limitations of the methodology**

The ASC-CSQ had not undergone test-retest for reliability due to a lack of time and resources. Reliability could be affected by loopholes in the instrument, such as improper instructions to respondents and poorly constructed questions, or the by the conditions of respondents, such as illness or fatigue. Therefore, test-retest should be conducted to confirm the degree of reliability by testing the questionnaire twice with the same group of respondents under the same conditions at different times, and to compare the results (Acorn and Barnett 1999).



## 3.3 Results

### 3.3.1 Demographic characteristics

During the data collection period, there were 370 person-times receiving health care services from ASC (some clients visited more than once during the period). A total of 233 clients were approached and 166 clients returned the ASC-CSQ, resulting in a response rate of 71%. The sample group size was around 5% of all clients attending ASC in 2007. Table 9 on page 77 shows the demographic information of the respondents.

93% of the respondents were male, 6% were female and one respondent was a transgender. Over half of the respondents were Australian (59%); others were European (18%) and then Asian (11%). According to the attendance records at ASC, the distribution of gender and geographic origins for the respondents was comparable to those for all clients attending ASC in 2007 (Goulder 2007a; Goulder 2007b).

Consistent with the data from the NSW Department of Health, the largest client-age-group in this study was 30-39 years (31%), followed by 40-49 years (26%), then 20-29 years (20%) (NSW Department of Health 2008). The mean age was 40.5 years, ranging from 21 and 71 years. The majority of the respondents were homosexuals (76%), followed by heterosexuals (18%). All female respondents were heterosexuals.

A large majority of the respondents were HIV positive (69%), others were HIV negative (24%) and of unknown HIV status (8%). Respondents who were HIV negative or with unknown status mainly came for blood test, to obtain test results, or for a sexual health check-up. The main risk factor for HIV infection among respondents was through “*unprotected intercourse*” (81%, 100 males, 7 females), followed by “*injecting drug use*”

(8%, 9 males, 1 female), these were found to be consistent with the data from the NSW Department of Health (Hardwick and Cotton 2005).

**Table 9** Demographic information of respondents

<b>Category</b>	<b>Number of respondents</b>	<b>Percentage (%)</b>
N= total number of respondents		
<b>Gender (N=160)</b>		
Male	149	93
Female	10	6
Transgender	1	1
<b>Geographic origin (N=158)</b>		
Australia	93	59
Europe	29	18
Asia	17	11
North America	12	8
Africa	3	2
New Zealand	2	1
Central America	1	1
Pacific Island	1	1
<b>Age (N=156)</b>		
20-29	31	20
30-39	48	31
40-49	41	26
50-59	29	19
60-69	6	4
70-79	1	1
<b>Sexual Orientation (N=158)</b>		
Homosexual	120	76
Heterosexual	28	18
Bisexual	7	4
Other	3	2
<b>HIV status and length of time since diagnosed (N=163)</b>		
HIV Positive	111	68
0-9 years	54	33
10-19 years	36	22
20-29 years	18	11
Did not know how long	3	2
HIV Negative	39	24
Unknown status	13	8

**Table 9** Demographic information of respondents (continued)

<b>Category</b>	<b>Number of respondents</b>	<b>Percentage (%)</b>
N= total number of respondents		
Percentages have been rounded off		
<b>Main risk factor for HIV infection (N=133)</b>		
Unprotected intercourse	107	80
Injecting drug use	11	8
Occupational exposure	5	4
Unknown	5	4
Others	3	2
Oral sex	2	2
<b>Education Level (N=159)</b>		
University	65	41
Vocational	48	30
Secondary (to Year 12)	26	16
Secondary (to Year 10)	18	11
Primary	2	1
<b>Current employment status (N=156)</b>		
Full time	79	51
Part time/casual	27	17
Unemployed	20	13
Retired (receive pension)	16	10
Student	9	6
Retired (self-funded)	5	3
<b>Possession of types of Health Care Card (N=170)</b>		
None	69	41
Health Care Card	60	35
Pensioner Concession Card	37	22
Commonwealth Seniors Health Card	4	2
Note: one respondent can possess more than one type of card		
<b>Length of time being an ASC client (N=158)</b>		
First time receiving services at ASC	17	11
Regular client (years)	141	89
0-4	69	44
5-9	32	20
10-14	18	11
15-19	14	9
20-24	8	5
<b>Frequency of attending for services (N=140)</b>		
Weekly	5	4
Fortnightly	1	1
Monthly	41	29
Quarterly	62	44
6-monthly	20	14
Once a year or longer	11	8

Table 10 shows the different types of services the respondents received on the day when they completed the ASC-CSQ, ranked in descending order of number of respondents receiving the service at ASC. The most common service was “*regular check-up*” (43%), followed by “*HIV blood test*” (28%), and “*Obtain HIV blood test results*” (20%). The number of respondents decreased as the number of services received on the day when they completed the ASC-CSQ increased. 64% of the respondents came for one service only, 21% came for two services, 11% came for three services, while 5% came for four or more services. 83% of the respondents indicated that they only accessed ASC for HIV health care services, while 7% also accessed a private GP, and the rest also accessed public hospitals.

**Table 10** Types of services the respondents received at ASC

Note: some respondents received more than one service

<b>Types of services</b>	<b>Number of respondents receiving the service</b>	<b>Percentage (%)</b>
Regular check-up	71	43
HIV blood test	47	28
Obtain test results	33	20
Sexual health check-up	30	18
Obtain a prescription	23	14
Psychological counselling	21	13
Pick up medication from pharmacy	18	11
Particular treatment in ambulatory care	11	7
Nutritional counselling	7	4
Vaccination	4	2
Clinical trials research visit	3	2
Others	2	1

### **3.3.2 Research question 1:**

#### **How satisfied with care and the HCP are clients attending an HIV/AIDS health care facility?**

##### **Overall and individual aspects**

Table 11 on page 81 ranks the sixteen aspects in descending order of satisfaction. Six were overall aspects (marked with asterisks\*) and ten were individual aspects of service provision. Satisfaction of each individual aspect was measured over all HCP categories, namely doctors, nurses, psychologists, nutritionists, pharmacists, researchers, and receptionists. However, too few respondents consulted researchers and consequently statistical analysis for this HCP category was not possible. It should be noted that “satisfied respondents” referred to those who scored “4” or “5” for rating an aspect, whereas “dissatisfied respondents” referred to those who scored “1” or “2” (refer to Tables 8 on page 69). The mean satisfaction score for each aspect was also shown, ranging from “1” to “5”, where “5” is the most satisfied and “1” the least.

The percentage of satisfied respondents ranged from 34% to 97% for the 16 aspects, with a mean percentage of 86%. It was observed that the overall aspects had higher satisfaction levels when compared with the individual aspects. All 6 overall aspects yielded over 90% satisfied respondents whereas only 4 individual aspects yielded over 90%. The respondents were most satisfied with aspects “*maintenance of client confidentiality*” (97%), followed by the “*knowledge of HCP*” (96%), then “*overall satisfaction*” (95%), then “*attitudes of HCP*” (94%) and “*HCP understood clients’ needs*” (94%).

The mean percentage of dissatisfied respondents was 7%. All aspects had less than 10% dissatisfied respondents except the aspect “*waiting time before consultation*”, which had more than half of the respondents (53%) dissatisfied over all HCP categories. This aspect also had a mean satisfaction score of 2.74 only, which was much lower than those of other aspects. Respondents were also less satisfied with the aspects “*benefited more than expected*”, “*availability of HCP*”, “*uninterrupted consultation*”, and “*length of consultation time*”.

**Table 11** Ranking of the 16 aspects (overall and individual) in descending order of satisfaction

- Note: 1.) Satisfaction of each individual aspect (without asterisks) was averaged over all HCP categories  
 2.) The total numbers of respondents rating individual aspects were not shown because they varied for each HCP category

Ranking	Aspects (Overall aspects were marked with asterisks *) N=total number of respondents	% of dissatisfied respondents	% of satisfied respondents	Mean satisfaction score (range: 1-5)
1	Confidentiality* (N=150)	2	97	4.45
2	Knowledge of HCP	2	96	4.74
3	Overall Satisfaction* (N=150)	3	95	4.46
4	Attitude of HCP	4	94	4.73
5	HCP understood clients' needs	2	94	4.68
6	Environment (waiting areas)* (N=149)	3	93	4.22
7	Appointment time* (N=150)	3	91	4.29
8	Management of staff (at waiting areas)* (N=148)	1	91	4.21
9	Accessibility of ASC* (N=151)	5	91	4.27
10	Information given during consultation	7	90	4.53
11	Included clients' decisions in treatment	5	89	4.56
12	Length of consultation time	5	84	4.45
13	Uninterrupted consultation	6	83	4.31
14	Availability of HCP	9	83	4.28
15	Benefited more than expected	6	79	4.15
16	Waiting time before consultation	53	34	2.74
	<b>Mean</b>	<b>7</b>	<b>86</b>	<b>4.32</b>

### Grouping overall and individual aspects into dimensions

All aspects were grouped according to their nature into Ware's dimensions of patient satisfaction. This reduced the number of aspects and gave a better understanding of which areas the respondents were satisfied or dissatisfied with (Ware et al. 1983). No aspects were grouped into "*finance*" and "*continuity*" because consultations were free of charge, and some respondents might be HIV negative and so did not need continuous care.

Table 12 shows the ranking of the dimensions in descending order of satisfaction over all HCP categories. The respondents were most satisfied with "*technical quality*" (96%), then "*interpersonal manner*" (94%), "*physical environment*" (92%), "*efficacy/outcomes*" (87%), "*overall availability*" (86%), and "*accessibility/convenience*" (77%).

**Table 12** Ranking of dimensions suggested by Ware in descending order of satisfaction over all HCP categories

Ranking	Dimensions suggested by Ware	Aspects (Overall aspects were marked with asterisks *)	% of dissatisfied respondents	% of satisfied respondents	Mean satisfaction scores
	N/A	Confidentiality*	2	97	4.45
1	Technical quality	Knowledge of HCP	2	96	4.74
	N/A	Overall satisfaction*	3	95	4.46
2	Interpersonal manner	Attitude of HCP	4	94	4.73
3	Physical environment	Environment (waiting areas)*	2	92	4.22
		Management of staff (at waiting areas)*			
4	Efficacy/outcomes	HCP understood clients' needs	4	87	4.46
		Included clients' decisions in treatment			
		Benefited more than expected			
5	Overall availability	Information given during consultation	8	86	4.41
		Availability of HCP			
6	Accessibility/convenience	Appointment time*	14	77	4.01
		Accessibility of ASC*			
		Length of consultation time			
		Uninterrupted consultation			
		Waiting time before consultation			

### Health Care Provider (HCP) categories

Table 13 shows the ranking of the HCP categories in descending order of satisfaction over all individual aspects. The percentage of satisfied respondents ranged from 77% to 86%, whereas the percentage of dissatisfied respondents ranged from 7% to 15%. “Nurses” scored the highest among all HCP categories, followed by “psychologists”, then “doctors”, “pharmacists”, “receptionists”, and “nutritionists”. It should be noted that the results for “researchers” were not shown here as the sample size of this HCP category was too small for meaningful analysis.

The respondents were the most satisfied with the individual aspects “knowledge” and “attitude” in the majority of HCP categories, whereas all of them were the least satisfied for “waiting time before consultation”. The individual aspects “benefited more than expected” and “uninterrupted consultation” were also commonly less satisfactory over all HCP categories. The satisfaction ranking of individual aspects for each HCP category was detailed in Appendix 6 on page 221.

**Table 13** Ranking of HCP categories in descending order of satisfaction over the 10 individual aspects

Ranking	HCP category	% of dissatisfied respondents	% of satisfied respondents	Mean satisfaction score
1	Nurses	7	86	4.42
2	Psychologists	12	84	4.34
3	Doctors	7	83	4.36
4	Pharmacists	10	83	4.34
5	Receptionists	15	80	4.22
6	Nutritionists	12	77	4.17
	<b>Mean</b>	<b>10</b>	<b>82</b>	<b>4.31</b>



"Nurses" were often ranked either the first or the second for all individual aspects. They were most satisfactory for their "knowledge" and "understood clients' needs". The aspects "waiting time before consultation", "benefited more than expected" and "availability" were least satisfactory for this category.

"Psychologists" were most satisfactory for their "knowledge" and "attitude". They also had the highest level of satisfaction for the aspect "benefited more than expected" among all HCP categories. However, they had rather low levels of satisfaction for "included clients' decision in treatment" and "availability" among all HCP categories.

"Doctors" were also most satisfactory for their "knowledge" and "attitude" among all HCP categories. However, the satisfaction for "availability" of doctors was the lowest among all HCP categories.

"Pharmacists" were ranked the first among all HCP categories in "understood clients' needs" and "information given during consultation time", but were ranked the lowest among all HCP categories for "benefited more than expected" and "uninterrupted consultation".

"Receptionists" ranked consistently low for most of the aspects. They were most satisfactory for their "attitudes" and "understood clients' needs". And they were the least satisfactory for the aspect "knowledge" among all HCP categories.

Although "nutritionists" ranked consistently low in most of the aspects, there were no dissatisfied respondents for the aspects "knowledge", "included clients' decision in treatment", and "understood clients' needs". Both the aspects "waiting time before

*consultation*” and “*information given during consultation time*” were least satisfactory within the category and among all categories. However, due to the relatively small sample size compared to the other HCP categories, errors in estimation for certain aspects were expected. Therefore it was not possible to conclude that clients were truly the least satisfied with nutritionists.

### **Overall satisfaction levels of ASC-CSQ**

By combining the satisfaction scores for all aspects and HCP categories a respondent rated, an overall satisfaction score, called the “ASC-CSQ score”, could be calculated for each respondent based on the following formula used for calculating the *Client Satisfaction Inventory* score. This formula proved to be valid and reliable for calculating Client Satisfaction Inventory scores:

$$\text{ASC-CSQ score} = (\text{Sum}(Y) - N)(100) / [(N)(4)]$$

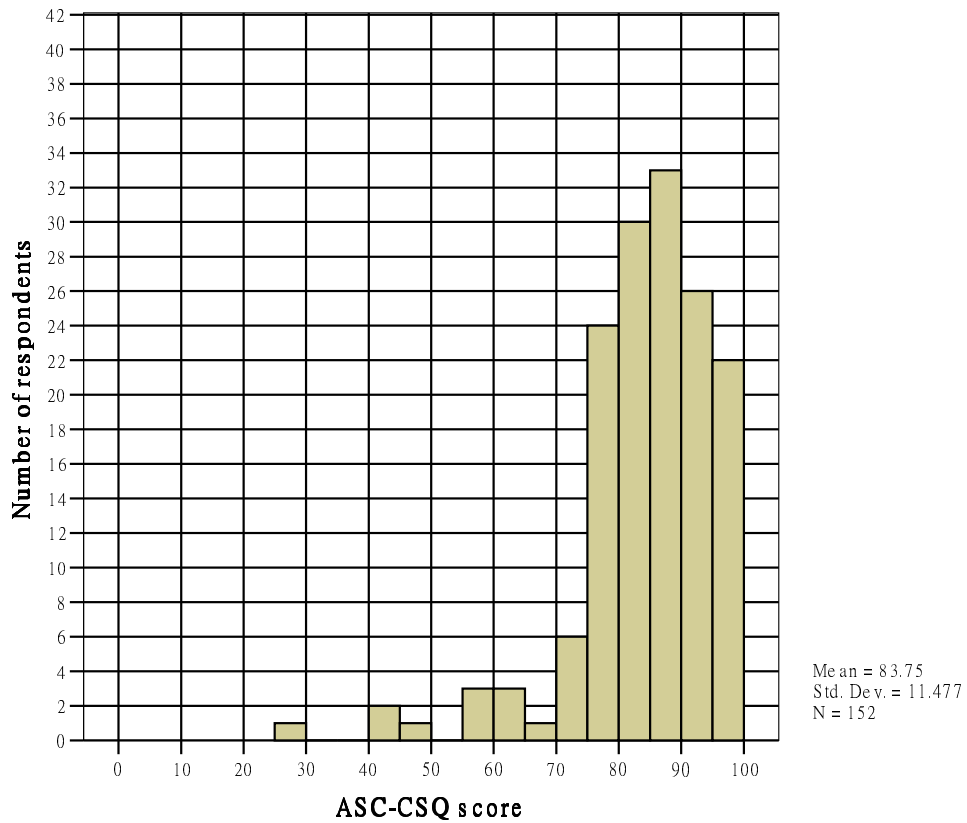
where Y is the satisfaction score rated for each aspect in each HCP category

N is the number of items answered by the respondent. There are 69 items in total.

If a client visited all HCP categories, the value of N would be 69.

Similar to the Client Satisfaction Inventory, an advantage of this formula was that scores could be calculated regardless of the number of items the respondent omitted or scored improperly (McMurtry and Hudson 2000). Therefore, an ASC-CSQ score could be calculated for each respondent, regardless of how many HCP categories the respondent consulted.

Fig. 4 shows the distribution of ASC-CSQ scores for the respondents. The distribution is negatively skewed towards higher scores, signifying that more respondents were satisfied than those not satisfied. The ASC-CSQ scores ranged from 30 to 100, with a mean value of 84. The peak of the distribution corresponded to 33 respondents with a score between 86 and 90.



**Fig. 4** Distribution of ASC-CSQ scores for the respondents

### **Dissatisfaction among respondents**

There were 10 (7%) respondents scored lower than 70. Their ASC-CSQ scores were examined to identify any common dissatisfied aspects. About half of them were dissatisfied with the following aspects:

- “*Waiting time before consultation*”, particularly for doctors
- “*Information received during consultation*”, particularly for doctors and psychologists
- “*HCP included clients’ decisions in treatment*”, particularly for psychologists
- “*Benefited more than expected*”, particularly for doctors and psychologists
- “*Accessibility of ASC*”
- “*Uninterrupted consultations*”, particularly doctors, psychologists, and pharmacists

These 6 dissatisfactory aspects belong to the last 3 dimensions (*efficacy/outcomes, overall availability, and accessibility/convenience*), which were all ranked low in Table 11 on page 81. This confirmed that these aspects were also of low satisfaction besides these 10 dissatisfied respondents.

### **Additional comments from open-ended questions**

There were two open-ended questions in the questionnaire where respondents had opportunities to give additional comments on the services they received and how the Centre could be improved.

Appendix 7 on page 224 outlines all the comments made by 77 respondents (46% of all respondents). They were grouped according to the eight patient satisfaction dimensions suggested by Ware (Ware et al. 1983). There were altogether 48 negative comments, 37 positive comments and 4 suggestions for certain types of services.

No respondent provided negative comments on the “*technical quality*” and “*efficacy/outcome*” dimensions. On the contrary, a number of respondents appreciated the attitudes and efforts of the staff. Some of them also took this opportunity to thank the ASC staff for providing treatment and other services, which they found of great help to their health physically and mentally. Some even named their HCP, praised them for being professional, and knowledgeable, and expressed their gratitude towards them. One wrote, “*Thankyou for 20 years of wonderful service, it has been great to help my quality of life*”.

Six negative and fifteen positive comments addressed the “*interpersonal manner*” dimension. On the negative side, some respondents pointed out that the staff should not be judgmental towards users of the service, should acknowledge clients when they come in, and should manage patients rather than just treat them. For positive comments, the respondents expressed their thanks to the staff for their courtesy and friendly attitudes which made their visits comfortable. “*Good interpersonal manner*” was the most frequently provided positive comment.

Six comments were made on the dimension “*overall availability*”. Some respondents would like to have more doctors and nurses for check-up, sexual transmission infection screens and dermatology procedures. One felt that clients really needed more psychologists and counsellors to tackle their mental health problems. Another hoped to have more Aboriginal people as service providers, while another hoped ASC could provide magazines or articles about Hepatitis C.

Fifteen negative comments and suggestions addressed the dimension “*Physical environment*”. A few clients proposed to renovate the clinical building to create a more “modern” look. Others hoped to have more privacy in the reception and waiting areas, for example, separating drug-using patients and general health patients. Six respondents hoped ASC would re-introduce coffee, tea and biscuits in the waiting area.

There were also sixteen negative comments and suggestions on “*Accessibility/convenience*”. Seven comments were related to long waiting times and five were related to extension of opening hours in the evenings and/or weekends for more convenient appointment times. Two respondents suggested enabling medication to be pre-ordered and employing casual staff at the pharmacy during peak hours to minimise waiting time.

Besides clinical services, some respondents suggested the ASC organise social groups and dating service, and inform clients of other services being available at ASC and other HIV health care organisations, such as legal rights and other social support services.

### 3.3.3 Research question 2:

#### **What aspects of HIV health care are perceived as important among clients?**

The importance of each individual aspect was rated by each respondent and the rating was converted into an importance score (Table 8(b) on page 70), which ranged from “1” to “5”, with “5” the most important. “Important” individual aspects were those who scored “4” or “5”. Table 14 ranks the importance of each individual aspect according to the mean importance score, which ranged from 3.86 to 4.75. It could be seen that “*knowledge*”, “*attitude*”, and “*HCP understood clients’ needs*” were not only the three most satisfactory aspects, they were also the most important aspects perceived by the respondents. Whereas for “*uninterrupted consultation*” and “*availability of HCP*”, less than 70% of the respondents thought that they were important.

All individual aspects were further grouped together according to Ware’s list of patient satisfaction dimensions similar to what was done in Table 12 on page 82. However, “*physical environment*” was not included here because the respondents were not requested to rate its importance. The ranking for importance was the same as that for satisfaction. The most important dimension was “*technical quality*” (mean importance score=4.75), followed by “*interpersonal manner*” (4.69), then “*efficacy/outcomes*” (4.55), then “*overall availability*” (4.24), and the last, “*accessibility/convenience*” (4.02).

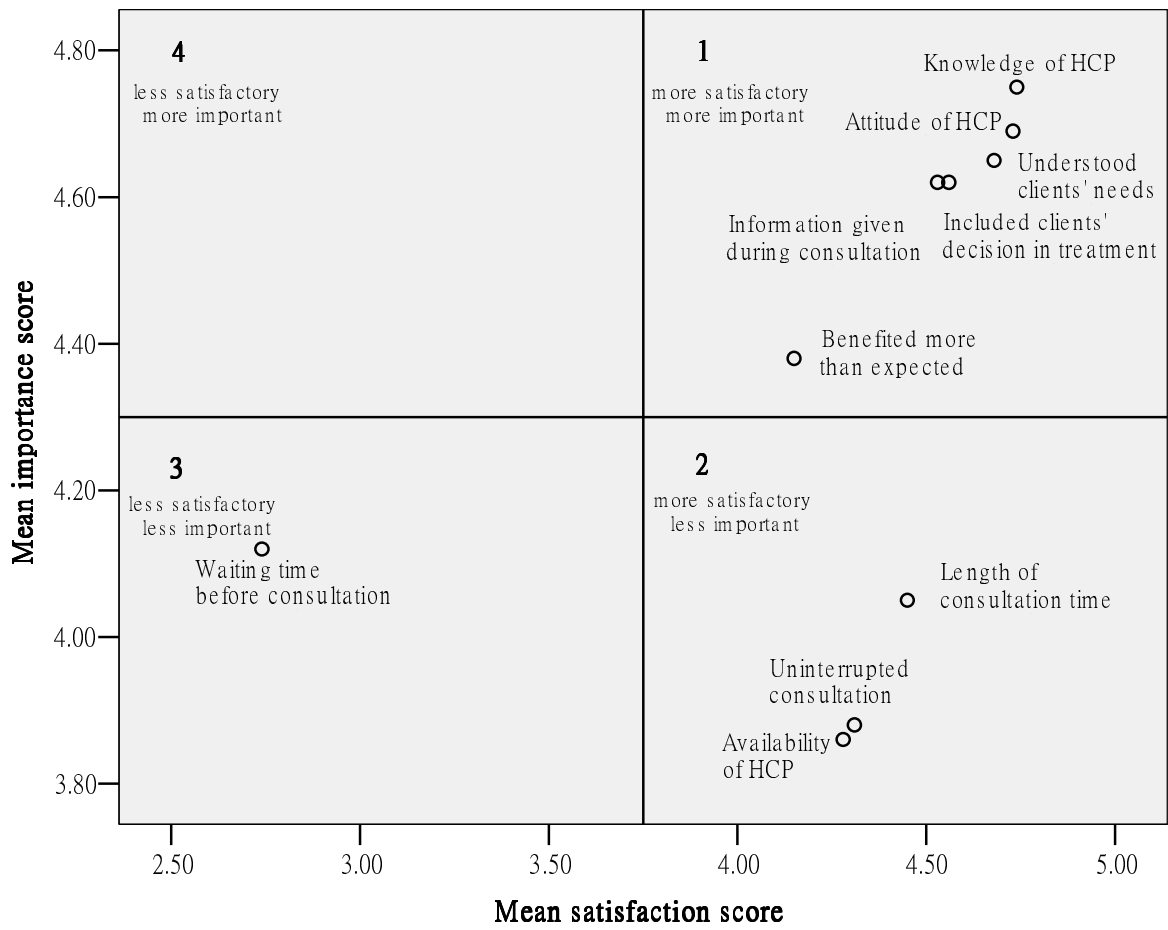
**Table 14** Ranking of individual aspects according to the level of importance

<b>Aspects</b> N= total number of respondents	<b>% of respondents rated "Important"</b>	<b>Mean importance score</b>
Knowledge of HCP (N=109)	97	4.75
Attitude of HCP (N=111)	99	4.69
HCP understood clients' needs (N=103)	97	4.65
Information given during consultation (N=101)	96	4.62
Included clients' decision in treatment (N=99)	95	4.62
Benefit more than expected (N=101)	87	4.38
Waiting time before consultation (N=105)	83	4.12
Length of consultation time (N=100)	77	4.05
Uninterrupted consultation (N=98)	67	3.88
Availability of HCP (N=102)	69	3.86
<b>Mean</b>	<b>87</b>	<b>4.36</b>

Fig. 5 shows the relationship between satisfaction levels and importance levels of the individual aspects. Aspects located within the first quadrant: "knowledge of HCP", "attitude of HCP", "HCP understood clients' needs", "included clients' decision in treatment", "information given during consultation", and "benefited more than expected" were rated with relatively high mean satisfaction scores AND importance scores. Aspects located within the second quadrant: "length of consultation time", "uninterrupted consultation", and "availability of HCP" were rated with relatively high mean satisfaction scores AND lower importance scores. The aspect "waiting time before consultation" within the third quadrant was rated with relatively low mean satisfaction scores AND importance scores. No aspects were located within the fourth quadrant.

Except for "*waiting time before consultation*", all other mean satisfaction scores of the individual aspects roughly correlated with their mean importance scores, with a correlation coefficient of 0.747. This indicated that aspects of higher mean satisfaction scores generally have higher importance scores, and vice versa.





**Fig. 5** The relationship between satisfaction and importance levels of the 10 individual aspects

### **3.3.4 Research question 3:**

#### **Are there any significant differences in satisfaction among clients with different characteristics?**

One-way ANOVA was used to compare the ASC-CSQ scores among respondents of different demographic characteristics. Equality should be emphasised in high quality services and ideally there should be no significant differences in ASC-CSQ scores in any clients of different demographic categories.

Significant differences in satisfaction were found for respondents with different HIV status, education level, employment status, length of time since being a client, possession of Health Care Card, and frequency of visits. No significant differences in satisfaction levels were found for respondents with different geographic origin, gender, age, sexual orientation, and number of services received at ASC. Table 15 shows the respondents grouped into different demographic characteristics and their mean ASC-CSQ scores. Table 16 shows a summary of the analysis of satisfaction for these different groups of respondents. A p-value smaller than 0.05 is considered to have significant differences in ASC-CSQ scores. This analysis excluded those client groups with extreme small sample sizes to ensure fair comparisons.

**Table 15** Respondents in groups of different demographic characteristics and their mean ASC-CSQ scores

<b>Category</b>	<b>Mean ASC-CSQ score</b>	<b>Category</b>	<b>Mean ASC-CSQ score</b>
HIV status		Frequency of visits	
- HIV negative	86	- First visit	89
- Unknown status	85	- Weekly	76
- HIV positive within 5 years	85	- Monthly	80
- HIV positive for 6-10 years	82	- Quarterly	85
- HIV positive for 11-15 years	84	- 6-monthly	84
- HIV positive for 16-20 years	84	- Once a year or longer	86
- HIV positive for 21-25 years	77		
Education level		Geographic origin	
- Secondary (to year 10)	86	- Australian	83
- Secondary (to year 12)	85	- American	84
- Vocational	80	- Asian	83
- University	85	- European	87
Employment status		Age (years old)	
- Working (Full time+Part time/Casual)	86	- 20-24	88
- Non-working (Student+Retired+Unemployed)	81	- 25-29	85
- Full time	86	- 30-34	83
- Part time/ Casual	85	- 35-39	85
- Unemployed	83	- 40-44	82
- Retired (self-funded)	82	- 45-49	84
- Retired (receive pension)	79	- 50-54	85
- Student	80	- 55-59	83
Length of time since being a client		Gender	
- First visit	89	- Male	84
- Within 5 years	85	- Female	89
- From 6-10 years	80	Sexual Orientation	
- From 11-15 years	81	- Homosexual	83
- From 16-20 years	80	- Bisexual	82
		- Heterosexual	87
Possession of Health Care Card		Number of services received	
- Without card	86	- One	85
- With card (Health Care Card + Pensioner Concession Card)	83	- Two	83
- Health Care Card	85	- Three	83
- Pensioner Concession Card	79	- Four	80

**Table 16** Summary of analysis of satisfaction for different respondents groups: more satisfied group versus less satisfied group

<b>Factors which affect the level of satisfaction</b>	<b>More satisfied group</b>	<b>Less satisfied group</b>	<b>p- value</b>
• HIV status	- HIV negative	- HIV positive for 21-25 years	0.026
• Education level	- University	- Vocational	0.014
• Employment status	- Working category (Full time + Part time/Casual)	- Non-working category (Student + Retired + Unemployed)	0.033
	- Full time	- Retired (receive pension)	0.024
• Length of time since being a client	- First visit	- Non-first visit	0.016
	- First visit + within 5 years	- 6-20 years	0.004
• Possession of Health Care Card	- No card	- With card	0.033
	- Health Care card	- Pensioner Concession Card	0.034
• Frequency of visits	- Quarterly + 6-monthly + Once a year or longer	- Weekly + Monthly	0.023
	- First visit	- Weekly	0.036
	- First visit	- Monthly	0.007
<b>Factors which do NOT affect level of satisfaction</b>			
• Geographic origin			
• Gender			
• Age			
• Sexual orientation			
• Number of services received at ASC			

### 3.3.5 Validation of the instrument—ASC-CSQ

Four types of validity were addressed in this study for the validation of the ASC-CSQ, which were: content validity, face validity, criterion-related validity, and construct validity. Section 3.2.4 on page 60 already demonstrated the content validity by detailed review of the literature and extensive evaluation of the ASC-CSQ drafts by HCP. Face validity was demonstrated by conducting pilot study with ASC clients to determine the appropriateness of the instrument. The following presents the results of the level of criterion-related validity and construct validity. An internal reliability test was also conducted to determine the reliability (or repetitiveness) of the ASC-CSQ.

#### Criterion-related validity

The 25-item *Client Satisfaction Inventory* (section 2) was a previously validated questionnaire incorporated into the ASC-CSQ. A Client Satisfaction Inventory score was calculated for each respondent using the formula shown below. The score ranged from 1 to 100, which a higher score indicating a higher satisfaction level.

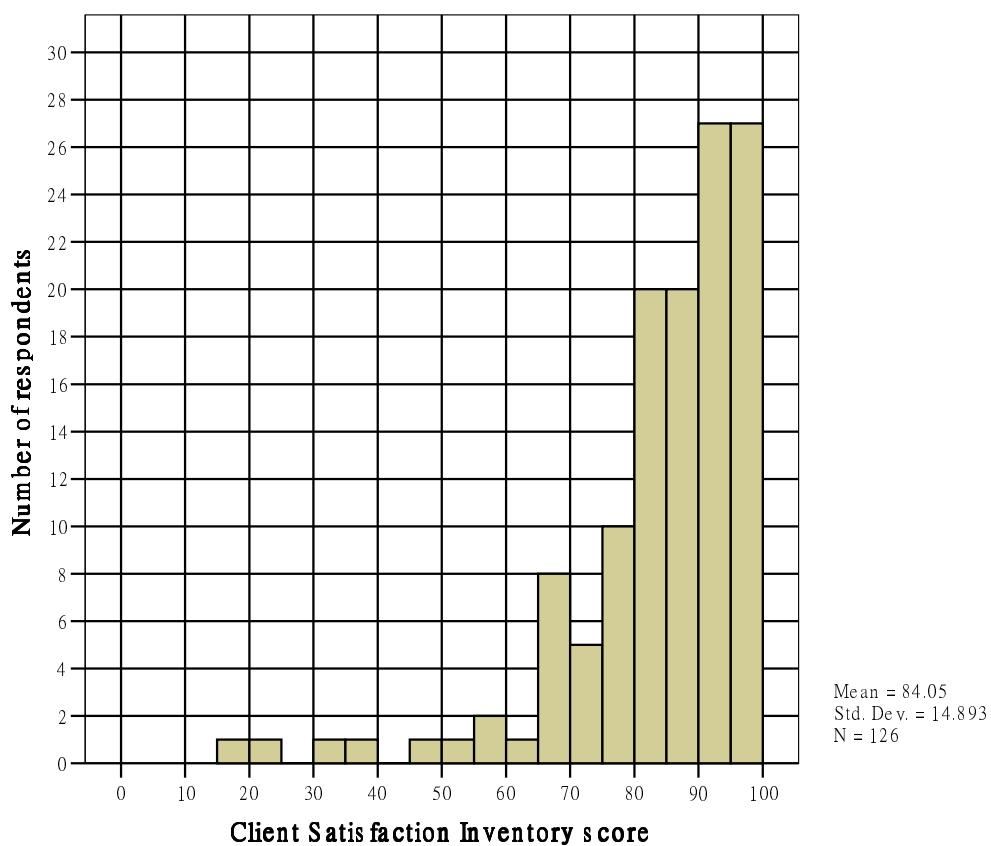
$$\text{Client Satisfaction Inventory score} = (\text{Sum}(Y) - N)(100) / [(N)(6)]$$

where Y is the score for each item (ranging from 1 to 7) of the Client Satisfaction Inventory.

N is the total number of items correctly completed by the respondent (excluding items marked with “X”, meaning “Not applicable”).

The maximum number of N is 25.

Fig. 6 shows the distribution of Client Satisfaction Inventory scores of the respondents. Only respondents who completed more than 20 items (i.e. less than 5 “X” or blanks) were included in this analysis, as more reliable scores were obtained with more items answered (McMurtry and Hudson 2000). The distribution was negatively skewed toward higher scores with a mean score of 84, which was the same as the mean ASC-CSQ score (see Fig. 4 on page 86). The range of the Client Satisfaction Inventory scores was 20 to 100, which was larger than that of the ASC-CSQ scores (30 to 100).



**Fig. 6** Distribution of Client Satisfaction Inventory scores for the respondents

Paired samples t-test of the ASC-CSQ score to the Client Satisfaction Inventory score indicated no significant difference between the two scores ( $p=0.202$ ). There was a correlation between the ASC-CSQ and Client Satisfaction Inventory ( $r=0.707$ ,  $p=0.000$ ). According to Cohen, a correlation coefficient of 0.7 was considered large (especially in social research), and this showed the validity of ASC-CSQ for measuring client satisfaction with HIV services (Cohen 1988).

The *Marlowe-Crowne Social Desirability Scale* (section 5) was another previously validated questionnaire incorporated into the ASC-CSQ. Independent samples t-test indicated that there was a significant difference between the Marlowe-Crowne Social Desirability Scale score and the ASC-CSQ score ( $p=0.000$ ). The correlation between the two scores was 0.219 ( $p=0.009$ ), which was considered small according to Cohen (Cohen 1988). Therefore, it could be concluded that the social desirability bias in this study was small.

### **Construct validity**

Of the respondents who answered the open-ended questions, 10 of them were selected randomly from the 37 ASC-CSQ with positive comments, another 10 were selected from the 48 ASC-CSQ with negative comments. The mean ASC-CSQ scores of these two groups of respondents were 88 and 74 respectively, with a significant difference of a p-value of 0.015. Hence, positive comments correlated with high ASC-CSQ scores and negative comments correlated with low ASC-CSQ scores. No evidence was observed for positive comments associated with low scores or vice versa.

### Internal reliability

Cronbach's alphas were calculated using the SPSS to determine the internal consistency of the ASC-CSQ, which indicated how well the individual aspects measured the same issue. Cronbach's alphas of 0.6 to 0.7 are generally regarded as acceptable reliability, and 0.8 or higher indicate good reliability, which signify that the instrument is reproducible, consistent, and stable (Erwin 2000).

Table 17 shows the Cronbach's alphas for each HCP category over all aspects and Table 18 shows the Cronbach's alphas for each dimension of satisfaction over the doctor and nurse categories. Cronbach's alphas were available for doctor and nurse categories only because the sample sizes for other HCP categories were too small for such an analysis. Cronbach's alphas for the dimensions "*technical quality*" and "*interpersonal manner*" were not necessary as there was only one question for each of these dimensions. The Cronbach's alphas ranged from 0.70 to 0.88, which indicated a reasonably high reliability and reproducibility.

**Table 17** Cronbach's alpha for each HCP category over all aspects

HCP Category	Cronbach's alpha
Doctors	0.81
Nurses	0.82
Psychologists	0.84
Nutritionists	0.74
Pharmacists	0.71
Receptionists	0.72

**Table 18** Cronbach's alpha for each dimension of satisfaction over doctor and nurse categories

Dimension	Cronbach's alpha
Efficacy/Outcomes	0.88
Availability	0.82
Physical environment	0.86
Accessibility/Convenience	0.70
Overall aspects	0.88



## **3.4 Research implications**

### **3.4.1 The need to investigate patient dissatisfaction**

In the majority of the patient satisfaction research, “satisfaction” has been measured much more frequently than “dissatisfaction” (Williams et al. 1998). Despite this, studying aspects clients are dissatisfied with is valuable for four reasons:

Firstly, clients satisfied with particular aspects may be dissatisfied with other aspects at the same time. Therefore evaluation may not be comprehensive enough unless both satisfaction and dissatisfaction levels are assessed.

Secondly, focussing on satisfaction may only capture patients’ positive expectations and values rather than their actual experiences with HIV health care. Therefore, research should focus on identifying sources of dissatisfaction, as they reflect the actual negative experiences for a comparative benchmark (Burke et al. 2003).

Thirdly, findings do not reflect much information if the majority of the sample group is very satisfied overall, because it is difficult to distinguish the more satisfied clients from the less satisfied clients. In that case, assessing dissatisfaction will be more meaningful than assessing satisfaction (Hudak and Wright 2000).

Fourthly, HCP and administrative staff can only seek room for improvement by finding out what is wrong (dissatisfaction), and not what is right (satisfaction) (Carr-Hill 1992). However, it is always more preferable to investigate both satisfaction and dissatisfaction for identifying gaps which exist in service provision.

### **3.4.2 The need to investigate unmet needs**

It is generally acknowledged that patient satisfaction surveys play an important role in evaluating the quality of health care services (Cleary and McNeil 1988; Donabedian 1988; Nelson and Niederberger 1990; Aharony and Strasser 1993). Yet, even if clients are extremely satisfied with current services (or no dissatisfaction is found), this does not necessarily indicate that the highest quality of care is provided. This is because clients may still have unmet needs in health care service.

Similar to patient satisfaction and dissatisfaction, HIV-infected individuals with unmet needs are associated with poorer adherence to medication and treatment, and will be at higher risk for poorer health outcomes (Reif et al. 2006). And as mentioned before, HIV health care service is a type of chronic long term care of which clients need to access a broader range of services as compared with acute care clients (Ryan 1993). Thus, identifying unmet needs of clients helps narrow the gap between service provision and demand, thus fostering better communication between clients and the HCP, which in turn increases the quality of health care and client satisfaction.

### **3.4.3 The need to conduct qualitative studies**

Having seen the importance of investigating dissatisfaction levels and unmet needs of clients, the next step is to determine what data collection method is suitable for carrying out these investigations. One approach for identifying dissatisfaction is by probing satisfied responses more thoroughly using qualitative techniques (Carr-Hill 1992). Quantitative research differs from qualitative research as it focuses on “what” and “how much”, e.g. what aspects HIV patients were most satisfied? To what extent were HIV patients satisfied with a certain group of HCP? Qualitative research deals more with human interaction, and studies how people interpret interaction (Mays and Pope 1999 (p.5)). It focuses on “why” and “how”, e.g. why are clients dissatisfied with a certain aspect? How did they react to it?

Patient satisfaction evaluations should not be based only on statistical analysis, but also include the “how” and “why” components for a more comprehensive study. In fact, although studies indicated that patients express high levels of satisfaction through quantitative patient satisfaction evaluations, qualitative in-depth interviews reveal many negative perceptions and experiences (Dougall et al. 2000; Hudak and Wright 2000). Morse observed that a large component of health care research is the exploration of health care in the community. For example, unmet needs for patients who were “falling through the cracks” in the health care system were often identified using qualitative methods (Morse 2007).

It is suggested that there are two main ways qualitative methods complement quantitative methods. Firstly, qualitative methods can explore areas not amenable to quantitative methods, such as behaviour, attitudes, and interactions. Despite the pilot study conducted before administering the quantitative client satisfaction survey, the terms used in the ASC-CSQ may have different meanings to clients which may risk threatening the overall validity of responses. Qualitative methods help locate ambiguities and misunderstandings which researchers may not have expected (Mays and Pope 1999). Secondly, together with the

quantitative method, the qualitative method can comprise a “mixed methods approach” or “triangulation” (see “Definition of Terms” on page xi) to enhance validity and reliability in measuring client satisfaction (Minichiello 1995; Mays and Pope 1999).

Investigating dissatisfaction and unmet needs require more client input than only those issues which researchers think are important. Hence, the humane and client-oriented natures of qualitative methods are able to serve this purpose effectively and to complement the limitations of quantitative surveys. Such a qualitative study will be described in Chapter 4.

## **Chapter 4—The Qualitative Interviews**

The assessment of client satisfaction levels at the ASC in the previous chapter acted as a platform, giving the researcher a general understanding of how satisfied clients were with HIV health care services they received and their HCP at ASC, as well as an opportunity to ascertain those issues which might affect their satisfaction. The development of the qualitative study detailed in this chapter was based mainly on the ASC-CSQ and its findings.

There are three reasons for taking this approach. Firstly, the ASC-CSQ was capable of measuring what it was intended to measure as discussed in Chapter 3. Therefore asking questions similar to those in the ASC-CSQ in an open-ended format enabled researchers to understand clients' personal experiences and to investigate their satisfaction levels further, which could not be achieved using closed-ended questions. Secondly, as mentioned in the last section of Chapter 3, this qualitative study could be viewed as an alternative for measuring satisfaction levels which helps increasing the validity of the findings. This study coupled with the quantitative survey can be described as a "mixed methods approach". Thirdly, this study was prompted to investigate the causes of dissatisfaction and unmet needs among clients. Through this, a more comprehensive evaluation of HIV health care can be achieved, which is an essential step in leading to improvement of quality of HIV health care.

## **4.1 Research questions and outline of the chapter**

Two research questions will be addressed in this chapter. They are:

4. Is there any dissatisfaction among clients about HIV care at ASC?
5. Are there any unmet needs among clients about HIV care at ASC?

Similar to the previous chapter, this chapter begins with a detailed description of the methodology, followed by the results.

## **4.2 Methodology**

### **4.2.1 Study Design**

This study used a cross-sectional design. Qualitative in-depth semi-structured interviews were conducted to investigate the attitudes, perceptions and experiences of clients towards the HIV health care services received and their HCP at ASC. The questions were designed based on the results of the ASC-CSQ, particularly from findings of the open-ended questions. Participants were interviewed face-to-face individually and were also asked to complete a one-page self-administered demographic questionnaire. Qualitative thematic analysis was used to group and analyse the data.

### **4.2.2 Selection of the data collection method**

Data collected in qualitative research in health care is mainly obtained using one (or more) of the following three methods: observational studies, focus groups, and qualitative interviews. The following section describes the advantages and disadvantages of each method and justifies the choice used in this study.

As mentioned in section 1.5 on page 7, observational studies have the advantage of enabling researchers to observe actual behaviours of patients and the HCP, instead of obtaining verbal information from them that might not reflect the truth, as patients tend to answer questions in a socially desirable way. However, patients and HCP tend to change their confirmed habits of practice if they know they are being observed overtly. Also, this method is time-consuming and depends very much on the researcher's skills (Mays and Pope 1999). Furthermore, overt observation is not possible because confidentiality of clients has to be maintained. Secret video-taping or covert observation with researchers pretending to be a HCP is also not possible because regular clients usually consult the same HCP each time and consultations are held privately in a room. The above reasons suggest that observational studies are not appropriate in HIV health care facilities.

In focus groups, the researcher acts as a moderator and facilitates a group discussion so that group members are encouraged to respond to the topic of interest. Although this method is particularly useful in needs assessments and in identifying community concerns on a health issue, ASC is an ambulatory care clinic where clients consult HCP on an individual basis at various times and leave immediately after consultations. Hence this service nature makes it inappropriate to gather clients at a particular time for holding focus groups.

For qualitative interviews, there are two main types: unstructured and semi-structured interviews. Unstructured interviews resemble normal every day conversations, without fixed plans of interview schedule and ordering of questions, and are capable of exploring more in-depth for each participant. However, they depend on the social interaction between the interviewers and participants, which require skill from the interviewers as they have to develop rapport with the participants, to control the conversation and not let them digress away from the topic (Minichiello 1995).

Semi-structured interviews can avoid the above limitation as they involve the use of interview guides (or schedules), which are developed around a list of topics to act as frameworks for guiding the interviewer to ask a series of questions. But the order of asking the questions follows the unstructured interview process (Minichiello 1995). This method can collect in-depth information from participants, but less skill is required from interviewers as compared with unstructured interviews.

Balancing the pros and cons of each qualitative data collection method (observation, focus groups, qualitative interviews), the flexibility, efficiency, ability to maintain confidentiality, and resource-saving nature of qualitative face-to-face interviews make them the most appropriate way of obtaining information from clients in HIV health care facilities.



### **4.2.3 Participants and sampling**

Potential participants for this study were the same as those for the quantitative survey discussed in Chapter 3. They were all ASC clients over 18 years old waiting for health care services in the waiting area beside the reception. Clients who did not take part included those who could not communicate in English or those who refused to take part due to poor health or other reasons. Clients participating in the interviews need not be respondents of the quantitative survey discussed in Chapter 3.

Random selection has rarely been used in HIV/AIDS needs assessments due to the emphasis of confidentiality and nature of the research focus (Loo 2003). It has been found that the findings obtained using non-random sampling are reasonably generalisable, provided that the demographic characteristics of the sample group are more or less the same as those in the potential sample group (Kerr et al. 1998 (Unit 85)).

The qualitative interviews described in this chapter used a type of non-random sampling called theoretical sampling, in which the objective of developing theory guides the process of sampling and data collection (Mays and Pope 1999 (p.13)). Thus, the collection and analysis of data for each participant are conducted concurrently, and the final total number of participants recruited depends on the results of all the previous interviews (Carr 2001). However, it was estimated that new ideas or main themes would stop emerging beyond a sample size of 20, which is referred to as the “saturation point” (Morse 2000). Therefore, the planned sample size of this study is around 20 participants.

#### **4.2.4 Instrument—Preparation of the interview guide**

The interview guide (Appendix 8 on page 229) was based mainly on the topics and findings of the ASC-CSQ. It comprises three sections:

1. Satisfaction and dissatisfaction with overall and individual service aspects
2. Needs on health care services
3. Satisfaction and dissatisfaction towards HCP

The interview guide was reviewed by the ASC professional staff to ensure the issues raised were appropriate for the sample group. The interviews focussed more on the dissatisfaction aspects, which, as mentioned in Chapter 3, enabled room for improvement. It would have been preferable if the participants were also respondents of the quantitative survey, so that results from both studies could be compared to check for validity and reliability. However, this was not possible because the respondents of the quantitative survey were unidentifiable. Table 19 shows the topics in the interview guide.

Demographic information was collected from the participants through a self-administered one-page questionnaire, which included ethnic background, gender, age, education level, employment status, HIV status and length of time since diagnosis, sexual orientation, and risk of HIV infection. Similar to the quantitative survey, the information was collected to determine if the sample was representative of clients at ASC, and if demographic factors were associated with levels of satisfaction or unmet needs.

**Table 19** Topics in the interview guide for the qualitative interviews

<b>Topic</b>	<b>Topic content</b>	<b>Rationale</b>
<b>Section 1: Satisfaction and dissatisfaction with overall environment and services</b>		
1	<b>Length of time since being a client and services received at ASC</b>	To obtain basic information from participants.
2	<b>Location</b> Any difficulties in getting to the centre before	Accessibility and convenience are proved to be factors of concern for patients with limited ability of movement due to poor health and for those who are employed. (Ware et al. 1983; Donabedian 1990)
3	<b>Time</b> Any difficulties in getting suitable appointment times and any dissatisfaction about waiting time	
4	<b>Physical environment</b> Any dissatisfaction towards physical environment of the clinic, suggestions for improvement	Amenities (or physical environment) including convenience, comfort, quiet, privacy etc. are agreed to be an issue distinct from quality of care but is important to be included in patient satisfaction. (Donabedian 1988; Acorn and Barnett 1999; Hudak and Wright 2000)
5	<b>Basic services</b> Any dissatisfaction in receiving sufficient information, e.g. pamphlets, brochures, etc. Suggestions for improvement	HIV health care facilities have the responsibility to provide sufficient information and education to clients in addition to clinical services. This helps HIV patients improve their quality of life and prevent them from infecting other people.
<b>Section 2: Needs on health care services</b>		
6	<b>Attend any HIV health care facilities other than ASC</b>	To understand the reasons for attending elsewhere for services. To study factors which affect their choice of suitable HIV services, and to compare the health care facilities with ASC if possible.
7	<b>Needs on HIV health care services at ASC</b> To investigate if clients received all services they needed at ASC in the past year	To ascertain if services provided at ASC met service demands of clients, and barriers in obtaining suitable services.
8	<b>Any unmet needs on HIV health care not provided at ASC</b>	Needs assessment to discover any demands for HIV health care but currently not provided at ASC.
<b>Section 3: Satisfaction and dissatisfaction towards HCP</b>		
9	<b>Clients were asked to comment on their HCP on:</b> - <b>Information provided</b> - <b>Attitudes</b> - <b>Availability</b> - <b>Management on the consultations</b>	These aspects asked in ASC-CSQ were the most influential factors determining client satisfaction. This question enables clients to share more in-depth about their experiences with HCP and enable the researcher to understand the reasons for their perceptions and behaviours.
10	<b>Aspects of ASC services clients thought could be improved</b>	Clients were encouraged to address any issues they were dissatisfied with, and to provide suggestions for improving the quality of services at ASC.

## **Pilot study**

Prior to the actual qualitative interviews, a pilot study was conducted where four clients were interviewed. The purpose of this pilot study was to enable the interviewer to rehearse and become familiar with the interviewing process. This helped the interviewer minimise the chance of asking questions inappropriately, and be more skilful in prompting, probing, and observing, which are interviewing techniques that increase validity. The interviews for this pilot study used the same procedure as those for the actual interviews, but were conducted at the ASC waiting area rather than in private rooms. Information collected from these four clients was analysed to provide practice, but was not recorded in this thesis.

### **4.2.5 Ethical considerations**

This study was approved by the Human Research Ethics Committee (HREC) of the University of Sydney (Appendix 9 on page 230) and the South Eastern Sydney & Illawara Area Health Service (SESIAHS) (Appendix 10 on page 232).

**Beneficence**—This was assured by giving out a Participation Information Statement (Appendix 11 on page 234) to the client when inviting them to participate in the study. The purpose, significance, benefits and risks of the study were explained clearly in the statement. It was stated that “Clients’ participation is completely voluntary and it is possible to refuse to participate or withdraw from the study at any time without having to give a reason, services you received at the Centre will not be affected and you do not have to bear any consequences.” Clients who were willing to take part in the interviews were asked to sign two identical Consent forms, one for the researcher and the other for themselves (Appendix 12 on page 236), which indicated that the participant read, understood and agreed the contents of the Participant Information Statement.

**Non-maleficence**—The questions asked in the interview were designed in such a way that they are not harmful, offensive, threatening or unnerving. Although interviews were audio-recorded, it was emphasised to the participants verbally and through the Participant Information Statement and Consent forms that “the recordings could only be accessed by the researchers involved in this study for analysing data, and would be destroyed after the study was finished”. No identifiable information (name, telephone, address) was collected in the demographic questionnaires and they were destroyed after the research was finished.

**Respect for persons**—Confidentiality and anonymity were stated on the Participant Information Statement, the Consent forms, the demographic questionnaire, and were assured verbally. Only adults took part in this study and all interviews were conducted in a private room at ASC, where no third party was involved in the interviewing process.

**Justice**—It was stated on the Participant Information Statement that there would be no risks to participation. The participants would not benefit individually as a result of participating in the interviews, but the findings would help improve HIV health care services in the future.

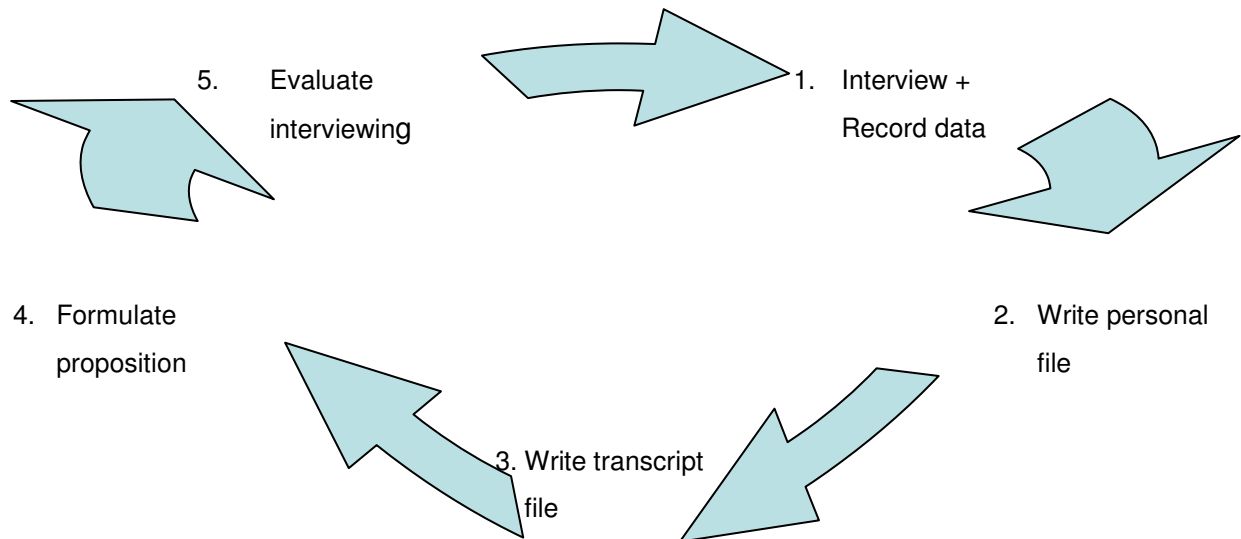
#### **4.2.6 Data collection**

The interviews were conducted by the researcher over 29 days from 3<sup>rd</sup> April to 13<sup>th</sup> May 2008 during ASC clinic opening hours. The interviewer approached every client waiting for consultations at the waiting area during this period, regardless of HIV status and the length of time since being a client (see Appendix for 13 on page 237 for verbal preamble). Once a client agreed to take part, the interviewer stopped inviting other clients until the interview with that client was finished. The “number of participants” and “number of clients who refused or unable to take part (non-participants)” were recorded every day during the period.

The purpose, significance, risks, benefits of the study, and the process of the interviews were verbally explained by the interviewer and were stated on the Participant Information Statement for the clients to read (Appendix 11). The interviewer emphasised that interviews would be audio-recorded, but they were de-identified and only researchers in the study could access the recordings. Once clients agreed to take part in the study, they were asked to sign two identical consent forms, one for themselves to keep and the other for the interviewer (Appendix 12). They were also asked to approach the interviewer after consultation, and the interviews were conducted in a private room at ASC. To help make the process more informal, biscuits were offered during the interviews. Participants were asked to complete a one-page self-administered demographic questionnaire after the interviews (Appendix 14 on page 238).

Unlike quantitative research, a preliminary analysis and collection of data for every qualitative interview were conducted concurrently. This was because findings from the previous interview enabled the interviewer to have a better understanding of what information should be collected in the next interview, and to equip the interviewer to ask more appropriate questions based on the interview guide, to prompt, and to probe the participants at the right time in subsequent interviews. A considerable length of time was

needed for transcription of the recordings and for preliminary analysis. Therefore the interviewer interviewed only one to two clients each day to allow sufficient time for data analysis. Fig. 7 shows this cyclical qualitative research process.



**Fig. 7** The qualitative research process

### **4.2.7 Data analysis**

Demographic information collected through the self-administered questionnaire was analysed using the Statistical Package for Social Sciences (SPSS) for Windows 13.0. Data were analysed in the form of descriptive statistics such as mean, standard deviation, range, maximum and minimum values. Tables showing the numbers and percentages of participants for each demographic characteristic were produced.

Interviews were analysed using the iterative mode of the analytical induction method. An ongoing preliminary analysis which involved writing a “personal file” and a “transcript file” was conducted as soon as the first interview was finished. They enabled the interviewer to obtain a general picture of the information given by each participant, to highlight misunderstandings, and to take note of missing information.

The personal file resembled a diary of the research process. It consisted of characteristic descriptions of the interviews and settings, including observations before, during, and after the interview, personal impression, a summary of the interview, and reflections on the interview method. Appendix 15 on page 239 shows an example of a personal file. Afterwards, the transcript file was prepared and it comprised 3 sections: a transcription of the interview, an evaluation of the interviewing method, and a summary of the views of the participant. Appendix 16 and 17 on pages 240 and 253 respectively show two examples of the transcript file.

After conducting all the interviews and writing up of all personal files and transcript files, a thematic analysis was conducted to further identify the emerging themes raised by the participants. A summary file was prepared by grouping together the insightful verbal quotes of the same theme selected from the transcript file, where recurrent emerging themes were particularly noted. Also, new themes which did not appear in the interview guide were also



highlighted and grouped together. Appendix 18 on page 265 shows an example of a summary file. In addition, responses from participants of different demographic characteristics were grouped separately to scrutinise and discover if there were any dissatisfaction and unmet needs for particular groups of clients. The participants were categorised into the following groups:

- Australians versus non-Australians
- 30 to 49 years old versus 50 to 69 years old
- Homosexuals versus non-homosexuals
- HIV positive versus HIV negative
- being an ASC client for less than 5 years versus 5 years or more
- Vocational education level or above versus below vocational education level
- Full time employees versus non-full time employees

#### **4.2.8 Strengths of the methodology**

This study has a fairly high inter-rater reliability because the interviewer took notes while the interview was being audio-recorded, which increased the chance for the interviewer keeping eye contact with the participant, thus enabling better rapport built between them, and enabling the interviewer to be more observant in detecting non-verbal signs. Furthermore, audio-recording enabled analysis to be conducted based on raw data with exact verbal quotes, hence reducing the chance of having missing information. In addition, other researchers (supervisors of the interviewer) read through the transcripts and summaries documented by the interviewer, so they were able to follow and discuss the analysing procedure, thus increasing the reliability and validity of the study.

The design of this study also minimised the effect of social desirability in a number of ways. Firstly, unlike many other studies in which doctors interviewed their own clients, the interviewer of this study was not an ASC staff member and was not connected to ASC in any way, therefore the participants did not need to worry that their identities and dissatisfaction would be made known to HCP. Secondly, the participants were assured that their responses would be de-identified and were strongly encouraged to give responses honestly. Thirdly, all interviews were conducted in a private room so no staff members or other clients heard the content. As a result, participants would be more open to express their views, without concerning if their answers were socially acceptable. In fact, it was found that the venue had an effect on clients' behaviours. Compared with interviews conducted in private rooms, clients interviewed at the waiting area during the pilot study were found to express their views less freely, tended to lower their voices, and were easily distracted by the reception staff or other clients.

Furthermore, this study avoided “extreme responses bias” which occurred in some needs assessment studies where the tick-box method was used. Most clients wanted various types of services to be provided to them and therefore they tended to rate “very important” for each unmet need. As a result, findings using the tick-box method would not be reflecting the services most needed (Ryan 1993; Erwin 2000). The qualitative interview method avoided this weakness by asking clients directly whether they felt that there were any health care services they needed which were not provided at ASC. In this way, clients were able to address their most unmet need(s) and their reasons, as well as their difficulties in accessing the services.

#### **4.2.9 Limitations of the methodology**

The format and wordings of questions asked during interviews could be a possible threat to validity. For example, occasionally the transcripts revealed that the interviewer asked leading questions which might introduce acquiesce bias, such as “Did they have a good attitude towards clients?” Double-barrelled questions such as “Do you think the waiting area is comfortable **AND** well-managed?” were confusing because it consisted of two questions. Also, vague and lengthy questions led to misunderstanding of questions and the participant might answer wrongly, for example: “I’m now going to read a list of services, so in the past 12 months if you needed it, you just tell me? So you need...” This study tried to minimise sources of interviewer bias by conducting pilot studies with ASC clients at the same setting using the same procedures as the main interviews. This enabled the interviewer to practise interviewing skills before conducting the main interviews.

Fig. 8 in the next page is a concise description of the methodology used in this research.

**Phase 1—Quantitative survey (N=166)**

***Preparation of questionnaire (ASC-CSQ)***

Content validity— 1. Reviewed past literature extensively to identify satisfaction aspects  
2. Discussed drafts with professional staff members

Criterion-related validity—Incorporated 2 previously validated scales into ASC-CSQ

Face validity—Conducted a pilot study with 11 clients

Construct validity—Compared ASC-CSQ scores of respondents with their comments in response to the open-ended questions

Internal Reliability—Determined item to item correlations using Cronbach's alpha

***Sampling***

Field researcher stationed in the waiting area for 11 days. All adult clients who spoke and read English were invited to participate

***Data collection***

Respondents completed the self-administered ASC-CSQ while waiting for services and inserted them into a central collection box

***Data analysis***

Statistical Package for Social Sciences (SPSS) for demographic information and satisfaction ratings.  
Thematic analysis for comments in the open-ended questions

**Phase 2—Qualitative interviews (N=22)**

***Preparation of interview guide***

1. Devised the interview guide based on the findings of Phase 1
2. Discussed the drafts with professional staff members
3. Conducted a pilot study with 4 clients

**Fig. 8** A summary of the methodology (quantitative survey and qualitative interviews)

## **4.3 Results**

### **4.3.1 Demographic characteristics**

A total of 87 clients were approached during the collection period and 22 participated, with a response rate of 25%. Those who declined to be interviewed were mainly because they were not willing to stay behind after consultations due to work commitments. No participants had participated in the quantitative survey described in Chapter 3. Each interview lasted for 15 to 90 minutes, with a mean duration of 30 minutes. Table 20 shows the demographic information of the participants.

Only one participant was female and the rest were males. The largest group were Australians (10 participants), followed by Europeans (5), then Asians (4), New Zealanders (2), and South American (1). The ages of participants ranged from 34 to 67 years, with a mean age of 49.4 years, which was larger than that of the respondents in the quantitative survey (40.5 years).

Sixteen participants were homosexual males, five were heterosexual males and one bisexual. This sexual orientation distribution was fairly comparable to that of the quantitative survey in Chapter 3. Four participants were HIV negative, and among the 18 HIV positive participants, half of them were diagnosed with HIV within 10 years. The main risk factor for HIV infection was homosexual unprotected intercourse (16).

The mean length of time since being an ASC client was 8 years, with the shortest length of 2 weeks and the longest length of 24 years. 50% of the participants were employed full-time.

**Table 20** Demographic information of the participants

<b>Demographic characteristic</b>	<b>Number of participants</b> (Total= 22)	<b>Percentage (%)</b> Percentages have been rounded off
<b>Gender</b>		
Male	21	95
Female	1	5
<b>Geographic origin</b>		
Australian	10	45
European	5	23
Asian	4	18
New Zealander	2	9
South American	1	5
<b>Age</b>		
30-39	4	18
40-49	8	36
50-59	5	23
60-69	5	23
<b>Sexual Orientation</b>		
Homosexual	16	73
Heterosexual	5	23
Bisexual	1	5
<b>HIV status and length of time since diagnosed (years)</b>		
Positive	18	82
0-9	9	41
10-19	2	9
20-29	7	32
Negative	4	18
<b>Main risk factor for HIV infection</b>		
Unprotected intercourse (homosexual)	16	73
Injecting drug use	4	18
Unprotected intercourse (heterosexual)	3	14
Oral sex	1	5
Dental procedures	1	5
Blood transfusion	1	5
	Note: There could be one or more risk factors	
<b>Education level</b>		
University	4	18
Vocational	8	36
Secondary (to year 12)	4	18
Secondary (to year 10)	5	23
Primary	1	5
<b>Employment status</b>		
Full time	11	50
Retired (self-funded)	3	14
Retired (receive pension)	3	14
Unemployed	3	14
Part time/ Casual	2	9
<b>Length of time being a client (years)</b>		
0-9	15	68
10-19	4	18
20-29	3	14

Qualitative data from the interviews will be presented through answering the two research questions in sections 4.3.2 and 4.3.3. Section 4.3.2 presents findings about satisfaction and dissatisfaction of the overall environment, basic services, HCP and their services provided, and “other topics” emerged from the interviews which are worthy of note. Section 4.3.3 presents findings about unmet needs identified in HIV health care.

#### **4.3.2 Research question 4:**

##### **Is there any dissatisfaction among clients with HIV care provided?**

###### **Location**

Altogether 19 participants were satisfied with the location. The main reason was due to the proximity of ASC to home or work. A few of them mentioned the convenience of parking cars nearby and the advantage of being centrally located to the gay community. 7 of them travelled by car, 10 came on foot, 3 by train and 3 by bus.

Three participants were less satisfied, and their main concern was inconvenient transportation from their homes to ASC. They generally took more than an hour of travelling because they lived in the Western and Northern part of Sydney. One of the participants said:

“Always a hassle to come to the city and here. Couldn’t park in the front...but I get on a bus. I have a friend who used to pick me up and bring me here. I couldn’t go out.”

(HIV positive Australian homosexual male, aged 55)

Although these participants hoped to have a better location, they did not express genuine dissatisfaction. Indeed, continuing to come to ASC indicated that they accepted the fact. The chronic nature of HIV indicates that clients usually consult their doctors once every three months, and this does not create extreme inconvenience. Two participants lived outside

Sydney and had to spend half a day taking intercity trains for consultations. Another participant was not an Australian resident and had to fly to Sydney twice a year to visit ASC. Their reasons for staying with ASC were continuity, confidentiality, and satisfaction of the quality of care received, which they found to be more important than the location (accessibility). One participant pointed out that:

“The location is a minor thing, because I only have to come at this stage every 3 months, it’s not that much of a problem. But I found that the benefit of the care that I get here and the fact that it’s paid for the government outweighs the inconvenience factor of where it is.”

(HIV positive Australian heterosexual male, aged 35)

However, location has still a considerable level of importance in influencing clients’ decisions. Three participants had left ASC before to attend other HIV clinics because of better accessibility. One of them came back eventually because he moved to the city area near ASC, whereas the other 2 came back because the other clinics closed down. Another 2 participants switched from their original clinic to ASC because of better accessibility. One participant explained that he could only access services within walking distance because his health did not allow him to take public transport.



## **Appointment time**

Only one participant was dissatisfied with the appointment time. The reason was that the HCP missed his appointment twice due to miscommunication between him and the receptionists:

“It’s just mixed signals or someone wiping out the appointments, like when [his doctors] wasn’t gonna be here they cancelled all appointments, coz if the doctor’s wasn’t gonna be here they’ll let me know, and they cancel that appointment. But whoever cancelled on the computer cancelled all the other appointments...Once or twice people have made assumptions and just not made appointments or not followed through the stuff. Like one day I really needed to see [his psychologist], and they never...they tried to ring him and then I went to the nurses, and I came back out and he never got informed and nobody told him.”

(HIV positive Australian bisexual male, aged 43)

The rest were satisfied because they were provided with a convenient appointment time. A number of participants had flexible schedules, whereas some put health at a higher priority and therefore appointment time was not an issue to them. It was interesting to note that one of the reasons that the participants were satisfied with the appointment time was because they viewed their regular appointments as non-urgent, so they could book them a few weeks in advance, and thus appointment time did not pose any problems to them.

## Waiting time

Respondents from the quantitative survey (Chapter 3) were the least satisfied with the “waiting time before consultations”. However in the current study, only one participant was truly dissatisfied. He said he usually needed to wait for 30 minutes, and sometimes even 50 minutes to 1 hour:

“Because I gotta work, if my appointments are 12, I get here at 12 and I’d like to be seeing at 12 obviously, but I mean that cannot always be the case. But I think 30 minutes is starting to get a bit long.”

(HIV positive European homosexual male, aged 45)

This inconvenience caused him to come once for collecting medication and another time for consulting doctor, in order to avoid the long waiting time he would have if he came for both services in one day. Although he was not happy about waiting so long, he did not reflect the issue to his doctor or any other staff members because he only wanted to talk about medical issues when he was with the doctor.

About 50% of the participants had no problems about waiting time and the other 50% found it acceptable. The mean waiting time was 15 to 20 minutes. The participants gave three reasons why they were willing to wait. Firstly, they believed that waiting for consultations was the norm no matter in what health care facilities because of limited resources:

“Apart from waiting for half an hour up there where I believe I need to. Um...if you’re dealing with the health care system ANYWHERE, you’ve got to wait...that’s the reality of the health care system.”

(HIV positive Australian homosexual male, aged 48)

“Some people may get upset with those things (waiting for a long time), I don’t. If you go to some doctors, you may have to wait for half a day to get the appointment!”

(HIV positive Australian homosexual male, aged 55)

Secondly, they expected to wait because ASC is a public health care facility and it provides free services:

“Some people might find it (20 mins) long, don’t like being kept waiting. But I mean you have to think that you’re come here basically getting free service...Well the waiting room can be busy, quite a few people.....but sometimes you have to wait a little while for your appointment, they can be running behind the schedule...you can’t just expect to see your doctor straight away, of course. So I accept that, that doesn’t particularly bother me really.”

(HIV positive European homosexual male, aged 60)

Thirdly, some of them believed a longer waiting time indicated that clients were having longer consultation time with the doctors and hence a more thorough check-up.

“15 minutes, 20 minutes, sometimes half an hour (waiting time). I think it is not because the doctor is late, because sometimes patients take more time with the doctor, which is a good thing too. Because I mean they have to listen to what you have to say...like it or not, you have to accept it.”

(HIV positive South American homosexual male, aged 62)

Separating participants into groups of different demographic characteristics indicated that those with a lower education level (below vocational education level) or those who were clients for a longer time (5 years or more) were relatively less satisfied with waiting time.

## Physical environment

About 25% of participants were less satisfied (not necessarily dissatisfied) with the physical environment. The small size of the waiting area and the relatively old design of the building were the main factors they were concerned about. A few found that the crowded waiting area created some inconvenience:

“I think the pharmacy’s space is a bit crowded. Sometimes I’ve been up there, I’ve had to stand to wait for the drugs...because there has been a lot of people already there.”

(HIV positive European homosexual male, aged 45)

“...if I were an architect, I am sure the professionals will say to me this is not good enough...the rooms are small. I don’t know whether they have properly or fully utilised or used by people like you and me, but it would appear to me it’s a bit crowded.”

(HIV positive Australian homosexual male, aged 67)

Others felt that the clinical building needed renovation or something to brighten the environment up:

“Cold and sterile (physical environment). It does feel like an old hospital, I know it’s an old building and old area, but it’d be nice if they brightened it up a bit and make it a bit more modern. Particularly in winter you sit in the waiting room. For someone who is getting their HIV testified, if they are HIV positive or not, it’s a little bit of a cold environment. I think I’d be a little bit apprehensive sitting there. I think it’s not very welcoming. The staff are very welcoming and friendly, but the actual environment of the centre itself, I think it’s a bit cold and run down. It needs a little bit updating...I realise that funding costs a lot of money to do that sort of stuff, and they probably got far better things to spend their money on.”

(HIV positive Australian heterosexual male, aged 35)

The other 75% of participants were satisfied with the physical environment. They described the waiting area as “pleasant”, “relaxing”, and “clean”, and they appreciated ASC for maintaining a reasonably good environment under limited resources from the government. Some praised ASC for sufficient facilities, having a fish tank at the waiting area and music playing from the radio.

The design of the clinical building, particularly at the waiting area, is not only related to visual comfort and appropriate use of space, but also affects a number of aspects which HIV clients may be concerned about, such as emotion levels and privacy. A few participants suggested that a clinical environment with brighter colours is crucial in bringing better moods to clients and making the atmosphere warmer and more welcoming:

“You’ll be feeling down and you can just look around (at the waiting area), and things can be a bit brighter, or lighter, or whatever, you’ll feel better, I do anyway...So I think colours (of walls) are very important, because they can contrast moods.”

(HIV positive Australian homosexual male, aged 42)

A few participants appreciated the glass screen near the exit because it separated the clients at the waiting area from the rest of the clinic, so they could wait at a more private area without being distracted easily. In fact, 3 clients chose to come to ASC partly because of its small size, which offered more privacy to them when compared with other hospitals:

“I think it’s more private. In St. Vincent’s (a public hospital in Sydney), it is so huge, like a hospital...also because the patients have the same problems...so I think you think a feel less embarrassed to be in the waiting room, that’s how I look at.”

(HIV positive Australian homosexual male, aged 62)

“Because there are so many people you can see trying to be at these STD clinics. Some people you know, and they see you, and say, ‘what are you doing there?’ And they keep asking, asking and asking, and I don’t like, giving deterrents about my private life.”

(HIV positive South American homosexual male, aged 62)

### **Basic services**

Basic services refer to information about HIV/AIDS and sexually transmitted diseases (STD) provided through pamphlets, condoms, magazines and other materials available at the waiting areas. Nearly two-thirds of the participants were satisfied with these services and described them as “comprehensive”, “informative”, “well-displayed”, “readily available”, and “self-contained”. They also appreciated the various types of magazines provided so that “every one has something to read”.

About half of the satisfied participants said they browsed through the health education pamphlets available at the waiting area while waiting for consultations. One of them said he self-educated and updated himself regularly with the pamphlets and kept them at home. Another participated in clinical trials through recruitment pamphlets at the waiting area. He felt obligated to take part in research studies so that he is helping himself and other PLWHA. However, the majority of the participants preferred to approach their HCP if they had questions about HIV, rather than to search through the pamphlets for answers.

Although the majority of homosexual participants were satisfied with the basic services, nearly all of the heterosexual participants were not satisfied due to the insufficient information targeting them. One of the heterosexual participants said he would only read the pamphlets when he felt bored, but found them to be unsuitable. Another female heterosexual participant had no comments about the pamphlets as she knew that they did

not concern her and so did not read them. Some other heterosexual participants complained that most of the magazines, pamphlets and advice lines were targeting homosexuals only, and they hoped to have more services focussing on heterosexuals:

“I found there’s very few pamphlets or reading information available for straight people like me. It’s mostly geared towards gays, I understand that it’s the majority, but yeah that’s not really much for straights. So some more information for straight people would be pretty cool...You know there’s a lot of straight couples when one person in a relationship might be positive, and that partner might be negative, and they’re very happy together. But you know sometimes they could probably use some counselling or help in that situation if they need someone to talk to, particularly for the straight, negative person in the relationship. I find there’s very few services like that for straight people. There’re probably up there (upstairs at the psychology unit), but I don’t know whether they are publicised or having information on it. Most of the advice lines and things like that I think tend towards the gay people with HIV, rather than straight people with HIV.”

(HIV positive Australian heterosexual male, aged 35)

In order to obtain a more objective view on the information provided, all reading materials available at the two waiting areas of ASC (one beside the reception and one beside the pharmacy) were collected by the interviewer. Out of the total 69 pamphlets collected, nearly 50% were provided by AIDS Council Of New South Wales (ACON), 14% were provided by ASC, and the remainder 36% were from pharmaceutical companies, the NSW government, and non-government organisations. 40% targeted towards PLWHA in general, 20% were specifically for homosexuals/bisexuals, but only one pamphlet was specifically written for heterosexuals. The pamphlets contained mainly advice for HIV clients, promotion of services of various organisations, and medical information about HIV/AIDS and STD. Besides pamphlets, around 8 to 10 types of magazines were available at the waiting areas, about half were gay local papers and others were entertainment magazines targeting all types of people.

In addition, free lubricant and condoms were available for clients. Table 21 shows the sources, target groups and contents of the 69 pamphlets provided at the ASC waiting areas.

**Table 21** Pamphlets provided at ASC waiting areas

	<b>Number of pamphlets</b> (Total=69)
<b>Organisations</b> <ul style="list-style-type: none"> <li>• AIDS Council Of New South Wales (ACON) 33</li> <li>• Albion Street Centre (ASC) 10</li> <li>• Private organisations (pharmaceutical companies, non-profit organisations) 8</li> <li>• Organisations funded by the government 7</li> <li>• NSW Government 5</li> <li>• Australian Federation of AIDS Organisations (AFAO) 4</li> <li>• Bobby Gold Smith Foundation (BGF) 2</li> </ul>	
<b>Target groups</b> <ul style="list-style-type: none"> <li>• HIV clients in general 27</li> <li>• Bisexuals/ homosexuals only 14</li> <li>• Clients in general (sexual health information) 14</li> <li>• Others (men, women, sex workers, clients interested in knowing Hepatitis C, travel vaccine, and travelling) 8</li> <li>• Injecting drug users (IDU) with HIV 5</li> <li>• Heterosexuals only 1</li> </ul>	
<b>Contents</b> <ul style="list-style-type: none"> <li>• Advices 30 <ul style="list-style-type: none"> <li>- HIV medication 13</li> <li>- For HIV positive clients in general 6</li> <li>- Safe sex 4</li> <li>- Relationships between homosexual couples 3</li> <li>- For IDU 2</li> <li>- Sexual health 1</li> <li>- Travel vaccine 1</li> </ul> </li> <li>• Promoting services 23 <ul style="list-style-type: none"> <li>- Social services (social groups, activities) 11</li> <li>- Financial and support services 6</li> <li>- Clinical and psychology services 4</li> <li>- For IDU 1</li> <li>- For sex workers 1</li> </ul> </li> <li>• Medical information about sexual transmitted diseases (STD) 15</li> <li>• Travelling 1</li> </ul>	



Besides heterosexuals, participants who were younger (below 50 years old) or with a lower education level (below vocation education level) were also relatively less satisfied with the basic services.

Nearly one-third of the participants mentioned the unavailability of beverages at the waiting area. They noted that tea and coffee were provided in the past but not now. They missed this and hoped they would be re-introduced.

“You can ask the reception to give you a voucher or something, or you can leave the coffee at the reception and you can ask someone for it...doesn't cost a lot. You have the free sample ones, you give them in motels and things...use sachets of coffee, keep them in the office.”

(The participant gave suggestions to avoid people abusing the service)

(HIV positive Australian homosexual male, aged 55)

Water was initially available at the waiting area but the water machine was broken during the data collection period. A few participants raised the unavailability of water which they viewed as essential, especially for those who came for blood test.

“Today's there's no water there, they should have some orange juice or something, you know little containers of orange juice or something you could just drink, if that's not available, if the water facility is not available...that's handy too, have some water before you give blood.”

(HIV positive European homosexual male, aged 45)

Two participants suggested the possibility of advertising services provided through posters placed inside the centre and at pubs or places where gay people are socially active, because they explained that the advertising and safe sex messages would influence PLWHA or those at risk of infection more than those on TV commercials.

“...the nutrition side...I only went to the first consultation last week, it’s only because I found out about that by the signs in the waiting room...it’s really the best place to promoting the services in the waiting room they are doing now. They’ve got a poster on how they cover many different aspects of health care, and I think that’s a great thing.”

(HIV positive Asian homosexual male, aged 34)

### **Utilisation of other services related to HIV**

There were a total of 10 participants utilising services related to HIV outside ASC. They sought those services not because the services were unavailable at ASC, but because they started utilising them before coming to ASC, and continued utilising them after becoming ASC clients, even though they knew that ASC provided those services. Among them, participants who were homosexual, with low levels of education (below vocational education level), without a full-time job, or at ASC for a longer time (5 years or longer) were more likely to utilise services outside ASC.

- Clinical services:

Two participants had their own HIV specialist GP, and they only came to ASC for counselling services and collect medication. Their reasons for utilising HIV services at other facilities were that they already established a certain level of relationship with their HIV physicians and continuity.

- Psychological services:

Two participants utilised psychological counselling services elsewhere. One needed another counsellor to deal with emotional issues with his partner together, but he did not want to have the same counsellor he was consulting with alone. Another participant consulted a counsellor at AIDS Council Of New South Wales (ACON) because he

happened to see an advertisement there when he needed counselling services.

- Nutritional services:

One participant took part in a nutritional research study at a private clinic and was given nutritional drinks which aimed to help improve health of HIV people. Another participant attended a nutrition meeting outside ASC to obtain more knowledge about nutrition and to expand his social circle.

- Pharmacy services:

Three participants collected HIV medication and anti-depressants (depression due to HIV) from other pharmacies. One participant's GP did not have a pharmacy at his clinic and so he had to collect medication at a public hospital. Another participant was not an Australian resident and had to order medication from another country. The other collected medication from his own local chemist because of continuity.

- Social support services:

Three participants attended private organizations such as the Luncheon Club, AIDS Council Of New South Wales (ACON), and Bobby Goldsmith Foundation (BGF) for social activities, legal and financial aid services.

## **Attitudes and interpersonal manner of the HCP**

No participants were dissatisfied or had any complaints about the attitudes and interpersonal manner of the HCP. They described them in their own words as “friendly”, “caring”, “helpful”, “polite”, “inviting to come”, “professional”, and “personal”. Nearly all participants were satisfied with the interpersonal manners of the HCP:

“And I just remembered that he (his doctor) explained everything so well...he was comforting, reassuring, but also explain a little bit of the technical knowledge and things. And I think that got me over that hurdle, the initial hurdle I think. I loved his really positive attitude, and helpfulness. And I think it's important that you got a good relationship with the doctor that you feel comfortable with...I have seen one or two other doctors when [his doctor's] been away or others have been away. And yes, are professional, but I just, he's just a doctor... Whereas [his doctor], you can feel he knows about you, and that going with the same person over and over, they know your history.”

(HIV positive New Zealander homosexual male, aged 56)

“And at that point, when I was really scared, they (nutritionists) offered fortnightly injections to help.....retard weight loss or rebuild muscles or something like that.”

(HIV positive Australian homosexual male, aged 52)

“When the doctors came and talk with everybody else, they will discreet, um keep their voices low and um didn't state what the patient has.”

(HIV positive New Zealander homosexual male, aged 52)

Although doctors seemed to be the most influential in determining satisfaction in clients, paramedical HCP, such as receptionists, played a decisive role in contributing to the overall impression and atmosphere of the clinical setting. This is because they were the first group of staff to communicate with clients even before they attended the clinic:

“The staff has always make you feel at home, relaxed, very nice, even when you ring up over the phone for an appointment.”

(HIV negative Australian homosexual male, aged 45)

“Just the friendliness of it...people (receptionists) know my name when I come in, it feels good to come in. People look at your card and they know who you are at the reception, they have good memories there...it’s not like a family, but you feel like you are friends. When I was there, I like to come in and have a cup of tea , talk to staff and that, even there wasn’t an appointment! That is sort of the way you’ve be into feel in that place.”

(HIV negative Australian heterosexual male, aged 47)

### **Information provided by HCP**

Again no participants were dissatisfied with obtaining information from their HCP. They were particularly satisfied with the doctors and nurses as they answered questions thoroughly and professionally.

“I was working overseas and she (his doctor) would email...I come in, come back to Australia to have my bloods done, and she would email me with the results. She takes the time to explain things, if I have any queries, she would explain it to me, if she thinks it’s an impossible problem, she then looks for alternatives.”

(HIV positive European homosexual male, aged 47)

“And if they (nurses) don’t (know the answers), most of the time they do endeavoured to find out for me. But more often than not, they have an answer, and I have a lot of confidence in their answers.”

(HIV positive Asian homosexual male, aged 34)

“So yes they (nurses) do explain, they don’t just inject the needle and walk away.”

(HIV positive Australian homosexual male, aged 52)

“She (psychologist) used to give me information print outs to take home, self-help type stuff, yeah. Like little foundations to self-help, she gave me print outs, say, read this, give me action plans to improve certain areas of life and stuff like that.”

(HIV positive Australian homosexual male, aged 42)

A few mentioned that apart from the first few consultations when they needed more information from the HCP because they were just diagnosed with HIV, they now had regular consultations and the procedures were the same every time. Their doctors were monitoring their health very well and therefore they did not need any extra information unless they have sudden changes in health status or when they need to start HIV medication.

### **Availability of HCP**

No dissatisfaction was reported about availability. Half of the participants were satisfied and the other half found it acceptable. Australian participants or those who had higher education levels (vocational or above) were more likely to find the availability only acceptable rather than satisfactory. The satisfied participants found that HCP kept appointment times, were accessible on the telephone, and could consult them earlier than the appointed time if they arrived early or even if they had not booked for a consultation session:

“They go out of their way to fit you in, as busy as they are. They try to fit around what suits you, convenience to both parties. Flexible I suppose. I came in really urgent that day, they quickly find a time and quickly fit me in straight away.”

(HIV positive Australian homosexual male, aged 55)

Those who felt the availability acceptable actually expected their HCP had poor availability because of limited resources. This was particularly true for specialists such as dermatologists and psychiatrists who are only at ASC on certain days a month:

“In my case, it wasn’t that much of a hassle, you know, he wasn’t there that day, and I can understand that, because you can’t have a bloody specialist sitting by every day of the week. It’s what 9000 something (people with HIV) in the whole state.”

(HIV positive European heterosexual male, aged 60)

One participant expressed his difficulty in finding a doctor to monitor his HIV progress regularly due to his deteriorating health and sudden drop in T-cells. He believed it was due to poor availability of doctors. However he was not genuinely dissatisfied:

“Of course I can’t see [a doctor at ASC] at the moment, coz she’s busy, or I just seemed to make for appointments with the wrong partner.”

(HIV positive Australian bisexual male, aged 43)

### **Topics emerged from interviews**

A number of important issues which were not included in the interview guide arose during the interviews. These 6 issues are enlightening for maintaining high quality health care.

They can be categorised into 3 categories:

- Specifically related to HCP
  - “Rapport with HCP”
  - “Caring nature of HCP”
  - “Trust towards HCP and continuity”
  
- Related to both HCP and the HIV facility
  - “Stigma, confidentiality and privacy”
  
- Specifically related to the nature of the facility
  - “Level of expectation”
  - “Multi-disciplinary nature of health care”

## **Rapport with HCP**

Due to the chronic nature of HIV, they did not view their HCP as professionals who just monitored their health at one stage in their lives, but rather viewed them as life-time companions. Therefore they were not only concerned about basic politeness and courtesy of the HCP, but more at a higher level—establishing a personal relationship with the HCP. A number of participants shared about their relationship with their HCP and admitted that having good rapport was the main reason for staying with the same HCP for years, or even decades. Participants who had better rapport with their doctors had more confidence in them and tended to be more satisfied with their health status.

“He’s (his doctor) attentive and has empathy for my situation, so he’s quite understanding. I’ve seen him for a couple of years so he knows me well, has a familiarity now, which was good...he knows my situation, where in my health is. And I feel quite comfortable raising any concerns with him, or bringing any issues to his attention. So his manner is very professional.”

(HIV positive European homosexual male, aged 45)

The rapport can be enhanced by involving clients in treatment plans. Since clients have been living with this chronic disease for a considerable length of time, they are usually more knowledgeable than expected, as they often obtain HIV knowledge from different sources such as books, internet, and friends who are PLWHA. The participants reflected that they hoped to participate actively and discuss the treatment with the HCP, that the HCP listen to their views and understand them more:

“I’d rather people to sit down and discuss with me, rather than, to say, no, take this one.”

(HIV positive Australian bisexual male, aged 43)



“When you give a treatment to someone, they have to be looking for what you want to give, otherwise they are not going to be satisfied...I got to the point where the way we saw our medicine and the way the doctor (his previous doctor) see the medicine didn't agree. We had to find a new doctor...that's not their fault, you need to find the right person on the way they could give.”

(HIV positive Australian homosexual male, aged 48)

Some other participants' definition of “having a good relationship with HCP” was that the HCP was non-judgmental, and clients could talk with their HCP comfortably about issues of daily living apart from health and treatment. It was also important that they have to like their HCP being not only their “HCP”, but as “people” too:

“I've been regular user here for so long. While taking bloods, we just had a chat about how's work, you know..... we (he and his partner) are going to New Zealand for holidays, so [his doctor] had been to New Zealand, he drew a little map of New Zealand. So these are good places to go.....”

(HIV positive Australian homosexual male, aged 48)

“Feeling comfortable that you can talk about anything, he's non-judgmental, you know all those.....hard to put into words, you know...that you feel at one with that person...As soon as I meet a doctor, you just know whether you'll get on with him or not.”

(HIV positive New Zealander homosexual male, aged 56)

Another participant pointed out that his way of addressing a HCP showed the relationship between them. Calling a doctor “Doctor” signified that their relationship ended and he would not want to stay with this doctor anymore:

“And the first name turned all that sort of thing, yes. Gone in the day we call a doctor  
‘doctor’”

(HIV positive New Zealander homosexual male, aged 52)

More rapport can be built up if the HCP was willing to help clients outside their scope of responsibilities. One participant was very grateful to his doctor because he acted as a counsellor in soothing him and his wife’s emotions when she was first diagnosed to have HIV. Some other participants needed help from their doctors in writing recommendation letters and testimonies to corresponding departments for referrals, housing aid, or applying for permanent residency etc.

“My wife (also HIV positive) and he (their doctor) had a good rapport, a wonderful rapport... he did so much to ease her through the early trauma, because it was hell of a trauma for her. Coming from Thailand, and suddenly found out to have HIV, was like a death sentence...We first came in here and she was in tears...she can’t go home, she can’t tell the family. In the early days, they are good to give the emotional support.”

(HIV positive European heterosexual male, aged 60)

### **Caring nature of HCP**

Care was another element raised by participants that could enhance rapport. From their viewpoint, care meant “the HCP has empathy” for them. HCP who were considerate and caring helped to alleviate clients’ emotional pain. A few participants illustrated examples which demonstrated care by the HCP: On certain occasions they came to the centre early and were admitted without having to wait until the appointed time. Some even managed to consult their HCP although they did not book for a consultation.

“It’s always very busy here, but I mean provided you got the time you can wait. They’re (HCP) fantastic, they’ll definitely slip you in if they can. They’re really cool.”

(HIV positive European homosexual male, aged 47)

“If they (HCP) didn’t care, they wouldn’t squeeze me in today. I didn’t have an appointment, I just came with flu vaccination, and a nurse organised everything, and that was the request forms, and then came back giving me. If they didn’t care, they’d tell me to go away.”

(HIV positive Australian homosexual male, aged 52)

“I was having a bad day, so I just couldn’t come in to see someone usually, they (psychologists) have a dropping centre...Yeah you might have to wait till they have finished talking to someone else, but you don’t say you have to come back in a week or a month.”

(HIV positive Australian bisexual male, aged 43)

Another example was observed by the interviewer while chatting with a client (who was one of the participants) at the waiting area while he was waiting for consultation. One of the nurses greeted and chatted with him, and poured a cup of water for him. After the nurse left, the client told the interviewer, “See, that’s what I am talking about (how caring the HCP was).”

Similarly, another participant recalled that his wife (who was also HIV positive) was not an Australian resident when she first came to ASC for help. However she was still admitted as a client because, as the participant believed, the HCP put “humanity in front of legality”. Also an interpreter was arranged for her because of the language barrier, which made her feel less frustrated.

### **Trust towards HCP and continuity**

Trust and continuity are outcomes of rapport and care. The participants emphasised that when trust disappeared, an emotional distance existed between them and their HCP, despite how professional the HCP were in carrying out their responsibilities. One of the participants described his previous HCP (not at ASC) as “standoff-ish”. The participants would then seek a second opinion from another HCP, and the consultations gradually became less frequent, until they lost their complete trust and stayed with another HCP. One participant explained that he left his previous doctor and came to ASC because he “lost connection with her”:

“If you can’t trust your doctor’s advice, you have to find another doctor. You can’t continue with that person as your doctor...You have to find someone that you can trust, and they see the world vaguely the same way you do. And you need to shop around to find that person, it may not be the first person you approach, but you need to find the right person...So if he has a totally different conception of the world, you get a clash.”

(HIV positive Australian homosexual male, aged 48)

Based on the relationship built through time, ASC did not only provide health care, but has become a sanctuary for the participants because they trust it could provide actual help in critical moments:

“(After he thought he has been infected) I didn’t go to other GP, I didn’t go to other hospitals, I went straight to ASC. If I hadn’t been coming to ASC within 24 hours, I might be wandering around, didn’t know what to do, and would have been very depressed...There is no place like here. Cannot afford to lose this place.”

(HIV negative Australian heterosexual male, aged 47)

Continuity in receiving health care services with the same HCP will naturally occur if trust exists. The longer the clients spent with their HCP, the less likely they are to change, especially those who were diagnosed as HIV positive by that HCP. In fact, a number of participants stayed with the same HCP since attending ASC after they were diagnosed as HIV positive by their own GP. For those who changed HCP, this was either because they did not have a good relationship with them, or were forced to change because they were no longer accessible. Continuity was often a factor which outweighed the location of the centre (some participants lived outside Sydney), the availability of the HCP (some had to take office leave for consultations), and the financial cost (some had to pay for consultations at private HIV GP). Some participants even said they would follow their HCP if they moved to somewhere else.

“I don’t like changing doctors if I find I work it out fine with him. A rapport with your medical...your physician helps a lot.”

(HIV positive New Zealander homosexual male, aged 52)

“I spent quite a lot of time with [her doctor] going through what is this, what to go from here, what kind of things that I need, do I need treatment...So it’s been a good relationship with [her doctor] because she’s been guiding me from the beginning...And with [her doctor] I can talk to her about this, because she knows me, and she’s been treating me for this long, so I don’t see the need that I have to go to another doctor.”

(HIV positive Asian heterosexual female, aged 36)

## **Stigma, confidentiality and privacy**

The problem of stigma attached to HIV people still exists although HIV is now more understood by the community. A number of participants talked about having a difficult time living with HIV and the necessity to hide their illness as much as possible. One of them came to ASC because he was discriminated and did not have privacy in his residence area:

“Because I live in a country town, and in country towns you don’t have privacy...you can have confidentiality and privacy with respect to doctors, but you can’t have with receptionists, and their clerks...clerical workers, receptionists, tend to chat. In a big city like this, you have a certain amount of anonymity. But you don’t have that kind of anonymity in small, rural cities, or small towns.”

(HIV positive Australian homosexual male, aged 67)

“They (people in the community) also assume automatically that, if you are a female, an Asian, being HIV, married to a Westerner, you gotta be a prostitute. That’s part of a mind set. You must be a Filipino or Thai bar girl.”

(The participant talking about his wife who was also HIV positive)

(HIV positive European heterosexual male, aged 60)

“I need to come back to see her (her doctor) because living with HIV is not easy, and to let someone else know that you are HIV positive is a nightmare. And basically you just try to cover it as much as you can.”

(HIV positive Asian heterosexual female, aged 36)

As a result, many of them preferred to have consultations at HIV specialist clinics rather than at GP or hospitals for two reasons: Firstly, all clients at specialist clinics have the same type of illness and so they felt less stigmatised. Secondly, the participants appreciated the fact that HCP were HIV specialists and not ordinary GP:

“They (nurses) tell me to go to general practitioner, no way! I won’t even tell them I got Hep C, no, it’s stigma.”

(HIV negative Australian heterosexual male, aged 47)

“I do trust them (ASC doctors), because they have a huge amount of knowledge, you don’t have to explain anything. I guess my GP is pretty good, but if you imagine you going to a doctor, they just doesn’t understand a lot about HIV stuff.”

(HIV positive New Zealander homosexual male, aged 56)

Not only were these participants stigmatised by people in the community, some also came across problems with other doctors at hospitals or clinics. They discovered that those doctors had a tendency to always associate their illnesses with HIV, which they thought might also be due to the stigma attached to HIV.

“They (doctors outside who were not HIV specialists) immediately blame or try to put the blame and anything else that I might have on the fact that I am HIV positive, you know...this undermine thing, that if I got a problem, if I got an infection, or if I have something wrong with me, it must be HIV attributable.”

(HIV positive European heterosexual male, aged 60)

## **Level of expectation**

A number of participants admitted that one of the reasons they came to ASC was because of free consultations. Australian residents only need to pay a limited amount of money for HIV medication. One told the researcher that he had nutritional counselling because he could obtain food supplements at a cost much lower than from a chemist. They appreciated these services very much and thought they would not be able to afford similar services from a private clinic (not bulk-billed):

“I couldn’t afford it (private health care service)! And that’s I mean...This clinic has provided to him and to myself um...site services that would be extremely difficult to access in any other way, and would be extremely expensive. We have had those services available to us through this clinic...that is highly valuable.”

(HIV positive Australian homosexual male, aged 48)

Since these clients were receiving services at a low cost, they showed a tendency for lower expectations for the quality of services, particularly in terms of waiting time and availability:

“Well the waiting room can be busy, quite a few people....but sometimes you have to wait a little while for your appointment, they (doctors) can be running behind the schedule...you can’t just expect to see your doctor straight away, of course. So I accept that, that doesn’t particularly bother me really...Some people might find it (20 mins) long, don’t like being kept waiting. But I mean you have to think that you’re come here basically getting free service.”

(HIV positive European homosexual male, aged 60)

“Yeah you pay for your treatment and you get what you like. But you are going to realise it is that we are not paying a penny!”

(HIV positive European heterosexual male, aged 60)



### **Multi-disciplinary nature of health care**

In addition to praising the low cost services, participants were also grateful about the multi-disciplinary nature of the clinic which enabled them to receive different types of HIV related health care services at one venue. Besides increasing the convenience, it also avoided the problem of being stigmatised by other HCP and general patients if they utilised services outside (such as collecting HIV medication).

“It provides everything in one place, which you got pharmacy here, you got your doctors, you got your nurses, you got your blood test here. Everything that you need is here, even the psychologist I got for the moment. Everything is in one building and one place...I guess I have taken it (the multi-disciplinary nature) for granted, it's only I've been talking to you now that I realise that, yeah all the positive things that we just take for granted, the doctor and the nurse. So I can sit here and in two minutes I can get all my bloods done, then I can go up and get my tablets, and it's all in the same thing.”

(HIV positive New Zealander homosexual male, aged 56)

### **4.3.3 Research question 5:**

#### **Are there any unmet needs among clients about HIV care?**

Unmet needs in this study referred to any HIV-related health care (physically or mentally) that was required by clients but not provided at ASC, or services available at ASC which they required but were unable to receive. This study yielded no common unmet needs for any participant. They were satisfied that they obtained all services they needed at ASC in the previous year, because they sought advice from their HCP if they had any needs. Even if they needed health care services which ASC could not provide such as specialist services which were non-HIV-related, their HCP would give them appropriate referrals so that they could receive the treatment much quicker than they sought themselves. They also praised the HCP for being serious and pro-active in dealing with their illnesses not related to HIV:

“They (doctors at ASC) have dealt with a number of other issues, health-wise. I ended up going to Prince of Wales for an eye operation...That was all handled through this clinic.”

(HIV positive Australian homosexual male, aged 48)

A number of participants were confident that even if they have any needs in the future, they would be able to obtain the services through ASC:

“I’m coming for what I need, and I get what I need out of it, if there’s anything that I require I can speak to [her doctor] about it.”

(HIV positive Asian heterosexual female, aged 36)

“I think there’s a lot of services available in this area, so it’s pretty well covered. But if there was something I wasn’t sure of, and I couldn’t find it from the paper or the internet or what, I would ask [his doctor] for sure, if he knew somebody.”

(HIV positive European homosexual male, aged 45)

## **Chapter 5—Discussion and Recommendations**

The previous two chapters investigated client satisfaction, dissatisfaction, and unmet needs using quantitative and qualitative research methods. Results of client satisfaction, the main focus of this thesis, were presented as numbers and figures in the quantitative survey in Chapter 3, and as words and themes in the qualitative face-to-face semi-structured interviews in Chapter 4. This chapter first discusses findings in each of the two chapters, and then summarises the whole research by more consolidated and meaningful findings. Afterwards, recommendations to increasing client satisfaction are suggested through answering the last research question: “what has to be done to address the dissatisfaction and unmet needs”. The strengths and limitations of this research are also discussed, followed by highlighting the strengths of practising the mixed methods approach and summarising the contributions of the whole research, before suggesting issues for future research.

## 5.1 Discussion of the Quantitative Survey

This study is one of the very few conducted in Australia focussing on client satisfaction in an HIV ambulatory care facility. Findings from this study are generally comparable to those reported in the literature in relation to other patient satisfaction in HIV health care facilities around the world. However, some findings from this study have never been reported in the literature before and are therefore make a valuable contribution to the field of health care in HIV/AIDS.

### 5.1.1 Research question 1:

#### **How satisfied with care and the HCP are clients attending an HIV/AIDS health care facility?**

##### **Overall and individual aspects**

The 166 respondents at ASC who participated in the quantitative survey were generally satisfied with the care and management provided. The ASC-CSQ scores for all the respondents range from 30 to 100 with a mean of 84 out of 100. The distribution of these scores is negatively skewed, which is a universal finding in patient satisfaction studies worldwide, suggesting that more respondents were satisfied than dissatisfied (Canales 1998; Dykeman 1998; Beck et al. 1999; Erwin 2000; Miles et al. 2003; Bodenlos et al. 2004).

From Table 11 on page 81, over 90% of the respondents were satisfied with most of the 16 aspects covered in the ASC-CSQ. They were most satisfied with the “*confidentiality*” of their personal information kept by the HCP (97%), followed by “*knowledge*” (96%) and “*attitudes*” of HCP (94%), and “*HCP understood clients’ needs*” (94%). The very high satisfaction levels for knowledge and attitudes of HCP are encouraging as they have previously been shown to be associated with increases in patients’ appointment attendance, continuity in receiving

care, and return to follow-up; better adherence to and cooperation with treatment and HCP; and eventually, have improvements in clinical outcomes (Stein et al. 1993; Hudak and Wright 2000; Sullivan et al. 2000; Beach et al. 2005; Bova et al. 2006).

The respondents were least satisfied with “*waiting time before consultation*” (34% satisfied), followed by “*benefited more than expected after consultations*” (79%), then “*availability of HCP*” (83%), “and “*uninterrupted consultation*” (83%). It should be particularly noted that the proportion of respondents dissatisfied with waiting time was as large as 53%, while the proportion of dissatisfied respondents for all other aspects were within 10% only.

It may seem that decreasing consultation time could decrease waiting time, and thereby increase clients’ satisfaction. However, the individual aspect “length of consultation time” was not particularly satisfactory in the quantitative survey (only 84% of respondents satisfied), therefore it would risk bringing more dissatisfaction if consultation time was shortened. Paradoxically, Feddock pointed out that if HCP have a longer consultation time with their clients, the negative effects of long waiting time can be counteracted by longer consultation time (Feddock et al. 2005). However this relationship has not been verified in this research and is worthwhile to investigate in the future.

It is interesting that the respondents tended to rate overall aspects (appointment time, location, confidentiality, physical environment) more satisfactorily than individual aspects (aspects related to consultations or HCP). This confirms the observation by Sitzia and Wood that questions which are more specific are associated with lower satisfaction ratings than general questions (Sitzia and Wood 1997). This also justifies the advantage of including more specific questions in questionnaires to maximise the possibility of finding what the clients are dissatisfied with.

The 16 aspects covered in the ASC-CSQ were also categorised into different dimensions suggested by Ware according to their nature for easier administration and analyses (Ware et al. 1983). The most satisfactory dimension was “*technical quality*” of HCP, followed by “*interpersonal manner*” of HCP, then “*physical environment*”, “*efficacy/outcomes*”, “*overall availability*”, and the last, “*accessibility/convenience*”.

Comparing the results from this quantitative survey with those from previous research, common trends were noted. “Technical knowledge” and “interpersonal manner” of HCP are often the most satisfactory aspects and they affect overall satisfaction the most; whereas “accessibility/convenience” is often the least satisfactory in HIV health care facilities (Linder-Pelz and NSW AIDS Bureau 1990; Burcham et al. 1993; Beck et al. 1999; Sullivan et al. 2000; Tsasis et al. 2000; Burke et al. 2003).

Low satisfaction with waiting time was not a surprising finding in this survey, because it was also noticed in research conducted in the Australian context or overseas (Linder-Pelz and NSW AIDS Bureau 1990; Burcham et al. 1993; Menz 1997; Colebunders et al. 2001). It was observed in an US outpatient clinic that only 12% of the respondents were “very satisfied” with the waiting time, whereas 46% were “somewhat” or “very dissatisfied” (Erwin 2000). It is worthwhile to find out the reason for this observed trend of low satisfaction, whether it was because the HCP and management staff tended to neglect the “accessibility/convenience” dimension, or the clients had high expectations of it.

### **Health care provider (HCP) categories**

The literature review in Chapter 2 revealed that there were only very few previous studies measuring clients' satisfaction with each HCP category. A large number of studies evaluated nursing care only, because researchers believed that only nurses were directly associated with overall patient satisfaction (Yellen et al. 2002). Even for studies that evaluated each HCP category, respondents were only asked to rate their overall satisfaction with the HCP categories and not individual aspects (Dykeman 1998).

The ASC-CSQ of this quantitative survey overcame this weakness by enabling respondents to rate each HCP category for each individual aspect, which could not be reflected by their overall satisfaction. Combining the results for all aspects showed that the most satisfactory HCP category was nurses (86% of the respondents satisfied), followed by psychologists (84%), then doctors (83%), pharmacists (83%), receptionists (80%), and then, nutritionists (77%) (see Appendix 6 on page 221 for more details) .

Although comparisons could be made between HCP categories, it should be borne in mind that each HCP category could be influenced by different factors. For example, some studies reported that depressed patients tended to have higher satisfaction levels but some found the opposite (Kersnik et al. 2001; Burke et al. 2003; Frosthalm et al. 2005). More depressed clients consult psychologists than other HCP, and therefore a differential bias may result in assessing satisfaction with psychologists and other HCP categories. As another example, fewer ASC clients consulted "nutritionists" and "psychologists" than "doctors" and "nurses". In a smaller sample group, the ASC-CSQ score would be affected more by extreme ratings of a respondent. Errors in assessing satisfaction were expected and therefore it could not be easily concluded that the respondents were least satisfied with the nutritionists.

*"Waiting time before consultation"* was the least satisfactory aspect over all HCP categories. Some aspects specific to each HCP category were also of lower satisfaction, such as the

“availability” of doctors and psychologists; “included clients’ decisions in treatment” for doctors, psychologists, and nutritionists; “uninterrupted consultation” for pharmacists; and “knowledge” of receptionists.

Very few patient satisfaction studies evaluated each HCP category. The only study which the researcher is aware of is the 1996 Client Satisfaction Survey conducted at ASC, in which nurses were also ranked the highest (97% of the respondents satisfied), followed by nutritionists (95%), then doctors (93%), psychologists (87%), and the last, pharmacists (86%) (Menz 1997). Apparently, the levels of satisfaction with all HCP in the present survey were lower than those in the 1996 survey. However, it should be noted that the format, standard, and criteria of the questionnaires used for both surveys were different. Also, the 1996 survey was much less comprehensive since only 4 aspects were used in assessing clients’ satisfaction with HCP compared with 10 aspects used in the present survey. Thus, the results from these two surveys cannot be compared directly, and the results of the present survey do not reflect the actual change in client satisfaction since the 1996 survey.

### **Attributes addressed in the open-ended questions**

The best way to accurately find out patients’ perceptions in detail is to conduct needs assessment through qualitative research, but this method usually does not allow researchers to approach many patients due to resource constraints. Therefore, two optional open-ended questions were included in the ASC-CSQ for clients to provide qualitative data. More than half of the respondents made valuable comments for future improvements through this means (see Appendix 7 on page 224 for all the comments).

The contents of the comments and their frequencies more or less reflected similar levels of satisfaction assessed with the closed-ended questions. No respondents gave negative comments on the “*technical quality*” and “*efficacy/outcome*” dimensions. This might be



accounted for by the fact that the respondents believed they did not have adequate professional knowledge to comment on how the HCP treated them. Or maybe these two dimensions were too personal and too specific to comment on, despite the anonymity assured before they completed the ASC-CSQ.

*“Interpersonal manner”*, however, was a dimension the respondents felt free to discuss. Comments on this dimension were extreme as a few criticised the poor attitudes of a few HCP, while many others expressed their gratitude towards the politeness and helpfulness of the staff. Thus, the perception of HCP attitudes is a matter of personal experiences which can be unique for each client. For the 13 respondents who praised the staff for their courtesy and friendly attitudes, their ASC-CSQ scores were significantly higher than the mean ASC-CSQ score. These findings further support the notion indicated in previous research that patient-provider relationships have great influence on overall satisfaction with services, because high satisfaction levels can eventually improve the clients’ health.

It was also observed that *“accessibility/convenience”*, the least satisfactory dimension assessed in the closed-ended questions, had the largest number of negative comments, despite it was perceived as the least important among all dimensions. This was because this dimension also involved other dimensions such as *“physical environment”*. For example, a respondent commented that clients with physical disabilities have poor accessibility to the centre due to a lack of consideration in designing the physical environment (stairs are steep). He suggested the centre to provide facilities such as an inclinor or an elevator. In fact, an HIV health care facility with better accessibility and being more convenient to clients is seen to be more caring and considerate.

Furthermore, confidentiality-related issues were also found not only to relate to the staff’s responsibility but also to the physical environment, as the clients suggested to have “more privacy in reception and waiting areas” and “make a separation between drug-using patients

and general health patients”. Although physical environment was not perceived as an extremely important dimension in this quantitative survey, its intrinsic importance should not be neglected because its improvement will bring satisfaction in other dimensions.

The qualitative information from the open-ended questions also acted as a cogent supplement to the quantitative information from the closed-ended questions, and can be used to scrutinise the dissatisfactory aspects with an aim to improve them. For example, a number of respondents who rated low satisfaction for “*waiting time before consultation*” not only expressed their inconvenience brought by long waiting time, but also suggested feasible solutions, such as extending clinical hours during the week, employing some casuals in the pharmacy, and allowing medications to be pre-ordered. Although these suggestions may not necessarily be adopted in the future, they are valuable to the HCP and managerial staff.

A few respondents mentioned needs for social support such as organising social groups, legal assistance, and providing information to clients about where they can seek these services. Although these services are not directly related to HIV health care, they have been found crucial and often considered as unmet needs in previous studies (Smith and Rapkin 1995; Rajabiun et al. 2007; Tobias et al. 2007). This survey did not investigate the relationships between the provision of support services and satisfaction levels. However, considering that only 17% of the respondents received HIV services elsewhere other than ASC, enhancing the only current social support service at ASC: the Ankali scheme (emotional support for HIV clients on a one-to-one basis) will be necessary. Since the Ankali scheme also provides services for clients outside ASC, more research is needed to assess the possibility of introducing more support services for clients coming to ASC for HIV health care services.

### 5.1.2 Research question 2:

#### **What aspects of HIV health care are perceived as important among clients?**

The aspects “*knowledge*” and “*attitudes*” of HCP, “*understood clients’ needs*”, “*information given during consultation*”, and “*included clients’ decisions in treatment*” were rated by more than 90% of the respondents as important (Table 11 on page 81). When the individual aspects were grouped into Ware’s list of dimensions, the most important dimension was “*technical quality*”, followed by “*interpersonal manner*”, then “*efficacy/outcomes*”, and then “*overall availability*”, and the last, “*accessibility/convenience*” (Table 12 on page 82). This ranking of the dimensions (from the most important to the least) was the same as that of the satisfaction levels (from the most satisfactory to the least).

Except for “*waiting time before consultation*” which was perceived by respondents to be fairly important but rated as poorly satisfactory, other aspects perceived as very important were also rated as highly satisfactory. Coincidentally, aspects perceived as less important were also rated as fairly satisfactory. This phenomenon signifies that it is more important to maintain the quality of aspects already highly satisfactory, than to make changes in those aspects which are less satisfactory.

The ranking of importance also matches the findings from the meta-analysis of Sitzia and Wood, which the most important dimensions are the “*interpersonal manners of HCP*” and “*clinical outcome*”, whereas “*accessibility of facilities*” and “*waiting times*” are the least important (Sitzia and Wood 1997). The high importance levels of “*technical quality*” and “*interpersonal manner*” also agree with Donabedian’s theory of “*Levels of which quality may be assessed*” in Fig. 3 on page 34, where he mentioned that these two dimensions are the core aspects to be assessed first when evaluating the quality of health care service (Donabedian 1997).

The importance of “*understood clients’ needs*” and “*included clients’ decisions in treatment*” also uphold the concept that “empathy” of HCP is essential, which has been shown to increase patient satisfaction and decrease the extent of having unmet needs (AIDS Alert 2000; Davis-Michaud et al. 2004; Thiedke 2007). It can be concluded that patients from different health care facilities, with different diseases, or having different satisfaction levels have similar expectations towards health care service. The respondents of this quantitative survey showed no exception.

### **5.1.3 Research question 3:**

#### **Are there any significant differences in satisfaction among clients with different characteristics?**

“*Geographic origin*”, “*gender*”, “*age*”, “*sexual orientation*”, and “*number of services received on the day completing the questionnaire*” were found to have no relationships with satisfaction levels. These findings are consistent with those reported in the literature, although some studies found that satisfaction levels are higher for females and older clients (Hall and Dornan 1988; Aharony and Strasser 1993; Katz et al. 1997; Tsasis et al. 2000; Burke et al. 2003; Bodenlos et al. 2004). Results show that ASC clients were treated by the HCP in the same way regardless of race, gender, age, and sexual orientation, or at least there was no evidence of discrimination against clients of different characteristics.

HIV negative respondents were found to be more satisfied than those who had been HIV positive for 21 years or more. This may be explained by the fact that respondents who have been HIV positive for a longer time have poorer health, and some studies found that poorer health is related to lower satisfaction levels (Aharony and Strasser 1993; Stein et al. 1993; Katz et al. 1997; Burke et al. 2003). However, this conclusion cannot be verified unless they

are also asked about their health status in the survey questionnaire. It was also found that clients who visited ASC for the first time were more satisfied than those who visited ASC more than once, no matter how long they have been its clients and how frequent they visited the centre. This contradicts a previous finding that patients who spent more years at a clinic were associated with higher satisfaction levels (Dykeman 1998).

Employed respondents were found to be more satisfied than the unemployed. This is an unexpected finding since one might anticipate that employed clients would be less patient while waiting for health care services, as they were less available due to job commitments. However, previous studies have not shown any relationship between employment status and satisfaction levels (Beck et al. 1999).

Analyses of the ASC-CSQ scores indicate that respondents with a vocational background were less satisfied than those with a university background. But no significant differences in satisfaction levels were found for other education level categories. Therefore, similar to the conflicting data in previous studies, there is still not enough evidence to conclude the existence of a certain relationship between education level and client satisfaction level (Katz et al. 1997; Canales 1998; Erwin 2000; Miles et al. 2003; Thiedke 2007).

Respondents of lower socioeconomic status (in possession of Health Care Card or Pensioner Concession Card) were significantly less satisfied than those with higher socioeconomic status (without any types of Health Care Card). This result is consistent with previous findings (Thiedke 2007).

#### **5.1.4 Validation of the instrument—ASC-CSQ**

The ASC-CSQ used as a measure of client satisfaction in an HIV ambulatory health care facility has undergone four validity-check procedures and one test for reliability. Content validity was assured by reviewing the literature extensively, drafting the ASC-CSQ based on a number of previously validated HIV patient satisfaction questionnaires, and reviewing the drafts by professionals and HCP at ASC.

Criterion-related validity was assured by incorporating two previously validated questionnaires—the *Client Satisfaction Inventory* and the *Marlowe-Crowne Social Desirability Scale* into the ASC-CSQ. Analyses show that ASC-CSQ scores are capable of reflecting true satisfaction levels and are free from social desirability bias.

Face validity was assured by conducting a pilot study with 11 ASC clients using the draft of the ASC-CSQ before the main survey began. The purpose of the pilot study was to increase the clarity of the ASC-CSQ and to make sure it was ethical for clients.

Construct validity was assured by showing that respondents with positive comments in the open-ended questions had significantly higher ASC-CSQ scores than those with negative comments, and there was no evidence of respondents with positive comments having low scores or vice versa.

Reliability of the ASC-CSQ was checked in terms of Cronbach's alpha, the most commonly used coefficient in psychosocial constructs. The Cronbach's alpha was reasonably high for each dimension and each HCP category of the ASC-CSQ, showing that all aspects in the questionnaire are reproducible, consistent, and reliable.

The above validity and reliability check procedures confirmed that the ASC-CSQ as an appropriate instrument for evaluation of the quality of HIV health care in terms of client satisfaction. It allows longitudinal studies to be conducted regularly in the future using the same instrument (ASC-CSQ), and it can compare the findings and can assess the trends of satisfaction for improvement. The Client Satisfaction Inventory and Marlowe-Crowne Social Desirability Scale incorporated for testing criterion-related validity can be removed from the ASC-CSQ. It is anticipated that the shorter ASC-CSQ can make the respondents more cooperative in answering every item and takes them less time to complete, resulting in fewer missing and invalid items.

Besides assessing client satisfaction at ASC, the ASC-CSQ can be utilised in other HIV ambulatory health care facilities in Sydney or even in other parts of Australia. Results thus allow comparison of client satisfaction trends at different geographical locations, so that HIV health care can be evaluated more extensively for aiding the development of national standards of HIV care. HCP categories which do not exist in other HIV health care facilities can be deleted from the ASC-CSQ and new HCP categories can be added to the ASC-CSQ to make it applicable. This flexibility characteristic of the ASC-CSQ makes it suitable for all types of multi-dimensional HIV health care facilities in assessing client satisfaction.

## 5.2 Discussion of the Qualitative Interviews

Similar to the quantitative survey, this qualitative study is one of the very few, if not the first one conducted in Australia, to ascertain dissatisfaction and needs of HIV health care service using semi-structured interviews. The sample size of 22 clients was considered optimal in this study as the saturation point was reached and a wide range of opinions were collected. Considering that about half of the clients attending ASC were working full time and no financial incentives were offered to participate in the research, a response rate of 25% was reasonable. The distribution of clients' demographic characteristics was relatively comparable to that of the quantitative survey in Chapter 3 and the PLWHA in Sydney (Hardwick and Cotton 2005), in which homosexual males and Australians comprised the dominant groups utilising the services, although a steady increase in PLWHA of other geographic origins was found in the past decade..

### 5.2.1 Research question 4:

#### **Is there any dissatisfaction among clients with HIV care provided?**

A majority of the participants gave high levels of praise and reported no dissatisfaction with the services. Consistent with the findings of the quantitative survey, the participants were particularly satisfied with the "*interpersonal manner of HCP*" and "*information given by HCP*". Although a few participants shared some disagreeable experiences with their HCP, they were considered very personal and little dissatisfaction could be identified through the analysis.

This section covers the discussion of aspects of client satisfaction in HIV health care in detail, which include "location", "waiting time", "appointment time and availability", "physical environment", "basic services", "interpersonal manner and information provided by HCP", "rapport, care, trust and continuity", "confidentiality and privacy", "multi-disciplinary nature", and "health care system and expectations".



## **Location**

A majority of the clients were satisfied with the location of ASC because of the proximity to their residences or working places and they perceived this convenience as important. Besides this study, previous studies conducted in both Australia and in foreign countries have shown that location influences clients' choices of health care facilities. A study conducted at sexual health clinics in Sydney and outskirts demonstrated that geographic proximity of clinics to home or work is the reason for 50% of the clients in choosing their clinics (Vijayasarithi 2006). In England, 49% of HIV patients and Genito-Urinary Medicine (GUM) outpatients consider "inconvenient location" as a factor influencing them in leaving a clinic (Hope et al. 2001).

However, the importance of location is often under-estimated as it is generally perceived that only the "technical ability" and "interpersonal manner" of the HCP are the main determinants of client satisfaction. Yet, "accessibility/convenience", which is mainly determined by location, is also one of the very important client satisfaction determinants (Ware et al. 1983). HIV clients with poor health were more likely to be dissatisfied than those with better health (Burke et al. 2003), and therefore location is particularly important as they cannot travel for a long time or even take public transport. Although it is not clear if improved accessibility improves health outcomes, it is expected that a health care facility at a convenient location increases usage of health care services clients deserved, and decreases the chance of having unmet needs.

However, location is a difficult aspect to be evaluated due to funding matters and ownership of the clinical building. Unless the location poses a threat to the safety of clients, it is rare that health care administrators will move the site even if a considerable number of clients are dissatisfied, because they have to balance the feasibility of the changes with the opportunity cost. It will be crucial for health administrators to choose an optimal location for new HIV health care facilities in the future, preferably centrally located to the residences of

PLWHA and easily accessed by public transport.

### **Appointment time and availability of HCP**

Consistent with findings of previous studies, the convenience of obtaining a suitable appointment time was not a general concern because the clients had flexible schedules and they perceived their consultations as non-urgent. In the quantitative survey, a few respondents expressed having inconvenient appointment times, especially consultations from specialists who were only stationed at ASC for a few times per month. However, such comments were not voiced in the qualitative interviews. Instead, the participants understood and accepted the fact that some HCP were not always available.

Although clients from other studies supported extending service opening hours to enable clients utilise walk-in services in case of emergency (Hope et al. 2001), only one participant raised this need in this study (total opening hours of ASC is 35 hours a week with extended opening hours on Thursday evenings). It can be concluded that the clients were generally satisfied with the availability of the service times. But it is also expected that extending opening hours increases accessibility/convenience which decreases the chance of having unmet needs.

### **Waiting time**

When compared with the high level of dissatisfaction with waiting time in the quantitative survey (53%), there was much less dissatisfaction in the qualitative interviews. The interviews revealed that the clients were not truly dissatisfied, but only had relatively low expectations about the availability of their HCP, and hence they accepted to wait before consultations. Only one participant was truly dissatisfied, and he sometimes waited for an hour before consultations. This is consistent with the finding of a previous research that a

waiting time of more than 30 minutes is considered to be unacceptable (Hope et al. 2001). Although half of the participants expressed their willingness to wait for a short period of time before consultations, improvement is imperative because a previous research indicated that as many as 58% of HIV patients will consider leaving a clinic if they are not satisfied with waiting time, which has a larger influence than poor interpersonal manner of HCP (50%) (Hope et al. 2001).

Section 5.1.1 on page 151 mentioned Feddock's theory that the negative effects of long waiting time can be counteracted by longer consultation time (Feddock et al. 2005). This theory was verified in one of these qualitative interviews where a participant explained that he accepted a longer waiting time because it signified a more thorough check-up. However, if the HCP addresses the problem of long waiting time by increasing the consultation time, the waiting time will be even longer and this creates a vicious cycle, which is not a long-term solution to solve the problem.

Another theory by Pruyn is more practical and applicable to the situation at ASC. He suggested that waiting time can be resolved into objective (real) waiting time and perceived waiting time, and clients are more affected by the latter than by the former. Therefore decreasing their perceived waiting time rather than real waiting time is more pragmatic in increasing client satisfaction. Perceived waiting time can be decreased, for example, by improving the attractiveness of waiting environment (Pruyn and Smidts 1998), which will be discussed in section 5.6 on page 182. However, ideally real waiting time should still be kept within 20 minutes to minimise dissatisfaction.

## **Physical environment**

About three-quarters of the participants were satisfied with the waiting area despite its limited size, because they understood that ASC had limited funds. The remaining quarter of the participants expressed or implied that the waiting area should be improved due to its smallness and aged design. From the researcher's observation, sometimes the waiting area could be quite crowded and the seats were all occupied. The size of the clinical building has not changed since 1996 for accommodating a more than 50% increase in the number of clients (Goulder 1996a; Goulder 2007a). Besides reducing perceived waiting time, previous studies showed that an appropriate physical environment encourages clients' healing process, decreasing their anxiety and blood pressure (Schweitzer et al. 2004; Douglas and Douglas 2005; Dijkstra et al. 2006).

Similar to location, physical environment is difficult to change because it depends much on the resources available from the government. HCP and health administrators are often not owners of the clinical building and thus it is not possible to alter architectural features. However, it is possible to alter "less permanent" elements such as the interior design and ambient features. These elements are essential because clients sometimes spend even more time in the waiting area than in consultation rooms, therefore their first impression on the waiting area will influence their perception of the clinic as a whole. Suggestions for altering the interior design and ambient features will be discussed in section 5.6 on page 182.

## **Basic services**

Most participants were generally satisfied with the basic services provided, except the heterosexual clients, who felt that there were limited reading materials such as pamphlets and magazines specifically for them. This can be explained by the fact that a very large number of PLWHA in Australia are homosexuals, so HIV organisations tend to publish reading materials relevant to their needs. A review of the reading material by the researcher at ASC revealed that those pamphlets suitable for heterosexuals only contained general medical advice for all PLWHA and were not specific enough. Provision of specific reading materials, advice lines and counselling services inclined towards HIV heterosexual clients not only improve their satisfaction as they will not feel neglected, but also indirectly assist them in better taking care of themselves.

In addition, some participants suggested that the notice boards at the waiting area are good sources for promoting services at ASC and other HIV organisations, and for displaying HIV/AIDS and Sexually Transmitted Diseases (STD) knowledge for educational purposes. Not only can this decrease their perceived waiting time, but also make them fully utilise their time at the centre, and save the time of HCP in explaining medical knowledge to them. However, the effect of providing information at the waiting area on clients' knowledge and satisfaction has not been ascertained before.

Provision of beverages was unexpectedly important to the participants, as one-third of them hoped that coffee and tea would be re-introduced (beverages were provided some years ago but stopped). This issue was not addressed in previous studies and it implies that seemingly insignificant services, especially those not directly related to clinical services, are indispensable, because they can make a significant contribution to clients' satisfaction by enabling them to feel welcomed. This is expected to increase the continuity of care, which is a necessary element in treating chronic disease.

### **Interpersonal manner and information provided by HCP**

The participants were mostly very satisfied with these two aspects without any dissatisfaction. The high satisfaction levels in these two aspects agree with many other previous studies. HIV is still an incurable disease and clients have to try various combinations of HIV medication throughout their lifelong treatment. Therefore, the significance of the HCP having a good manner and providing clear explanation of medical knowledge is particularly amplified in HIV health care when compared with general health care.

Although clients spend most of the time with doctors and nurses during their visits, the interpersonal manners of paramedical HCP, such as receptionists, are not to be neglected as they are the first group of HCP to communicate with clients (both over the phone and during visits). It is important for future patient satisfaction studies to take account of them for a more exhaustive evaluation, as this was not done in many previous studies.

### **Rapport, care, trust, and continuity**

Similar to the review in Chapter 2, the qualitative interviews showed that if quality health care is to be achieved, HCP should not only have good interpersonal manner and friendly attitude, but also be in rapport with clients. In this research, it is found that rapport, care, trust, and continuity come in line in HIV health care and they are inter-related to each other and have mutual effects. When clients and HCP develop rapport, HCP will care more for clients. Also, clients will establish more trust in HCP, and continuity (consulting the same HCP) will naturally appear. Similarly, more trust and continuity naturally improves rapport and results in better care.

Consistent with the previous findings, if trust disappears, dissatisfaction will occur and will lead to discontinuity in seeking health care (Carr 2001). A lack of trust is also expected to

associate with the chance of having unmet needs, as clients who lose their confidence in searching for a trust-worthy HCP will stop seeking HIV health care more easily. Therefore, genuine trust must exist between HIV clients and HCP if quality care is to be achieved. Table 22 shows a list of behaviours a caring HCP should have from the perspectives of the participants.

**Table 22** Behaviours of a caring HCP from the perspectives of the participants

What a caring HCP will do:	Reasons
Discuss treatment plans with clients and include their decisions for treatment.	Clients are more knowledgeable than expected. More communication between HCP and clients in discussing treatment plans shows a sense of respect to clients.
Chat with clients about daily living issues other than HIV treatment.	So that clients and HCP have more interflow and communication.
Be non-judgmental.	HCP should view issues from clients' perspectives and have empathy for them.
Give emotional support at times (HCP other than counsellors/psychologists).	Although this is the responsibility of psychologists/ counsellors, HIV clients are often mentally vulnerable, which can be a larger threat to their health than HIV itself.
Admit clients earlier if they arrive at the clinic earlier than the appointed time, or even if they have not booked for an appointment.	This signifies that HCP are readily available, considerate, and put clients' interests in the first place. Clients will feel more secure and being cared for.
Handle health-related issues other than HIV treatment, e.g. referral, writing recommendation letters for financial or legal assistance.	HIV clients will feel being cared for and have more confidence to face life if HCP help them other than dealing with HIV treatment only. This is particularly significant for clients who have opportunistic infections, for whom the HIV facility does not have not enough equipments or specialists to provide treatment.
Allow clients to call his/her first name and not with a title, e.g. Dr. XX.	Calling first names shows a less formal relationship and is a symbol for clients that they are in rapport with HCP.

Findings in the interviews suggest that those participants satisfied with the services overall were in good rapport with their HCP, which was their paramount reason for staying at ASC. These participants were very willing to raise issues to their HCP about their health and

medication, to facilitate information exchange between them, and to have better understanding of their HCP. Such bi-directional communication definitely enables clients to understand their health better, to adhere to the most appropriate medication, to take care of themselves and those who may be at risk of being infected by them. However, since nearly all participants were in good rapport with their HCP, hence it was not possible to compare the extent of effect of rapport on overall satisfaction.

Some participants were particularly grateful to their HCP for writing recommendation letters and testimonies to corresponding departments for referrals, housing aid, or applying for permanent residency etc. These jobs might seem trivial and time-consuming to the HCP, but these small actions demonstrated care for clients who desperately needed help physically, mentally, and financially, so that they felt much more welcomed and their visits were more enjoyable.

### **Confidentiality and privacy**

It is encouraging that most participants were satisfied with the confidentiality throughout the whole process of receiving health care at ASC. They appreciated not only the professional integrity of the staff members in protecting their health status and identities, but also the glass screens separating the waiting area and the reception, giving them sufficient privacy while waiting for services. ASC was also perceived by the participants to have a higher level of privacy and confidentiality than other hospitals, because it is a smaller and specialised HIV clinic, as compared with general hospitals where patients of other illnesses also have access for services. This supports the fact that HIV ambulatory care plays a very crucial role in enabling HIV clients to receive health care comfortably (Petchey et al. 2000).

In contrast to general health care, HIV health care has to stress much more on confidentiality and privacy because of the stigma attached to the disease itself. Some



participants in this study, particularly Asians, expressed their difficulties in living with HIV due to a lack of understanding of HIV in their community. The stigma is already a hindrance for conducting client satisfaction studies at HIV facilities because the clients are reluctant to participate due to the fear of exposing their identities. Therefore, protecting privacy of clients can foster opportunities for health care evaluation. In fact, a previous study concluded that for clients attending for an HIV blood test, privacy/anonymity is even more important than the location, price and availability of an HIV facility (Phillips et al. 2002).

Confidentiality and privacy can be kept in two ways: the design of the physical environment and the staff members. For example, consultation rooms and waiting areas separated by solid walls than by curtains are preferred (Dijkstra et al. 2006). Also, HCP can keep the anonymity and confidentiality of clients by not calling their names in public and not disclosing their medical information to any other people. Health care administrators and HCP should be particularly aware of these issues when a HIV facility is renovated or newly established, so that clients can receive health care without worrying about being stigmatised.

### **Multi-disciplinary nature**

The importance of a multi-disciplinary HIV facility is a new issue emerging during the interviews. A few participants expressed their gratitude to ASC in providing them with most, if not all HIV services in one place, so that they could receive the services efficiently at the lowest cost. The convenience brought by multi-disciplinary HIV health care facilities is particularly important for vulnerable groups who have limited locomotion due to physical and financial reasons. Therefore it is most likely that clients at multi-disciplinary HIV health care facilities receive most if not all services they required, and have fewer unmet needs. In addition, these facilities minimise the chance of clients being stigmatised by seeing HCP and patients at other health care facilities.

### **Health care system and expectations**

Since ASC is under the NSW Government, consultations are free of charge as they are covered by MediCare, and HIV medication is only subjected to a limited cost for Australian residents. The participants' high level of appreciation about the financial aspect of care suggests that public health care serves its purpose of alleviating financial burden for low-income clients. However, evaluating the cost of receiving HIV health care concerns health care system policies, which is beyond the scope of this research.

Yet, it was observed that the low financial cost might cause a confounding effect on satisfaction levels. Therefore, in order to determine whether satisfaction levels are truly influenced by the cost, studies need to be conducted at private health care facilities where HIV health care is not free of charge, such as HIV specialist GP. These studies are especially important in Australia as PLWHA are more likely to seek HIV care from a GP due to an increase in demand for HIV health care services (NSW Department of Health 2000; Petchey et al. 2000; Hardwick and Cotton 2005).

Nevertheless, due to a lack of standardisation of data and inconsistency in the nature of reporting, no reliable data are available from the NSW Department of Health about the proportions of PLWHA in NSW or in Sydney attending public and private HIV ambulatory health care facilities (Hardwick and Cotton 2005). Hence, it is difficult to determine the effect of financial costs on the true levels of satisfaction.

## **5.2.2 Research question 5:**

### **Are there any unmet needs among clients about HIV care?**

Despite the fact that nearly half of the participants were accessing HIV health care or social support services outside ASC, they did not consider themselves to have unmet needs. This is because their main reason for seeking HIV health care outside was “continuity”. As many of them accessed those services before coming to ASC, and as long as rapport and trust had been developed, continuity of care was natural even though the accessibility of the facility was poor.

According to a needs analysis conducted in US, unmet needs are less common as HIV infection advances, and there are relatively fewer unmet needs for core HIV medical care than for housing, financial assistance, and other social support services (Ryan 1993; Erwin 2000; Young et al. 2005). However, investigating unmet needs for housing, financial, and social support services is beyond the scope of this research, but is worthwhile to conduct such research in the Australian social context.

Some participants raised out a need for HIV-friendly dental care service. This was also reported to be the most needed care of PLWHA in another needs assessment study in US (Bonuck 1994). Although dental care is not directly related to HIV health care, it is worthwhile to put more attention to advocate for more HIV-friendly dentists for providing services to HIV clients.

As far as HIV health care was concerned, the participants not only received the HIV health care services they needed in the past year, but were also confident that their HCP would refer them to appropriate hospitals efficiently if they had any health care needs (such as specialist services) that could not be provided at ASC. This was a direct consequence of the participants being in rapport with their HCP, and further support the acknowledgement by the

NSW Department of Health, that “the quality of doctor-patient relationship is central to the successful long term management of HIV” (Hardwick and Cotton 2005 (p.50)).

It should also be borne in mind that the referral of HIV clients to appropriate health care facilities for treating illnesses other than HIV is often more important to the clients than the HCP expected. This is because being chronic disease HIV patients, complications and opportunistic infections are frequent. A simple referral by the HCP can greatly increase their accessibility to specialist services which are otherwise impossible for them to seek by themselves.

### **5.3 Summary of findings from the Quantitative Survey and the Qualitative Interviews**

Findings from both the quantitative survey and the qualitative interviews are integrated and the summary is presented in this section.

The demographic distributions of the sample groups were similar in both the quantitative survey and qualitative interviews. They were also comparable to the true distributions at ASC and PLWHA in NSW (Hardwick and Cotton 2005; Goulder 2007a; Goulder 2007b). Male clients predominated at ASC with a proportion of more than 90%. Australians were the largest geographic origin group and occupied about 50%, followed by Europeans (20%), and Asians (15%). Similar to most of the Western countries, more than 70% of the participants were/could be infected by “unprotected intercourse between men” (UNAIDS and WHO 2008b). 23% were HIV negative, and around 70% became clients of ASC within the past 10 years.

The majority of findings in the quantitative and qualitative studies were more or less comparable. Satisfaction levels were generally very high, with an average of over 90% of clients satisfied with all the services. Although dissatisfaction and unmet needs were the research focus of the qualitative study, few such concerns were reported. Therefore, more emphasis was placed on the reasons and the determinants of satisfaction with services.

Both the quantitative survey and the qualitative interviews indicated that the most satisfied aspects of client satisfaction were “technical quality” and “interpersonal manner” of HCP, “confidentiality/privacy” and “information given during consultation”. The clients were satisfied because they understood that ASC was an HIV specialist clinic, and therefore the doctors were HIV specialists who had better knowledge of HIV than private GP. Also, the discreet way of the HCP handling their medical information and the separate waiting area

were crucial factors leading to their satisfaction with confidentiality/privacy. In addition, the patience of the HCP in explaining medical information, and their caring and considerate manner enabled clients to develop good relationships with and trust in them. Indeed, this was found to be the main reason for some clients to stay at ASC despite its poor accessibility to them.

The aspects which the clients found acceptable, or less satisfactory (not necessarily dissatisfactory), were “accessibility (location)”, “waiting time”, “availability of HCP”, and “information available for heterosexual clients”. Based on the views of the heterosexual clients coupled with the researcher’s observations (on collection of pamphlets at the waiting areas), the information provided to heterosexual clients at the waiting areas was insufficient. While waiting time and availability were the two aspects that had the lowest satisfaction levels, the clients who gave such ratings were not necessarily dissatisfied, but might consider them as acceptable because of their low expectations due to the low service costs. Extreme views were reported on the accessibility and the physical environment of the waiting area.

The ratings for importance of aspects and comments from the participants both indicated that “technical quality of HCP” and “the relationship with HCP” were the two largest determinants of satisfaction. It was particularly important for the HCP to demonstrate consideration, care, empathy and non-judgmental attitudes in order to build rapport and continuity. Once relationships were established, poor location or inconvenience in accessing for services were generally not major concerns for clients, even though “accessibility/convenience” was also found to be an influential determinant. Moreover, maintenance of “confidentiality/privacy” was shown in both studies to be fundamental in HIV health care facilities, because the clients would stop attending the clinic if confidentiality could not be maintained. Furthermore, the multi-disciplinary nature of the HIV health care facility allowed all services to be received at one setting, making it more convenient to the

clients and increasing their satisfaction. In addition, the provision of complimentary beverages was regarded as a determinant of satisfaction which has not been reported in previous studies.

Common unmet needs related to HIV health care were not addressed in either the open-ended questions or in the interviews. Although in the qualitative interviews, nearly half of the participants received HIV services elsewhere other than ASC, they did not consider themselves as having unmet needs because they utilised those services out of continuity. The participants were confident that they had received the services they should receive in the previous year at ASC, and were offered referrals for specialist services if the required services were not available. By discussing their needs with their HCP, the participants were confident that they would be able to obtain the most appropriate services in the future. However, the need for an HIV-friendly dental care as an additional service at ASC was raised.

No significant differences in satisfaction levels were found in clients among different “geographic origins”, “gender”, and “numbers of services received at ASC”. The HIV negative clients were more satisfied with the services overall than the HIV positive clients. The same was observed between the employed clients (full-time and part-time) and non-working clients (unemployed, student, retired); those who visited ASC less frequently (once in 3 months or less) and those visited more frequently (weekly and monthly); and between those without any type of Health Care card and those who possessed one. Younger clients (below 50 years old) and heterosexual clients were less satisfied with the information provided in the waiting area. Clients with a lower education level (below vocational education level) and those who have been ASC clients for a longer time (5 years or more) were less satisfied with the waiting time. Although there was not enough evidence to conclude that the quality of health care provision differed for different groups of clients, this was the first time that such an analysis was conducted in Australia.

## 5.4 Strengths of this research

Four strengths have been identified in this research:

Firstly, findings from both the quantitative survey and the qualitative interviews add value to existing knowledge concerning client satisfaction in HIV health care facilities. While a number of patient satisfaction studies have been conducted in primary health care facilities, few were conducted like this one on HIV-infected individuals and people at risk of being infected, particularly in Australia. Unlike the majority of patient satisfaction studies, this research focussed on ascertaining dissatisfaction and unmet needs, so that not only satisfaction levels were measured to indicate the quality of health care, but also negative experiences of clients were investigated to provide practical recommendations for improvement. This echoed Burke's reminder that "identifying sources of dissatisfaction enabled clients to reflect the presence of actual negative experiences, and not raising positive expectations", which is what satisfaction studies usually do not do (Burke et al. 2003 (p.452)).

Secondly, a diverse background of the sample group ensures that satisfaction level results and views from a wide range of clients were considered. Nearly all previous patient satisfaction studies conducted in Australia and overseas did not include people who were HIV negative clients in the sample group. Unlike those studies, this research included HIV negative clients who were at high risk of HIV infection or utilised non-HIV clinical services such as sexual health check-up. Although HIV negative clients at ASC are the minority among all clients (23% in this research), their satisfaction levels and perceptions on HIV health care are not to be neglected because they are at risk of infection and are vulnerable. Indeed, ambulatory HIV health care services are now in greater demand by HIV negative individuals as they attend clinics regularly for HIV blood test (Hardwick and Cotton 2005). Therefore, including HIV negative clients for evaluation helps to identify their barriers in



receiving the most appropriate HIV health care, thus reducing the chance of having new HIV infections.

Thirdly, this research evaluated each HCP category in both the quantitative survey and the qualitative interviews, which has seldom (if ever) been conducted in previous patient satisfaction studies. The ASC-CSQ is one of the very few instruments designed to enable the respondents to rate and compare their satisfaction levels for each HCP category and each individual aspect, and the interview questions enabled the participants to express their experiences in consultations with HCP of each category. This avoids the limitation of rating overall satisfaction levels only, which do not truly reflect clients' experiences in consultations and do not provide clear directions for improvement (Dykeman 1998).

Fourthly, this research not only assessed satisfaction levels, but also investigated the determinants of HIV patient satisfaction by asking the respondents to rate the importance of individual aspects in the ASC-CSQ, and by investigating the participants' concerns through the interviews. Identifying the importance of these determinants overcomes the weakness often identified in other questionnaires, where the questions usually reflect the concerns of the researchers, but not necessarily of the patients (Nelson and Niederberger 1990). Also, the importance level can act as a weight factor in judging of the quality of care to provide information for the administrative staff to decide whether the improvement of a particular aspect is needed. For example, the improvement of an aspect with a low satisfaction level and a low importance level can be put at a lower priority, when compared with the improvement of an aspect with a low satisfaction level but a high importance level.

## 5.5 Limitations of this research

Three limitations have been identified in this research.

Firstly, the findings of this research may be under-representing the true levels of satisfaction, dissatisfaction and unmet needs, because the survey and the interviews were conducted with clients visiting ASC for services, but not those who may have withdrawn from ASC due to dissatisfaction. As a result, the participants appeared to be less dissatisfied and have fewer unmet needs because they were already utilising the services (Hudak and Wright 2000). However, the gap between the reported levels and the true levels of dissatisfaction and unmet needs was difficult to ascertain because no data were available for those who have withdrawn from the services.

Secondly, the findings of this research may lack generalisability and external validity. Although ASC is the largest ambulatory HIV health care facility in Australia, it is only one of the level 5/6 HIV health care facilities in NSW. Since the sample group is from the same HIV health care facility, the findings are applicable to ASC but may not be generalised for other HIV health care facilities in Sydney or in NSW, particularly for private HIV specialist GP. Fortunately, since the demographic distribution of the ASC clients is roughly comparable to that of the PLWHA in Sydney, the findings still contain considerable levels of generalisability.

In practice, the level of generalisability can be better estimated if the proportions of PLWHA in Sydney (or NSW) who utilised services at ASC and other HIV health care facilities are known. However, as mentioned before, such data are unavailable due to inconsistency in reporting. For example, some facilities counted per visit of clients as one occasion of service, whereas some counted the number of consultations with HCP per visit as the number of occasions of service. This kind of ambiguity makes the estimation of generalisability difficult. Generalisability can be improved by conducting client satisfaction surveys in multiple HIV

health care facilities to obtain a larger sample size for a more diverse range of respondents.

Thirdly, there were missing and invalid data in the quantitative survey due to the length of the ASC-CSQ. Among the clients who agreed to take part in the study, 86% returned the ASC-CSQ. The rest of the clients (14%) might be interrupted by their HCP for consultation while they were completing the ASC-CSQ, and did not return them after the consultation, resulting in a smaller number of respondents than expected. Fortunately, these clients were not all from a particular group with similar characteristics, and hence contributed no differential bias.

Furthermore, despite the pilot study conducted, only 118 (71%) ASC-CSQ had complete and valid answers among the 166 questionnaires collected. Some respondents did not read the instructions carefully and ticked all the boxes in the same column (respond sets) where they were only required to tick boxes of the HCP categories they have consulted; while some did not rate their satisfaction for certain HCP categories although they indicated previous consultations with them. Also, the HCP category “receptionists” was placed after all other HCP categories, hence a number of respondents overlooked this category and did not rate for them. The researcher provided more verbal explanation to the respondents on the seventh day of the data collection period and fewer invalid responses resulted. Clients were also found to be more helpful and willing to take part when the researcher communicated more with them.

## **5.6 Research question 6:**

### **What, if anything, has to be done to address the dissatisfaction and unmet needs?**

Merging the findings from the existing literature, and both the quantitative survey and qualitative interviews, Table 23 shows a number of specific and feasible recommendations to address the less satisfactory aspects. Table 24 lists a number of aspects which ASC should maintain to sustain current high satisfaction levels. Table 25 also suggests a few issues worth noting when a new HIV health care facility is established. Although this research was conducted at ASC, the recommendations are likely to be applicable to other HIV health care facilities as well because they are based on human nature of likes and dislikes.

Table 23 lists aspects relate to “physical environment”, “basic services”, “rapport and trust between the HCP and clients”. They are suggested after balancing the feasibility, effectiveness, and available resources. Although HCP and health administrators usually do not own health care facilities and therefore do not participate in architectural design, they may be responsible for the interior design and amenities.

**Table 23** Recommendations for improving client satisfaction

Aspect	Improvement	Justification
<b>Physical environment</b>		
Painting of walls	Use warm pastel colours such as mild yellow, light green and purple.	A welcoming environment that looks comfortable and soothing enables clients to have better moods, decreases anxiety and blood pressure. (Reichel 1956; Segvic 1961; Miller et al. 1985; Stichler 2001)
Decorations at waiting area	Add more potted plants and art work, e.g. paintings.	A more attractive environment makes the clinic look less like a hospital and decreases clients' subjective perception of waiting time.
		Aesthetics and art have beneficial effects on clients with psychological problems (Caspari et al. 2007; Norma et al. 2008)
Music at waiting area	Play tapes of natural sounds e.g. ocean waves and bird-chirping.	To create a more relaxed environment and soothe clients psychologically. (Dijkstra et al. 2006)
Odours at waiting area	Introduce fragrance e.g. orange and lavender.	Studies indicate fragrance can reduce anxiety and improve mood. (Lehrner et al. 2005)
<b>Basic services</b>		
Water machine at waiting area	Water (hot and cold) and cups should always be provided.	This is a fundamental service that should be available in any health care facility. Clients should take in fluid before having blood tests.
Provision of beverages	Packets of instant coffee powder, tea bags and milk kept at the reception and distributed to clients when they arrive.	Clients will feel much more welcomed. This has an indirect effect on their willingness in coming to the clinic and reduces concerns about waiting time.
Information at the waiting area	Increase variety of reading materials and services targeting heterosexual clients.	Heterosexual PLWHA are the minority group among PLWHA who need more information and help.
	Make full use of notice boards for educational, health promotion purposes, and services available at ASC and elsewhere.	Clients can utilise the waiting time to acquire knowledge related to HIV and Sexually Transmitted Diseases (STD) so as to save time in asking HCP questions.
		Knowing services available to them decreases the chance of having unmet needs.  More information for clients to read decreases their perceived waiting time.
<b>Rapport and trust between HCP and clients</b>		
Develop more rapport	Involving clients in treatment plans by discussing the choices instead of giving directives.	Clients will feel respected and be more involved in taking care of their own health. It was shown to be directly related to satisfaction. (Davis-Michaud et al. 2004; Saila et al. 2008)

The recommendations for physical environment involve simple alterations which can be implemented immediately but have good effects. The aim is to stimulate clients' sense of sight, hearing, and smell to promote a relaxed environment and improve moods of clients, for example, painting walls with warm pastel colours, playing tapes of natural sounds such as ocean waves, and introducing mild fragrance such as orange and lavender. Also adding artistic decorations and potted plants at the waiting area will make it more attractive and interesting, and has previously been shown to improve satisfaction directly and have a positive effect on clients' perception of waiting time (Pruyn and Smidts 1998).

Provision of water is fundamental in every health care facility and should be always available, particularly in HIV facilities where clients need to replenish loss of water after blood tests. Providing beverages is a simple and relatively inexpensive way to demonstrate consideration for clients. Packets of coffee, sugar, milk and tea bags can be kept at the reception and be distributed by receptionists to clients, so as to prevent services from being abused.

Similar to most of the Western countries, heterosexual HIV clients at ASC are the minority group among PLWHA who are even more helpless and vulnerable than homosexual HIV clients. A wider variety of reading materials and services targeting specifically this group should be available at the waiting areas. These include magazines, pamphlets, and advice lines regarding HIV support services, health promotion and prevention strategies, such as safe sex information for couples in whom one of them is HIV positive and the other is HIV negative. Although it is understandable that most reading materials distributed by the HIV-related organisations are homosexual-oriented, HIV health care facilities still have the obligation to provide sufficient information for all types of clients. More social support services for HIV clients are associated with better knowledge about HIV and positive attitudes, which are also related to better medication adherence (Olley 2007; Wolf et al. 2007).

In addition, HIV health care facilities can effectively utilise the notice boards at the waiting areas for disseminating relevant information. Information on notice boards are even more beneficial in educating and advertising services than the pamphlets on shelves, because posters are more prominent in capturing clients' attention, especially if they spend only 5 to 10 minutes at the waiting areas. Reader-friendly posters about medical information (HIV, STD, Hepatitis C), guidelines for taking HIV medication, nutrition information, advertisements of HIV-related social support services, or recruitments for clinical trials etc. should be readily available from corresponding organisations or from the NSW Government for display. ASC and other HIV health care facilities can also consider liaising with universities to offer internship projects for medical or public health students, so they have opportunities to design the notice boards. Posters should be changed regularly every 2 or 3 months so that clients who usually have quarterly consultations can receive new information every visit. This can also alleviate the working burden of HCP and health administrators.

HIV-related service advertisements and health promotion posters can also be supplied regularly by HIV health care facilities to gay pubs, parties and sex venues, where homosexuals and sexually active individuals gather. Owners of the venues should be encouraged to display them at their settings to advertise HIV health care services and promote safe sex to PLWHA and people at risk of HIV infection.

In addition to the improvements of the physical environment and basic services, HCP at ASC have room for improvement, even though they have carried out their duties diligently resulting in very high levels of client satisfaction. It has to be remembered that more care fosters improved relationship with clients, promotes continuity, increases clients' adherence to medication, and eventually improves their health outcomes. This can be achieved by inviting clients to discuss treatment plans and including their decisions in treatment, rather than only giving them directives. Although this communication mode may seem to require more time for each consultation, it will save time in the long term, as clients and HCP

increase their understanding of each other and decisions can be made efficiently and appropriately.

After gathering findings from the quantitative survey and qualitative interviews, Table 24 shows a list of aspects that the ASC and its HCP have already been practicing to achieve high satisfaction levels. Health care administrators of other HIV health care facilities can also refer to this list as guidelines and recommendations for improving client satisfaction. It covers the aspects of “interpersonal manner”, “care”, “information provided”, “physical environment”, and “confidentiality/privacy”.

**Table 24** Aspects ASC and HCP already practised and should maintain to sustain client satisfaction

**Interpersonal manner of HCP**

- Greet clients with a smile every time.
- Chat to clients about lives and daily concerns besides HIV treatment.
- Be non-judgmental at all times.

**Care of HCP**

- Have empathy towards clients.
- Try the best to help clients on issues out of responsibility, e.g. referral, written approvals and documents.
- Try to admit clients early if they arrived earlier than the appointed time or if they have not booked a consultation.

**Information provided by HCP**

- Clear explanation of clinical procedures and medical information.
- Try the best in answering any queries raised by clients, and looking for alternatives if the question is not solved.

**Physical environment**

- Provision of magazines for clients in general and local gay papers at waiting area.
- Fish tank and potted plants at the waiting area.

**Confidentiality and privacy**

- HCP maintain discretion in handling confidentiality.
- Physical structures which enable clients to have more privacy, e.g. glass screens separating the waiting area and the reception.



HCP should greet clients with a smile, be non-judgmental, clarify any clients' uncertainties, and maintain discretion in handling confidentiality at all times. Findings of this research reflect that small gestures can mean a lot to clients. For example, asking clients about their lives and daily concerns besides discussing HIV treatment; offering services not clinically-related such as arranging an interpreter, writing letters of recommendation or testimony if clients need to apply for financial or legal assistance; and providing early consultations if clients arrive earlier than the appointed time, or even if they have not booked for a consultation. Furthermore, glass screens separating the waiting area and the reception area provide a certain level of privacy, while provision of a fish tank at the waiting area helps clients feel more relaxed while waiting for consultations.

Table 25 presents a list of aspects which HIV health care decision makers should consider before choosing a site to establish an ambulatory HIV health care facility. It covers the aspects in "accessibility/convenience", "physical environment", and "availability". Since large-scale alterations are required, it will be unrealistic for ASC or other already established health care facilities to change these aspects even if dissatisfaction exists. However, for those who are responsible for establishing a new HIV health care facility, such guidelines should prove useful.

**Table 25** Aspects to consider when establishing a new HIV health care facility

Aspect	Improvement	Justification
<b>Accessibility/convenience</b>		
Location	<p>Close to public transport routes as possible.</p> <p>Have parking facilities nearby.</p>	<p>Accessibility is directly related to satisfaction and clients with limited locomotion can also have access to services. This reduces the chance of having unmet needs. (Ware et al. 1983; Sitzia and Wood 1997)</p>
<b>Physical environment</b>		
Spatial layout of waiting area	<p>Large enough to accommodate the increasing number of clients.</p> <p>Chairs comfortable and with armrests.</p> <p>Arrange the layout of chairs and waiting area in a way that people from outside cannot look into the clinic.</p>	<p>Clients will not feel over-crowded and do not need to stand up while waiting. A crowded environment deprives clients of the privacy they deserve.</p> <p>A more comfortable environment decreases clients' perception of waiting time.</p>
Layout of consultation rooms	<p>Separate rooms by solid walls and not by curtains.</p>	<p>Clients perceive a lower sense of privacy if rooms are separated by curtains. (Barlas et al. 2001; Dijkstra et al. 2006)</p>
Windows	<p>Include more windows when designing the clinical building.</p>	<p>Presence of windows with natural view, especially letting sunlight into the building has positive effects on patients and creates better moods. (Beauchemin and Hays 1996; Dijkstra et al. 2006)</p>
Signs	<p>Clear signs such as "Toilets", "Waiting area", "Consultation rooms" should be immediately visible upon entering the building.</p>	<p>This is a basic requirement for every health care facility. Buildings with clear signs are more welcoming. (Jones and Tamari 1997)</p>
Elevators/escalators	<p>Include elevators or escalators when designing the building.</p> <p>Stairs should be avoided.</p>	<p>Disabled HIV clients or those with poor physical health can have access to services more conveniently.</p>
<b>Availability</b>		
Opening hours	<p>Extend clinical and pharmacy opening hours e.g. Tuesdays and Thursdays open till 7pm.</p>	<p>To increase the availability for full-time employed clients who work during office hours.</p>
Specialist HCP	<p>Health administrators liaise with public hospitals for sending more specialists (dermatologists, psychiatrists etc.) to the centre, or to have specialists spending a longer time for each visit at the centre.</p>	<p>Public ambulatory HIV health care facilities such as ASC usually have their own HIV doctors but not specialists, thus having poorer availability. Clients often have to wait for a long time before having their next consultations, or even have to attend other public hospitals for specialist services.</p>

Although “Accessibility/convenience”, “physical environment”, and “availability” were not perceived as the most important determinants of patient satisfaction by the ASC clients, they should not be neglected. Besides locating near the PLWHA population (presumably the homosexual community), the HIV facility should also be as close to public transport routes as possible, e.g. near bus stops and train stations, and should have parking facilities. So for clients who are worried of being stigmatised, those with poor health, or those living far away from the facility can have access to services by various means of transport without difficulty.

In addition, if possible, the size of the waiting area should be larger to accommodate the increasing number of clients. More comfortable chairs should be placed so that HIV clients feel welcomed and do not feel crowded during busy times. Privacy is particularly important in HIV health care facilities as clients are likely to perceive a longer waiting time if the environment is uncomfortable. Furthermore, windows which introduce sunlight into rooms have beneficial effects on clients, including decrease in stress and pain (Dijkstra et al. 2006). The inclusion of elevators or escalators has a similar effect as choosing a good location, as this promotes a convenient and user-friendly environment for clients. Similarly, signage indicating the locations of elevators, toilets, and consultation rooms should be immediately visible upon entering the building (Jones and Tamari 1997). An appropriate architectural design benefits not only clients but also HCP as they can work under a pleasing environment.

A longer than usual opening hours for a few days per week can improve satisfaction with availability, particularly for full-time employed clients. Public ambulatory care facilities are playing more active roles in HIV health care. And since specialists are in short supply and are not stationed at the same clinic permanently like GP, more liaison with public hospitals is necessary to arrange more specialists for longer sessions during each visit at the clinic to meet the increasing demands of clients.

## **5.7 Strengths of using mixed method approach**

The mixed method approach used in this research is superior to the methodologies used in other patient satisfaction studies. Both the quantitative survey and the qualitative interviews serve different purposes at various stages of a client satisfaction research. They can be combined for a beneficial effect.

The quantitative survey has the advantage of quantifying clients' satisfaction and the importance of health care aspects into scores and percentages, which enable easy data administration and clear data display despite the large number of respondents. However, it has the disadvantage of not being able to investigate the reasons for satisfaction and details of clients' encounter with HCP. The qualitative interviews enable clients to act as informants by actively expressing their views. This is essentially exploratory and enables new themes and insights to emerge. However, it has the disadvantages of covering only a small number of participants and having the risk of interviewer bias. Therefore, the two methods are not interchangeable, but rather, complement each other to promote strengths and reduce limitations.

This mixed method approach, also known as triangulation, clarifies ambiguities of the findings of each study, thus increasing the validity and the reliability of this research as a whole. Since the clients might have various reasons for dissatisfaction and different expectations for ASC, the satisfaction study could not be based on the scores and percentages from the quantitative survey alone, but had also to rely on sharing of experiences face-to-face through open-ended interviews. For example, the quantitative survey indicated that the satisfaction levels were low for waiting time and availability of HCP. However, the qualitative interviews showed that the clients were not truly dissatisfied, but only had relatively low expectations of the availability of their HCP, and hence they accepted to wait before consultations. As another example, some recommendations or criticisms were

made by the clients in the open-ended questions of the ASC-CSQ without any justifications, but they were validated through the interviews, where the participants not only gave logical and sensible reasons to support their views, but also suggested feasible recommendations for improvement. Below are some examples which illustrate how using mixed methods can be beneficial.

### **Findings which are congruent in both the quantitative survey and qualitative interviews**

In the quantitative survey, aspects such as “location”, “appointment time”, “attitudes”, and “confidentiality” resulted high satisfaction levels of 91%, 91%, 94%, and 97% respectively. The qualitative interviews also highlighted that the vast majority of participants were able to access the centre on foot or by convenient transportation and with suitable appointment time. Thus, using two methods to assess the satisfaction of the same aspect gives more confidence in the validity and reliability of the findings than only using either method.

### **Findings from the qualitative interviews which explain the findings from the quantitative survey**

In the quantitative survey, 34% and 83% of respondents were satisfied with the aspect “waiting time” and “availability of HCP” respectively. These relatively low satisfaction levels were specifically investigated during the qualitative interviews, in which the participants explained that they “accepted” the reality to wait before consultations and poor availability of HCP at times, since they have relatively low expectations for the free services provided.

### **Findings from the qualitative interviews which add knowledge to the findings from the quantitative survey**

In the quantitative survey, respondents were limited to rating their satisfaction towards the physical environment and only statistical data were produced. Although some comments regarding physical environment were provided in response to the two open-ended questions,

they were suggestions only and not the reasons to justify their satisfaction ratings. In the qualitative interviews, participants provided some insights for being satisfied (or less satisfied) with the physical environment. This provided a logical reasoning for the improvements respondents/participants suggested in both the open-ended questions and in the interviews.

### **Unique findings from each Phase**

The need for more information provided in the waiting area targeting heterosexual clients was raised by participants in the qualitative interviews but not in the quantitative survey, because the ASC-CSQ did not specifically ask the respondents to rate this aspect. Furthermore, although the ASC-CSQ asked the respondents to rate the importance of attitudes of HCP in the quantitative survey, new insights were explored in the qualitative interviews, such as the importance of “rapport and care” and “provision of a broad range of services at one setting”. Similarly, while the qualitative interviews did not show the trends of satisfaction level in a client group of a certain characteristic, the quantitative survey was able to show statistically that clients of negative HIV status were more satisfied than those with positive HIV status, and that clients who visited the Centre less frequently were more satisfied than those visited more frequently.

To date, few patient satisfaction studies have been conducted using the mixed method approach with equal emphasis given to both the quantitative and qualitative methods. The majority of previous patient satisfaction studies have used only a structured questionnaire, while others used either interviews or focus groups only. Although some studies included a questionnaire survey and interviews with patients, the interviews were not their main focuses because the purpose of the interviews was only to obtain a collection of ideas for devising the most appropriate questionnaire (Beck et al. 1999; Hekkink et al. 2003; Miles et al. 2003).

The mixed method approach adopted in this research proved to be an efficient and accurate way of researching into a broad range of aspects. Besides assessing satisfaction levels, it also provided opportunities for investigating the cause-and-effect relationship of satisfaction and behaviours, as well as the determinants of satisfaction. The mixed method approach should be promoted more in future patient satisfaction studies so that the scale (number of participants) and the extent (the depth) of the research will not be limiting factors.

## 5.8 Research implications

Six issues have been identified in this research on which future HIV patient satisfaction research should focus on.

1. Previous patient satisfaction studies were mainly conducted in the US. There is ample evidence that more studies and needs analyses should be conducted in the Australian context, especially using a mixed method approach. Therefore two targets for future HIV patient satisfaction research are: to compare the satisfaction levels in HIV health care facilities within Australia, and to compare the satisfaction levels in HIV health care facilities in Australia with those in foreign countries.
2. Longitudinal studies are more valuable in generating conclusive evidence when compared with cross-sectional studies. They can be conducted using the same instrument to assess satisfaction levels regularly, preferably once a year for continuous evaluation. Large-scale evaluations involving a number of facilities in Australia can act as benchmarks for quality care comparisons with foreign countries; whereas small-scale evaluations within a clinic can improve the quality of health care by implementing the recommendations specific for the clinic. However, due to the confidentiality and the risk of exposing identities of clients, it remains a challenge to carry out longitudinal studies on the same group of clients at an HIV health care facility.
3. This research is likely to under-estimate the true levels of dissatisfaction and unmet needs among all HIV affected people, because the sample groups are clients who have been receiving HIV health care services for some time. A more exhaustive in-depth study of dissatisfaction and a detailed needs analysis can be conducted at venues where PLWHA or those at risk of HIV infection gather, for example at gay bars, sex and party venues. It is then possible to track those who left HIV health care facilities



because of dissatisfaction. The reported levels of satisfaction at HIV facilities can be compared with those from discontinuing participants, so that the reasons for dissatisfaction can be more understood. However, due to privacy and stigmatisation issues, recruitment at these venues can be much more difficult than that at HIV health care facilities.

4. Since this research was conducted in only one facility, generalisability can be improved by repeating the study at more ambulatory HIV health care facilities in Sydney or even in NSW. Considering that utilisation of services from HIV specialist GP has been increasing rapidly in this decade, satisfaction studies should be conducted at both public and private facilities, especially to investigate whether the hypothesis “financial aspects affect client expectations and hence, satisfaction levels” raised in this research is correct or not. Comparison of results for public and private facilities will provide valuable information to health administrators of the NSW Government to allocate funds, formulate strategies and policies more appropriately, so that public and private facilities can complement and cooperate with each other to meet the service demands.
5. Although clients are the ultimate service recipients, HCP are the service providers who are equally crucial in health care. HCP have a more global view and are more professional in terms of HIV treatment. Therefore, in addition to clients' views, including views of HIV health care from HCP and health care administrators signifies a more comprehensive and balanced evaluation (Carr 2001). Gap analysis can also be conducted by studying the discrepancies between the perceptions of HCP and clients, so that any misunderstandings between them can be understood fully at a glance. The gap is also an indicator for patient-provider relationships. It was shown that HCP who have more contact with clients perceive the unmet needs of clients better than HCP with less client contact (Ryan 1993).

6. Four research questions are brought up from this research and are worth answering in future patient satisfaction research:
  - i. Does an increase in the length of consultation time decrease clients' perception of waiting time, and hence increase clients' satisfaction with waiting time?
  - ii. The "accessibility/convenience" dimension was found to be the least satisfactory among all other dimensions in this research and in previous studies. Was it because the HCP and the administrative staff tended to neglect this dimension, or because clients had higher expectation of it?
  - iii. Do clients who receive emotional support tend to have higher satisfaction levels with HIV health care services than those who do not?
  - iv. Do clients who are exposed to more information about HIV or availability of HIV services at the waiting area (e.g. in the form of pamphlets, posters on notice boards) have more medical knowledge and higher satisfaction levels?

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## **Appendices (1 to 18)**

## Appendix 1: Photos of the Albion Street Centre



(a) The clinical building of Albion Street Centre



(b) The waiting area beside the reception

**Appendix 1: Photos of the Albion Street Centre (continued)**



(c) Notice boards and the fish tank at the waiting area beside the reception



(d) Reading materials at the waiting area beside the reception

**Appendix 2: The Albion Street Centre-Client Satisfaction Questionnaire (ASC-CSQ)**



**The Albion Street Centre Client Satisfaction Survey**

**SECTION 1: Instructions for completion**

**Please tick the box(es) that best matches your answer. All your information and responses will remain completely confidential and anonymous. There are no right or wrong answers, and your responses will not affect your eligibility to receive services in any way.**

1. I came to the Centre <b>today</b> for the following services (Please tick <b>all</b> responses that apply)	
<input type="checkbox"/> For a regular check up	<input type="checkbox"/> For a particular treatment in ambulatory care
<input type="checkbox"/> To obtain a prescription	<input type="checkbox"/> To obtain test results
<input type="checkbox"/> To have a sexual health check-up	<input type="checkbox"/> For an HIV blood test
<input type="checkbox"/> For psychological counselling	<input type="checkbox"/> For a clinical trials research visit
<input type="checkbox"/> For nutritional counselling	<input type="checkbox"/> Pick up medication from pharmacy
<input type="checkbox"/> Others (Please specify): _____	

2. Who did you consult <b>today</b> ? (Please tick <b>all</b> responses that apply)					
<input type="checkbox"/> Doctor	<input type="checkbox"/> Nurse	<input type="checkbox"/> Psychologist	<input type="checkbox"/> Nutritionist	<input type="checkbox"/> Pharmacist	<input type="checkbox"/> Researcher

3. How long have you been a client of this Centre?	
<input type="checkbox"/> This is my first visit (Please go to <b>Question 7</b> )	Months _____ or Years _____

4. How often do you come to this Centre for services?				
<input type="checkbox"/> Weekly	<input type="checkbox"/> Monthly	<input type="checkbox"/> Quarterly	<input type="checkbox"/> 6 monthly	<input type="checkbox"/> Once a year or longer

5. When was your last visit?	
<input type="checkbox"/> Less than 1 month ago	<input type="checkbox"/> 2-6 months ago
<input type="checkbox"/> 7-12 months ago	<input type="checkbox"/> More than 1 year ago

6. Who have you consulted in the <b>past 6 months</b> ? (Please tick <b>all</b> responses that apply)					
<input type="checkbox"/> Doctors	<input type="checkbox"/> Nurses	<input type="checkbox"/> Psychologists	<input type="checkbox"/> Nutritionists	<input type="checkbox"/> Pharmacists	<input type="checkbox"/> Researchers

7. Are you HIV positive?			
<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't Know	
If <b>Yes</b> , how long have you known of your HIV status?			
Months _____ or Years _____			

8. Are you also accessing other HIV/AIDS health care service(s) elsewhere?	
<input type="checkbox"/> Yes (Please specify): _____	<input type="checkbox"/> No

**Appendix 2: The Albion Street Centre-Client Satisfaction Questionnaire (ASC-CSQ)**  
(continued)

**SECTION 2: Client Satisfaction Inventory**

*Questions 9-33 are some statements about the overall services in this Centre. Please answer each item carefully and accurately by placing a number beside each one as follows:*

<b>1=None of the time</b>	<b>2=Very rarely</b>	<b>3=A little of the time</b>	<b>4=Some of the time</b>
<b>5=A good part of the time</b>	<b>6=Most of the time</b>	<b>7=All of the time</b>	<b>X=Does not apply</b>

9. The services I get here are a big help to me	_____
10. People here really seem to care about me	_____
11. I would come back here if I need help again	_____
12. I feel that no one here really listens to me	_____
13. People here treat me like a person, not like a number	_____
14. I have learnt a lot here about how to deal with my problems	_____
15. People here want to do things their way, instead of helping me find my way	_____
16. I would recommend this place to people I care about	_____
17. People here really know what they are doing	_____
18. I get the kind of help here that I really need	_____
19. People here accept me for who I am	_____
20. I feel much better now than when I first came here	_____
21. I thought no one could help me until I came here	_____
22. The help I get here is really worth what it costs	_____
23. People here put my needs ahead of their needs	_____
24. People here put me down when I disagree with them	_____
25. The biggest help I get here is learning how to help myself	_____
26. People here are just trying to get rid of me	_____
27. People who know me say this place has made a positive change in me	_____
28. People here have shown me how to get help from other places	_____
29. People here seem to understand how I feel	_____
30. People here are only concerned about getting paid	_____
31. I feel I can really talk to people here	_____
32. The help I get here is better than I expected	_____
33. I look forward to the sessions I have with people here	_____



**Appendix 2: The Albion Street Centre-Client Satisfaction Questionnaire (ASC-CSQ)**  
(continued)

**SECTION 3:**

***Below are some statements concerning the different healthcare workers in this Centre. Please answer the questions based on your experiences within the past 6 months. If you have not consulted a certain healthcare worker in the past 6 months, tick “Does not apply”.***

<b>34. Within the past 6 months, I was unable to see the <u>healthcare workers</u> of my choice as they were away or unavailable</b>						
	Never	Rarely	Sometimes	Most Times	All of the Time	Does not apply
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>This issue is important to me</b>	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Neither agree or disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Does not apply

<b>35. Within the past 6 months, I did not have to wait long to see the <u>healthcare workers</u></b>						
	Never	Rarely	Sometimes	Most Times	All of the Time	Does not apply
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receptionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>This issue is important to me</b>	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Neither agree or disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Does not apply

<b>36. Within the past 6 months, the <u>healthcare workers</u> were polite, friendly and respectful</b>						
	Never	Rarely	Sometimes	Most Times	All of the Time	Does not apply
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receptionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>This issue is important to me</b>	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Neither agree or disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Does not apply

**Appendix 2: The Albion Street Centre-Client Satisfaction Questionnaire (ASC-CSQ)**  
(continued)

<b>37. Within the past 6 months, the healthcare workers appeared to have good knowledge of their fields</b>						
	Never	Rarely	Sometimes	Most Times	All of the Time	Does not apply
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receptionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>This issue is important to me</b>	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Neither agree or disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Does not apply

<b>38. Within the past 6 months, the <u>healthcare workers</u> understood my needs</b>						
	Never	Rarely	Sometimes	Most Times	All of the Time	Does not apply
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receptionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>This issue is important to me</b>	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Neither agree or disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Does not apply

<b>39. Within the past 6 months, I felt the consultation time with the <u>healthcare workers</u> was too short</b>						
	Never	Rarely	Sometimes	Most Times	All of the Time	Does not apply
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>This issue is important to me</b>	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Neither agree or disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Does not apply

**Appendix 2: The Albion Street Centre-Client Satisfaction Questionnaire (ASC-CSQ)**  
(continued)

<b>40. Within the past 6 months, I was given sufficient information from the <u>healthcare workers</u></b>						
	Never	Rarely	Sometimes	Most Times	All of the Time	Does not apply
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receptionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>This issue is important to me</b>	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Neither agree or disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Does not apply

<b>41. Within the past 6 months, I feel that the <u>healthcare workers</u> included me in decisions about my treatment</b>						
	Never	Rarely	Sometimes	Most Times	All of the Time	Does not apply
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>This issue is important to me</b>	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Neither agree or disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Does not apply

<b>42. Within the past 6 months, I benefited more than expected from the <u>healthcare workers</u></b>						
	Never	Rarely	Sometimes	Most Times	All of the Time	Does not apply
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>This issue is important to me</b>	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Neither agree or disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Does not apply

**Appendix 2: The Albion Street Centre-Client Satisfaction Questionnaire (ASC-CSQ)**  
(continued)

43. Within the past 6 months, the <u>healthcare workers</u> were interrupted during my consultation e.g. phone calls etc						
	Never	Rarely	Sometimes	Most Times	All of the Time	Does not apply
Doctors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nutritionists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Researchers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>This issue is important to me</b>	<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Neither agree or disagree	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Does not apply

**Below are some statements about the environment and overall services in this Centre. Please answer the questions based on your experiences within the past 6 months and tick only the box that best matches your opinion.**

Within the past 6 months,	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
44. The appointment time given was convenient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. I was able to get to this Centre easily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. The waiting areas are physically comfortable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. I believe the waiting areas are managed effectively by the staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. I believe the staff keep my information totally confidential	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. I have been satisfied with the services at this Centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**50. How do you think the Albion Street Centre could improve?  
(Your comments are really valuable to us)**

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**Appendix 2: The Albion Street Centre-Client Satisfaction Questionnaire (ASC-CSQ)**  
(continued)

**SECTION 4:**

***Below are some questions about your background which are being asked to make sure we are hearing from clients from a wide range of backgrounds. Please tick only one box for each question.***

51. What is your background?			
<input type="checkbox"/> Australian	<input type="checkbox"/> Pacific Islander	<input type="checkbox"/> American	<input type="checkbox"/> Asian
<input type="checkbox"/> African	<input type="checkbox"/> European	<input type="checkbox"/> Others (Please specify): _____	

52. Do you identify as an Australian Aboriginal / Torres Strait Islander?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
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53. What is your gender?	<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> Transgender
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54. What is your age?	____yrs
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55. What is the highest level of education you have completed?		
<input type="checkbox"/> Primary	<input type="checkbox"/> Secondary (to Year 10)	<input type="checkbox"/> Secondary (to Year 12)
<input type="checkbox"/> Vocational (e.g. TAFE, technical college)		<input type="checkbox"/> University

56. What is your current employment status?		
<input type="checkbox"/> Full time	<input type="checkbox"/> Part time/Casual	<input type="checkbox"/> Student
<input type="checkbox"/> Retired (self-funded)	<input type="checkbox"/> Retired (receive pension)	<input type="checkbox"/> Unemployed

57. Do you have any of the following?	
<input type="checkbox"/> Health Care card	<input type="checkbox"/> Pensioner Concession card
<input type="checkbox"/> Commonwealth Seniors Health card	<input type="checkbox"/> Department Veterans Affairs card
<input type="checkbox"/> None of the above	

58. Which group do you most identify with?			
<input type="checkbox"/> Gay	<input type="checkbox"/> Lesbian	<input type="checkbox"/> Bisexual	<input type="checkbox"/> Heterosexual
<input type="checkbox"/> Men who have sex with men (MSM)		<input type="checkbox"/> Other (Please specify): _____	

59. What could be your main risk factor for HIV infection?	
<input type="checkbox"/> Unprotected intercourse	<input type="checkbox"/> Occupational exposure
<input type="checkbox"/> Injecting drug use	<input type="checkbox"/> Others (Please specify): _____

**Appendix 2: The Albion Street Centre-Client Satisfaction Questionnaire (ASC-CSQ)**  
(continued)

**SECTION 5: Marlowe-Crowne 2(10) Scale**

*Questions 60-69 are a number of statements concerning personal attitudes. Read each item and decide whether the statement is true or false as it relates to you personally.*

60. I never hesitate to go out of my way to help someone in trouble	<input type="checkbox"/> True	<input type="checkbox"/> False
61. I have never intensely disliked anyone	<input type="checkbox"/> True	<input type="checkbox"/> False
62. There have been times when I was quite jealous of the good fortune of others	<input type="checkbox"/> True	<input type="checkbox"/> False
63. I would never think of letting someone else be punished for my wrong doings	<input type="checkbox"/> True	<input type="checkbox"/> False
64. I sometimes feel resentful when I don't get my way	<input type="checkbox"/> True	<input type="checkbox"/> False
65. There have been times when I felt like rebelling against people in authority even though I knew they were right	<input type="checkbox"/> True	<input type="checkbox"/> False
66. I am always courteous, even to people who are disagreeable	<input type="checkbox"/> True	<input type="checkbox"/> False
67. When I don't know something I don't at all mind admitting it	<input type="checkbox"/> True	<input type="checkbox"/> False
68. I can remember "playing sick" to get out of something	<input type="checkbox"/> True	<input type="checkbox"/> False
69. I am sometimes irritated by people who ask favours of me	<input type="checkbox"/> True	<input type="checkbox"/> False

70. Is there anything else you would like to tell us about the Centre and our service or staff?  
(Your comments are really valuable to us)

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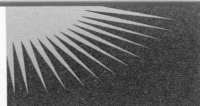
*This is the end of the questionnaire.*

**Thank you** for taking the time to complete this survey.

*When you are finished,  
please return this questionnaire to the box located at the reception.*

**Appendix 3: South Eastern Sydney and Illawarra Area Health Service (SESIAHS) Human Research Ethics Committee (HREC) Approval Letter for conducting the Quantitative survey**

Note: The recipient of this letter (Rachel Musson) was a staff member at ASC. The ethics approval was applied through ASC.



**SOUTH EAST HEALTH**

South Eastern Sydney Area Health Service

**HUMAN RESEARCH ETHICS COMMITTEE - Northern Network**

Room G71, EBB  
Cnr High & Avoca Strs  
RANDWICK NSW 2031  
Tel: 9382 3587  
Fax: 9382 2813

6 June 2007

Ms. Rachel Musson  
Albion Street Centre  
150 Albion Street  
Surry Hills NSW 2010

Dear Rachel

**RE: Albion Street: Client Satisfaction Survey. Our Reference: 07/160.**

The Human Research Ethics Committee is in receipt of your application seeking ethics approval for the above project.

Following consideration Executive approval was given on 6 June 2007 for this project to be conducted at the Albion Street Centre.

This interim decision will be placed before the full Committee for Ratification at the next meeting on 26 June 2007.

This project has been given the reference number: **QA 07/160** Please quote this number in all correspondence with the Committee.

**Approval has been granted for this project to commence. Approval has been given for 5 years.**

Please note that any approval, relates to the ethical content of the trial, and individual arrangements should be negotiated with the Heads of Departments in those situations where the use of their resources is involved.

Yours sincerely

**Kim Breheny**  
Executive Officer  
Human Research Ethics Committee – Northern Section

## Appendix 4: Participant Information Statement for the Quantitative survey



# **Client Satisfaction Survey** **Service at Albion Street Centre 2007**

## **INFORMATION FOR PARTICIPANTS**

There are now about 9,933 people in New South Wales who are living with HIV/AIDS. As Australia's largest HIV/AIDS ambulatory care centre, the Albion Street Centre (ASC) plays a crucial role in contributing to quality of life among people living with HIV/AIDS and strives to provide high quality services to our clients.

The ASC wants to find out what **our clients** think about our services, so we can improve them if required. Therefore we have developed a client satisfaction survey. Participants will be asked to complete a questionnaire regarding their visits to the Centre, attitudes towards services they receive and some background and psychosocial information.

### **Is it compulsory to take part in the survey?**

Clients' participation is completely voluntary and it is possible to refuse to participate or withdraw from the survey at anytime without affecting the services they receive at the Centre.

### **Will the data be identifiable?**

No identifiable information will be collected in the survey. All information, including personal information, will remain confidential, anonymous and unidentifiable. No individual participant information will be identified in any findings published from this activity.

### **Will the results of the survey be released to the clients?**

It is expected that results of the survey will be available at the beginning of August. A short summary of the results of the survey will be posted on the notice board for clients in the main waiting area of the clinic throughout August.

### **Benefits and risks of participation**

There will be no risks to participation. We cannot, and do not, claim that you will obtain any benefit by participating in this survey, however it is an opportunity to express your opinion of the service you are currently receiving, and we would very much appreciate your involvement.

When you have read this information and if you have any further queries, please do not hesitate to contact Ms Rachel Musson (Senior Project Coordinator) at the Albion Street Centre at (02) 9332-9697 on Tue, Wed or Thur 9am to 5pm, or Ms Maria Chow at the Albion Street Centre at 9332-9723 on Wed or Fri 9am to 5pm.

Any person with concerns or complaints about the conduct of the survey can contact the Executive Officer, South Eastern Sydney and Illawarra Area Health Service Research Ethics Committee at (02) 9382 3587 or email [kim.breheny@sesiahs.health.nsw.gov.au](mailto:kim.breheny@sesiahs.health.nsw.gov.au)



## **Appendix 5: Verbal preamble for the Quantitative survey**

### **Verbal Preamble for recruitment of subjects for the Client Satisfaction Survey**

**Staff:** Good Morning! My name is [name of researcher] and I work here in the Albion Street Centre. We are interested in knowing if you are satisfied with the quality of the services you received here, so that we can improve in the future. So do you mind spending about 5 to 10 minutes helping us to fill out a questionnaire?

**Client:** Sure!

**Staff:** Thank you. Let me explain a little bit about how to complete the questionnaire. For question 6, for example if you have only consulted doctors and nurses in the past 6 months, you only need to tick the boxes here (flip to Section 3) corresponding to the doctor's and nurse's rows. For others you have not consulted, just tick "does not apply". But remember to tick the boxes for "receptionists". All your answers are kept confidential. After you have finished, just put it into the brown box over there (point to the client satisfaction survey collection box).

**Appendix 6:** Ranking of individual aspects in descending order of satisfaction for each HCP category

(a) Nurses (b) Psychologists

(a) NURSES				
Aspects		Number of dissatisfied respondents (%)	Number of satisfied respondents (%)	Mean satisfaction score
Knowledge of HCP	(N=117)	0 (0)	115 (98)	4.82
HCP understood clients' needs	(N=114)	1 (1)	110 (97)	4.74
Attitude of HCP	(N=117)	2 (2)	112 (96)	4.78
Information given during consultation	(N=112)	5 (5)	105 (94)	4.61
Included clients' decision in treatment	(N=105)	3 (3)	97 (92)	4.60
Length of consultation time	(N=109)	2 (2)	100 (92)	4.61
Availability of HCP	(N=93)	3 (3)	85 (91)	4.59
Uninterrupted consultation	(N=117)	1 (1)	106 (91)	4.58
Benefit more than expected	(N=104)	8 (8)	81 (78)	4.12
Waiting time before consultation	(N=112)	55 (50)	39 (35)	2.79
	Mean	(7.3%)	(86.3%)	4.42

(b) PSYCHOLOGISTS				
Aspects		Number of dissatisfied respondents (%)	Number of satisfied respondents (%)	Mean satisfaction score
Attitude of HCP	(N=41)	1 (2)	40 (98)	4.88
Knowledge of HCP	(N=41)	2 (5)	38 (93)	4.68
HCP understood clients' needs	(N=41)	2 (5)	38 (93)	4.63
Information given during consultation	(N=41)	4 (10)	37 (90)	4.51
Uninterrupted consultation	(N=40)	3 (8)	36 (90)	4.46
Included clients' decision in treatment	(N=35)	3 (9)	30 (86)	4.51
Benefit more than expected	(N=40)	3 (8)	34 (85)	4.25
Availability of HCP	(N=34)	4 (12)	28 (82)	4.21
Length of consultation time	(N=38)	3 (8)	31 (82)	4.42
Waiting time before consultation	(N=38)	20 (53)	14 (37)	2.82
	Mean	(11.8%)	(83.5%)	4.34

**Appendix 6:** Ranking of individual aspects in descending order of satisfaction for each HCP category (continued)

(c) Doctors (d) Pharmacists

(c) DOCTORS				
Aspects		Number of dissatisfied respondents (%)	Number of satisfied respondents (%)	Mean satisfaction score
Knowledge of HCP	(N=128)	0 (0)	128 (100)	4.86
Attitude of HCP	(N=128)	1 (1)	125 (98)	4.84
HCP understood clients' needs	(N=126)	0 (0)	120 (95)	4.72
Included clients' decision in treatment	(N=121)	3 (3)	113 (93)	4.65
Information given during consultation	(N=125)	5 (4)	116 (93)	4.63
Length of consultation time	(N=121)	5 (4)	99 (82)	4.36
Uninterrupted consultation	(N=126)	5 (4)	103 (82)	4.28
Benefit more than expected	(N=116)	7 (6)	92 (79)	4.19
Availability of HCP	(N=114)	5 (4)	83 (73)	4.14
Waiting time before consultation	(N=121)	53 (44)	45 (37)	2.90
	Mean	(7.0%)	(83.2%)	4.36

(d) PHARMACISTS				
Aspects		Number of dissatisfied respondents (%)	Number of satisfied respondents (%)	Mean satisfaction score
HCP understood clients' needs	(N=55)	0 (0)	55 (100)	4.82
Knowledge of HCP	(N=56)	0 (0)	55 (98)	4.88
Attitude of HCP	(N=55)	2 (4)	52 (95)	4.76
Information given during consultation	(N=53)	1 (2)	50 (94)	4.72
Included clients' decision in treatment	(N=45)	4 (9)	40 (89)	4.49
Length of consultation time	(N=51)	3 (6)	44 (86)	4.51
Benefit more than expected	(N=46)	5 (11)	35 (76)	4.02
Uninterrupted consultation	(N=49)	4 (8)	37 (76)	4.02
Waiting time before consultation	(N=54)	25 (46)	19 (35)	2.83
	Mean	(9.5%)	(83.2%)	4.34

**Appendix 6: Ranking of individual aspects in descending order of satisfaction for each HCP category (continued)**

(e) Receptionists (f) Nutritionists

(e) RECEPTIONISTS				
Aspects		Number of dissatisfied respondents (%)	Number of satisfied respondents (%)	Mean satisfaction score
Attitude of HCP	(N=103)	2 (2)	96 (93)	4.70
HCP understood clients' needs	(N=92)	3 (3)	85 (92)	4.67
Knowledge of HCP	(N=102)	2 (2)	94 (92)	4.62
Information given during consultation	(N=92)	5 (5)	84 (91)	4.58
Waiting time before consultation	(N=91)	56 (62)	30 (33)	2.51
	Mean	(14.8%)	(80.4%)	4.22

(f) NUTRITIONISTS				
Aspects		Number of dissatisfied respondents (%)	Number of satisfied respondents (%)	Mean satisfaction score
Knowledge of HCP	(N=14)	0 (0)	13 (93)	4.57
Included clients' decision in treatment	(N=14)	0 (0)	12 (86)	4.57
HCP understood clients' needs	(N=14)	0 (0)	12 (86)	4.50
Attitude of HCP	(N=14)	2 (14)	12 (86)	4.43
Availability of HCP	(N=12)	2 (17)	10 (83)	4.17
Length of consultation time	(N=14)	1 (7)	11 (79)	4.36
Information given during consultation	(N=14)	2 (14)	11 (79)	4.14
Benefit more than expected	(N=13)	0 (0)	10 (77)	4.15
Uninterrupted consultation	(N=13)	1 (8)	10 (77)	4.23
Waiting time before consultation	(N=14)	9 (64)	4 (29)	2.57
	Mean	(12.4%)	(77.3%)	4.17

## Appendix 7: Comments of the open-ended questions in the ASC-CSQ

### Negative comments

#### Interpersonal manner

- Get rid of the mean nurse [description of the nurse]
- By your admin staff recognising its not about them here Albion St! By the end of my visit I have come to the conclusion that the poofs who work here are just rude!
- Manage patients rather than just treat them
- By not being judgemental towards users that also use the service.
- Nurse was a bit rude
- Your chap on reception [description of the receptionist] should be asked to at least acknowledge a client when they come through the door instead of ignoring them to stare at the computer screen, he makes the environment even more intimidating than it already is! Sorry 4-this comment!

#### Availability

- More doctors and nurses, particularly for STI screens
- Availability of more doctors to avoid waiting too long
- When get the result I need more checkup like in Brisbane
- Overall I think this is service is fantastic. The only thing that I could say is maybe a few more things magazines/ articles about Hep C (which is what I have). But I would thank everyone here for there help.
- I have suffered from depression for most of the last 20 yrs (pre HIV) and really feel mental health and HIV patients need a lot more services and DR's
- need more Aboriginal people in the service delivery mode.

#### Physical environment

- Inclination or elevator joining floors as the stairs are steep. No good for people in wheel chair or on walking stick into peripheral neuropathy.
- Services excellent—a bit of a refurb would be nice!
- Modernize waiting room—very 70's needs a more today look
- More privacy in reception and waiting areas.
- New paint job, new air-conditioning for summer!
- Yes better building more space.
- Make a separation between drug-using patients and general health patients.
- Coffee and tea and maybe biscuits (for after blood tests especially).

## Appendix 7: Comments of the open-ended questions in the ASC-CSQ (continued)

- Jelly beans after giving blood for being good  
Tissues in waiting area  
Overall very happy
- Bring back the coffee and tea in the waiting room please.
- Sometimes the telephones/switchboard can get busy.
- Reintroduce tea/coffee at reception please; online service with availability and information for all services of other extra services.
- Tea and coffee facilities in the waiting room. All and all very high levels of services. Thank you.
- Tea or coffee facilities have been. When coming here it is an effort for most patients and hot beverages are most welcome.
- Give more funding (I miss the biscuits with coffee).

### Accessibility/ convenience

- Allow easy procedure for medications to be pre-ordered. Script can be ready from previous visit and filled after making a phone call saying you will be visiting the clinic to pick up medications.
- Keep waiting times to a minimum.
- Open in the evenings/weekends.
- Late hours or weekends for people who are working.
- Buy [name of a HCP at ASC] a watch.
- Improve waiting between DR and nurse (bloods etc).
- To ensure that the people here are here specifically for HIV treatment not street people and use these services here for medical treatments.
- I did wait a while the first time for consultation.
- Consider full time workers who have job commitments—we cannot make appointments when you want them.
- Later hours a couple of times during the week.
- Some casual for peak work hours in the pharmacy.
- Shorten waiting time.
- Reduce waiting times; have more funding from POWH for more modern facilities.
- Shorter initial waiting times to see health professionals; more health professionals; bigger government expenditure on HIV +mental and drug related care here.
- I have needed to see dermatologist on a few occasions and have had to have time off work, as I need to make an appointment with dietitian but find it difficult to coordinate due to limited times of these two specialists.

## Appendix 7: Comments of the open-ended questions in the ASC-CSQ (continued)

### Suggestion for services

- As I am on a low wage I would greatly appreciate a GP service while the centre is open instead of seeing the specialist, with Bulk Billing available.
- Dating service.
- Being able to do simple dermatology procedures on-site.
- Maybe to suggest or inform on what other services are available here and at other organisations. E.g. ACON; e.g. legal rights when applying for a job—blood test can only be taken if consent taken.

### Positive comments

#### Technical quality

- I think its very professional as it is!
- I would not be able suggest as everything is fine. Please don't change anything.
- [Name of a HCP at ASC] is one of the most professional and helpful and communicative doctors I have ever dealt with here or in London! Although (selfishly) he tends to go away quite a bit with international jobs which means there can be some delays in getting to see him!
- The centre has been one of the most valuable resources in my life to date. I am very grateful to everybody here especially to [names of 2 HCP at ASC] who do a fantastically professional job.

#### Interpersonal manner

- I was really surprised how nice everyone is.
- Keep up doing your good job already, I like it, all of you very nice.
- I like the centre and the wonderful service during 20 years. I strongly agree is one of a kind and the personnel is great make my life better.
- I am extremely happy with the wonderful people and feel at home when I come here. Keep up the good work.
- Keep going! Very helpful, with a very good listening.
- You are very helpful and courteous, don't change the format you work too!
- Thank you for such good service and courteous staff.
- Felt very comfortable and knowing can ask any questions that may arise about my treatment.
- The staff are very friendly and very nice to talk to. Keep up the good work!
- The staff they are very good friendly.

## Appendix 7: Comments of the open-ended questions in the ASC-CSQ (continued)

- Staff are excellent, new staff are well trained, all staff are knowledgeable and polite, if they weren't I wouldn't still come here after over 21 years!
- Staff are friendly and supportive—excellent.
- The staff are consistently courteous and helpful given the extremes of character and the emotional distress of their client base.
- I think the staff from reception, right through the whole of the centre is friendly, well informed and professional and caring!
- Excellent, friendly.

### Efficacy/ outcomes

- Thankyou for 20 years of wonderful service is has been great to help my quality of life As a first time visitor to your clinic, I was very impressed by your service, staff and facilities offered.
- I believe the centre is a brilliant health service provider, it believes in discretion and confidentiality and the staff are all human in their approach.
- This service is invaluable in promoting awareness of sexual health and related issues.
- Life saving. Forever grateful. Top people for the last 11 years of visiting clinic.
- The Albion St clinic is like a sanctuary for us (clients) in times of bad mental and physical health. It is great!

### Other positive comments:

- Happy with conditions here and happy with the staff etc.
- Just keep up the good work they are already doing.
- Doing great keep up the good work and keep smiling.
- How could you improve perfection?
- I can't think of any improvements. As the old saying goes, "if something works, don't fix it!!"
- Quite satisfied with it as it is.
- It's a great service.
- I think they do a good job.
- I really appreciate the workers and service received here.
- Continued support.
- Great work.
- All staff are great!
- Excellent staff members all round.
- Fantastic service am very happy here!
- Keep up your good work, love all of it.



## Appendix 7: Comments of the open-ended questions in the ASC-CSQ (continued)

- Keep the good work!
- I think you do an amazing job helping others. Your services are important and vital. Thankyou all for your generosity and help.
- Great work.
- The staff are great, thank you.
- Great service, should be more clinics like this one.
- Thanks for putting up with my erratic behaviours—it takes two to Tango!
- The centre is very good, your question form is to long, to complete it took me half hour.
- Keep up the good work. Just remember we all have bad days.
- Wonderful.
- Once again thanks to everyone at the centre for your help and concern.
- Its invaluable. Its great. Its fantastic.
- Thankyou.

### Others

- Some of these questions were really stupid or badly worded. Quite a lazy survey really!
- In Brisbane the best.
- As pushed as the wonderful DR's and staff are here at Albion St, we really need more! My personal view of the psychologist is very poor, this REALLY needs improvement!!
- Remaining with the psychologist of my choice was very disconcerting after not seeing him for some time. I was told I would have to see someone else as it had been quite a while. This was upsetting especially at the time when you need to vent your concerns/ problems even more so when you have no one else to talk to on serious personal issues.
- Psychologists can be a bit confronting as some of them have pre-conceived ideas.
- You could have social groups that other positive guys can meet.
- If they were paid more money. Everyone here is exceptional.
- More pay for staff and funding.

## Appendix 8: Interview guide for the Qualitative interviews



The University of Sydney



ALBION STREET CENTRE

### Interview Topic list

1. Did you participate the client satisfaction survey or not? (Self-reported questionnaire done in early July)
  
2. Satisfaction towards the **overall environment and services**
  - **Location**
  - **Time**
  - **Physical environment**
  - **Basic services**
  
3. In the past 12 months, did you need the following **health care services**?
  - Regular/sexual health check up
  - Obtain a prescription from a doctor
  - HIV blood test
  - For a particular treatment in ambulatory care (e.g. to see a dermatologist, vaccination etc.)
  - Psychological counseling
  - Nutritional counseling
  - Pick up medication from pharmacy
  - Clinical trials research visit

Did you receive all the health care services you needed?  
If not, which types of services did you not receive and why?

4. Have you seen the following **health care providers (HCP)** in the past 12 months?
  - Doctors
  - Nurses
  - Psychologists
  - Nutritionists
  - Pharmacists
  - Researchers
  - Receptionists

For each of the HCP you have seen, what do you think of their.....(ask the following aspects for each HCP they have seen)

- **Sufficient information given throughout the consultation**
- **Attitudes**
- **Availability**
- **Quality of medical treatment**
- **Any services which you needed but is not available in this Centre**

**Appendix 9: The University of Sydney Human Research Ethics Committee (HREC)**  
Approval letter for conducting the Qualitative interviews



The University of Sydney

NSW 2006 Australia

**Human Research Ethics Committee**

[www.usyd.edu.au/ethics/human](http://www.usyd.edu.au/ethics/human)

**Senior Ethics Officer:**

Gail Briody

Telephone: (02) 9351 4811

Facsimile: (02) 9351 6706

Email: [gbriody@usyd.edu.au](mailto:gbriody@usyd.edu.au)

Rooms L4.14 & L6.04 Main Quadrangle A14

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**Human Secretariat**

Telephone: (02) 9036 9309

(02) 9036 9308

Facsimile: (02) 9036 9310

22 November 2007

Associate Professor Susan Quine  
School of Public Health  
Room 311, Edward Ford Building – A27  
The University of Sydney

Dear Professor Quine

Thank you for your correspondence received on 16 November 2007 addressing comments made to you by the Human Research Ethics Committee (HREC). After considering the additional information, the Executive Committee at its meeting on **21 November 2007** approved your protocol entitled **“Clients’ unmet needs identified in HIV/AIDS service”**.

Details of the approval are as follows:

<b>Ref No.:</b>	<b>11-2007/10415</b>
<b>Approval Period:</b>	<b>November 2007 to November 2008</b>
<b>Authorised Personnel:</b>	<b>Associate Professor S Quine</b>
	<b>Dr M Li</b>
	<b>Professor J Gold</b>
	<b>Ms Y K Chow</b>

The HREC is a fully constituted Ethics Committee in accordance with the *National Statement on Ethical Conduct in Research Involving Humans-March 2007* under Section 5.1.29

The approval of this project is **conditional** upon your continuing compliance with the *National Statement on Ethical Conduct in Research Involving Humans*. We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed.

**Chief Investigator / Supervisor’s responsibilities to ensure that:**

- (1) All serious and unexpected adverse events should be reported to the HREC as soon as possible.
- (2) All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.

**Appendix 9: The University of Sydney Human Research Ethics Committee (HREC)  
Approval letter for conducting the Qualitative interviews (continued)**

- (3) The HREC must be notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. These include:-
  - If any of the investigators change or leave the University.
  - Any changes to the Participant Information Statement and/or Consent Form.
- (4) All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The Participant Information Statement and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee and the following statement must appear on the bottom of the Participant Information Statement. *Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, University of Sydney, on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or [gbriody@usyd.edu.au](mailto:gbriody@usyd.edu.au) (Email).*
- (5) Copies of all signed Consent Forms must be retained and made available to the HREC on request.
- (6) It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.
- (7) The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Investigators are requested to submit a progress report annually.
- (8) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely



**Professor D I Cook  
Chairman  
Human Research Ethics Committee**

cc Ms Maria Yui Kwan Chow, 24 Angus Street, Earlwood NSW 2206

Encl.  
Participant Information Statement  
Participant Consent Form

**Appendix 10: South Eastern Sydney and Illawarra Area Health Service (SESIAHS)  
Human Research Ethics Committee (HREC) Approval letter for conducting  
the Qualitative interviews**



**HUMAN RESEARCH ETHICS COMMITTEE – Northern Hospital Network**

Room G71, EBB  
Cnr High & Avoca Strs  
RANDWICK NSW 2031  
Tel: 02-9382 3587  
Fax: 02-9382 2813

14<sup>th</sup> April, 2008

Ms Maria Chow  
24 Angus Street  
Earlwood NSW 2006

Dear Ms Chow,

**Project Title: Clients' Unmet Needs Identified in HIV/AIDS Service**  
**HREC Reference Number: 08/020**

Thank you for submitting the above project for ethical and scientific review. The project was first considered by the HREC, Northern Hospital Network at its meeting held on 25<sup>th</sup> March 2008.

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Research Involving Humans* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

I am pleased to advise that the Committee at a meeting on 25<sup>th</sup> March 2008 has granted ethical approval of the above project to be conducted at Albion Street Centre, Surry Hills.

The following documentation has been reviewed and approved by the HREC:

- NEAF
- PIS & PCF dated 2 April 08.
- Interview questionnaire
- Letter from Professor Gold dated 10/01/08
- Research Protocol dated 06/03/08.
- Letter of approval - Sydney University HREC dated 22/11/07

Please note the following conditions of approval:

1. This approval is valid for five years, and the Committee requires that you furnish it with annual reports on the study's progress beginning in March 2009.
2. The Co-ordinating Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project and any complaints made by study participants regarding the conduct of the study.
3. Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review, in the specified format.

South Eastern Sydney and Illawarra Area Health Service  
Locked Mail Bag 8808 South Coast Mail Centre NSW 2521  
Level 4 Lawson House Wollongong Hospital  
Tel (02) 4253 4882 Fax (02) 4253 4878  
ABN 78 390 886 131

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**Appendix 10: South Eastern Sydney and Illawarra Area Health Service (SESIAHS)  
Human Research Ethics Committee (HREC) Approval letter for conducting  
the Qualitative interviews (continued)**

4. The HREC will be notified, giving reasons, if the project is discontinued before the expected date of completion.
5. The Co-ordinating Investigator will provide a progress report, in the specified format, annually to the HREC as well as at the completion of the study.

HREC approval is valid for 5 years from the date of this letter.

**Optional** Please note it is the responsibility of the sponsor or the principal (or co-ordinating) investigator of the project to register this study on a publicly available online registry (eg Australian Clinical Trial Registry [www.actr.org.au](http://www.actr.org.au)).

**You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained.**

Should you have any queries about your project please contact the Human Research Ethics Secretariat, Research Support Office, tel: 02-9382 3583. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office.

Please quote **HREC Reference Number: 08/020** in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely



**Carmel Edwards  
Acting Executive Officer  
Research Support Office (NHN)  
HREC – NHN**

Cc: A/Prof Susan Quine  
Room 311, Edward Ford Building (A27)  
University of Sydney  
Sydney NSW 2006

## Appendix 11: Participant Information Statement for the Qualitative interviews



The University of Sydney

### School of Public Health

Room 311 Edward Ford Building (A27)  
University of Sydney NSW 2006  
Australia  
Telephone: +61 2 9351 4371  
Facsimile: +61 2 9351 7420  
Email: [sueq@health.usyd.edu.au](mailto:sueq@health.usyd.edu.au)  
Web: <http://www.health.usyd.edu.au>



ALBION STREET CENTRE

150-154 Albion Street  
Surry Hills NSW 2010  
Australia  
Telephone: +61 2 9332 9600  
Facsimile: +61 2 9331 3490  
Web: <http://www.sesahs.nsw.gov.au>

## Clients' unmet needs identified in HIV/AIDS service

### PARTICIPANT INFORMATION STATEMENT

There are now about 9,933 people in New South Wales who are living with HIV/AIDS. As Australia's largest HIV/AIDS ambulatory care centre, the Albion Street Centre (ASC) plays an important role in contributing to quality of life among people living with HIV/AIDS and to provide high quality services to clients.

#### What is the study about?

Early in July 2007, a Client Satisfaction Survey was conducted to assess the satisfaction levels of the clients' who attended ASC. This study is done to further find out whether the health care services provided here fulfil the clients' needs, and to identify whether there are unmet needs.

The results of the study help understanding if there are any service gaps between health care services provided and clients' needs, so that it can **help improving the quality of health care services in the future.**

This study is being conducted by Maria Chow to meet the requirements for the degree Master of Philosophy of medicine under the supervision of Susan Quine (Tel: 9351 4371) and Mu Li (Tel: 9351 5996) of the School of Public Health at the University of Sydney, and Julian Gold from the Albion Street Centre (Tel: 9332 9664).

#### What do I have to do if I agreed to participate?

If you agree to participate in this study, you will be asked to sign 2 participant consent forms, one is for you to keep as record and the other is kept by the researcher.

Then an interview will be conducted at the Albion Street Centre clinic after you have received your health care services today, questions about how you feel and think about the health care services will be asked. The interview will be audio-recorded ONLY if you are willing to. Only the researchers mentioned above can have access to the recording, and it will be destroyed after the study is finished. Some personal information will also be collected by filling in a one-page questionnaire, however the information collected will not be identifiable and it will be kept in a locked room at the School of Public Health, University of Sydney. Only the researchers mentioned above will have access to the information. The overall results of the study may be discussed with staff members of the Albion Street Centre, however, they will not have access to the raw data.

## **Clients' unmet needs identified in HIV/AIDS service**

### **How long will the study take?**

The whole interview will take approximately 20 to 30 minutes.

### **Is it compulsory to take part in the survey?**

Clients' participation is completely voluntary and it is possible to refuse to participate or withdraw from the study at anytime without having to give a reason, the services you receive at the Centre will not be affected and you do not have to bear any consequences. If you withdraw during the study, information collected from you will not be kept and will be destroyed immediately.

### **Will anyone else know the results?**

All aspects of the study, including results, will be strictly confidential and only the researchers mentioned above will have access to information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

### **Are there any benefits and risks of participation?**

There will be no risks to participation. We cannot, and do not, claim that you will obtain any benefit by participating in this study, however it is an opportunity to express your opinion of the services you are currently receiving, and we would very much appreciate your involvement.

### **What if I require further information?**

When you have read this information, Maria Chow will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Maria on 9332 9723. This information statement is for you to keep.

### **What if I have a complaint or concerns?**

Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gbriody@mail.usyd.edu.au (Email).



**Appendix 12: Participant Consent Form for the Qualitative interviews**



**The University of Sydney**



**ALBION STREET CENTRE**

**School of Public Health**  
Room 311 Edward Ford Building (A27)  
University of Sydney NSW 2006  
Australia  
Telephone: +61 2 9351 4371  
Facsimile: +61 2 9351 7420  
Email: sueq@health.usyd.edu.au  
Web: <http://www.health.usyd.edu.au>

150-154 Albion Street  
Surry Hills NSW 2010  
Australia  
Telephone: +61 2 9332 9600  
Facsimile: +61 2 9331 3490  
Web: <http://www.sesahs.nsw.gov.au>

**Clients' unmet needs identified in HIV/AIDS service**

**PARTICIPANT CONSENT FORM**

I,..... , give consent to my participation in the above named research project.

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
3. I understand that the participation is completely voluntary, I can withdraw from the study at any time, without affecting the services I receive in any way.
4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.
5. I understand that I can have the choice of the interview being audio-recorded or not, and only the researchers mentioned in the Participant Information Statement can have access to the recording, and the tapes will be destroyed after the project is completed.

**Signed:** .....

**Name:** .....

**Date:** .....

## **Appendix 13: Verbal Preamble for the Qualitative interviews**

### **Verbal preamble when inviting clients for the qualitative interviews**

Good morning, my name is [name of interviewer] and I'm from the Albion Street Centre. Are you a client here?

The Albion Street Centre and the University of Sydney would like to find out if clients are satisfied with the services provided here, and also to find out if they have any unmet needs about HIV services, so that the centre can improve the quality in the future.

We are now conducting interviews with clients, which is about 20-30 minutes, it's just a casual talk, have a cup of coffee and some biscuits, and I'll ask questions like are you satisfied with the services and the staff, and do you have any needs about HIV services but cannot receive it here, something like that. The interview will be held after you have finished all the services. All your answers will be confidential.

Here is some more information about this interview, and you can have a look first. It tells you what this study is about and what you have to do if you participate.

#### If disagreed to participate

That's alright, no worries. Thank you very much.

#### If agreed to participate

Thanks very much! First I need you to sign up 2 consent forms, which means that you agree to have the interview. It's the same, one is for you to keep and one is for me. Just to remind you that the interviews will be audio-recorded, but it's just because I'm afraid that I don't have enough time to jot down all the notes. Nobody will hear it again except me. (Sign consent forms) Thanks. Could you come and find me after you have finished, I'll wait for you here.

(after consultation, bring the client upstairs to the interview room.)

Here are some biscuits. I'm going to make you a cup of coffee. In the mean time, could you please fill out this questionnaire and seal it into this envelope?

Thank you again for your time. This interview takes about 20-30 minutes and your responses will be confidential and unidentifiable. The interview will be recorded but only me will listen to it, and the recording will be destroyed after this study is finished. Shall we start now?

Appendix 14: Demographic Questionnaire for the Qualitative interviews



The University of Sydney



Clients' unmet needs identified in HIV/AIDS services

Thankyou for taking time to complete the interview. Below are some questions about your background, this is to make sure we hear from clients from a wide range of backgrounds. Please tick the appropriate box(es). All your information will remain completely confidential and anonymous.

71. What is your background?			
<input type="checkbox"/> Australian	<input type="checkbox"/> Pacific Islander	<input type="checkbox"/> American	<input type="checkbox"/> Asian
<input type="checkbox"/> African	<input type="checkbox"/> European	<input type="checkbox"/> Others (Please specify): _____	

72. What is your gender?	<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> Transgender
--------------------------	-------------------------------	---------------------------------	--------------------------------------

73. What is your age?	____yrs
-----------------------	---------

74. What is the highest level of education you have completed?		
<input type="checkbox"/> Primary	<input type="checkbox"/> Secondary (to Year 10)	<input type="checkbox"/> Secondary (to Year 12)
<input type="checkbox"/> Vocational (e.g. TAFE, technical college)		<input type="checkbox"/> University

75. What is your current employment status?		
<input type="checkbox"/> Full time	<input type="checkbox"/> Part time/Casual	<input type="checkbox"/> Student
<input type="checkbox"/> Retired (self-funded)	<input type="checkbox"/> Retired (receive pension)	<input type="checkbox"/> Unemployed

76. Are you HIV positive?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't Know
If Yes, how long have you known of your HIV status?			
Months _____		or	Years _____

77. Which group do you most identify with?			
<input type="checkbox"/> Gay	<input type="checkbox"/> Lesbian	<input type="checkbox"/> Bisexual	<input type="checkbox"/> Heterosexual
<input type="checkbox"/> Men who have sex with men (MSM)		<input type="checkbox"/> Other (Please specify): _____	

78. What was/ could be your main risk factor for HIV infection?	
<input type="checkbox"/> Unprotected intercourse	<input type="checkbox"/> Occupational exposure
<input type="checkbox"/> Injecting drug use	<input type="checkbox"/> Others (Please specify): _____

Thank you for completing the interview and the questionnaire!

## **Appendix 15:** Example of a Personal File for data analysis in the Qualitative interviews

Client 11

Date: 14/4/08 (Mon)

Time: 11:35am-12:05pm (~30 mins), after consultation

Place: Consultation room

C11 delightfully agreed to participate and was very cooperative. He politely refused to have the biscuits and was perfectly fine for recording the interview. Being extremely voluble, he told me he was on and off visiting ASC, but has been coming regularly since 10 years ago.

He stressed the need to have the right HCP that matches the need of clients. If the HCP's provision of services does not meet his need, he cannot trust the HCP and has to find another one. He said it is not the matter of right and wrong, just the matter of match or does not match. C11 seems to have many needs about services and HCP, can I say that he is picky? Maybe it is just that he has his own theory about choosing services and HCP which can deal with his physical and mental health the most efficiently and effectively. He does not conform to HCP assigned to him and he has to find the one who really understands and can give him what he needed. His theory applies more to psychological counselling than to routine clinical treatment, because it involves more "personal" and "emotional" issues. Also, regular checkup is not an issue for him because his physical health is progressing well now. So far, he sounds to me that he has found HCP in ASC who understand his need, and so he has been coming to ASC for a long time.

C11 has so much to talk about that I find it difficult to ask him questions following the interview protocol. He talked much about his perceptions towards health care, his need, and his experience. I therefore let him speak as long as he is not digressing away, guiding him back to the research focus by interrupting at appropriate points, and by asking questions relating back to the research. Nevertheless, it is hard for clients to digress away, because even they talked much about their past experiences that were not in ASC, they were expressing their needs and perceptions towards for HIV health care. Hence, I feel that I could obtain more information from them by letting them express freely rather than to ask them answer questions in a rigid manner.

**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews

Client 19

Date: 30/4/08 (Wednesday)

Time: 11:00-11:30am (~30 mins), after consultation

Place: Consultation room

(HIV+ for 8 years)

New Zealander, Aged 56, University, Full time, Gay, Unprotected intercourse

Note: M=Interviewer, C19=Client 19

Evaluation of interviewing format	Time	Transcription	Summary of client's views
<p>Good to ask the types of services he received in the beginning of the interview</p>	0:00	<p>M: Once again thanks for being interviewed. How long have you been a client here?</p> <p>C19: I think it's about 2000.</p> <p>M: And you're a regular client?</p> <p>C19: Yes.</p> <p>M: Since 2000. How frequent do you come to the Albion Street Centre?</p> <p>C19: It'll be every 3 months.</p> <p>M: So you come here every 3 months for routine checkup.</p> <p>C19: Routine checkups for HIV.</p>	<p>Have been a regular client for 8 years. He comes every month to collection medication and once in 3 months for routine checkup. He sees a counsellor currently (2:00). He saw nutritionists before (17:30)</p>
	0:30	<p>M: Which includes....what kinds of procedures do you need to take?</p> <p>C19: Blood tests, basically.</p> <p>M: And then see the doctor? (C19: yes) And then get the prescriptions...</p> <p>C19: get prescriptions, sorry, yes. I usually come every month for that.</p> <p>M: To get the prescriptions.</p> <p>C19: Yes</p> <p>M: Why is it that frequent? I heard from other clients, they said they come here, like once in 3 months, and then they get medication...</p>	
	1:00	<p>C19: Because I live around the corner, I think that's why. I get a months' supply, and...</p> <p>M: Why don't you just get 3 months?</p>	

**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	<p>1:30</p> <p>2:00</p> <p>2:30</p>	<p>C19: I never, I never thought about it! (M:*laugh*) It's just that I never thought of getting 3 months at a time. I think if I lived a long way I probably would, but because I have 2 minutes walk away, it's no problem for me.</p> <p>M: So you come here every month to get the medication, (C19: just the medication) and then once in every 3 months to do the routine checkup. Do you see a specialist here? Like a dermatologist, get vaccination, something like that?</p> <p>C19: *shook head*</p> <p>M: Never?</p> <p>C19: No. I didn't even know that there were specialists!</p> <p>M: Yes, there is, but they're only available sometimes only once per month, the dermatology or Hep C something like that.</p> <p>C19: I'm not having any need for getting about that.</p> <p>M: Hm...Did you have any psychological counselling or nutritional counselling?</p> <p>C19: Yes. Psychological counselling.</p> <p>M: You're having counselling at the moment.</p> <p>C19: At the moment yeah.</p> <p>M: How long do you usually see the psychologist?</p> <p>C19: You mean how long is a session? Or...</p> <p>M: I mean how frequent.</p> <p>C19: Oh, oh. Once a week. Once a week. Forgot about that, sorry.</p> <p>M: That's alright. So you're been here quite often! You have to get here weekly, and monthly.</p> <p>C19: I had a heart operation...I had a coronary bypass last October...August, and then 4 months later, I had really bad bout of depression, quick bad bout of depression, and that is when I started seeing a psychologist here.</p>	<p>He lives very near here, only 2 minutes walk, so location is not a problem</p> <p>He did not know ASC has specialist because he did not need such service</p> <p>He has been seeing a counsellor for about 5 months after a heart operation last year. His depression was not related to HIV, but ASC still admit him as a client</p>

**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	<p>3:00</p> <p>3:30</p> <p>4:00</p> <p>4:30</p>	<p>M: So it's since last August you see a psychologist here.</p> <p>C19: Uh...I got to see him in about November I think or December, something like that.</p> <p>M: But is it related to HIV?</p> <p>C19: No. (M: It's just) It's the operation</p> <p>M: But they still um.....admit you as a client although it's not HIV related.</p> <p>C19: Yes.</p> <p>M: Okay. *pause* Last year I also conducted a client satisfaction survey, I distributed questionnaires for clients to fill out. It's about um.....also satisfaction about the services, I just wonder if you have participated in it or not?</p> <p>C19: I don't think so.</p> <p>M: Okay. So just now you said that you lived near here, did you have any problems before in coming to the centre?</p> <p>C19: No.</p> <p>M: So you've been living near here since 2000.</p> <p>C19: Been living here since 2000.</p> <p>M: How about the appointment time, have you had a convenient appointment time today?</p> <p>C19: Yes, yes.</p> <p>M: And before? Did you have any difficulties in getting a suitable appointment time?</p> <p>C19: No, I don't have any problems, and normally it's not, it's not in emergency situation, so you know I can book a week in an advance, it is not an issue. And I don't have any restrictions on my time as to when I can come.</p> <p>M: Usually you choose a time or they assign a time for you?</p> <p>C19: I choose a time. Ah yes, because usually it's at least a week in advance, so I pick a time that suits me more than anything else.</p>	<p>He has not participated ASC-CSQ</p> <p>Appointment time is not a problem to him because he chooses the appointment time, and his case is not an emergency situation, and he is flexible, he usually book at least a week in advance</p>

**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
<p>Good to pause for 8 seconds and further prompting by rephrasing the question</p>	5:00	<p>M: Are they, I mean the doctors and nurses, are they readily available? So when you want to see them at a certain time, you usually get that appointed time</p> <p>C19: I'm not...um...the answer is yes. But I'm not restricted in....it's never an emergency for me, you know what I mean.</p> <p>M: Okay, that means you're quite flexible.</p> <p>C19: I'm flexible, yeah.</p> <p>M: How about the physical environment here? I mean the waiting rooms outside, the consultation rooms, what do you think of them? Is it too small, too large, too crowded, too...ha ha</p>	<p>He is satisfied with the physical environment, he does not feel there is a lack of privacy at the waiting area. He said because he usually spends a few minutes at the waiting area outside the pharmacy and usually there were only 2 or 3 people, so he does not need a huge waiting area, he would rather to have space for the staff</p>
	5:30	<p>C19: No, they're fine.</p> <p>M: I heard from some other clients saying that, probably because they, I don't know...maybe because they are HIV positive, they think that they lack privacy out there in the waiting area.</p> <p>C19: It doesn't concern me.</p>	
	6:00	<p>M: *pause* And also the waiting area upstairs in the pharmacy, I mean the whole building environment, the whole clinic environment.</p> <p>C19: Sometimes there is 2 or 3 people sitting upstairs, but it's normally never more than that.</p> <p>M: You mean outside the pharmacy.</p> <p>C19: Outside the pharmacy, yeah. But you're only there 3 or 4 minutes at a time, 5 minutes at the most, so.....</p> <p>M: So you think it's comfortable and well-managed? Overall up there and down here.</p>	
6:30	<p>C19: Look it's good! I don't, I don't want to have a huge waiting room up there for the pharmacy, I'd rather have the space for the pharmacists or the doctors. It's enough, I mean if there was 1 chair there and there are 7 people, I'll complain, but you know, that's enough for 4 or 5 people.</p>		



**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
<p>Good to probe the reason why he does not need them</p>	7:00	<p>M: Okay. And um...you see that outside the waiting room there is a shelf, and some pamphlets and brochures about HIV services and sexual health information. You see that there are magazines, um...free condoms and stuffs like that. Do you find that the Albion Street Centre has provided enough such kind of basic services? I mean the information they provided, is it enough?</p>	<p>He thinks ASC has provided enough basic information although he said he does not need them anymore and he does not read them. He does not need to look for information because he tends to ask the doctor if he has any questions. Also he is getting along very well with the tablets and progressing well, so he does not need to find any information (i.e. he has no needs about information)</p>
	7:30	<p>C19: I, I personally don't need it anymore, and um so I guess the answer is yes.</p>	
	8:00	<p>M: You don't need anymore, is it because you already know them, know all the information, or why is that?</p> <p>C19: *pause* it's a good question! Either I ignore it, or um....or I know it. And I think if know it, I ask the doctor I think. I just think if I have ever picked up a magazine, I think I picked up one on food once. Um...and I already not having any problems with HIV, so it's not like I think I need anymore information about it</p>	
	8:30	<p>M: How long have you been diagnosed?</p> <p>C19: I think it's 2000.</p> <p>M: 2000. That means you've been got used to that, and you're carrying normal procedures, so you don't have any particular question about HIV in mind.</p>	
	9:00	<p>C19: No, because I've been on the same set of tablets all the time, I'm well.....I'm tolerating them really well, I don't have any side effects, you know. Um...you know, and I'm...so...</p> <p>M: So you're getting along very well with your medication and stuffs, so nothing...for the time being nothing is bothering you that you need to find any information.</p>	
	9:30	<p>But you should have such questions in mind when you were first diagnosed to have HIV, didn't you?</p> <p>C19: Probably. But now I can't remember, you get over that learning curve. But I think most of my....I'm trying to think where my information came from. Look, probably from the doctor. I remember the first time I was with Professor _____, is it?</p>	

**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	<p>10:00</p> <p>10:30</p> <p>11:00</p> <p>11:30</p>	<p>M: _____ [Name of the doctor]?</p> <p>C19: _____ [Name of the doctor]. And I just remembered that he explained everything so well, you know. He was...he um...uh...and he was comforting, reassuring, but also explain a little bit of the technical knowledge and things. And I think that was...that got me over that hurdle, the initial hurdle I think. I've been diagnosed...</p> <p>M: So are you still following Professor _____? (C19: No, no) I saw you were following _____ [Name of the doctor].</p> <p>C19: _____ [Name of the doctor]. And before that, I was with the one who retired about a year ago, forgot his name.</p> <p>M: That's alright. So let's talk about the doctors' attitudes here, what do you think about their interpersonal manner?</p> <p>C19: You know, I just loved him. I think he has just got such a...I get on with him really well, you know...I loved his really positive attitude, and helpfulness. And I think it's important that you got a good relationship with the doctor, that you feel comfortable with.</p> <p>M: What do you mean by having a good relationship with a doctor?</p> <p>C19: Feeling comfortable that you can talk about anything, he's non-judgmental, you know all those.....hard to put into words, you know...that you feel at one with that person.</p> <p>M: But it's, so it's like friends, and he understands you. How long have you been with _____ [Name of the doctor]?</p> <p>C19: Probably a couple of years.</p> <p>M: A couple of years already. So that means you have established a fairly good relationship with him.</p> <p>C19: But I don't know. As soon as I meet a doctor, you just know whether you'll get on with him or not.</p>	<p>He was very satisfied with his doctors as they provided sufficient information, have good interpersonal manner, as well as being very caring, helpful, and comforting. He thinks it is important to have a good relationship with the doctor, which he provided an explanation to what a good relationship means.</p> <p>He said when he first met a doctor, he would know whether he would get along with him or not, just by the comfort feeling. He met some other doctors when his own doctor was away, although they are professional, they are different from his own doctor who understands him and knows his history</p>

**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	<p>12:00</p> <p>12:30</p> <p>13:00</p> <p>13:30</p>	<p>M: You mean for the first visit.</p> <p>C19: Yeah, generally for the first time. Yeah, often.</p> <p>M: How do you judge that, I mean...just by feeling?</p> <p>C19: I don't know. Just the comfort feeling.</p> <p>M: Just by talking to him?</p> <p>C19: Yeah, I mean I have seen 1 or 2 other doctors when _____ [Name of the doctor] has been away or others have been away. And yes, are professional, but I just, it's just a doctor, do you know what I mean? Whereas _____ [Name of the doctor], you can feel he knows about you, and uh...you know he's dealt...and that going with the same person over and over, they know your history.</p> <p>M: Yeah, yeah, especially for HIV, sort of chronic disease, and um...so it's really important to have a doctor who knows your history, and understands your situation.</p> <p>C19: And particularly I've been through this coronary heart problem, um...there that's another thing that's added to it.</p> <p>M: So you're seeing uh...the cardiologist in ASC or elsewhere?</p> <p>C19: No, um...I saw them down at St. Vincent's.</p> <p>M: You're referred by doctors here or you just go...you know there's a doctor there and you just go.....</p> <p>C19: I don't....this operation, okay, I've been cleared by my cardiologist, and he doesn't want to see my again.</p> <p>M: It's your own GP or it's elsewhere?</p> <p>C19: No, no. You're talking about my cardiologist?</p> <p>M: Yeah, yeah, yeah.</p> <p>C19: At St. Vincent's. _____ [Name of the doctor]. Yeah he's cleared me, he says I don't need to go back to see him.</p> <p>M: Oh okay, okay. But before when you had your surgery...</p>	<p>He was referred to the cardiologist at St. Vincent's by his own GP</p>

**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
<p>Good to bring him back into talking about then the need for counselling related to HIV</p>		<p>C19: Okay the first, that came not from here, that came my GP.</p>	
	14:00	<p>M: Okay, so your own GP referred you to St. Vincent's, (C19: yup) and then you also needed a counsellor for emotional issues, so you come here.</p> <p>C19: That was about 4 or 5 months after surgery.</p> <p>M: So are you progressing well emotionally? I mean after seeing the counsellor here? You benefited?</p>	
	14:30	<p>C19: Yeah, I mean I was really really bad, you know, very crippy, really bad. And then I sort of came out of this black hole of depression quite quickly.</p> <p>M: But I'm just curious, um...because usually... comparing with heart problems, HIV should be more devastating and more threatening, were you um.....very emotionally....having emotional problems when you were first diagnosed with HIV?</p> <p>C19: No, no.</p> <p>M: But that's interesting to me because cardiology problem should be less serious.</p>	
	15:00	<p>C19: But it's the same with cardiology. I mean I went through the hospital, yeah, it was a bit of a shock, you know, but very quickly I gone over it. And I came out of the hospital, I was a bit sore, but I progressed very well. For 4 months I was exercising really well, I was progressing, I felt the BEST I've ever felt. And for a period of 2 or 3 days I just literally crashed, and it was such a shock to me.</p> <p>M: You mean physically.</p> <p>C19: Mentally, mentally. I just went into big deep depression and anxiety depression. And it all happened in only 2 or 3 days.</p>	
	15:30	<p>M: It's because of the cardiology problem?</p> <p>C19: It's the cardiology. They warn you about that, they warn you constantly, you know. After you've had your surgery, you go to classes, they warn you depression's a big issue. But I didn't...</p>	



**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	17:30	M: About after the heart surgery	
		C19: Surgery, yeah.	
		M: So it's also not related to the heart surgery. (C19: yeah) So you saw _____ [Name of the nutritionist] once and...	
	18:00	C19: I saw _____ [Name of the nutritionist] once and that was pre...that was um.....that was probably a couple of years ago. Um...actually I saw him a couple of times. I'm not a very good cook and I eat out a lot, and you know...I don't have a bad diet, but it's just...I just try to get some ideas from him.	
		M: Did you benefit?	
	18:30	C19: Yeah, he gave me some recipes and sort of get me back trying to get me to do a little bit of cooking. And then after the surgery I came to see the dietitian here, just to talk about things again about the diet.	
		M: But you're not seeing the dietitian (C19: regularly) regularly. Because you can't, you can't control your diet, because you eat out and you won't cook yourself.	
	19:00	C19: Well I cook a little bit, I just don't like cooking very much. And when I eat out, look I'm reasonably careful. Um...I don't go to McDonald's, I don't eat pizzas and chips and all those sorts of things, I just don't eat those sorts of things.	
	19:30	M: So um...did the nutritionists and psychologists, these counsellors, did they give you sufficient information during consultations do you think?	
		C19: Yes, yes.	
		M: *pause* Um...yup about the waiting time, did you need to wait for a long time outside before the appointment?	
		C19: No, no.	
		M: Usually how long do you have to wait?	
		C19: Usually probably about 10 minutes.	
		M: You think it's acceptable to you?	

**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	20:00	C19: Yeah. And often I'll get the first appointment of the day, so often there's often no waiting for me.	He does not have any unmet needs about HIV services
		M: So you choose the earliest time slot.	
		C19: Often I choose the earliest time slot, not because of the waiting time, but it's just open in the beginning of the day.	
	20:30	M: Okay. And actually do you have any needs about HIV health care services currently, but you're not receiving from here?	
		C19: No.	
		M: Okay, so you're doing your routine checkups, um...every now and then, so it's progressing quite well and you find that it's fine for you.	
		C19: Yeah it's fine.	
		M: How about the attitudes of the receptionists outside?	
	21:00	C19: Excellent. Helpful. *pause*	
		M: And honestly, do you have any dissatisfaction about the centre?	
		C19: No, no. I love coming here. I think it's just a really really good setup.	
	21:30	M: What do you think is the best thing in the ASC? What makes you really love coming here, attracts you coming here?	
		C19: *Sighed* It's hard to say, but I think because this... my perception is that it's an HIV specialist. (M: the sorry?) because it's an HIV specialist... clinic, practice, building...whatever you like to call it. Um...and everyone's experienced in that, you know what I mean? And it's a comfortable place to come, you know.	
	22:00	M: Different from other hospitals that they admit all sorts of patients, but here it's um...	
		C19: Well haven't been to any other hospitals, I only got that and the GP to compare with.	
		M: But I mean all doctors and nurses, they are specialised in treating and dealing with HIV, so you're...can I say that you're...you trust them, you have confidence in them.	
	22:30		

**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	<p>23:00</p> <p>23:30</p> <p>24:00</p> <p>24:30</p>	<p>C19: You know I do trust them, but they have a huge amount of knowledge, you don't have to explain anything, whereas if you went to...I guess my GP is pretty good, but if you imagine you going to a doctor, they just doesn't understand a lot about HIV stuff.</p> <p>M: *pause* Okay, the last question, do you think there are any areas the ASC service can improve?</p> <p>C19: Not for me!</p> <p>M: So you got...</p> <p>C19: It gives me everything that I need.</p> <p>M: Okay, no suggestions or anything?</p> <p>C19: Maybe my needs are just minimal, but it provides everything that I need. *pause* Because I've got...Going back to what it is, it provides everything in one place, which you got pharmacy here, you got your doctors, you got your nurses, you got your blood test here. And I think that's...everything that you need is here, even the psychologist I got for the moment. Everything is in 1 building and 1 place.</p> <p>M: We call it a multi-disciplinary clinic, you got every type....different types of services related to HIV.</p> <p>C19: I don't realise, but that's probably the most important thing about this</p> <p>M: Do you know there are any other clinic like here which are also multi-disciplinary?</p> <p>C19: Look I don't know, I personally don't know any, it's not to say that there aren't any, but I.....</p> <p>M: From what I know, I think there are hospitals that provide HIV services, but I mean public hospitals, they provide other services for um...other patients with normal illness like flu or what. So if we're talking about only HIV services, then I think this is the only centre, from what I understand. If there are no new clinics establish.</p> <p>C19: If there are others I don't know about them, then I never needed to use them, so...and I live in this area, so I'm very fortunate that I got such an excellent facility here.</p>	<p>He thinks that the most important credit of this clinic is the multi-disciplinary nature. Every type of service related to HIV is inside one building.</p>



**Appendix 16:** Example of Transcript File 1 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	<p>25:00</p> <p>25:30</p>	<p>M: Good to hear that.</p> <p>C19: And I guess I have taken it for granted, it's only I've been talking to you now that I realise that, yeah all the positive things that we just take for granted, the doctor and the nurse, and you know. So I can sit here and in 2 minutes I can get all my bloods done, then I can go up and get my tablets, and it's all in the same thing. And I never...because you grew up with that, you just think that that's the normal, and I suddenly realise that it's not very normal. Because I go to my GP, I gotta go around the corner to the chemist, I gotta go up the road to have my blood test if I have one. Um...yeah...</p> <p>M: And the most important thing is that, it's free.</p> <p>C19: Oh yes that's good too</p> <p>M: The consultation free. That's true. Thanks very much, it's done. Good to hear that it's so positive. Because also I interviewed other clients, most of them they are very satisfied with the services here, not many of them are.... dissatisfaction, so which is a very good thing.</p>	<p>He said he took things for granted and now he realised that it is so convenient to receive the services. He would have to go to many different places to receive the same type of health care if he consults a GP</p>

**Appendix 17: Example of Transcript File 2 for data analysis in the Qualitative interviews**

Client 21

Date: 2/5/08 (Friday)

Time: 10:35-11:00am (~25 mins), after consultation

Place: Nutrition room

(HIV+ for 3 years)

Australian, Aged 35, University, Full time, Heterosexual, Blood transfusion

Note: M=Interviewer, C21=Client 21

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	0:00	M: Once again thanks for being interviewed. (C21: that's okay) Just now you said that you have been a client for 3 years. Have you always been a regular client coming frequently?	He has been a regular client for 3 years. He also had an overseas doctor in the 3 years because he worked overseas, but now he has moved back so he started coming here 2-3 times a year.
	0:30		
		C21: Um I actually...until a couple of months ago, lived in overseas, but I got a doctor overseas who looks after me, but now I'm living back in Australia, I used to come back for a checkup every time I was back for holidays, so about 2 times a year, 2 or 3 times a year I have been coming here. So yeah I'm a regular patient.	
		M: So are you still going overseas regularly?	
	1:00	C21: I still travel regularly, but I live in Australia now. Before I lived overseas, up until 3 months ago, but now I've moved back here.	
		M: So you now come here for example like twice a year.	
		C21: Well about every 3 months for checkup.	
		M: Um so what services will you use every time you come here?	
	1:30	C21: Uh when I come here I use obviously services of my doctor, and also the pathology services, taking of my blood, and checking out...that the 2 services I use	
		M: Are you um....getting medication from the pharmacy?	
		C21: No, I'm not on medication yet.	
		M: Okay.	

**Appendix 17: Example of Transcript File 2 for data analysis in the Qualitative interviews**  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	2:00	<p>C21: Only I've been HIV positive for 3 years, um...I got...it's kind of unusual, I'm straight, not gay. I got HIV from a blood transfusion in Vietnam, (M: oh no) after a bike accident, so...yeah, that's okay, can't change it, so...yeah it's still the way it is, but my body is coping very well.</p>	<p>He is not gay. He was diagnosed HIV for 3 years as he contracted through blood transfusion in Vietnam after a bike accident</p>
		<p>M: Right. You got that from donating blood or receiving blood?</p>	
	2:30	<p>C21: No, no, from receiving blood, it was a motorbike accident in Vietnam. I got taken to the hospital for blood transfusion, but apparently the blood...well not apparently, the blood they gave me was obviously contaminated, because they don't have valid screen procedures in third world countries, but I didn't have a choice as either that or die. Um and a routine blood test after that confirmed that I actually contracted HIV from the transfusion, so I guess not a regular sort of case. Um but I... my body is dealing it very well, um at this stage I don't need medication, so I don't get medication.</p>	
		<p>M: So your doctor's monitoring your progress now...</p>	
	3:00	<p>C21: Yeah just monitoring my cell counts and my viral counts and everything's okay. And yes, it's till early for me for the medication at this stage.</p>	<p>He does not see a counsellor and dietitian</p>
		<p>M: Apart from consulting the doctors, are you also using psychology counselling services and nutritional?</p>	
		<p>C21: No. I don't use these services.</p>	
	3:30	<p>M: Right. Let's talk about the location here first. Do you think it's convenient for you coming here?</p>	
	4:00	<p>C21: No. (M: *laugh*) I live on the north side of town, and I found that it's quite um...it's easy to get to, but it could be easier. Um...not being on a train line is a little bit inconvenient, and I think there are buses going up here Albion Street, but I'm not sure where you catch one, and in any case I would have to catch a bus from my home on the northern beaches into town, and then change buses to get here. Um what I usually do is I catch a bus to town and walk from Central, but I hate that hill. It's too big!</p>	<p>He is not quite satisfied with the location because his place is at Northern side, and is not along the train line, he had to catch a bus to town and walk up the hill, which he had to take 1 hr 15 mins.</p>

**Appendix 17: Example of Transcript File 2 for data analysis in the Qualitative interviews**  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
<p>Good to ask the reason for coming here despite the distance</p>	<p>4:30</p>	<p>M: Yeah have to walk like 10-15 minutes and it's quite steep.</p> <p>C21: Yeah let's say it's not a major inconvenience to get to, but it's a little bit inconvenient.</p> <p>M: How long do you usually need to take from your place?</p> <p>C21: from my house to here? (M: yeah) I would allow about an hour and 15 minutes.</p> <p>M: So what makes you still coming here although it's so far away? Because I know that there are hospitals up north, they also admit HIV clients.</p> <p>C21: Yeah sure, there's 2 reasons for that. One I believe that the health care here is very very good. HIV is what they specialise in, uh...and I got a very good relationship with my doctors so I feel confident in here. I mean here is HIV doctor so he is a specialist, so this is the main reason I come here. And the second reason I come here is because Medicare pays for it, so it's free. So I don't have to pay. I get very good care for free, so I can't argue with that.</p> <p>M: It's because of public services, so the Medicare covers it.</p> <p>C21: Yeah, exactly.</p> <p>M: And you don't need to take medication yet, so basically all services are free.</p> <p>C21: Correct, yes.</p> <p>M: So who are you with? I mean the doctor.</p> <p>C21: My doctor's name? [Name of doctor].</p>	<p>3 reasons for still coming to ASC despite the distance</p> <ol style="list-style-type: none"> <li>1. health care is very good here, doctors are specialised in HIV</li> <li>2. he developed good relationship with his doctor</li> <li>3. he does not have to pay for services because of Medicare</li> </ol>
<p>My response sounded a bit redundant? But just wanted to confirm it and he made a good point after that</p>	<p>5:30</p>	<p>M: Okay. So although the location is not convenient for you, you still keep coming here.</p> <p>C21: I still keep coming back. Yeah I mean the location is a minor thing, because I only have to come at this stage every 3 months, um...it's not that much of a problem. But I found that the benefit of the care that I get here and the fact that it's pay for the government outweighs the inconvenience factor of where it is.</p>	<p>Although he is not satisfied with the location, distance is only a minor thing which was outweighed by the benefits he got from the services</p>

**Appendix 17: Example of Transcript File 2 for data analysis in the Qualitative interviews**  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	<p>6:00</p> <p>6:30</p> <p>7:00</p> <p>7:30</p>	<p>M: Okay. How about the appointment time? Did you always have a convenient appointment time?</p> <p>C21: Yeah the appointment time is good. I find that ...I'm not sure with the other doctors, but with _____ [Name of doctor], I know he's got a lot of patients. So generally to get the appointment that I want, I usually have to call up 3 weeks before. If I do it the week before, it's very few times available, so I try to arrange as early as I can. But if I do that, the appointment time I want is often available.</p> <p>M: So you just only need to call up 3 weeks before the consultation.</p> <p>C21: Yup, and then I can pretty much get whatever time I need.</p> <p>M: Okay. Usually you choose your time or they assign a time?</p> <p>C21: Usually I choose.</p> <p>M: Um...are the doctors and nurses always readily available? Like did you...did they missed your appointment time before?</p> <p>C21: No.</p> <p>M: *paused* So you consider um...that _____ [Name of doctor]'s availability is uh...good?</p> <p>C21: Um yeah. Um I know he goes overseas a lot, uh for me that hasn't been a problem, because up until recently I was living in Asia, so I could always emailed him and find out when he's gonna be here, and make an appointment around that. Now that I'm back in Sydney, um _____ [Name of doctor] going overseas might mean I have to change time sometimes, but up until now this stage his availability's being fine for me, no problem.</p> <p>M: How about the physical environment of this centre? Like, downstairs the waiting room, the consultation rooms, I mean the whole building environment.</p> <p>C21: It's a bit cold and sterile.</p> <p>M: Cold and...</p> <p>C21: Sterile</p>	<p>He is satisfied with the appointment time. He only needs to call 3 weeks before to make the appointment. If he calls 1 week before it might be less likely. But he can choose his consultation time.</p> <p>He is satisfied with the doctor's availability up till now although he goes overseas a lot</p>

**Appendix 17:** Example of Transcript File 2 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
<p>I should not provide my personal views because I am supposed to look for participant's views</p>	8:00	<p>M: Sterile. *laugh* So hospital feeling.</p>	<p>He is not very satisfied with the physical environment because it is a bit old and run down, clients would feel apprehensive and it needs updating. E.g. new paints, chairs, carpet, nice music, prints on the wall, potted plants (see 23:30)</p>
	8:30	<p>C21: I mean...yeah it does feel like an old hospital, um I think they...I know it's an old building and old area, but it'd be nice if they brightened it up a bit and make it a bit more modern. Particularly in winter you sit in the waiting room and it...for someone who may be...is you know getting their HIV testified. If they are HIV positive or not, it's a little bit of a cold environment, I think I'd be a little bit...you know, apprehensive sitting there. I think it's not very welcoming. The staff are very welcoming and friendly, but the actual environment of the centre itself, I think it's a bit cold and run down. It needs a little bit updating.</p> <p>M: What will you suggest to brighten it up?</p> <p>C21: Carpet, new paint job, new chairs, some nice prints on the wall, some nice music playing. You're going to.....you've probably been to a modern medical centre here in Australia, and they're quite modern and bright, and pot plants...you know, sort of look less like a hospital. So something a little more welcoming, just a little bit of updating the carpet, new paints and some plants and...just to make it a little more welcoming at home.</p> <p>M: Okay. Many things to change haha...might need a renovation.</p> <p>C21: Oh they're not bad things, they're minor things, but you asked...</p>	
	9:00	<p>M: Yeah, yeah. That's true, I think it's somehow a bit old. (C21: yeah it was just a little bit timed) Because it was established I think in the 80s', so...(C21: it hasn't updated a lot) it hasn't changed a lot..</p>	
	9:30	<p>And you see downstairs in the waiting area, there's a shelf, and there are brochures and pamphlets about HIV services, some information about sexual health etcetera, and there are magazines and free condoms etcetera. So do you think the Albion Street Centre has provided enough such kind of basic services to clients?</p>	
	10:00		

**Appendix 17: Example of Transcript File 2 for data analysis in the Qualitative interviews**  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
<p>I should ask what types of basic information should be provided for heterosexual people, but good that he gave examples though I did not ask</p>	10:30	<p>C21: Yeah but I was thinking today, most of the magazines and pamphlets are geared towards gays. (M: yeah that's true) And obviously there's straight people with HIV too. So I found there's very few pamphlets or reading information available for straight people like me. It's mostly geared towards gays, I understand that it's the majority, but yeah that's not really much for straights. So some more information for straight people would be pretty cool.</p> <p>M: You mean um HIV services, uh...sexual health information target straight...</p>	<p>He found that most of the basic information (pamphlets, advice lines) provided are geared towards homosexuals. Very few pamphlets and services for heterosexual people. E.g. straight couples in which one of them are positive and the other is negative might need counselling and help, but these services are not very well publicised</p>
	11:00	<p>C21: Yeah, targeting straight people who have HIV. You know there's a lot of...lot of couples out there where you know, straight couples I mean, when one person in a relationship might be positive, and that partner might be negative, and they're very happy together. But you know sometimes they could probably use some counselling or help in that situation if they need someone to talk to, particularly for the straight, uh... negative person in the relationship. Um...I find there's very few services like that for straight people. There're probably up there, but I don't know whether they are publicised or having information on it. Most of the advice lines and things like that I think tend towards the gay people with HIV, rather than straight people with HIV.</p> <p>M: That's true, yeah. Because I think there are about 80 something % clients coming here, um or maybe 80 something % of people living with HIV/AIDS in Sydney are gay people. So the other um about less than 20%, they are straight people or...</p>	
	11:30	<p>C21: There is very few resources for us</p> <p>M: Yes that's true. And even less people are like you who contracted HIV through this way. (C21: yeah exactly) I'm really sorry to hear that, I...</p>	
	12:00	<p>C21: Don't be sorry, it's like it's...my destiny and life, and it's happened and there's no point in being sad about it. I mean people sort of like...I've told my dad, I haven't told my mum, coz she'll just worry. I've told my dad and probably 4 really close friends. And when I first told them, they were like, "Oh my God, that's bad!" But that's the way it is, I can't change it. Doesn't change my as a person, doesn't change my heart or my mind. Um and look, these days you don't die from HIV, you know, if you got....</p>	

**Appendix 17: Example of Transcript File 2 for data analysis in the Qualitative interviews**  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	<p>12:30</p> <p>13:00</p> <p>13:30</p> <p>14:00</p>	<p>M: That's true People live with HIV for 20 something years or maybe even longer.</p> <p>C21: More than that. I mean these the medication is so good that the side effects are really minimal. They compare that to having diabetes, you know something you can control and live with. And as long as you take medication when the time comes, and you can control it, you have a normal life! You know..._____ [Name of doctor] says plan for my retirement this stage. I'm 35, so at this stage, _____ [Name of doctor] says like, you know be more worried more about cancer, or Alzheimer's and things like that than HIV, because we can control that. There's no problem, you know you'll live to 75 or 80 if nothing else comes. And by that stage, he knows what sort of medications and drugs I'll have, so I'm not going to die, I'm going to be here for a long time. But don't say sorry, coz it's I know what you mean. Well I don't feel like uh I've had a bad luck or something like that, maybe I had, but it's just my life. And it's what happened and I just deal with it, so you know, life's too short to worry about stuffs like that.</p> <p>M: Yeah that's true, good that you can be so optimistic.</p> <p>C21: I've lived in Asia for 6 years, I saw the most amazing poverty over there. And I saw....there were so many people out there um worse than me. So yeah having HIV is not the greatest thing in the world, this doesn't stop me leading a normal life. I go to work everyday, I see my friends, I go to a party, I do this I do that, I go on holidays. I'm just normal, same as everyone else, there's no difference.</p> <p>M: So you're still going to Asia to work?</p> <p>C21: Yeah I work for an Asian travel company.</p> <p>M: So will you seek HIV health care over there?</p> <p>C21: No that I'm not living there. I did before, I lived in Bangkok for 6 years, and I had a doctor over there, a specialist to look after me. Um but now I go over there so I'll save for 1 or 2 weeks at a time, so I won't need health care while this place is the primary place in getting health care</p>	<p>He is not very sad about having HIV because he believes that people do not die from HIV these days because of the medication. His doctor told him he should be more worried about other diseases which might also kill rather than HIV. So he is confident that he will live a long time</p> <p>He received HIV health care in Thailand while he was working in Asia. He occasionally came back to Sydney where he received care at ASC</p>



**Appendix 17: Example of Transcript File 2 for data analysis in the Qualitative interviews**  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
<p>Good to ask him about the difference in HIV services in Thailand and ASC</p>	14:30	<p>M: So was it during that period when you were living in Bangkok, you consulted doctors in Thailand, as well as coming to the Albion Street Centre?</p> <p>C21: That's correct yup.</p> <p>M: Why do you need to go both ways and not stick to one place?</p> <p>C21 When you are in the situation where I am, where you've had a _____ blood too long, and still don't need medication, you have to check your blood every 3 months. Just monitor the level of virus in your blood, and monitor your immune system. And I used to come home every 6 months, so 3 months I get a check there, and I get the next one here, and I pass the information to my doctors, so that's why I have to do that.</p>	<p>He is very satisfied with the health care services in Thailand because his doctor was a renowned HIV specialist, all doctors are well-trained. The hospital services are efficient and facilities are modern and clean. He thinks services in Thailand and ASC are both very good. But in terms of other illnesses, he prefers to get treated in Thailand more than in Australia</p> <p>Because Thailand has acknowledged HIV as nearly 2% of people in Thailand have HIV, and medical tourism is growing fast, so health care services in Thailand are growing rapidly</p>
	15:00	<p>M: Comparing with the Thai doctors and Thai HIV health care services, what difference can you find?</p> <p>C21: That's a really really good question. Um...Thailand is one of the lucky countries in Asia, in terms of it has acknowledged HIV, and HIV positive people. The hospital I went to is probably the best hospital in Bangkok, and the doctor that I went to is an HIV specialist, and he went to University over Harvard in the States, and he is probably in the top, top 20 HIV doctors in the world. He's very well-trained, he knows pretty much knows everything about it. The health care facilities are modern, they're spotlessly clean, they're very efficient, the level of care is exceptional. Um...not just talking about HIV, but for pretty much any serious health care problem, I would prefer to treat...get treated over there than I would here in Australia.</p>	
	15:30	<p>M: It's even better than in Australia!</p>	
	16:00	<p>C21: Absolutely, the health care over there is fantastic. The private hospitals are amazing, the doctors are all very well-trained, they are educated overseas, um...the level of care is superb, the level of facilities are superb, everything's modern and up to date, they are clean and spotless, and um...yeah it's very good. So in terms of being treated for HIV infection, um here and there I would put on a par. My doctors are both very good, I'm very happy with the treatment in both places.</p>	
	16:30		

**Appendix 17:** Example of Transcript File 2 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	<p>17:00</p> <p>17:30</p> <p>18:00</p> <p>18:30</p>	<p>M: Um I'm surprised to know that there are such good health care services in Thailand, yeah.</p> <p>C21: It's amazing! Thailand and Singapore are amazing for health care. Vietnam, Cambodia, no. Um... Malaysia, so-so. But yeah, Thailand's amazing for health care, a lot of people... the fastest growing area in tourism sector in Thailand is medical tourism. People going to have cosmetic surgery and major surgery. And then they go and have their surgery, stay at hospital and then go and recuperate on a nice beach somewhere for a week or two. Much better than down here.</p> <p>M: Yeah just as you said, because Thailand has acknowledged HIV, because maybe the um sex tourism is so...(C21: rapidly) yeah so prosperous, they have to admit that. But like comparing with other South East Asian countries like Indonesia or Malaysia or what, they still think HIV... (C21: they bury their head in the sand so much) yeah, yeah, still have stigma attached to them.</p> <p>C21: You know in Thailand, 1 million of people are HIV positive in Thailand, that means 1 in 60.</p> <p>M: 1 in 60?</p> <p>C21: There are 60 million people in Thailand, 1 million have HIV. (M: wow) So 1 in 60 is a lot, that's huge, um...</p> <p>M: Nearly 2%.</p> <p>C21: Yeah, so they've basically got to acknowledged it and they have done that, so it's really good.</p> <p>M: So um after you've um...come back to Sydney, I mean currently. Apart from seeing doctors in the Albion Street Centre, are you also accessing other HIV health care services elsewhere?</p> <p>C21: No. (M: okay). I tend to think about that, Maria, it's like I said, I just have a normal life, and I come here, and when the time comes to take medication, I'll take 2 pills a day, and my life goes normal. Um...I don't feel the need for counselling, I'm a strong person. When I don't have to come here, which is 2 months and 29 days in every 3 month period, I don't think about it, it's normal person you know? Like I said, my brain's the same, my heart's the same, everything's the same. Except there's some problem with my blood, so...yeah, I don't use other services at all.</p>	<p>He compared the hospitals in different SE Asian countries</p> <p>He does not attend other HIV health care settings apart from ASC. He has no unmet needs about services said he does not need to have counselling or specialist services. He said he does not think about having HIV at other times when he is not coming to the centre</p>

**Appendix 17: Example of Transcript File 2 for data analysis in the Qualitative interviews**  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	<p>19:00</p> <p>19:30</p> <p>20:00</p> <p>20:30</p>	<p>M: Yeah. Do you also need to see a specialist here? Like dermatologist or other...</p> <p>C21: No, not at all.</p> <p>M: Good. So are there any other health care needs uh that you would like to have, but I mean it's unmet, you know what I mean?</p> <p>C21: Personally for me no, not that I can think of. Yup.</p> <p>M: Let's talk about the attitudes of the health care providers here, so you come here to see doctors for consultation, and nurses for blood test, and also receptionists only. What do you think of their attitudes?</p> <p>C21: They're fantastic, everyone here is happy, positive, probably shouldn't say the word positive, (M: *laugh*) they're happy, they're up be, they're friendly, they're polite, they make you feel welcomed. You know the reception staff are always friendly when you're on the phone to make an appointment, or when you are coming to say that you are here, they're always polite, um... [Name of doctor] my doctor is fantastic, he's very knowledgeable, he's very open, he communicates easily, I can ask him anything, he could always answer, and very nice man. The nurse staff are great, they know that I hate needles, (*laugh*) so they always keep chatting to me while taking blood, doesn't hurt at all, I'm only be a big baby about that. Um but they're always happy and friendly, and um they don't cause me any pain or discomfort when I'm giving blood at all. So the staff here are great, 10 out of 10.</p> <p>M: 10 out of 10. Did they give you sufficient information? Like when you're having blood test, did they explain clearly the procedures and give you all information about you should know about HIV.</p>	<p>He is very satisfied with the staff's attitudes. Receptionists are friendly and polite on the phone and at the clinic. His doctor is knowledgeable, open, communicates easily. Nurses are happy, positive, keep chatting to him while having blood test.</p>

**Appendix 17: Example of Transcript File 2 for data analysis in the Qualitative interviews**  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
I should ask why he thinks there is such a difference rather than me giving him my views	21:00	C21: They...the first time I was here having blood test they did. Obviously I have been quite a few times since there. Every time I go for a blood test, the nurse will say, "okay, you have done this before." And I'm like, "yeah I'm fine, I know what goes on." So there is no need to explain that, but I'm sure that if I want anything to be explained, I would. I mean I asked today why...I asked the nurse why the blood they take from me is dark red where other parts of the blood are bright red. And she explained that to me about blood having oxygen removed from and etcetera, and the blood coming from the arteries is full of oxygen , that's why it's bright red and bla bla bla...so they're always really good with explanations, if I want to know anything, if I had any stupid questions. (M: *laughed*)	He is satisfied with the information given to him, as he was explained clearly the procedures the first time he came here. But afterwards everything becomes routine and he does not need to have any explanations from them. But the nurses are ready to answer him any questions and he gave an example for that
	21:30	M: *pause* Do doctors and nurses in Thailand um also explain these things clearly? Like the ones in Australia?	
	22:00	C21: Only if you ask, they explain if you ask. They're very very good, uh but they'll provide information if you ask them. Generally in Thailand, if you don't ask they won't offer the information. They'll know it, but for some reason in my experience, I found that you've got to draw it out from them a little bit, whereas here they'll explain things to you in advance.	Thailand doctors are less friendly and less willing to provide information, they'll answer questions only if he asked them. They are highly respected and tend to be more serious and business-like. He also agrees it is because of cultural difference. Australian doctors and clients are in a more on a par and less serious.
	22:30	M: Are they also as friendly as doctors and nurses here? I mean with a cultural difference...  C21: No, I mean...yeah I think it's a huge cultural difference. Um...in Australia, think nurses, staffs and doctors are more on a par with their patients socially. Whereas in Asia, you're a Chinese right? (M: I am Chinese) I've been to China many times, but I haven't been to a doctor there. But in Thailand, doctors are very very highly respected. So people...patients treat them with respect, always called them doctor. Whereas I call _____ [Name of doctor], for example, um...and doctors tend to be a lot of more serious over there, there are no sort of jobbies or up beat, so as the nursing staff. But um...yeah they're friendly, they're not rude, but they're very matter of fact business like in what they do. So um yeah they're not going to make any jokes or anything else like the staff here. But they're very good in what they do, but they just tend to be very business like about it, very focussed in what they're doing.	

**Appendix 17:** Example of Transcript File 2 for data analysis in the Qualitative interviews  
(continued)

Evaluation of interviewing format	Time	Transcription	Summary of client's views
	23:00	<p>M: Perhaps it's not only in the medical sector, in all other sectors, it's because of the culture</p> <p>C21: Yeah, it's the status levels and things like that, yeah.</p>	<p>He finds the waiting area a bit scary and cold for people coming to check for their HIV status. He hoped to update the waiting room and add some decorations to create a more welcoming environment. But he understands people do not come here because of the environment, and funding might be an issue which it might be spent in other more urgent areas</p> <p>He found out ASC by searching in the internet. He did not know this place before because he never expected himself to have HIV. He could have gone to a normal GP but he preferred to go to a specialist</p>
23:30	<p>M: Um...actually we're nearly finished. So the last question, are they any other areas of Albion Street Centre services you think they can improve? Or anything you just want to raise out I haven't covered.</p> <p>C21: No not really, just that I think the place needs brushing up a little bit, it needs a bit of decorative work done. But you know you don't come here for that, I just think for someone coming here who may think they're HIV positive for example, may want to have the blood to see if they are or not, it's sort of a scary cold environment for them to sort of waiting. I think it could be a lot more welcoming in terms of the deco, but people are fantastic, the cares are fantastic, um...you know it's probably the only thing I would have is updated a little bit and make it a little bit more modern. I realise that funding costs a lot of money to do that sort of stuff, and they probably got far better things to spend their money on, I understand that. That's my only one little concern.</p>		
24:00	<p>M: How did you find this place in the first place?</p> <p>C21: Um...when I found out that I had, next time I came back to Australia I looked online. And found it online in the internet.</p> <p>M: So you wasn't, so you weren't referred to this place by GP or what.</p>		
24:30	<p>C21: No I wasn't aware even if it existed. I mean why would I have HIV, so why would I sort of look it up, you know what I mean? Um but I obviously to find...I could have just gone through the normal doctor when I came home, but I prefer to go to a specialist, that sort of...just deals with this, so yeah did a few searches and came it up in Google I think.</p> <p>M: This place is the largest outpatient, so it specialise in HIV, so good that you are here!</p> <p>C21: Yeah exactly.</p> <p>M: Great! So we're done, thanks very much!</p>		

## Appendix 18: Example of a client Summary File for data analysis in the Qualitative interviews

Client 23 (HIV+ for 15 years)

European, Aged 45, Secondary (to year 12), Full time, Gay, Unprotected intercourse

Date: 8/5/08 (Thursday)

Time: 1:10pm-1:35pm (~25 mins), after consultation

Place: Consultation room

Time since being client + Services used at ASC

- Regular client for 15 years,
- Diagnosed at GP→referred here→came for a few times→GP whom he lived near (5-6 years) → came back to ASC
- Regular checkup+ psychological (after 1<sup>st</sup> diagnosed)+ nutritional counselling (part of clinical trial)+ collect medication

Location

- Satisfied. Lives and works nearby, come in 20 mins. Took bus before he moved, <1 hr, no difficulties.
- Location was the factor which made him left ASC go to another doctor

Appointment time

- Satisfied. Only rang yesterday to book the time he wanted. Usually needs to book a few days in advance. Appointment time not an issue because he is flexible and can arrange his time to fit
- Dissatisfied with waiting time. Usually has to wait for 30 mins before consultation. The longest waiting time was 50 mins to 1 hour. Because he has to work, so would like to have the consultation on the appointed time  
“Because I gotta work, if my appointments are 12, I get here at 12 and I'd like to be seeing at 12, obviously, but I mean that cannot always be the case. But I think 30 minutes is starting to get a bit long.”  
He understood that his doctor might have a difficult patient, so consultation time is delayed. But has not reflected to anyone because once he was with the doctor, he only wanted to talk about medical issues.  
Because of long waiting time, he had to come to ASC 2 times (collect medication+ consultation), each shorter visit, than coming once but have to wait a long time

Physical environment

- Satisfied with waiting room downstairs. Pleasant, clean, has a fish tank, paintings and music. Was great to have a TV before, but now they have the radio which is also good
- Satisfied that ASC has already had improvements in ensuring privacy, because in the past there was no glass wall to shield clients in the waiting area. But now he feels better and more private.  
“there was a time where the glass wall wasn't there, so anybody who came through the door, you could be seen straight away. Since they put that there, it feels better, more private. So they have made some improvements.”
- Dissatisfied with waiting room outside the pharmacy because it was too crowded, sometimes there were a lot of clients and he had to stand and wait for medication  
“I think the pharmacy's space is a bit crowded. Sometimes I've been up there, I've had to stand to wait for the drugs...because there has been a lot of people already there.”

## Appendix 18: Example of a client Summary File for data analysis in the Qualitative interviews (continued)

### Basic services

- Satisfied. Especially condoms are not provided anywhere. Mainly read magazines when waiting for services and just briefly read pamphlets, because he works in a similar setting has already seen the posters before, so does not need to read them
- Dissatisfied that no water is available as the water machine is broken. He suggested to provide little containers of orange juice if water is not available, considering that clients come here for blood test and may need some liquid  
“Today’s there’s no water there, they should have some orange juice or something, you know little containers of orange juice or something you could just drink, if that’s not available, if the water facility is not available.”

Receive HIV health care at other settings: Only comes to ASC

### Unmet needs about HIV health care

- No unmet needs about HIV care, only wants to find dental care which is HIV friendly. Got information from local gay paper
- If he has any needs about HIV health care which he cannot find in the paper or internet, he will ask his doctor for appropriate referrals  
“I think there’s a lot of services available in this area, so it’s pretty well covered. But if there was something I wasn’t sure of, and I couldn’t find it from the paper or the internet or what, I would ask Don for sure, if he knew somebody.”

### HCP

- Satisfied with the attitudes of his doctor, he has empathy, understanding, attentive, professional, and is familiar with his situation. He is comfortable in raising any concerns with his doctor. Developed relationship and trust.  
“He’s (his doctor) attentive and has empathy for my situation, so he’s quite understanding. I’ve seen him for a couple of years so he knows me well, has a familiarity now, which was good...he knows my situation, where in my health is. And I feel quite comfortable raising any concerns with him, or bringing any issues to his attention. So he’s manner is very professional.”
- Satisfied with nurses here as they are friendly, welcoming and he is familiar with them, despite there were a lot more changes in nurses recently.
- No problems with pharmacists and receptionists. Happy that pharmacy changed the regulation so now he can collect medication 2 or 3 months a time instead of 1 month a time. More convenient for clients.
- Had one bad experience with the nurse a long time ago. During the blood test the needle popped out from his arm and he could see the blood, the nurse apologised and wanted to take the blood from the other arm, but he had enough and left. But was alright.

### Suggestions made during interview

- Suggested to provide little containers of orange juice if no water available.
- Shorten waiting time