Report of Community Assessment and Evaluation on HIV Prevention for People Living with HIV/AIDS in Hong Kong 2006

Working Group on HIV Prevention for People Living with HIV/AIDS
Community Forum on AIDS
Hong Kong Advisory Council on AIDS

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Under the auspice of the Community Forum on AIDS of the ACA, an exercise named Community Assessment and Evaluation was embarked in the first half of 2006 to draw community input for the formulation of Recommended Hong Kong AIDS Strategies 2007-2011. Working group on seven groups, viz. commercial sex workers and clients, men who have sex with men, injecting drug users, women and children, people living with HIV/AIDS, youth and cross-border travelers were formed to undertake the exercise. Each Working group was convened by a community expert in the field and with members drawn from key agencies, stakeholders and other persons involved. Technical and secretariat support was provided by Special Preventive Programme. A common framework of reviewing epidemiological data, evaluating current response, reviewing overseas guidelines and developing recommendations on prevention and care of local relevance was employed. A report was generated by each Working Group from the exercise.

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Foreword and Acknowledgement

The Community Forum on AIDS was convened to enhance communication between community stakeholders and ACA. It provided a platform where the views and expertise of the community can be directly shared and collected, to support policy formulation at the ACA level. The Community Forum's first key task was to mobilize stakeholders to take part in the Community Assessment and Evaluation exercise, an essential and integral component of the process of formulating the Recommended HIV/AIDS Strategies in 2007-2011.

It has been a stimulating and fruitful learning experience for us all to participate in reviewing Hong Kong's past and present AIDS situation and recommending strategies for the coming future. Although the various community groups have very different needs, it was quite clear that they shared common concerns. These were extensively discussed at all levels including the working group, the Community Forum, and ACA. Of particular concern were the effectiveness of existing funding mechanism for community-based projects, issues on the monitoring and evaluation of AIDS prevention programmes, and the prioritization and impact of such programmes on the local AIDS situation.

The recent visit of US expert Dr Tim Brown as an external consultant to review the latest epidemiological situation in Hong Kong laid a convincing scientific basis on which to focus urgent priorities in HIV prevention. The HIV epidemic in Hong Kong has moved from a slow phase to an early phase of fast growth, mainly driven by an increasing number of HIV infections in men who have sex with men (MSM). The key findings from Dr Tim Brown's reports and the Community Assessment and Evaluation exercise will culminate in the evidence-based, action-oriented interventions recommended in the HIV/AIDS Strategies.

The Community Assessment and Evaluation exercise also provided an opportunity for stakeholders to forge stronger ties and partnerships. Moreover, it facilitated capacity building and identification of expertise in the field. The active involvement of non-government organizations and AIDS workers to share their experiences and best practices provided the impetus to launch a local AIDS meeting, the Hong Kong AIDS Dialogue on 16 September 2006. I hope and fully believe that this will be only the start of a concerted movement to engage all relevant parties in the fight against HIV/AIDS in Hong Kong.

I would like to thank Professor CN Chen for providing visionary leadership, guidance and continuous support as ACA Chairman. He has spared no effort to improve communication among Government, policymakers, funding agencies, AIDS service organizations, frontline workers and vulnerable communities. The Community Assessment and Evaluation exercise would not have been possible without the leadership of the Conveners of the 7 Working Groups and the whole-hearted participation of the members. I would also like to record a vote of thanks to the hard-working Secretaries of the Working Group and the staff of the Special Preventive Programme for providing technical support. Finally I would like to express my gratitude to all those agencies, volunteers, interviewers, interviewees and participants who have given their time to support this initiative for the betterment of HIV prevention and care in Hong Kong.

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1. Background

1.1 The issues surrounding HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome) change very rapidly in recent years, especially those related to the medical treatment for people living with HIV/ AIDS (PLHA). Nowadays, people infected with HIV have much better prognosis. Although HIV infection remains incurable, with the development and advancement in treatment available to the HIV/ AIDS patients, it has essentially been transformed into a chronic disease controllable by long term therapy, rather than a universally fatal disease in the previous decade. Theoretically, with the effective treatment available nowadays, they can lead a normal life without any major health threats, just as any ordinary person.

1.2 Due to this revolutionary change, the situation faced by PLHA is completely different from that some years ago. PLHA have special and unique needs in terms of health, healthcare and social needs, which are specific to the situation and problems faced by the group. As time goes by, their needs and problems keep evolving. It is high time to have a comprehensive review of the situation faced by them.

1.3 In preparing the "Recommended HIV/ AIDS Strategies on AIDS 2007-2011", the Hong Kong Advisory Council on AIDS (ACA) has initiated a community assessment for several target groups. PLHA was identified as one of the priority groups. A working group comprised of frontline health care professionals, medical social worker, PLHA and representatives from non-governmental organizations (NGOs) providing services to PLHA has been convened and tasked with this community assessment on PLHA. The list of members is shown in Appendix 1.

2. Goal and Objectives

The objectives of this assessment and evaluation were to:

- Evaluate the existing services and support available to PLHA
- Assess the needs of PLHA
- To identify unmet needs and service gaps
- To make recommendations on ways to improve the care and welfare for PLHA

3. Framework and Methods

3.1 The whole assessment consisted of the following aspects:

- Study of the epidemiological profile of HIV/ AIDS in Hong Kong (HK) and the foreseeable trend
- Overview of existing services available to PLHA
- Overview of current and new initiatives / development in overseas countries
- Needs assessment of PLHA (see Para. 3.2 for details on this part)
- Recommendations to address unmet needs and to bridge gaps

3.2 A qualitative approach was chosen for the needs assessment. The process comprised of the following components:

(i) Questionnaire survey among PLHA

3.2.1 This was conducted during the period from 19 Dec 2005 to 10 Feb 2006 (8 weeks) in Kowloon Bay Integrated Treatment Centre (ITC) of the Department of Health (DH) and the HIV Clinic of the Special Medical Service of Queen Elizabeth Hospital (QEH). All patients going to these two clinics for follow up in the above period were given an anonymous self-administered questionnaire (Appendices 2 and 3) and were encouraged to fill in on a voluntary basis. It was intended to include as many PLHA as possible.

3.2.2 The objective was to solicit the views from the perspective of PLHA. In order to facilitate the subjects to express their life experiences, needs and problems in their own words, the questions were set to be opened–ended and qualitative in nature. Four main areas were focused in the questionnaire and were used as a structured framework to guide the responses from the participants:

- <u>Medical care and related services:</u> HIV out-patient services, hospital services, medications and treatment, other medical services (e.g. Genito-Urinary Medicine and dermatology clinic, eye clinic, TB and chest service, clinical psychology, etc.), health counselling in HIV clinic, protection of privacy and confidentiality, attitude and general knowledge of health care workers (including paramedics) not working in HIV-related service, etc.
- <u>Social services:</u> medical social workers, transportation and escort service to clinic or hospital for patients with mobility problem, financial assistance, employment support, peer counselling and patients' support group or self-help group, social support (e.g. home helper, child care, housing, etc.)

and services provided by NGOs, etc.

- Acceptance by and integration into society: encounters of discrimination, degree of acceptance by society, ways to help them to face the infection and be fully integrated into society, etc.
- Concerning services / support provided in the community, their perceived gap / deficiency leaving their needs in facing the conditions related to the infection unmet

3.2.3 Those who were unable to fill in the questionnaire by themselves would be helped by nursing staff. The questionnaires were to be put back into a collection box in the waiting area by the patients. A total of 100 questionnaires were collected at the end (82 in ITC, 16 in QEH and 2 through a NGO). The response rate was estimated to be about 10% in ITC. The response rate in QEH was much lower.

(ii) Focus groups

3.2.4 Four separate focus groups were conducted, including two involving PLHA, one involving health care workers and social worker of ITC, and one involving frontline service providers of AIDS-specific NGOs providing services to PLHA. The topic was on welfare and needs of PLHA and the perceived services gaps, with insights from the perspective of different stakeholders.

(iii) Semi-structured interviews

3.2.5 A nursing officer and a patient representative from HIV clinic of Special Medical Service of QEH and parents of three affected children were interviewed in order to gain more in-depth views from them.

3.3 Apart from the above work, the investigators sought broader consultation with individuals with experience and expertise in the area of HIV care through informal informant interviews. After the completion of the whole processes, all the ideas related to the needs and the recommended actions and solutions were analyzed. Emerging themes were identified and grouped into different categories and presented to members of the working group for discussion. Views from them were solicited and the results were discussed among them to reach consensus.

FINDINGS AND RESULTS

4. Epidemiological Trend

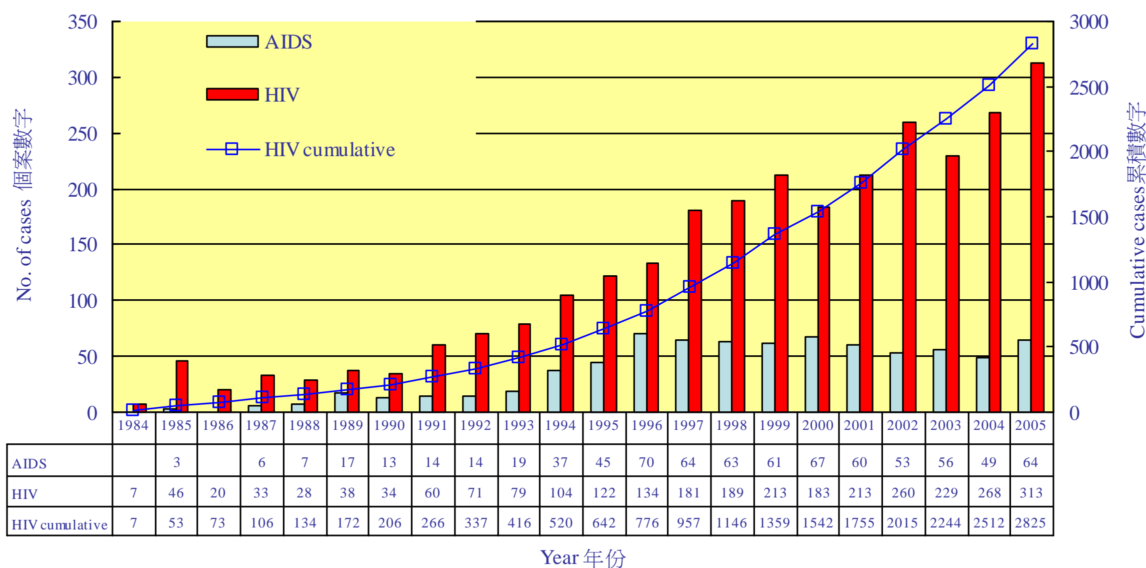
4.1 From the initial isolated reports in 1981 in the United States, AIDS has grown into a global problem. According to figures released by UNAIDS, the global number of PLHA has reached its highest level at the end of 2005 with an estimated 40.3 million people, up from an estimated 37.5 million in 2003. There were five million new infections in 2005. More than three million people died of AIDS-related illnesses in 2005; of these, more than 500000 were children.[1] In Asia, some 8.3 million people were living with HIV and 1.1 million people became newly infected in 2005.[2]

4.2 In HK, the accumulated totals from 1984-2005 have reached 2825 for HIV reports and 782 for AIDS reports respectively (Fig. 1). In 2005, DH received a total of 313 HIV reports and 64 AIDS reports. When compared to figures of the previous year, there was a 17% rise in HIV reports and a 31% rise in AIDS reports. Of which, 256 (82%) HIV reports were from men. This represented a 25% rise from last year's figures of 205 cases. The male to female ratio was 4.5:1.[3]

4.3 Of the cases reported in 2005, about 64% of these reports were believed to have been transmitted sexually, 8% through injecting drug use and 26% with risk undetermined. This means that sexual transmission has accounted for more than 85% of HIV reports with identified risks. For the accumulated total reports with known route of transmission since 1984, 91.6% acquired through the sexual route (of which, 68% heterosexual, 26% homosexual and 6% bisexual), 4.7% through injecting drug use, 3% through transfusion of blood / blood products and 0.7% through the perinatal route.

4.4 For children under 15, the number was very small. From 1996-2005, there were only a total of 16 HIV cases reported, 87.5% of which acquired through the perinatal route. Since the introduction of the universal antenatal screening programme in 2001, the number acquired through this route is expected to decrease further.

Fig. 1. Number of reported HIV and AIDS to DH from 1984-2005



	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
AIDS		3		6	7	17	13	14	14	19	37	45	70	64	63	61	67	60	53	56	49	64
HIV	7	46	20	33	28	38	34	60	71	79	104	122	134	181	189	213	183	213	260	229	268	313
HIV cumulative	7	53	73	106	134	172	206	266	337	416	520	642	776	957	1146	1359	1542	1755	2015	2244	2512	2825

5. Overview of Existing Services

A. Medical care and related services

5.1 In the public sector, patients can freely choose to be followed up in either the Integrated Treatment Centre run by DH or the HIV clinic of Special Medical Service in QEH run by the Hospital Authority (HA). Eligible persons (a holder of HK Identity Card and children who are HK residents and under 11 years of age) are charged at a highly subsidized rate ($100 at first attendance and $60 at subsequent attendances plus drug cost at $10 per item). For those with financial difficulties, waiver can be applied through medical social worker. The accessibility of the HIV medical services for eligible PLHA is considered great.

5.2 However, non-eligible persons are charged at a much higher rate to recover cost ($1,910 per consultation plus actual drug and pathology costs). This high financial burden might be barrier for non-eligible persons to have access to public HIV medical service.

5.3 In the ITC, a comprehensive range of services is provided, including

Dermatology and Genito-Urinary Medicine Clinics providing medical management and health counselling to persons with dermatological problems and sexually transmitted infections (STIs), medical social services, counselling services, psychiatric consultation, etc. PLHA requiring in-patient treatment can be referred for admission to Princess Margaret Hospital. There is also a range of preventive programmes such as partner counselling and referral services, HIV infected drug users' programme, etc.

5.4 The AIDS Clinical Service of QEH provides wide range of comprehensive care covering both in-patient and ambulatory care. The multidisciplinary care team consist of specialists of different specialties, medical social worker, dietician and clinical psychologist.

5.5 Most affected children are followed up in the Paediatric Unit of Queen Mary Hospital, while some were followed up in the HIV clinic in QEH together with their parents.

5.6 In 2005, 74% of the newly reported HIV cases were managed in public specialist services.

B. Employment support

5.7 Occupational therapists in QEH offer employment support programme to PLHA. For those with disability, the Social Welfare Department (SWD) provides supported employment to them.

5.8 Various supportive services related to employment are provided to the general public by Labour Department and are accessible to PLHA. Its Employment Services Division provides free employment and recruitment services to job seekers and employers. Selective Placement Division provides free employment assistance to job-seekers with disability and free recruitment service to employers. The Youth Employment Division implemented the Youth Work Experience and Training Scheme in 2002, which provides young people aged from 15-24 and with education attainment below degree level with on-the-job and job-related training for a period of 6 to 12 months.

5.9 In 1992, the Government established the Employees Retraining Board to provide retraining to unemployed persons with junior secondary education or below

and to assist them to take on new or enhanced skills so that they can adjust to changes in the economic environment. A network of training bodies funded by the Employees Retraining Fund is responsible for the provision of retraining courses and a wide variety of retraining places had been offered. The goal is to enhance their employability.

C. Continuing education

5.10 The Continuing Education Fund subsidizes adults with learning aspirations to pursue continuing education and training courses. Eligible applicants will be reimbursed 80% of their fees, subject to a maximum sum of HK$10000, on successful completion of a reimbursable course or module(s) forming part of the course.

D. Financial assistance

5.11 For assistance to PLHA with financial difficulties, there is a specific support fund administered by SWD for PLHA and their families. This provides temporary financial assistance to needy patients and their families.

5.12 For haemophiliacs and others infected with HIV through transfusion of blood or blood products prior to August 1985, grants of ex-gratia payments have been given to them from the AIDS Trust Fund (ATF) established in 1993 and a second round of additional ex-gratia payment and a long term financial scheme to support those still surviving have been launched since 2005.

5.13 Apart from the above, the Comprehensive Social Security Assistance Scheme provides a safety net for those who cannot support themselves financially. It is designed to bring their income up to a prescribed level to meet their basic needs. Residents who have resided in HK for at least seven years can apply. Those certified by doctors to have disability are also eligible to apply for disability allowances.

E. Services provided by non-governmental organisations

5.14 urrently, three NGOs provide direct services for PHA, namely Hong Kong AIDS Foundation (HKAF), AIDS Concern (AC) and the Society for AIDS Care (SAC). Different services were organised for PLHA over the years. Their financial sources are mainly from ATF and from other donations. ATF provides financial

support to publicity and public education programmes and medical and support services for HIV-infected patients to augment the existing services provided by HA and DH (see Appendix 4 for the amount of funding approved by the Medical and Support Services Sub-committee of ATF).

(i) Hong Kong AIDS Foundation

5.15 Since its establishment in 1991, HKAF has been providing a series of services specifically addressing the needs of PLHA. Counselling service in the form of case work is provided to PLHA and their significant others. There are also support groups to provide group work service. It also organises volunteer service to encourage PHA to participate in voluntary work and to make contributions to the HIV/AIDS services. To cultivate their working habit, some PLHA are trained to assist in the prevention work in different vulnerable communities and to provide hotline service to the public and buddy service to other PLHA. Besides, a resource corner was set up to provide (or lend) tangible goods to PLHA who are in need, including wheel chair, refrigerator, cooker, etc. Referral services provided include legal advice, advice on insurance issues, etc.

(ii) AIDS Concern

5.16 Established in 1990, AC is the earliest AIDS NGO in HK. Its support services to PLHA include a free soup delivery service, peer counselling service and a free "Ride Concern" transport service accompanying patients to clinic appointments. Besides, workshops are conducted and social gatherings are organised to strengthen patients' support for one another. One example is the Positive Living Group (樂生社) which is a self-help group for PLHA.

(iii) The Society for AIDS Care

5.17 SAC is the NGO specifically serving PLHA by providing a comprehensive range of services. Home care service is a direct community care service focusing on the psychosocial and physical needs of PLHA, their families and carers. Through intensive contacts, home care nurses and social workers fill in the gaps of their specific needs at their home, which hospitals and clinics cannot cater for. Nurses provide psychological support to PLHA and their family members by regular home and hospital / clinic visits. A 24-hour emergency service is provided for those who are in need of urgent consultation and assistance. It is a unique service that extends to

alleviate carers' anxiety. Bereavement support to family members is also offered.

5.18 A multi-disciplinary Day Centre is operated to provide facilities to improve the quality of life of their members and to fulfil their needs, e.g. rehabilitation and reintegration. Clients and carers may be referred to attend the Day Care Centre programs to share their concerns with other PLHA and workers. Other targeted activities include gym exercises, ballgames, Tai Chi class and various educational programs and talks. Aromatherapy and adventure-based programs are organized to help PLHA to manage stress and overcome fear. Transportation service is provided for wheel-chair bound and disabled PLHA so as to enable them to attend centre activities and rehabilitation programs. Physiotherapy service was commenced in early 2002 to assist physically impaired or incapacitated patients to improve the physical flexibility and to maintain their physical strengthen and the self-care ability. Peer support group activities, either centre based and outdoor, are regularly organised for PLHA and their families / carers.

F. Funeral services

5.19 Although the mortality of HIV/ AIDS has declined dramatically in recent years, funeral service is still a concern for PLHA. Some years ago, there was only one undertaker offering funeral service to HIV patients. In this assessment, a random telephone survey of 12 undertakers showed that only 4 of them refused to handle bodies of PLHA. The situation seems to be improved. However, some will charge a higher price from the clients.

5.20 The guideline "Precautions for Handling and Disposal of Dead Bodies" has been published jointly by DH, HA and Food and Environmental Hygiene Department in 1994 and revised four times with the latest edition published in 2005.[4] HIV infection is classified as Category 2, in which viewing in funeral parlour is allowed. However, some funeral service providers still hold the concept that the body of deceased AIDS patient is not allowed to be viewed.

6. Review of International Developments

6.1 PLHA are increasing recognized to be significant in overall HIV prevention. In the United States, the Centres for Disease Control and Prevention (CDC) published a report stating new strategies by emphasis on prevention of transmission by HIV-infected persons.[5] Through ongoing attention to prevention, risky sexual and needle-sharing behaviours among PLHA can be reduced and hence

transmission of HIV infection prevented. Medical care providers can substantially affect HIV transmission by screening their HIV-infected patients for risk behaviours; communicating prevention messages; discussing sexual and drug-use behaviour; positively reinforcing changes to safer behaviour; referring patients for services such as substance abuse treatment; facilitating partner notification, counselling, and testing; and identifying and treating other STIs.

6.2 Recently, CDC also developed the new initiative ***Advancing HIV Prevention*** (AHP) with prevention of new infections by working with PHA and their partners as one of the four strategies.[6] Through this initiative, CDC promotes preventive and treatment services for PLHA within and outside traditional medical settings by:[7]

- Working with Health Resources and Services Administration to reach those who have been diagnosed with HIV but who are not receiving treatment and care.
- Conducting demonstration projects through health departments to provide '*prevention case management*' and counselling for PLHA.
- Standardizing procedures for prevention interventions and evaluation activities to ensure that such measures are both appropriate and effective.
- Ensuring that requirements related to partner notification in grant guidance are fully met.
- Piloting new approaches to partner notification, including rapid HIV testing for partners and using peers to conduct appropriate partner notification, prevention counselling, and referral.

6.3 The 'Prevention Case Management' (PCM) advocated is a client-centred HIV prevention activity that combines HIV risk-reduction counselling and traditional case management to provide intensive, ongoing, individualized prevention counselling and support.[8] In this regard, CDC organizes PCM Demonstration Projects for community-based organizations with the goals to provide individually tailored assistance and HIV risk-reduction counselling to PLHA.

6.4 In 2005, the Presidential Advisory Council on HIV/AIDS has made the following recommendations on treatment and care to PLHA:[9]

- Programmatic initiatives and resource allocations should follow the epidemic and address the devastating and disproportionate impact of HIV disease on ethnic minority groups (African Americans and other communities of colour).

- Treatment and care should be integrated with prevention efforts.
- Testing should be encouraged wherever possible.
- Funds need to be distributed more effectively.
- The core medical service model should include a range of services to keep those needing HIV care in treatment, adhering to HIV medications and leading healthy, productive lives. Mental Health Services and Substance abuse treatment need to be included. Case management and adherence counselling, oral health care and treatment of co-morbid conditions accompanying HIV infection, such as Hepatitis B and C must also be covered.
- The federal government needs a comprehensive, invigorated communication campaign of domestic HIV/AIDS policies.
- Prisons should have intensive HIV education and counselling programs to protect inmates and the communities to which they will return.
- Creative solutions must be found to encourage more health care professionals to choose to develop the skills necessary to treat HIV.
- Research into new and novel pharmaceutical agents to better manage HIV infection must be encouraged.

6.5 All along, UNAIDS strongly encourages the involvement of PLHA in the design, implementation and evaluation of prevention strategies. The principle of Greater Involvement of People Living with HIV/AIDS (GIPA) in the AIDS effort was formally recognized at the 1994 Paris AIDS Summit, when 42 countries agreed that ensuring their full involvement at national regional and global levels would stimulate the creation of supportive political, legal and social environments. The aim of prevention for PLHA is to empower them to avoid acquiring new STIs, delay HIV disease progression and avoid passing their infection to others. Prevention counselling strategies increase knowledge of HIV transmission and improve safer sex negotiation skills. Other HIV prevention strategies also include scaling up, focusing and improving services and commodity delivery; services for serodiscordant couples; protecting human rights; strengthening community capacity for mobilization; and supporting advocacy, policy change and community awareness.[10]

7. Needs Assessment and Recommendations

7.1 'Prevention from the positives' will definitely be a dominant direction in the overall prevention strategies. Study has shown that interventions targeting PLHA are efficacious in reducing unprotected sex and acquisition of STIs and efficacious strategies should be incorporated into community HIV prevention efforts.[11]

Identifying and addressing the needs of PLHA contributes to the overall prevention efforts.

7.2 The findings of the needs assessment were grouped into a number of dominant themes under five main categories, namely (A) medical care and the related support; (B) social services ; (C) acceptance and integration into society; (D) children's needs; and (E) undiagnosed HIV-infected persons. They are shown below together with the suggested recommendations specific to each problem or need. The fact that some problems and needs are inter-related should be kept in mind and recommendation in one area might provide solution beyond the problem or need addressed directly by it.

A. Medical care and related support

7.3 In the physical aspects, the health status of PLHA under treatment has been improved markedly since the introduction of highly active anti-retroviral therapy (HAART) in 1997 and availability of effective prophylaxis against some opportunistic infections. The durations of survival and AIDS-free status extended markedly.[12] Moreover, the mortality and morbidity of advanced HIV disease have declined in HK.[13] Most of them were satisfied with the medical services offered to them. They regarded the universal access to affordable treatment immensely important. The main problems or needs are related medical fees (Box 1), sustainability (Box 2) and operation hours (Box 3).

Box 1

Problem/ need: Potential financial burden arising from medical fees
Unlike the free services in TB and chest clinics and social hygiene clinics, PLHA need to pay a small amount of fees for the consultation and the drugs in HIV clinics at the present moment. Some PLHA expressed worry on the possibility of rise in medical fees (e.g. consultation fee, hospitalization fee and also the increase in charge of the prescribed drugs) in the future medical reforms. Any great rise will definitely make the service unaffordable. The cumulating budget deficit of HA, the introduction of Standard Drug Formulary and its apparent plan to increase patients' share of the total cost made PLHA uneasy about the future charge on clinical services. As the costs of antiretroviral drugs are quite expensive and nearly all of them are unable to have medical insurance, this issue is particularly relevant in this context.
Recommendation: HIV clinical care must be ensured to be financially affordable to

all PLHA residing in HK.

As HIV can be considered as a life-long infectious disease with extended period of communicability depending on the viral load in the body, in order to prevent further spread from PLHA, treatment and intensive risk reduction counselling is of utmost importance. Study showed clinician-delivered HIV preventive intervention resulted in reductions in unprotected sex.[14] HIV clinical care contributes to more effective HIV prevention by providing a window of opportunity to focus prevention on PLHA. Early diagnosis and effective treatment and care are vital to stop the spread of HIV. Thus, treatment and care is part and parcel of prevention and should be integrated with prevention efforts.

Sustained progress in the response against AIDS will only be attained by intensifying HIV prevention and treatment simultaneously.[15] With this in mind, the clinical care and treatment provided to PLHA should be viewed as a form of public health prevention. It should be universally available to all PLHA in order to protect the public by preventing on-going spread and hence maintain HK as a low prevalence area.

As HIV clinical care costs far more than what an ordinary person can afford, the principle that no one should be denied of adequate medical treatment due to lack of means is particularly valid in the case of HIV / AIDS. Due consideration of their ability to pay should be taken in any rise in medical fees of HIV treatment in the future.

Box 2

Problem/ need: Sustainability of high quality medical care is at stake.

Concerns are raised on the foreseeable rapid increase in demand for the clinical services. The reason behind is the insidious escalation in number of patients over the years (Table. 1). First, this is due to the impact of decreased mortality since the introduction of HAART, which has so successfully turned HIV infection into a manageable chronic disease. Second, there is continual input of newly diagnosed cases. For instance, it is estimated the case load in ITC would likely to double in five years' time.

There are only two HIV clinics in HK. If the case load continues to rise at the current rate, the services provided will soon be stretched to the saturation limit and the existing manpower will not be able to cope with the workload. Shortage in manpower will constitute formidable challenges in maintaining the existing high quality clinical services. This sentiment is repeatedly echoed by different health care workers. Some respondents of the questionnaire survey also mentioned that they had to wait long time during each consultation. The sustainability of the current high

quality will be constrained by shortage of experienced HIV health care professionals. In the worst scenario, the service provided might be stretched 'thin' gradually and hence adversely affected (in terms of time spent on each patient and the frequency of follow up).

Recommendation: Adequate resources should be committed to cater for the foreseeable increase in demand.

Care to PLHA should never be compromised by lack of resources in both infrastructure and manpower. Engaging PLHA as partners in prevention in the clinical settings offers a very great opportunity to stop on-going transmission. Also, providing holistic service of high standard is essential to ensure perfect drug adherence and this is crucial in prevention of emergence of resistance strains which will render the current drugs ineffective. Nonetheless, effective prevention counselling on behavioural change (e.g. safer sex and no sharing of needles) is time-consuming and requires a lot of skilful staff. Apart from telling the messages to the patients, enough time need to be spent on developing good and enduring patient-provider relationship and gaining trust from the patients. All these are labour-intensive, but the price is worth paying.

Prudent planning on the long-term provision of HIV clinical care, basing on the existing and estimated increase in the number of patients, has to be conducted as early as possible so as to respond to the expected rising demand in the coming five years. Resource allocation should follow the development of the HIV epidemic and adequate resources should be committed to tackle the increase in demand.

Moreover, sufficient resources should be devoted by both DH and HA in the training of successive generations of health care professionals in HIV medicine. HIV is a devastating medical illness that requires a high level of expertise in its management. New technologies, increasing therapeutic options and changing treatment guidelines make treatment and care increasingly complex. Training of professionals with expertise in HIV care requires a long lead time and as such, planning is needed in advance. DH and HA might collaborate in the training of professionals in HIV medicine to enhance the preparedness and surge capacity. Also, in order to make this field more attractive to young doctors, the Hong Kong College of Physicians of the Hong Kong Academy of Medicine is recommended to look into the possibility of formalizing a structured training in HIV medicine and the recognition of this as a sub-specialty in internal medicine.

Table 1. Statistics of ITC 2001-2005

Year	New +ve case	New Case Consultation*	Cumulative Cases	Total number of consultations
2001	100	96	901	3774
2002	146	137	1047	4620
2003	109	114	1179	5389
2004	140	134	1318	5706
2005	172	162	1490	5813

*the referred cases actually turned up

Box 3

Problem/need: Current operating hours and location of clinics are not addressing the needs of some PLHA.

It is noticed that the existing clinical services do not cater for the needs of some PlHA in terms of operating hours and geographical location.

First, some PLHA find it difficult to take leave for follow up and thus miss scheduled appointments from time to time. Many of them have strong perceived non-acceptance by others and this barred them from letting their employers and colleagues know about their positive HIV status. Some worried about losing the job if the employer knew their infection. Therefore, they usually do not take sick leave for medical appointment. Rather, they would take their own vacation leave for personal affairs to attend the appointments. As time goes by, they find it embarrassing to have frequent "personal reasons" for absenteeism, though this situation has improved in recent years when they can enjoy more stable physical condition and manage to have less frequent clinic visits. Some with full employment prefer to have more flexible clinic hours (e.g. weekend or evening clinic).

Secondly, the location of the two clinics is inconvenient to some PLHA. They have to travel long distance to attend the clinic. They prefer to have one at another location (e.g. in the New Territories or Hong Kong Island) for them to choose.

Recommendation: More user friendly service should be provided within the limit of available resource.

Nearly all public specialist clinics in HK operate only during normal office hours. However, it is understandable that a few PLHA do have unique needs for services outside normal hours. Since the phenomenon of keeping the positive HIV status secret will not be altered in the future, further studies need to be carried out to assess the actual number of people with real difficulty in going to follow-up during normal hours and are at risk of default because of this reason. Defaulters are actually

wasting the existing resources and causing harm to their health. If it was found that the genuine need of access to medical appointments outside office hours was great, ways should be devised to solve this problem and to help them.

In view of the potential future expansion of service, if a new clinic is to be set up, a suitable location to allow greater accessibility to those living or working far away should be considered.

7.4 Nowadays, many PLHA would not progress into AIDS for many years and their life span is expected to be prolonged. The aging of PLHA, just like any ordinary people, will likely lead to more frequent occurrence of common chronic diseases, such as hypertension, diabetes, back pain, arthritis, etc. Due to the metabolic side effects of some common anti-retroviral drugs, the risk of cardiovascular diseases is also greater among PLHA. As they age, the prevalence of conditions not directly related to HIV / AIDS and requiring management by primary care doctors or other specialists increases (Box 4).

Box 4

Need: Primary medical care of non-HIV related conditions

Some PLHA prefer to have a one-stop clinic to cater for all their medical needs, including those not directly related to HIV infection. For example, it is suggested that primary care doctor should be available in HIV clinics. Firstly, they feel 'safe' and comfortable to stand out or disclose their identity in HIV clinic because other persons around are also PLHA. In other clinical settings, they are unwilling to disclose their status due to unpredictable attitude of staff. Then, they face the dilemma of whether to tell doctors about their status and/or current anti-retroviral medications. They think they are obliged to do so as some drugs prescribed might have interaction with the anti-retroviral drugs and also their HIV status might have bearing on doctor's clinical judgment. However, they are reluctant to do so in most of the time in order to avoid any negative consequence, unless absolutely necessary. Most of these worries originate from their perceived stigmatization or past unpleasant experience. Secondly, some worry that the health care workers outside HIV clinic might not have adequate knowledge on HIV/ AIDS.

On the contrary, some proposed the mainstreaming of general medical care provided to PLHA because any action to separate them as a distinct group in a specific HIV service location would propagate the labelling effect on PLHA, both by health care workers and the public. They prefer to go back to HIV clinic only when they have to be seen by HIV specialist. For other conditions, they prefer to go to other clinical settings just like any ordinary people. However, it is found that they

tend to withhold the positive status from other caregivers in some of the times, which might not be optimal in terms of medical care. Also, they are those without bad personal experience during previous encounters in other clinical settings.
Recommendation: Optimal mode of delivery of primary health care for PLHA needs to be looked into.
As PLHA live longer, more and more diseases unrelated to HIV infection or secondary to HIV infection but requiring management in family medicine or another specialty arise. Moreover, providing primary care by HIV specialists is expensive and is not the optimal approach. The perceived stigmatization by PLHA will continue to affect them and the associated problems are genuine. There is no simple solution. The options of either mainstreaming other non-HIV related medical services or providing comprehensive medical care in HIV clinics need further exploration before any suitable option can be decided on.

7.5 The degree of protection of confidentiality in HIV clinics is generally perceived to be guaranteed. PLHA have not encountered any breach of confidentiality inside HIV clinics. One reason is that they are less sensitive to their status in HIV clinic. One the other hand, in non-HIV clinical settings, the problems are related to protection of privacy (Box 5) and knowledge of health care workers on HIV/ AIDS (Box 6).

Box 5

Problem/need: Issues related to protection of privacy in non-HIV clinical settings
Some PLHA encountered occasional breaches of confidentiality in other health care environments. Some came across situations in hospital wards where their HIV status was talked about loudly, e.g. during the handover of duty by nurses. Some said their status was voiced out loudly by health care assistants in circumstances where there were many people around, e.g. X-ray department. Though these were not believed to be deliberate acts, the carelessness of these 'need-to-know' workers made the patient embarrassing and was considered undesirable.
Recommendation: To enhance education to health care workers on protection of patient's privacy
Education to health care workers on protecting the privacy of HIV patients needs to be enhanced. They should be trained to become more sensitive to the dignity and humanity of those infected with HIV. PLHA have the right to have their medical information properly safeguarded. In view of the stigmatization carried with this infection, extra precaution should be exercised to protect their privacy which is already vulnerable to intrusion.

Box 6

Problem/need: Inadequate basic knowledge on HIV infection among health care workers
In general, the knowledge on HIV/ AIDS among health care workers in non-HIV clinical settings are perceived to be poorer when compared with staff in HIV clinics, which is to a certain extent an expected phenomenon. Nevertheless, the degree of ignorance on HIV infection among some staff in non-HIV clinical settings is considered unacceptable, especially among paramedics and supporting staff and on infection control issues. Some staff do not fully aware of the routes of transmission of HIV so that they are 'over-precautious' in their work, e.g. wear glove when changing clothes for HIV-infected patients; request them to use disposable utensils; put them as the last case in a consultation session out of unjustified reason; put them into isolation ward; not allow them to use toilets in ward and request them to use pans, etc. Another example was refusal to admit a HIV-infected person with a condition not related to HIV by referring the patient back to the far-away hospital where the HIV infection is managed. The behind reasons might be scare, anxiety and feeling of incompetence to manage HIV patients. All these peculiar things done on PLHA may not mean that they discriminate against them, but rather out of ignorance on HIV infection. Unfortunately, these acts were perceived by PLHA to be a kind of uncivilized rejection and labelling on them and incident of requesting discharge against medical advice by patients because of these occurred in hospital.
Recommendation: To provide training to improve knowledge of health care workers on HIV
Information dissemination for different health care workers on the up-to-date knowledge of HIV and AIDS should be strengthened and additional training tailored to the needs and level of understanding of different ranks, especially on transmission routes and infection control, should be provided. Various guidelines can be promulgated in more effective means to reach the audience. Besides, the teaching on HIV/ AIDS in medical and nursing schools should be given more emphasis so that new generations of health care professionals can have adequate awareness and knowledge on HIV. This can help to promote acceptance and minimize unjustified precautious measures taken on PLHA, which will arouse misunderstandings and subsequent complaints on the health care workers.

7.6 Partner Counselling and Referral Services (PCRS) is recommended by overseas authorities as one component of a comprehensive HIV prevention

programme. In HK, the former Committee on Promoting Acceptance of People Living with HIV/AIDS of the ACA published the "Recommended Ethical Principles on Partner Counselling and Referral for HIV Infected Individuals in Hong Kong" in 2004[16]. The principles stated were:

- PCRS should be conducted by health professionals who are taking care of HIV infected patients. Appropriately conducted PCRS is beneficial to HIV infected individuals, their partners and the community.
- Approaches to provide PCRS is diversified with different pros and cons. Health professionals should work with the patient to decide on the most appropriate approach.
- The conduct of PCRS should always comply with local law and professional codes. PCRS protocol should be developed by individual health service taking care of HIV infected patients. In case of doubt when handling difficult cases, advice from relevant authority should be sought.

More guidance to health care professionals on this area is recommended (Box 7).

Box 7

Problem/ need: Inadequate guidance to frontline health care workers on PCRS
Despite knowing these principles, frontline staff sometimes find it difficult to handle partner counselling and referral without comprehensive and standardized guidelines. Also, it is recognized that there are discrepancies in the practice of PCRS in the two HIV clinics in HK, in terms of formats. It is also suggested that a central service responsible for PCRS be set up to standardise the procedure. However, as HIV infection is not a statutory notifiable disease in HK, there are many legal and ethical issues involved in this controversial subject.
Recommendation: Comprehensive guidelines should be disseminated to all frontline staff responsible for PCRS.
PCRS is critical to allow those at risk of infection to undergo HIV test, prevent HIV transmission to people who may be exposed either sexually or through needle sharing and also, improve care and support for the already infected partners. Health care professionals are encouraged to conduct PCRS on all PLHA. More guidance and support to frontline workers should be provided by HIV clinical units in order to offer state-of-the-art PCRS to PLHA, e.g. practice guidelines, training, etc. Innovative ways could be devised to strengthen PCRS in the future.

7.7 The prevalence of hepatitis C virus (HCV) infection among PHA is much higher than the general population. Limited study showed that the prevalence of anti-HCV antibody in new HIV/ AIDS patients in ITC from 2001 to 2004 (Data

source: ITC, CHP, DH) ranged from 7.9 – 18%.[17] This may be due to the shared routes of transmission, i.e. sexual route and needle sharing in injecting drug use. Scientific studies have shown that HCV and HIV co-infection can result in more rapid deterioration in both HIV infection and also the HCV infection, leading to increased morbidity and premature mortality among those co-infected with HCV. They are prone to suffer from accelerated liver disease.[18] The problem for PLHA is inadequate access to HCV treatment (Box 8).

Box 8

Problem: Inadequate provision of treatment service to those co-infected by Hepatitis C
Effective treatment for HCV is available nowadays, but this is not universally available to PLHA with HCV infection. The very limited access by PLHA may be resulted from the stringent selection criteria for treatment and also the high cost incurred by the treatment.
Recommendation: To enhance treatment of PLHA co-infected with HCV
Treatment of co-morbid conditions accompanying HIV infection, such as Hepatitis B and C, should be available to PLHA. Core medical services should include treatment for co-morbidities such as HCV. HIV infection per se should not be an exclusion criterion for access to treatment of HCV infection.

7.8 As PLHA can now lead a better life in the HARRT era and most of them remain healthy for years while on treatment, many will consider having their own children. Nearly all PLHA who desire procreation need counselling on reproductive options and access to services on assisted reproduction. The need for assisted reproduction is not met (Box 9).

Box 9

Problem/need: Insufficiency in assisted reproduction services
It is found that PLHA have difficulty in accessing services related to reproductive medicine, e.g., sperm washing, assisted reproductive technology provided to sub-fertility persons in obstetric and gynaecology units of local public hospitals, etc. Their demand on this aspect is not adequately met at the present moment.
Recommendation: To improve access to reproductive technology by PLHA
The various aspects of the issue of procreation in PLHA, including the ethical and the medical aspects, need to be looked into, especially for serodiscordant couples who might have a risk of transmission during unprotected intercourse. It

was stated in the "Recommended Ethical Principles Regarding the Use of Assisted Reproduction in HIV Infected Individuals" published by ACA in 2004 that HIV infected individuals should enjoy equal right to access assisted reproductive treatment in HK as those who are HIV negative.[19] They should be helped to make informed decision related to child bearing and their personal decision needs to be respected. Special attention should be paid to their greater demand than ordinary couples for professional advice on reproduction when they decide to procreate. Their access to assisted reproduction ought to be enhanced in the future.

7.9 Clinical psychology service is considered to be a necessary service, especially for newly diagnosed patients. Firstly, people newly found to be infected always encounter difficulty in facing this life crisis. They are often overwhelmed by fear and anger and may have emotional and adjustment problems, during which clinical psychologist can be of help to them to face the acute phase. Secondly, many PLHA suffer from psychological trauma and distress resulting from discrimination, guilt and self-blame, which may also need to be managed by clinical psychologist. The provision of clinical psychology service is limited (Box 10).

Box 10

Problem/ need: Clinical psychology service provided to PLHA is insufficient

Although clinical psychology service is available in both HIV clinics at the moment, the service is insufficient to meet the demand. The waiting time in ITC is long. For the clinical psychology service in QEH, it is supported by funding from ATF. There would be threat of cessation if further funds were unavailable. The clinical psychology service previously provided by a NGO was stopped because of cessation of funds.

Nurse counsellors in both HIV clinics provide some counselling on the emotional and psychosocial aspects, but they are not formally trained in psychology, the focus is still on the health and prevention aspects. To a certain extent, social workers can supplement the needs on this aspect, but those with abnormal psychological states are best to be managed by clinical psychologist. Also, psychiatric consultation is available in the ITC, but many patients think that psychiatric service is focused on mental illness and cannot replace clinical psychology service.

Recommendation: PLHA with psychological problems should have access to support by clinical psychologist.

As many PLHA have psychological stress, which hinders them from having a productive life even though they are physically healthy, clinical psychological

support to patients should be expanded to meet their needs. More resources should be devoted to strengthen clinical psychology service for the PLHA with needs. The benefit is two-fold. Solving their internal psychological conflicts not only helps them to face the disease more positively, but also contributes to better adherence, less risky behaviour and greater responsibility in halting on-going spread.

7.10 As time goes by, more PLHA will be put on anti-retroviral drugs (ARTs). Besides, the period they have been on ARTs will increase. These would increase the probability of the emergency of strains resistant to the current ARTs. In order to provide salvage therapy for those patients with resistance to the currents drugs, access to new or experimental drugs is tremendously important (Box 11).

Box 11

Problem/ need: Drug options for those with treatment failure are minimal.
The availability of all FDA approved drugs in HK is considered to be of paramount importance. This can allow doctors to have a wider choice of drugs to prescribe, especially for those with virological failure secondary to development of drug resistance. As there is absence of effective clinical trials system in HK, patients suffered from treatment failure with the current drug options have great difficulty to get access to experimental treatment.
Recommendation: Convenient access to new/ experimental anti-retroviral drugs in HK
The number of PLHA on ARTs is increasing and some are prone to the development of resistance. New drugs are vital to PLHA with failure to standard treatment. A mechanism should be in place to allow early registration of proven effective ARTs in HK and a system for clinicians to have access to experimental drugs should be in place in the future.

7.11 Last, some other supportive services were insufficient at the moment, including dental services (Box 12) and transportation services for those with difficulties in attending clinic appointments (Box 13).

Box 12

Problem/ need: Insufficient provision of public dental service
Dental service provided to PLHA is insufficient at the moment. People encountered dental problems can be referred to government dental clinic after assessment by doctors. Albeit the governmental dental service available to the general public at the moment is still very limited, except in emergency situation,

PLHA are of the opinion that they have a special need for a wider scope of service due to their infection. Presently, the government dental service classifies HIV patients in the Care Level 2, in which management of acute and chronic oral manifestations such as fungal infection, ulceration, hairy leukoplakia, Kaposi sarcoma, etc., is provided. However, ongoing follow up is not provided.

From their point of view, a responsible patient should tell a dentist about the HIV infection. Some concern about refusal of dental treatment by private dentist, but there is no evidence to substantiate this claim.

Recommendation: To improve dental service provided to PLHA

Overseas study showed that oral manifestations of HIV disease, such as thrush, warts, gum disease and rapidly progressing dental decay, occur in a very high percentage of PLHA.[20] Oral health care should be considered as part of core medical services available to them.

Providing more HIV education to the dental profession might help to increase their awareness and acceptance and hence alleviate the worry of some PLHA.

Some mainstream NGOs provide affordable dental service to the public. AIDS NGOs are encouraged to arrange such services in another format for those PLHA in need.

Box 13

Problem/ need: Transportation service provided to PLHA is insufficient

Some patients with ill or relatively unstable condition might require transportation by non-emergency ambulance to attend clinic appointments. In the ITC, the ambulance service has to be booked through the Fire Services Department (FSD). For its non-urgent ambulance service, the destination and the route have to be within the same cluster area because patients should be sent to the hospital units nearest to his/her residence. It is difficult to book non-urgent ambulance for a needed patient living in districts outside the cluster area where Kowloon Bay belongs to (i.e. across two regions). Currently, this problem is solved by liaison with staff of FSD with detailed explanation of the need.

For PLHA with mobility problem but with more stable physical condition, they do not require ambulance. Some NGOs provide transportation services for them to clinic visits. However, the services available are insufficient to meet the demand. Other than NGOs, the nurses can book the Rehabus service operated by the Hong Kong Society for Rehabilitation for them, but difficulties in the booking are always encountered because of the great demand.

Recommendation: Transportation services for PLHA to attend clinic appointments need to be strengthened.

Unlike most disease conditions which are managed within the hospital cluster of the patient's residence, for HIV care, PLHA often need to travel long distance to attend clinic appointment. In order to facilitate their clinic attendance and improve their quality of life, both the non-urgent ambulance service and also the transportation services for those with mobility problems should be enhanced in the future.

B. Social services

7.12 In the aspects on social services, apart from those provided to the general public, various specific services are available to them. Nowadays, their needs of social services are less different from the general public when compared with the past.

7.13 Through the unwearied efforts of many dedicated workers, the achievements of AIDS NGOs in HK are great despite limited resources. PLHA recognize the importance of services provided by these NGOs. Services which are particularly useful include transportation services, employment support services, counselling services, buddy services, etc. Besides, professional counselling service on how to cope with the illness in non-medical settings is helpful, especially in the initial stressful period after diagnosis. The needs or problems are related to the scope of services (Box 14), the funding mechanism (Box 15) and the monitoring and evaluation (Box 16).

Box 14

Problem: Scope of services of NGOs is not large enough in some areas.
Some of the needs of PLHA in social services are specific to the problems brought about by the infection and these are not met by the mainstream social services. Currently, there are only three AIDS NGOs with services specifically addressing the needs of PLHA and the scope of services is not large enough to have very significant impact. Many respondents of the questionnaire survey had no previous encounters with AIDS NGOs. Moreover, the provisions of some services are dominated by single organization. They think that some services can be provided by different NGOs at the same time to improve access.
Recommendation: More resources to and co-ordination between NGOs are needed.
More resources should be granted to NGOs serving PLHA so as to support them to organize various programmes, such as employment support, empowerment programme, transportation service, self-help and volunteer programmes, etc. This is in accord with the principle of GIPA, not just inside clinical settings but also in the

community. Also, services provided by NGOs should be catered to the changing needs of PLHA. Those areas considered more useful by PLHA ought to be expanded to meet the demand. Moreover, co-ordination between different NGOs is advantageous in allowing scarce resources to be used more cost-effectively.

Box 15

Problem: Funding mechanism of ATF does not cater for sustainability of services provided to PLHA.
Many NGOs find it difficult to raise funds by themselves due to the facts that HIV / AIDS is not an issue with high profile and also not generally accepted by the community as something with urgent needs. As a result, they have to rely on funding from the Government and other charitable organizations to sustain their work financially. However, in the current funding mechanism of the ATF, the approved funding can only support a programme for three years at most. As a result, they witnessed that a lot of good services were terminated because of the rejection of their re-application for further funds after the first three years. All agreed that ineffective or duplicated programmes should be ceased to be funded. But unlike preventive projects, many of the programmatic services provided to PLHA are of long term and continuing needs and should be regarded as normal service, e.g. transportation, counselling, etc. One example was the counselling service provided by HKAF, in which new referral was not accepted due to limited resources. On top of that, many NGOs comment that the current funding mechanism for programmes on a 3-yearly basis adversely affects any further development of services. Because the sustainability depends wholly on the approval of funds, they are reluctant to embark on ambitious programmes for PLHA due to the uncertainty of availability of funds.
Recommendation: Review of funding mechanism of ATF
The funding mechanism of ATF to NGOs should be reviewed so as to make some "essential and necessary" services with long-term and continuing needs and demonstrated usefulness sustainable into the future. Also, it is suggested that those programmes re-applying for continuation of funds should be processed at an earlier time before the expiry date so that NGOs can know in advance whether the programme can be continued.

Box 16

Problem: Limited monitoring of funded programmes by the funding body (ATF)
There is no well established formal mechanism to monitor the progress of implementation and to evaluate the effectiveness of the ATF-funded programmes.

The organizations applying for ATF are required to submit information on the implementation and evaluation in the application form. After approval, only activity reports and audited accounts are needed to be submitted during and after the completion of the funded programmes and projects. The funds would be granted with little reference to the quality of services delivered or whether the original targets were met.
Recommendation: Monitoring and evaluation mechanism should be incorporated into the funding process of ATF-funded projects.
Resources are scarce in an environment with many competing needs and demand. To ensure the most cost-effective use of allocated resources to achieve the objectives becomes a fundamental responsibility of a public funding body. A mechanism for continuing performance monitoring should be implemented in the ATF, so as to make sure that the funded services/ programmes meet the required standards and requirement of the funding body and hence to maintain the quality of services. Monitoring should include the quality aspect, which can be in the form of half-yearly report, final report and evaluation report, rather than just the financial and process aspects. It is also recommended that a mechanism to evaluate the effectiveness of programmes re-applying for subsequent rounds of funding from ATF should be integrated into the funding process.

7.14 Employment is a crucial element for PLHA to integrate back to the society. Many are not able to work in their previous job after recovered from a prolonged period of physical illness. Because some PLHA suffered from major illnesses at the early stage of diagnoses, especially those late-presenters who have progressed to AIDS at the moment of diagnosis, they are likely to lose their job after the acute phase. On top of that, some of them will gradually lose their confidence and have poor self image because they think their life has been changed after being diagnosed as a HIV patient. More often than not, they are unlikely to find a new job or a job comparable to their previous job, especially in a very competitive environment.

7.15 n the era of HAART, they no longer worry much about death or physical deterioration, but they concern about facing the future life and unemployment adds to their existing sufferings. Productive employment allows them to earn a living and also be integrated back into the society. Employment can improve their self-esteem and make them feel that they can contribute to the society like other persons. A more positive image of PLHA also helps to increase the acceptance of them by the community and to remove the negative image of PLHA as some useless persons with

multiple illnesses. Their need for vocational support exists (Box 17).

Box 17

Problem/ need: Employment support is not enough and not catered to the unique needs of PLHA.
Employment support service in the initial phase of job seeking is important and this is quite insufficient at the present moment. The kinds of employment support provided by AIDS NGOs are not well structured. Rooms for expansion and enhancement exist. Also, the retraining programmes offered by Employee's Retraining Board mainly focus on training in technical skills and are considered not tailored to their unique needs.
Recommendation: Efforts from the community in providing employment support to PLHA should be expanded.
Nowadays, as most PLHA can remain in a healthy state, vocational rehabilitative services addressing their distinct needs in order to help them to return to the society as a productive person should be provided, e.g. skills and capacity building, workshops on interview techniques, skill training workshops, supportive programmes to help them to accept themselves and to build up their confidence and self-esteem, etc. Besides, some PLHA think AIDS NGOs can offer short-term employment for PLHA, which serves as an interim to prepare them to go back to the main workforce. All these concerted efforts can improve their opportunities of finding a job.

7.16 Self-help groups are helpful to PLHA in many ways. Firstly, patient's peer support groups can offer a safe environment for them to share with and mutually support one another and thus reduce social isolation. Secondly, by providing more opportunities to work as volunteers, this can empower the community in addressing their own needs and to use the resources within the community of PLHA to benefit others. Moreover, they can unite their power to voice out their needs to the society and also advocate the Government on AIDS-related issues. Uniting their voices in the community can also reduce stigma. The strategy of greater involvement of people living with or affected by HIV/AIDS (GIPA) is promoted by UNAIDS.

7.17 To the patients, they think that many PLHA are willing to help and support others as peer counsellors. This service is of great value to them as PLHA themselves are in the best position to understand the down-to-earth problems faced by PLHA, e.g. the psychological toll of having to maintain a secret identity, ways to face the infection in a positive manner, etc. They treasure the chance to meet, talk and make

friends with other PHA. Peer counselling and support through the network of organized self-help groups cannot be replaced by other social and counselling services (Box 18).

Box 18

Problem/ need: Peer support among PLHA is weak.
All along, peer support among PLHA is weak. There are no well-organized self-help groups for PLHA in HK. Although some patient's groups were set up in both HIV clinics and by NGOs, the sizes are small and participation by them is not very keen. Also, some of the activities previously held in QEH were advised by the hospital administration to be stopped because the hospital policy has been discouraging voluntary services within the premises since the SARS outbreak in 2003 and subsequently during the yellow alert level of infection control since early 2005. Group activities organized by NGOs are also not well coordinated to recruit volunteers among PLHA.
Recommendation: Support and encouragement to active PLHA to establish self-help groups should be initiated.
With a long history and a good track record of working for PLHA, some NGOs are in a perfect position to take the lead to facilitate active PLHA to organize self-help groups for themselves. These NGOs are encouraged to support and nurture them in the form of liaison and capacity building so as to allow them to have meaningful and enthusiastic participation. Once established, it is hoped that NGOs might lead their start-off, development, proliferation and maintenance until the day they can sustain independently. These self-help groups might also apply financial support from ATF.

7.18 Physically or mentally disabled PLHA with activities of daily living (ADL) dependent on carers require to be stayed in nursing or residential care homes. They are usually those in the late morbid state of AIDS. They might not be sick enough to justify long hospital stay, but they are also not fit enough to take care of themselves independently. All along, the demand on residential care is not met (Box 19).

Box 19

Problem: Residential care for those with activities of daily living dependent is grossly lacking.
For elderly patients, though the waiting period is long, they are still eligible to be admitted to old age homes or care and attention homes. However, for those below 65 years old, there is no formal residential care available to them. Frontline workers

always encounter extremely great difficulty in searching a suitable place for those ADL dependent PLHA below 65 years. Only few private old age homes are willing to admit this kind of patients, but they have to bear the risk of breaching the licensing condition. In real life, many old age homes are reluctant to admit patients diagnosed with HIV/ AIDS.
Recommendation: The long standing problem of residential care for PLHA needs to be studied to find suitable solutions.
Although the demand for residential care in the present era is decreasing, PLHA presenting late and are in a fair condition upon diagnosis still occur from time to time. Residential care provided to this group of ADL dependent patients should be available, especially for those below 65 years.

C. Acceptance and ways for integration into society

7.19 Compared with the situation in the past, PLHA find it easier to face the infection nowadays. With effective treatment, there is much less outward manifestation of the disease. Their external appearance looks as normal as any ordinary people, so no one will know about their status. "Coming out" is not their concern because many PLHA feel comfortable in keeping their status secret and it is not necessary to disclose to anyone. Having said that, the situation looks completely different when they have to face people who know about their HIV infection. The needs or problems are related to non-acceptance (Box 20) and psychological rehabilitation (Box 21).

Box 20

Problem: Non-acceptance is still widespread in the community.
It is noted that after so many years of education and promotion, the basic knowledge on HIV/ AIDS among the general population, especially among people of middle age and the elder population and also those with lower education background, are still regrettably poor. Many still do not understand the transmission routes of HIV and hold a lot of misconceptions and believe in myths about AIDS, and these in turn generated unnecessary scare towards PLHA. Apart from ignorance, the negative image of HIV / AIDS portrayed in the eighties is still entrenched in many people's mind and has not been removed yet. Many still think that HIV infection is a universally fatal infectious disease and associate HIV / AIDS with behaviours that are considered socially unacceptable or immoral, such as drug abuse, prostitution, homosexuality, etc. All these make people stay away from PLHA and hence intensify the feeling of being rejected by the

society among PLHA.

Most of the PLHA are still subject to serious stigmatization and discrimination in circumstances when their status is known to others, both in the health care environment and in the society. The acceptance by the society is perceived to be low, though there was some improvement over the years. This makes them reluctant to disclose their status to others because of perceived adverse consequence of being stigmatized. Thus, telling others is a major hurdle to them. This evolves into a vicious cycle; the more they keep their status secret, the more sensitive they are in judging the attitude of others towards them. Some PLHA have to endure the ever lasing mental torture resulted from shame and distress, which is unbearable to them.

It is a pity to find that they have experienced more discriminating behaviours (either genuine or perceived) in health care environments in which their status is usually known to the staff. They are sometimes treated with judgemental attitude, which is well depicted in the following story. One patient said that an operation scheduled for him was cancelled by his doctor after knowing his HIV status. The reason given was that his condition for which surgery was indicated originally could now be more 'appropriately' managed conservatively without surgery. The patient thought that the surgery was cancelled because of the reluctance of the doctor to perform surgery on him, so he insisted the scheduled surgery be done. Before the operation, he heard the doctor made jokes with his infectious states in the theatre. In another example, the patient would never tell other health care workers about the HIV status after a bad experience of being stigmatized in hospital.

Worse still, stigmatization will deter individuals from finding out about their HIV status. Also, those who became infected might not take preventive measures because of worry of suspicion by sex partners.

Recommendation: The Government and community organizations should be united to put more effort to build a society where PLHA is accepted as normal citizens.

Stigma is the biggest enemy to effective HIV prevention nowadays. Stigmatization discourages individuals from going for HIV test if they have had high risk behaviour, even when treatment is available. It cripples the life of PLHA. The Government should strive to educate the public on HIV knowledge so as to allay the public's fear towards PLHA, especially on the knowledge that HIV infection can never be acquired through daily social contacts and treatment is available for HIV infection. Innovative methods employing the mass media can be devised. Large campaigns and publicity programmes targeting different segments of the community can be employed to dispel the myths and to correct any misunderstandings. More education in schools should be done as the younger generation can be guided to cultivate an accepting attitude during the formative

stage of their value judgement. This will help to tackle the social stigmatization and hence help PLHA to face their friends and family members and to come out.

Continuous efforts to promote acceptance and reduce discrimination is also important in fostering a social environment which is conducive for people who have had high risk behaviours or at risk of infection to come out for HIV test. As a result, more undiagnosed PHA can be diagnosed and receive early medical care and treatment. Also, PLHA who knew about their status could be counselled on taking active measures to protect their sex partners by using condoms.

Box 21

Problem/need: Poor self image of PLHA hinders them from integrating fully into the society.

The physical and health problem of PLHA is partly solved by the availability of HAART, which allow HIV infection to be managed like a chronic disease. However, what remains to disable them is their low self-esteem and perceived inferiority. Some of them have strong negative feeling about life and are unable to live positively. They think they do not deserve to live a long lifespan. To PLHA, this is still a disease which cannot be talked to other people. Sadly, some of them not even disclose to their close family members and would rather keep this secret until the time of their death.

Their low self image is of course related to the persistent non-acceptance by the society and the stigma associated with the disease. But to a certain extent, this is also related to how they see themselves and their own self non-acceptance. The followings are vivid illustrations of their frustration in the health care settings. Some think that some procedures such as showing of identity card to prove eligibility during purchase of prescription sheet will lead to the disclosure of their names. Some patients worry about the chance of meeting someone they know in the vicinity of the HIV clinic. Some think that when they obtain drugs from the pharmacy, the dispensers (who know their names) and people around might know about their status because of the special and large quantities of drugs they obtain (especially for patients in ITC). They consider it unnecessary and inappropriate for the dispenser to have knowledge on their status. In all these examples, there is no actual discrimination by the service providers. The reactions and thinking are just out of their own imagination or belief of being discriminated by others. This kind of self-stigmatization ruins their relationship with others and prevents them to lead a prosperous life.

Recommendation: Rehabilitative services to empower PLHA and to enhance their self confidence should be provided for PHLA.

Psychosocial factors which hinder PLHA from living optimistically with the disease should be explored in order to gain a broader understanding on this issue. Community organisations should be encouraged to organise more innovative activities and workshops aiming to empower PLHA in living positively. To lead a fulfilled life, PLHA should learn to love and respect themselves and others so that their sufferings from the disease could be alleviated and their social and psychological well-being restored and enhanced.

D. Children's needs

7.20 oncerning the medical services, no major problem is encountered by affected children. Parents generally consider the available services adequate to meet their child's needs.

7.21 Education and school life is a special issue for affected children. From the interviews of the parents of some affected children, it was revealed that the parents interviewed did not tell the school about the HIV status of their child. That is the reason why they do not encounter any difficulty in facing the issue of schooling of their child. Although the former Education Department and the Education & Manpower Bureau have issued information and guidance on HIV/AIDS for students and schools, they still have the concern that the disclosure might lead to the expulsion of their child from the school or any harassment their child might suffer in the school. One affected child's parents said that they would advise their child to be careful not to have any injury and to handle any wound or blood carefully in school. The root problem the parents facing is the general rejection and non-acceptance by the society. As parents and also PLHA themselves, they do not want their child to face any stigmatization during the child's school life, so they choose to keep the status secret. The problem is related to the disclosure to the affected children in the future (Box 22).

Box 22

Problem/ need: Disclosure of HIV status to the affected children
A major foreseeable problem is the disclosure of the status to the child. Parents do not want the child to know about the HIV infection, so they are also forced to withhold this information from the school. The parents interviewed do not tell their child about the disease as they think that their child is not able to understand the complex issues around AIDS at the moment. One affected child was told by their parents that the anti-retroviral medicines were nutritional supplements for the well-being of the body.

However, as the affected child grows up, the child has to know about the infection and this is the potential problem the parents do not know how to deal with. Worse still, there might be more than one affected children in some families. Also, there might be affected and unaffected siblings in the same family. As most of the affected children acquired through mother-to-child transmission, the parents worry about being blamed by the child. The on-going anxiety of having to disclose to the child in the future adds to the psychological burden of the parents.
Recommendation: Support to parents in disclosing the HIV status to their affected child in an appropriate way needs to be provided.
This is a very complicated issue which needs to be handled carefully and best be managed by a multi-disciplinary professional team comprising of social worker, clinical psychologist, school teachers and also health care professionals. If handling of this problem is inappropriate, there might be adverse effect on the future life of the affected children. The Government should take a proactive role to explore on the needs and support that can be rendered to these parents.

E. Undiagnosed HIV-infected persons

7.22 HIV infection is different nowadays because treatment is available. As such, it is appropriate to encourage all those who have had behaviours that could lead to HIV infection to go for test. Also, people who continue to have such behaviours should be tested regularly. On one hand, early diagnosis can allow PLHA to be followed up in HIV clinic and be offered treatment if indicated. On the other hand, they will have the opportunity to be counselled to stop having further at-risk behaviours and this will be beneficial to their partner(s) and the community as a whole. The need is to achieve a greater coverage of testing to identify as many undiagnosed PLHA as possible (Box 23).

Box 23

Problem/ need: PLHA remaining undiagnosed are putting others at risk of infection.
As the latency period of HIV infection is very long, those who miss the chance of being diagnosed during any acute symptomatic period after infection might have many years of asymptomatic phase. They have the probability of spreading the infection continuously by engaging in at-risk behaviours. Remaining undiagnosed also deprives them of the benefits of early treatment.
Recommendation: Innovative ways to make people who are at risk of infection accessible to testing should be promulgated.
Novel ways to encourage those who are at risk of HIV infection to receive test

should be devised, e.g. rapid test. In the clinical settings, more education is needed to heighten the vigilance of health care professionals in screening for HIV among patients presenting with compatible symptoms and also those with other conditions and behaviours associated with HIV infection. Clinical settings serve as an ideal environment for providing HIV test to persons belonging to some vulnerable and hard-to-reach groups, who are unlikely to self-initiate the test because of the lack of awareness on HIV.

On the other hand, innovative programmes to increase testing outside clinical settings can be explored, e.g. outreach testing service. Currently, some NGOs are already providing voluntary counselling and testing services to the public and also some specific groups, e.g. MSM (men having sex with men). More resources ought to be diverted to such testing services.

8. Limitations

Some old and new problems within the PLHA community were identified in this community assessment. However, this was not meant to be a comprehensive review. Due to the time constraint, there were a number of limitations that this assessment inherited:

- A lot of the needs and conclusions were drawn from the data obtained from the focus groups of PLHA. Whether the PLHA in focus groups can represent the whole community remained unknown. Obviously, they were deliberately chosen by the nursing staff and staff from NGOs because they were talkative and out-spoken. However, there was possibility that the collected information was biased towards their inclination rather than generalized phenomena.
- For the questionnaire survey, the response rate was low. Those who did not respond might have no problem or unwilling to talk about it. On the other hand, the problems/ needs expressed by those returning the questionnaires might be aggravated due to exceptional circumstances of the respondents.
- The coverage of the questionnaire survey was not exhaustive. Some patients would be excluded if they did not have appointment during the 8 weeks of the survey.
- The number of PLHA remained undiagnosed is unknown and there is no good way to know who they are and what their needs are.

9. Concluding Remarks

9.1 Medical advances in the past decade bring great hope and benefits to PLHA. In HK, access to medical services is almost universal for HK residents. They enjoy high quality holistic clinical care. Through this impact, many PLHA gain a “second” life. From the present review, many are very satisfied with the services provided. In the coming years, it is expected HIV medicine will continue to advance in a fast pace and more and better drug options with less side effects will be available. HK is a well developed city with world class medical infrastructure. Basic medical care to PLHA is unlikely to be constrained by economic factors. The sustainability of the state-of-the-art HIV care and treatment and the high quality service will depend on adequate resources and the maintenance of clinical expertise of professionals and a workforce of dedicated health care professionals.

9.2 To extend the benefit of medical advances to all PLHA, the direction should be set to attract more people to come out for testing by emphasizing the benefits of early diagnosis. Of course, in order not to spell out the wrong message that HIV infection is a curable disease, a delicate balance should be struck.

9.3 Unfortunately, the improvement in physical wellbeing does not always translate into a fruitful life for PLHA. Their sufferings still overwhelm their daily living. Non-acceptance, social stigmatization and their self-perpetuating psychological distress restrict them from enjoying a better health. Empowerment training to help them to face life is needed. Social services to help them to live a normal life should be strengthened. A lot of things still need to be done by the Government and the community to promote acceptance of PLHA. The negative image of HIV infection as a fatal disease and the judgmental attitude of the public towards PLHA should be dispelled in order for them to face the infection in a more positive manner. Education in schools and media campaigns will continue to play an important role in this on-going anti-discrimination battle. Success can only be achieved when there are concerted efforts by all sectors of the society.

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Appendix 1

Members of the working group on community assessment of PLHA

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Mr. Wong Wai-lun, Alan 黃偉倫

Secretary: Dr. AU Ka-wing, Albert 歐家榮

Appendix 2

問卷調查

愛滋病顧問局正籌備草擬二零零七年至二零一一年之香港愛滋病建議策略。其中，我們組成了一個工作小組去探討現時愛滋病感染者/病患者的現況，目的是找出他們現有的困難及需要；期望能夠爲改善他們日後的生活狀況而提供方向。現誠邀閣下在下列範疇中提供寶貴的意見 (本問卷是不記名的，可自由發揮，如無意見則可不用填寫。):

(因這是就整體需要作出意見收集，請勿就個別事件/ 人士作出點名批評，多謝合作。)

1. 醫護照顧服務方面

範疇	意見
愛滋病門診服務	
住院服務	
藥物及治療	
非愛滋病部門的醫護人員在愛滋病方面的知識和態度	
其他醫護服務 (如: 性病、皮膚科、眼科、胸肺科、心理治療等)	
門診內健康輔導服務	
在醫護環境中對私隱的保障	
其他意見	

(請轉後頁)

2. 社會服務方面

範疇	意見
醫務社工	
協助行動不便的感染者/ 病患者往返診所、醫院的護送服務	
經濟/ 就業援助	
病友互助支援及輔導	
社會支援服務 (如: 家務助理、托兒、房屋等)	
爲感染者/ 病患者提供服務的愛滋病非政府機構	
其他意見	

3. 社會對感染者/ 病患者的接受

範疇	意見
曾否遇過歧視行爲，如有，請說明	
社會對感染者/ 病患者的接納程度	
如何助你面對感染，融入社會?	
其他意見	

4. 你認爲現時社會在愛滋病服務方面，有哪些地方不能滿足你的需要或解決你因患病而面對的困難?

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(請放進大堂之收集箱或傳真至紅絲帶中心: 23380534，多謝)

Appendix 3

Questionnaire Survey

Advisory Council on AIDS is planning to formulate the Recommended HIV/AIDS Strategies for Hong Kong - 2007 to 2011. We have convened a working group comprising of front-line services providers and persons living with HIV/ AIDS (PHA) to study the present condition of PHA so as to find out problems faced by them and their needs. The aim is to inform the future direction of strategies to improve the lives of PHA. We would be grateful if you could provide us with your valuable ideas by completing the following anonymous questionnaire (please leave those items that you have no comment blank).

(Please note that this is to collect views on general aspects, please do not criticise/ complain any named person or isolated incident. Thank you.)

1. Medical services

Area	Views
HIV out-patient services	
Hospital services	
Medications & treatment	
Attitude & general knowledge of health care workers (including paramedics) not working in HIV service on HIV/AIDS	
Other medical services (e.g. STD clinic, dermatology, eye clinic, TB & chest service, clinical psychology, etc.)	
Health counselling in HIV clinic	
Protection of privacy/ confidentiality	
Others	

(Please turn over)

2. Social services

Area	Views
Medical social workers	
Transportation/ escort service to clinic or hospital for needed PHA	
Finance assistance/ employment support	
Peer counselling/ patients' support group or self help group	
Social support (e.g. home helper, child care, housing, etc.)	
Services provided by non-governmental organizations	
Others	

3. Acceptance by society

Area	Views
Encounter of discrimination, if yes, please specify	
Degree of acceptance by society	
How to help you to face the infection and be fully integrated into society?	
Others	

4. Concerning services /community support provided to PHA, is there any gap/ deficiency leaving your needs in facing the conditions related to the infection unmet?

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(Please drop this questionnaire into the box located in the waiting hall or fax to Red Ribbon Centre: 23380534, thank you.)

Appendix 4

The amount of money approved by the Council of ATF to support projects on Medical and Support Services for HIV-infected patients from 2000-2005:

00/01		01/02		02/03		03/04		04/05	
No.	Amount ($M)	No.	Amount ($M)	No.	Amount ($M)	No.	Amount ($M)	No.	Amount ($M)
18	17.936	20	16.610	7	5.903	15	9.976	3	10.132